From: Waylon Vajgrt
To: DHHS HCBS Public Comments
Subject: §1915(c) Home and Community- Based Services Waiver open comment
Date: Friday, January 2, 2026 11:32:42 PM

You don't often get email from [redacted] Learn why this is important

I respectfully submit this comment to express concern about the proposal's increased emphasis on reliance upon unpaid family members, informal supports, and community resources to meet essential care needs for individuals served by the Aged and Adults and Children with Disabilities (A&D) HCBS waiver.

Family members and community supports are valuable and should be welcomed when they are chosen, sustainable, and supplemental. However, they should not be treated as substitutes for services that would otherwise be provided if the individual were residing in a facility or under the direct care of the state.

When a person qualifies for nursing facility level of care, the state accepts responsibility for ensuring that their needs can be met safely and consistently. In an institutional setting, personal care, supervision, skilled support, and overnight assistance are not contingent upon the availability, health, or financial stability of family members. Shifting these same responsibilities to unpaid caregivers simply because the individual remains in the community creates an unequal standard of care based solely on setting.

This approach raises serious concerns of fairness and equity. Families are not interchangeable with paid care systems. They age, become ill, work full-time jobs, raise children, and experience burnout. Many caregivers already provide extraordinary levels of unpaid labor to keep loved ones at home. Expecting families to absorb additional responsibilities—particularly to offset service caps or cost limits—places undue strain on households and risks destabilizing the very community living arrangements the waiver is meant to support.

Moreover, reliance on informal supports assumes that such supports are universally available. Many individuals do not have nearby family, have family members with their own disabilities, or live in rural areas where community services are limited or nonexistent. Policies that depend on unpaid or informal care unintentionally disadvantage those without strong social networks and create inequitable access to services.

Ethically, it is troubling to suggest that unpaid labor should replace services that the state would otherwise be required to provide in an institutional setting. Community living should not come at the cost of unpaid caregiving becoming an expectation rather than a choice. The value of independence and integration should not be achieved by transferring the burden of care from the public system onto families without compensation, training, or adequate support.

If the goal of the A&D Waiver is truly to promote dignity, choice, and community inclusion, then community living must be supported with equivalent responsibility, not diminished responsibility. Families and community supports should enhance care, not be relied upon to fill gaps created by service limitations.

I urge the Department to reconsider any waiver provisions that implicitly or explicitly rely on unpaid family or informal supports as a means of offsetting service reductions or controlling costs. Sustainable community living requires adequate, reliable, and professionally supported services—regardless of whether care is delivered in a facility or in the home.

Thank you for the opportunity to comment and for considering the real-world impact of these policies on individuals and families across Nebraska.

Sincerely
Waylon Vajgrt

From: Shelly Louthan
To: DHHS HCBS Public Comments
Subject: 40 hour limit
Date: Tuesday, December 23, 2025 1:45:11 PM

You don't often get email from [redacted]. Learn why this is important

I am a mother 24/7 caregiver to my 32 year old son. I gave birth to him at 15 and have cared for him ever since, I am now 48. He is blind,severely developmentally disabled and tube fed 5 times a day. The level of care for him in a facility or nursing home would be the highest level and cost the state 20 times what it cost to provide in home care. This population of Nebraskans care does not end at 40 hours. Please do not take away people's right to care for loved ones at home or patients rights to stay at home. I have worked in Nursing homes,where my son would have to go. There might be 2 CNA's to 30 patients. That is not the one on one care these Nebraskan's need.Cutting these hours will force loved ones to make impossible decisions and cost Nebraska so much more money to care for them. This is wrong,inhumane and needs to stop. My son needs and deserves more care,not less. Picture yourself in a caregivers role to someone you love. What would you want for your family?

From: Tonya Kerres
To: DHHS HCBS Public Comments
Subject: 40 hour max for AD Waiver
Date: Wednesday, December 17, 2025 6:25:59 PM

> You don't often get email from [redacted]. Learn why this is important

I understand the need to lower costs for the state. I am the sole caregiver for my brother - he is intellectually challenged as well as dealing with Parkinson's disease. Currently I am allowed 70 hours per week to implement his 24/7 needs. If this is cut to 40 hours a week with the expectation that 30 hours a week could be covered by another caregiver - reality needs review here. There are very few options of family taking over 30 hours a week at $15.00 per hour. It is not a reasonable request. In my situation my brother is extremely anxious with anyone other than myself when it comes to extended care, I would have to remain available to keep him calm and feeling secure, that is inclusive of any other family members. He is worse with people he doesn't know, his anxiety and nervous response to strangers due to communication problems is terrible for him. I do not think it is right the state pays people other than the ones that love and always care for individuals to pay twice what a family member receives. That is if you can find anyone to do it. The availability for reliable transportation, dentist and just general care is absolutely not available. I would ask reconsideration of this matter. I am no longer able to work outside the home. This has become my sole responsibility as well as my income. I believe the consideration for increasing working hours or increased rates for in home care (as that is what has to be consistently available) should be put on the table. Perhaps the people that come into homes -the few that there are should have a lower pay rate than family that do this 24 hours a day. Thank you for your time and consideration.

From: Sam McGuirt
To: DHHS HCBS Public Comments
Subject: 1915(c) Medicaid Home & Community Based Services
Date: Friday, December 26, 2025 3:37:57 PM

You don't often get email from [redacted] Learn why this is important

My son and daughter-in-law live in St. Paul, NE and are the parents of 21 year old mentally and physically disabled young man that this proposal will affect if approved. He has had medical problems his entire life with multiple surgeries and weeks at a time in various hospitals. He has the mind of a 6-8 year old and believes in anything and everything (Santa is real, elves are real, he flies in his sleigh all over the world delivering toys to all the boys and girls all over the world. He believes the Easter Bunny is real, Star Wars, he believes. My daughter-in-law takes care of him 24-7-365. She is in his room cleaning, picking up, washing clothes, changing his medical needs or emptying the stoma bags (he has 2 (two) a urostomy and an ileostomy. These require a lot of work for SANITARY AND HEALTHCARE. His bag blows or gets tore off in bed or in the car; it's a big mess that has to be dealt with immediately no matter where you are or no matter what you are doing. He has a medical bed that raises and bends for comfort so he can eat and sleep in it. She attends to him several times through the night every night and it's a job that exceeds what most can't even imagine. Her wages currently before these proposed changes are a direct effect of our budgeted expenses and above needed supplies that his insurance does not cover. They depend on it just like my income, it's her job caring for him and his medical needs. When he's in the hospital, her care does not stop, she has to stay with him through the night most times showing nurses and aids how to empty, drain and dump his Ostomy bags and when it needs to be changed, she does it because most have never seen one before. Putting my 21 year old grandson in some facility is not what they want to do, or should have to do. Him being cared for at home is the best thing for him rather than in some facility that would 100%

require 24-7-365 supervision and care. Cutting hours from 70-80 a week to 40 is absolutely ridiculous. She has 100% dedication to giving him the best comfort and medical needs he requires and works well over 80 hrs a week. If cutting hours is to cut back on spending to save money or disperse it elsewhere is absurd. The families that take care of their loved ones should not sacrifice and lose their homes because of this. I understand why budget cuts are needed but I also understand that there are some areas that you just have to work them into the amount needed and cut the FAT from other places. Stop giving tax dollars to places that DO NOT NEED THEM they just can use the extra to benefit and make millions more. I know adults that ABUSE the system and receive monetary help and are perfectly capable of taking care of themselves, they are just LAZY, (start by cutting the FAT).

My daughter-in-law has dedicated her life to provide the best care for my grandson and sacrificed more than anyone can imagine. No facility can provide that for him and in his state-of-mind he will not understand why he has been placed in one. He will think he is being punished.

I am asking you to deny the proposed changes because not only is it going to put a hardship on their family, it will put mostly everyone involved in some type of negative situation. There are an unknown amount of people this will affect and dramatically change their lively hood. You're not just making a simple decision to save some money, your decision will be cutting some single mom or dads income in half and then what will happen? The answer is simple. (Proven medical and physical healthcare needs should never come after anything that doesn't need it). My grandson was born with these issues and they still adopted him. His life does MATTER, he's not just a number, he's their son. His needs are complex and complicated, His needs are not common at all. They have been told that no facility in Nebraska is equipped for his needs and that comes directly from his SERVICE COORDINATOR assigned to my grandson by the state.

Until you have walked in the shoes of many of these families you have no idea not only the hardship it will cause, but also the heartbreak of the impaired ones that don't understand why they are being punished for something they have no control over.

From: Julie Stahla
To: DHHS HCBS Public Comments
Subject: A & D Waiver
Date: Wednesday, December 31, 2025 9:28:42 AM

> You don't often get email from [redacted]. Learn why this is important

The A & D Waiver provides life-saving services to individuals in their homes and communities, saving the state millions of dollars every year. If the cuts proposed are enacted, Nebraskans with disabilities could be forced into institutionalization or nursing homes in order to qualify to receive care. These are not the proper places for people with disabilities or anyone on these waivers. Please reconsider the cuts to these important, life saving services.

Julie Stahla
[redacted]

From: Kathy Wohlgemuth Ross
To: DHHS HCBS Public Comments
Subject: A and D waiver
Date: Thursday, January 1, 2026 1:35:58 PM

You don't often get email from [redacted]. Learn why this is important

I am a recipient of the A and D waiver in Nebraska. I have an extremely rare condition related to ALS, Parkinson's Disease and MS for which there is no cure. While 40 hours a week caregiving is enough right now, as my disease progresses it won't be.

My husband, before I was on the waiver was shouldering this himself. We have friends with profoundly disabled (wheelchair bound and tube fed and another profoundly autistic with Epilepsy) whose parents are paid to take care of their adult children. Without the waiver, the adult children would need to be institutionalized, which actually goes against dhhs policy for A and D waiver by putting the disabled in more restrictive environments and not keeping their person- centered planning at the core.

The paying for 24-hour institutional care would actually be a move that would be more costly for the state. Please consider the needs of the loved ones of these profoundly disabled adults.

Thank you!

Kathy Ross

From:	Ashley Wustrack
To:	DHHS HCBS Public Comments; Green, Tony; Clark, Jennifer J; Sen. Beau Ballard
Subject:	A&D and TBI Waiver Amendments
Date:	Sunday, January 4, 2026 3:09:45 PM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Dear CEO Corsi, Director Green, Deputy Director Clark, and Senator Ballard:

I am writing as a concerned constituent and disability advocate to formally express my strong opposition to the proposed amendments to the Aged and Disabled (A&D) and Traumatic Brain Injury (TBI) waivers, specifically the introduction of utilization thresholds and spending caps.

The proposal to initiate a "high utilization review" at $138,657 and impose a hard spending cap of $161,766.50—175% of regular nursing facility costs—poses a serious threat to the independence, safety, and well-being of Nebraskans with disabilities who rely on home- and community-based services.

This policy represents a significant step backward for Nebraska for several reasons:

• It forces institutionalization. By capping home-based care at a percentage of regular nursing facility costs, the state is effectively forcing individuals with complex needs into institutional settings when their care "costs too much" to provide at home. For many of these individuals, there is no appropriate or available skilled nursing facility capable of meeting their needs.

• It unfairly penalizes family caregivers. Families who have worked tirelessly to support their loved ones in their homes and communities are now being told that home is no longer a viable option due to arbitrary financial limits rather than clinical need.

• It lacks transparency and meaningful stakeholder engagement. Announcing these life-altering changes on December 5 with a public comment period ending January 5 does not allow adequate time for impacted individuals, families, and advocates to fully understand or respond to the proposal.

I strongly urge you to remove these spending caps from the final waiver application and instead focus on expanding community-based resources for Nebraskans with disabilities to live in their own homes.

Nebraska must ensure that the safety, rights, dignity, independence, and overall well-being of people with disabilities are protected.

I look forward to your response and a public commitment to protecting the rights of the disability community.

Sincerely,

Ashley Wustrack
Legislative District 21
[redacted]

Sent from my iPhone

From: Hannah Vick
To: DHHS HCBS Public Comments; Green, Tony; Clark, Jennifer J
Subject: A&D and TBI Waivers
Date: Saturday, January 3, 2026 11:26:10 AM

You don't often get email from [redacted]. Learn why this is important

Dear CEO Corsi, Director Green, and Deputy Director Clark

I am writing as a concerned constituent and disability advocate to formally express my strong opposition to the proposed amendments to the Aged and Disabled (A&D) and Traumatic Brain Injury (TBI) waivers, specifically the introduction of utilization thresholds and spending caps.

The proposal to initiate a "high utilization review" at $138,657 and impose a hard spending cap of $161,766.50—175% of regular nursing facility costs—poses a serious threat to the independence, safety, and well-being of Nebraskans with disabilities who rely on home- and community-based services.

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Nebraska must ensure that the safety, rights, dignity, independence, and overall well-being of people with disabilities are protected.

I look forward to your response and a public commitment to protecting the rights of the disability community.

Sincerely,
Hannah Vick
[redacted]

From: [redacted]
To: DHHS HCBS Public Comments
Subject: A&D MEDICAID WAIVER APPLICATION AMENDMENT
Date: Friday, January 2, 2026 3:05:02 PM
Attachments: image001.png

You don't often get email from [redacted]. Learn why this is important

RE: A&D MEDICAID WAIVER APPLICATION AMENDMENT

We are writing with deep concern and urgency regarding the proposed drastic reduction of waiver service hours for our son, Jeffrey, who has relied on this program for over 30 years to live safely in his own home.

Our son is 53 years old, quadriplegic and ventilator dependent due to muscular dystrophy. He requires continuous 24/7 care to survive. This is not a preference or convenience- it's a medical necessity. Reducing his care to 110 hours per week leaves him without support for large portions of each day and places his life in immediate danger. He needs 24/7 care or 168 hours per week just like what he would receive if he were in an institutional facility.

For nearly 3 decades this waiver program has allowed our son to live with dignity in his home, surrounded by familiar caregivers who understand his complex medical needs. The only change seems to be a shift in policy, not in medical reality.

We have always had difficulty finding quality, consistent, and competent caregivers. Most people were not comfortable providing the care Jeff requires and some said that given his condition they didn't see it as a long lasting job and also with no benefits. We have tried many nursing agencies over the years with little success. It was very disruptive to our son's daily schedule when the nurses would be late because their last appointment ran over. That would mess up part of the day because we have young men transfer people coming over at noon from their regular jobs to transfer Jeff into his chair. As we understand things, this new Waiver would eliminate their position. So then how would we get Jeff into his wheel chair?

Furthermore, Susan would be the one to train all the nurses and usually a couple of months later they would change them out and she would have to train new ones again. The nurses came with very little training for vent care. They also had

difficulty doing bowel care and often needed Susan's assistance to do it. Also, the nursing agencies will only allow Registered nurses to come out, which is much more expensive. Each time an agency introduced new staff the cycle of retraining began again, placing a burden on our family. In contrast, our long- term caregivers are stable, dependable, and very familiar with our son's needs, his specific medical issues and emergency protocols. This continuity has been critical to his safety and quality of life.

Currently, the two primary day people (other than Susan) who are caring for Jeff have been with him for about 20 years. His brother has worked the night shift for him since he was in College. These are all people we trust and have confidence in to care for Jeff. The reality is that the weekly reduction in care hours to 110 would mean that only Susan would be working during the day and Steve Jr. during the night shift. And most of Susan's hours would be uncompensated under the 40 hour weekly limit.

So, why would you want to disrupt Jeff's life like that, especially since it would be more expensive for a facility like Madonna, where costs would be at least $1,000/day which far exceeds the 175% of average nursing home costs? In fact, to our knowledge, there is NO NURSING HOME IN THE STATE THAT CAN HANDLE VENT DEPENDENT PATIENTS WITH JEFF'S COMPLEX MEDICAL NEEDS.

In conclusion, the level of care the new WAIVER would provide is inadequate for someone who requires continuous 24/7 monitoring, ventilator management, suctioning, repositioning, skincare, and assistance with all activities of daily living. There is no way to meet his medical needs with these limitations. Would we like more help? Yes, and we've tried to hire other people but as we have said before, not many people are comfortable with Jeff's type of care needs or they simply don't work out for other reasons.

We have been told that if we don't accept this reduction, institutional placement is an option. The thought of forcing our son into a facility, against his will and at far greater cost is heartbreaking and makes little sense. It goes against the very purpose of the waiver program and violates the very fundamental principle that people with disabilities deserve to live in the least restrictive setting possible.

Right now, our son's overall care program is working well so should not be changed. The proposed WAIVER amendment changes threaten our son’s safety, health and life. Please do not let such a policy change undo 34 years of safe, humane and responsible care.

For these reasons we respectfully request receiving care from his long -standing private caregivers and that his current authorized hours be preserved, consistent with his medical needs.

Sincerely,

Steve and Susan Morris

P.S. In order to accommodate all VENT DEPENDENT patients there needs to be three changes to the AMENDED WAIVER APPLICATION. 1) the weekly hours need to reflect the 24/7 fully compensated care required, or 168 hours, the same that's provided in a rehab hospital like Madonna or the Ambassador in Lincoln, not a nursing home since none exist that provide such care. 2) The 40 hour limitation for live-in family caregivers needs to be eliminated since the reality is that live-in family caregivers need to fill in for the hours not provided by outside caregivers who work limited hours, take off when sick, on vacation or holidays. 3) The overall dollar limitation needs to be changed from 175% of average nursing home costs to 100% of the average rehab hospital costs which is at least $1,000/day. And finally, for just our son's care needs, there should be a daily allowance for transfers into and out of his wheelchair which is currently handled by some young men who perform that task each day.

From: randi mosiman
To: DHHS HCBS Public Comments
Subject: A&D Public Comment
Date: Monday, December 29, 2025 8:58:37 AM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Hello!
My name is Randi Mosiman. My son Elias Mosiman receives caregiver services through the A&D waiver. We were informed of the changes for the next school year, regarding the ability to clock in and out, while school is in cession, for our care providers. Elias has medical needs that prevent him from being about to handle being at school for the entirety of the school. He currently goes to school only 3 days a week for 3 hours a day. This year we tried 4 hours but that proved too much. After the first week Eli spent most of his days in bed and ended up have several seizures in the first two weeks. Even with the ability for schools to
Provide the space for a nap and quiet area, Eli gets overwhelmed and starts to have migraines that can cause stroke like situations, and has in the past caused paralysis of one side of his body. This took us 3 months to learn to use that side of his body and extensive therapy. He also does not eat well at times and his caregivers are very careful to keep trying to feed him by mouth. There are so many things that the school shouldn't and couldn't provide for my son, compared to his caregivers and obviously his parents. I ask you to seriously reconsider this matter, as it is not healthy for the children who are like Eli. As parents it's already hard enough not stressing about how our children are being treated and cared for, but now if this goes through then we will have to pay for our caregivers out of pocket. That would be $435 minimum if I used my vacation I saved, every week, totally $870 every two weeks and a total of $1740 a month. This would be more than our LRI is paying. I would rather the benefit of my caregivers get paid and take away the LRI. As much as we have all wanted the LRI, it doesn't pay enough to have either of us quit our jobs, so we would need to work. I'm all for cutting budgets, but this will be hurting families and children. I've kept my child alive for 12 years and he is stable for the
Most part but this will make him worse, and it doesn't benefit any party whatsoever, besides the state. Please I implore you to see reason and reconsider.

Thank you so much for taking the time to read my comment!

Sincerely,
Randi Mosiman

From: Tammy Caster
To: DHHS HCBS Public Comments
Subject: A&D waiver changes to hours
Date: Friday, January 2, 2026 4:50:08 AM

> You don't often get email from [redacted] Learn why this is important

It is 4:30am on January 2, 2026, and I have just been in my 30 year old son's room for the 6th time since he was put into bed for the night at 11:30pm just for repositioning due to the fact he cannot move any part of his body at all because he has Duchenne Muscular Dystrophy. On top of that, I have been in to suction mucus from his lungs through his tracheotomy 4 times, and helping him to go to the bathroom once. This is just the first 4 and 1/2 hours of my 12 hour shift beginning at midnight and ending at noon today.

I wanted to give you a small glimpse of just a few hours of what our life is like and then let you all tell me how you think it is fair to say that he only deserves to have 8 hours total of care in a 24 hour period and only Monday-Friday with your new plan??? So he doesn't deserve to have mucus suctioned from his lungs on the weekends?? He should just suffocate and die? Do you sleep in ONE POSITION ALL NIGHT LONG??? Try it!! You can't…I promise you. If you have to go to the bathroom, you are lucky enough to be able to get out of bed and go…he cannot.

I need you to consider the vulnerable people who will suffer if you pass these changes. I understand you need to make some changes. I get it… but our family members deserve dignity and care. Have you considered starting with just taking it done to no overtime??? I mean, honestly, we never know when or if that is coming, we couldn't tell you if we are even getting that paid correctly or not!! I think starting there is a fair compromise and making sure the most vulnerable patients, like my son and the others who are on ventilators, trachs, feeding tubes, have no use of their limbs, need complete care of there entire lives for everything (bathing, dressing, eating, toileting, drinking, moving hands, arms, head, etc) are getting the dignity and respectful treatment and care they deserve in their homes where they are not depressed and suffering from any mental or anxiety issues.

If you force them into facilities where they are not comfortable and not with family, their mental health will suffer and you will be the cause of their detrimental health decline. My son is already suffering from anxiety over this possibility.

Tammy Caster

Sent from Yahoo Mail for iPhone

From: The Nichols
To: DHHS HCBS Public Comments
Subject: A&D waiver changes
Date: Wednesday, December 31, 2025 3:48:28 PM

> You don't often get email from [redacted]. Learn why this is important

To whom it may concern,

If the whole point of the A & D waiver is “to provide the best care possible for Nebraska citizens in the comfort of their own homes with the caregiver of their choosing” then why is DHHS cutting the hours allowed to those home care givers? It’s my understanding that hours allowed are being cut in half (80 hours to 40). In addition, relatives caring for a loved one at home get paid $15 an hour (minimum wage? Really?!) while an agency nurse gets paid $45/hr for up to 70/week. How does that make any sense financially OR morally?!

Wake up and do the right thing for those who are willing and able to care for loved ones at home where they are most comfortable! Many of these individuals need taken care of 24/7. They require toileting, feeding, bathing, dressing, undressing, drinking, teeth brushing, nose blowing, medications, itching/scratching, moving of arms/legs, head adjustments, body rolling…literally everything! That care doesn’t stop at 40 hours nor fall into a nice, neat 9-5 Monday-Friday.

Please do not cut the hours for these angels on earth!

Respectfully,
Jenny Nichols
Bellevue, NE

"Fame is a vapor, popularity an accident, and riches take wings. Only one thing endures and that is character." -Horace Greeley, Newspaper Editor (1811-1872)

From: Waylon Vajgrt
To: DHHS HCBS Public Comments
Subject: A&D waiver open comment
Date: Monday, January 5, 2026 3:20:43 PM

I respectfully submit this comment to express concern and disagreement with the individual cost limits being established in the proposed Aged and Adults and Children with Disabilities (A&D) 1915(c) HCBS waiver renewal. Specifically, I am concerned that the cost limit methodology relies on average institutional or service costs associated with an aged population and does not adequately reflect the significantly higher and more variable costs incurred by medically complex individuals who require specialized, intensive, and ongoing care in the community.

Cost limits based on population averages do not reflect individual need or risk.

The A&D Waiver serves a diverse population that includes children and adults with complex medical conditions, progressive disabilities, and high support needs. Applying cost benchmarks derived from average nursing facility utilization among aged individuals fails to account for the specialized services, skilled supports, assistive technologies, and increased caregiver hours required to safely support medically complex participants in community settings.

These individuals often require services that exceed typical utilization patterns, not due to inefficiency, but due to medical necessity. Cost limits that do not reflect this reality risk functioning as a barrier to access rather than a fiscal safeguard.

Nebraska administrative requirements support individualized, needs-based services.

Nebraska administers HCBS waivers under the authority of Neb. Rev. Stat. § 68-901 et seq. and Title 471 of the Nebraska Administrative Code, which emphasize eligibility determinations, service authorization, and planning based on individual assessment and level of care. While cost neutrality is a federal requirement, it is intended to be evaluated at the waiver level, not as a rigid cap that overrides individual medical and functional needs.

Cost limits that rely on generalized averages undermine Nebraska's person-centered service planning framework by constraining service authorization before individual needs are fully considered.

Cost limits must account for medical complexity to avoid unintended institutionalization.

For medically complex individuals, community-based care—while sometimes more expensive on an individual basis—remains less costly and more appropriate than institutional alternatives over time. When cost limits are set too low to accommodate specialized care needs, participants may face preventable service reductions, unmet medical needs, increased hospitalizations, or forced transitions to institutional settings.

These outcomes conflict with Nebraska's stated waiver goal of rebalancing long-term care and may raise concerns under Olmstead v. L.C., which requires states to administer services in the most integrated setting appropriate to an individual's needs.

Averages obscure variability and penalize high-need participants.

Using average cost data from an aged population effectively shifts financial risk onto participants with disabilities and medical complexity. This approach fails to recognize that variability in cost is inherent to a waiver serving individuals with diverse diagnoses and support needs. Without meaningful flexibility or exceptions, cost limits may disproportionately impact children with disabilities, individuals with rare conditions, and adults requiring specialized or 24-hour supports.

Recommendation

I respectfully urge the Department to revise the individual cost limit methodology to better

account for medical complexity and individualized need. This could include the use of acuity-based adjustments, condition-specific considerations, enhanced exception processes, or alternative benchmarks that more accurately reflect the true cost of supporting medically complex individuals in community settings.

Ensuring that cost limits are flexible, individualized, and clinically informed will better align with Neb. Rev. Stat. § 68-901 et seq., Title 471 NAC, federal HCBS requirements, and Nebraska's commitment to community integration and person-centered care.

Thank you for the opportunity to comment and for considering the needs of medically complex individuals and their families who rely on the A&D Waiver to remain safely in their homes and communities.

Sincerely,
Waylon Vajgrt

From: Megan Naber
To: DHHS HCBS Public Comments
Subject: A&D waiver
Date: Thursday, January 1, 2026 1:30:58 PM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

To whom it may concern:
On December 5th DHHS released proposed changes to the AD waiver. Part of these changes was to LIMIT live in care giver hours to 40 hours per week. For some of these live-in providers and their clients, this change would be very detrimental. Some of the MOST disabled folks in our state receive the maximum amount of 112 hours per week for their paid care (payment for 16 hours per day of care). Of that group, live-in caregivers provide the majority of those hours. Many of these live-in caregivers are parents or spouses of these disabled people, and many of them have left careers to take care of their loved ones. Some have been caring for their loved ones for 30 years or more. To suddenly cut their hours and income by 72 hours per week is DANGEROUS and very destabilizing for these disabled clients. This could lead to the loss of homes, mental health crises, hospital stays, and possibly death for some of the most medically needy clients.
Families affected by these changes will face severe financial issues. A loss of 72 hours per week at $15.00/hour is a cut of $4320 per month for these households. How will they be able to find jobs that pay that much, as people who have been out of the work force for so long? These families must also balance doctor appointments, hospital stays and the stress of caring for their loved ones, which would make working outside of the home very difficult for them at times. This plan assumes that suddenly, after YEARS of searching, hiring, training and losing paid care givers, that they can find someone to do their jobs. This is further complicated by the fact that these paid caregivers aren't able to administer medications or provide the medical decision-making necessary to ensure proper care for clients at all times, which means our most disabled will be in danger.
This plan will NOT work for the most medically fragile and high needs disabled adults on this waiver. If you are to go forward with limiting live-in care givers to 40 hours per week, you will be forcing people to sell their homes and put their loved ones into nursing home facilities. The waiver program was created in order to stop this exact situation from happening. Also, moving disabled clients into nursing homes will be further complicated by a current shortage of Medicaid funded beds available.
Instead, we propose that since this waiver has enough funds to make it through this year, that you spend this year meeting with the families of these individuals and create a plan that will actually work. I believe there are solutions available in this situation! The current system that's in place was created for individualized care, and there are already evaluations that were created to determine services and hours. If you want to create caps, please do it moving forward--not retroactively and NOT so suddenly and NOT so drastically. Consider contracting with each family individually (perhaps less agency contracting and more live-in caregiver contracting?), consider a tiered system like DD services use to determine pay rates.
Respectfully,
Megan Naber, Doctor of Occupational Therapy

From: Reece Waugh
To: DHHS HCBS Public Comments
Subject: Accessible vehicle program is completely inaccessible
Date: Wednesday, December 17, 2025 5:43:43 PM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Given the income limits for the waivers how do you expect disabled individuals to afford a basically new vehicle? Often assessments for modifications can't be done until a vehicle is purchased but you need to know what modifications you need before buying a vehicle. This program is complete nonsense and does not work in any aspect. Thank you for your time.

From: [redacted]
To: Lieske, Jillion
Subject: AD & TBI waiver cuts
Date: Thursday, January 1, 2026 10:22:32 PM

You don't often get email from [redacted]. Learn why this is important

Hello

I would like to tell you about my son who is going to have his whole life challenged even more if these Medicaid cuts go into effect.
My son‘s name is Christopher. He was 23 when he had a seizure when riding his motorcycle to work. You see my son has worked all the way through high school. He had just started two businesses a landscaping and a tree service. He paid his taxes and donated time and services to people in need. And it all changed on August 19, 2011 when he had his accident.. Christopher now suffers from a traumatic brain injury from lack of oxygen, and he was left with catastrophic injuries. Chris can no longer talk, walk, paralyzed on his left side in a wheelchair, and he’s incontinent has seizures, swallow and his eating is affected, he’s not able to do bed mobility, his cognition is low and he is nonverbal. I have helped Chris go through all the stages of healing. We went from the vent unit to the acute care to long term care wing fighting to come home. You see this is so catastrophic. he had his whole life ahead of him. He feels like he’s lost his dignity, his pride, his future, and now with these cuts, he’s going to lose his home and the opportunity of living the best quality of life in this situation and that would be at home where there’s people that know how to care for him who want to care for him who love him. We have to be able to survive in order to take good care of him and ourselves. I worked several years as an independent contractor for State Nebraska caring for my son and received minimal pay. I can’t help but wonder if the people that are making these decisions, realize how much work the parents or loved ones do without pay. I mean, no one’s looking to get rich. We’re just trying to take care of our children and give them some kind of quality of life. I mean, my son is approved for 140 hours a week I work 85 of them hours through the agency because it’s hard to find help but they do supply help with the remaining 55 hours with a different aide. That’s not including the 28 hours that I work off the clock and the emergency hours from no call no show or they cannot fill the visit since we can only work 16 hours a day on the clock. I also hope that the people that are making these decisions realize that we have based our bills on our income and they’re taking that all the way, so I personally will be losing my house in Chris’s home!

I have two College Degrees and I have given that all up to take care of my son for the last 14 years. I am now 62 years old and in order to go back to work in my field of study I would have to take refresher courses and pass my boards again because I did not keep up with my continuing education classes because again I was caring for my son. And I did not complain. I was there and I did the work. stayed bedside while he was in ICU in Kearney I travel to Lincoln. I stayed with Chris while he was in the vent unit, but he went to acute care when he went to QLI in Omaha in for homebound care. I'm grateful that he is alive and here with me and I can take the best care of him. I can just hear him breath and know if he's struggling, you see my son cannot adjust himself in bed. He cannot lay flat or he could aspirate. My son cannot put his oxygen back on if it falls down which it happens a lot, my son aspirates on his own saliva so he needs suction on a regular basis . Christopher requires a G-tube place in his stomach to dispense his medication's, and his nutrition shakes and water. Chris does eat food orally with thicken liquids. Chris needs assistance with all his personal cares, brush his hair, brushing his teeth, showering toileting, eating dressing, communicating.He needs a lift to be transferred from bed to wheelchair, I have to make all his doctors appointments go to all his doctors appointments on or off the clock, arrange for Transportation to and from doctors appointments, therapy appointments, , talk to his service coordinator. Keep up with all his prescriptions. Apply splits to his arms after range of motion and stretching to his arms and legs because Christopher also suffers from spasticity that is so painful and severe that I have to take him to Omaha to get Botox injections to give any kind of relief for that child. He also has a baclofen pump is placed on his right flank that feeds a muscle relaxer up his spinal cord to help with decreasing spasticity and tightness . And please remember this is all going on to a person that was a upstanding citizen and now he has to feel like when he's at his lowest point in his life and needs taken care of his being throw in the trash and left feeling like he's less than and that just is not right. My son deserves better. I don't understand why the state would be willing to pay an extended family thousands of dollars a month but they complain about the little bit of money I get as his mother who's had him in my home for 14 years by myself I will add. I am a single mother. There is no help. His father died nine years ago of cancer and he didn't come around much anyway. Siblings are not able to help they have kids of their own and work lots of hours themselves due to increased cost of living.

Now let's talk about the modifications. I took care of my boy on little or nothing in an apartment that didn't deserve what I paid because it had nice wide hallways to aide in wheelchair movement. I finally was able to buy a house so

Christopher can live at home comfortably and the State paid for modifications which included a role in shower and a ramp for the entrance in the front door, which cost thousands of dollars. And you're telling me that in July, I will lose my house now. I will have to place my son in a nursing home that's not able to care for his needs. He falls into the category of the most vulnerable population for neglect abuse. And in my home, the state just paid for modifications to put in a roll in shower and a ramp for the entrance into the home which I know cost thousands of dollars. But you don't care about losing that money I mean, I just don't understand the thought process here. In the families that can't find a place for their children they'll have to go to the hospital in the ICU, which will cost three times. If not more for just a couple nights stay then it would at home with the parents or family member that was taken care of them originally with no problems and cheaper. The math is not adding up.

I would like to know the names of the people that's on this panel that's making all these decisions. I feel that the citizens of Nebraska have a right to know its aggressor because they definitely are not working to help us. They're literally killing our children. I'm also curious if there's any members on this so-called panel that has a disabled child is there anybody around this legislature that has any kind of idea what you're expecting out of these family? I ask that the people on this committee please take another look at your proposal and realize that this is unrealistic to do to so many people.

PLEASE READ!!!

Family Providers Are Performing a State-Delegated Role — Not Ordinary Parenting

• Under Nebraska law and Medicaid policy, once an individual reaches adulthood, they are legally responsible for themselves to the extent they are able.

• The State of Nebraska, through Medicaid and the AD Waiver, holds responsibility to ensure:

• Health and safety

• Access to long-term services and supports

• Alternatives to institutionalization

• When a parent or family member becomes a paid AD Waiver provider for an adult child, they are:

• Voluntarily assuming duties that would otherwise be fulfilled by the state

• Performing skilled, time-intensive, and often medically or behaviorally complex care

• Preventing the state from having to fund higher-cost agency or facility services

This is not compensation for parenting — it is reimbursement for delivering Medicaid-authorized services that the state is obligated to provide.

—

The Care Provided Exceeds Normal Parental Duties
• AD Waiver services involve:
• Assistance with multiple ADLs and IADLs
• Continuous supervision to prevent harm
• Behavioral intervention and crisis prevention
• Medical monitoring and hands-on personal care
• These tasks go far beyond what is expected of parents of adult children without disabilities.
• If a parent were not providing this care:
• The state would be required to pay an agency or facility to do so
• The legal obligation would not default back to the parent

—

Payment Recognizes Substitution for Paid Providers, Not Family Status
• Payment under the AD Waiver is based on:
• Authorized services
• Documented need
• Compliance with Medicaid rules
• The relationship of the provider (parent, sibling, spouse) does not change the nature of the service being delivered.
• The only reason parents are present in these roles is because:
• The workforce is insufficient
• The individual tolerates only trusted caregivers
• Families stepped in to prevent institutionalization

—

Denying or Limiting Family Providers Shifts State Responsibility Without Consent
• When family providers are capped or excluded:
• The care requirement does not disappear
• The burden is shifted back onto families without compensation
• This creates an unfunded mandate on families and undermines Medicaid’s

purpose.

Families did not create the need for these services — the disability did. The AD Waiver exists to meet that need regardless of who delivers the care.

—

Equity and Disability Rights Framing
• Adults without disabilities are not expected to rely on their parents for lifelong personal care.
• Expecting families of people with disabilities to provide extensive unpaid care solely because of family relationship is discriminatory.
• Paying family providers ensures equal access to services, not special treatment.

—

Parents and family members serving as AD Waiver providers are not being paid to parent. Parents are doing extraordinary cares. They are being reimbursed for delivering Medicaid-authorized services that the state is legally obligated to provide to an adult individual who cannot safely meet those needs independently. Limiting or dismissing family providers does not eliminate the state's responsibility — it simply shifts it onto families without compensation or consent.

Please don't support these cuts and caps!!!!

Michelle Nunnery
[redacted]

Sent from Yahoo Mail for iPhone

From: Dianna Mastny
To: DHHS HCBS Public Comments
Subject: AD and TBI Waiver Programs
Date: Thursday, January 1, 2026 1:59:18 PM

> You don't often get email from [redacted]. Learn why this is important

To whom it may concern,

As a tax payer in Nebraska, I'm begging you, PLEASE DO NOT CHANGE THE WAIVER PROGRAMS.

I know a little girl in Wausa who was paralyzed from the neck down in a car accident when she was 2 years old. She is now 6. Her mother is her primary caregiver. She is on a ventilator and requires life saving medications that need to be administered by a trained professional or her mother, who has been by her side since this nightmare happened to them. They are exhausted and worried but never complain. They need these benefits to care for Aubrey. These are the most vulnerable people and are the ones these types of services are meant to help care for.

I understand we need to be good stewards, but there are plenty of other areas in DHHS that can be looked at for savings.

Thank you for reading and I hope that these services are not cut.

Sincerely,
Dianna Mastny
[redacted]
Yahoo Mail: Search, Organize, Conquer

From: Jennifer Melvin
To: DHHS HCBS Public Comments
Subject: AD Cuts
Date: Sunday, January 4, 2026 10:05:29 PM

You don't often get email from [redacted]. Learn why this is important

To whom it may concern:

On December 5th DHHS released proposed changes to the AD waiver. Part of these changes was to LIMIT live in care giver hours to 40 hours per week. For some of these live-in providers and their clients, this change would be very detrimental. Some of the MOST disabled folks in our state receive the maximum amount of 112 hours per week for their paid care (payment for 16 hours per day of care). Of that group, live-in caregivers provide the majority of those hours. Many of these live-in caregivers are parents or spouses of these disabled people, and many of them have left careers to take care of their loved ones. Some have been caring for their loved ones for 30 years or more. To suddenly cut their hours and income by 72 hours per week is DANGEROUS and very destabilizing for these disabled clients. This could lead to the loss of homes, mental health crises, hospital stays, and possibly death for some of the most medically needy clients.

Families affected by these changes will face severe financial issues. A loss of 72 hours per week at $15.00/hour is a cut of $4320 per month for these households. How will they be able to find jobs that pay that much, as people who have been out of the work force for so long? These families must also balance doctor appointments, hospital stays and the stress of caring for their loved ones, which would make working outside of the home very difficult for them at times. This plan assumes that suddenly, after YEARS of searching, hiring, training and losing paid care givers, that they can find someone to do their jobs. This is further complicated by the fact that these paid caregivers aren't able to administer medications or provide the medical decision-making necessary to ensure proper care for clients at all times, which means our most disabled will be in danger.

This plan will NOT work for the most medically fragile and high needs disabled adults on this waiver. If you are to go forward with limiting live-in care givers to 40 hours per week, you will be forcing people to sell their homes and put their loved ones into nursing home facilities. The waiver program was created in order to stop this exact situation from happening. Also, moving disabled clients into nursing homes will be further complicated by a current shortage of Medicaid funded beds available.

Instead, we propose that since this waiver has enough funds to make it through this year, that you spend this year meeting with the families of these individuals and create a plan that will actually work. I believe there are solutions available in this situation! The current system that's in place was created for individualized care, and there are already evaluations that were created to determine services and hours. If you want to create caps, please do it moving forward--not retroactively and NOT so suddenly and NOT so drastically. Consider contracting with each family individually (perhaps less agency contracting and more live-in caregiver contracting?), consider a tiered system like DD services use to determine pay rates.

Also please consider seeking out the funds you need:

a. Find an agency or non-profit, or create one, and begin to hold an annual fundraiser that gives average Nebraskans and wealthy Nebraskans a chance to care for the disabled of our state.

b. Perhaps the Huskers could run a fundraiser at one home game a year where they advertise the needs of those who are disabled in our state and give a matching percentage of ticket sales

that day.
c. Would the Volleyball team and their fans want to help protect the disabled of our state?
d. Ask the Nebraska legislature to allocate more money for this program, due to the rising number of individuals in this program. I believe this sort of thing happens (for example, asking for raises for state employees, you look at the cost of living and then approve a 3-6% raise for your employees). A request for additional funding seems appropriate in this situation.
i. Or perhaps it would be a GREAT time for the legislators to PAUSE or freeze the corporate tax cuts that are creating some of these budget shortfalls?
e. Would Larry the cable guy be willing to help in some way as a Nebraskan with a HUGE platform? Would Warren Buffett want to help? We could ask some of the wealthiest Nebraskans to step up for those who are disabled in our state.

Please consider solutions that are PEOPLE focused, individualized and caring, not just focused on the dollar signs. Thoughtful policy making will ensure that those who are disabled, as well as their families, can continue receiving the care they need and avoid damaging and life-altering circumstances. This waiver program has blessed a whole lot of Nebraskans and allowed them to flourish. It has helped provide dignity and care for so many people! Please consider that as you move forward and make necessary changes.

PLEASE do NOT move forward with this unjust and dangerous proposal to cap live-in caregivers. please see how your own handbook says DO NOT DO THIS. it will hurt our most disabled Nebraskans.

Yes. Based specifically on the language on pages 127–128 of the AD Waiver proposal, there are several internal inconsistencies and conflicts when you line up personal care hour caps, exceptions, and who is allowed to provide the care. I'll break this down clearly so you can use it for comments, appeals, or advocacy.

—

1. Conflicting Hour Caps vs. "Health and Safety" Exception Language

What the proposal says
• 40-hour cap for Personal Care + LRI Personal Care when the caregiver is live-in
• 70-hour combined cap for Personal Care + LRI + Companion
• Exceptions may be approved by Central Office to meet immediate health and safety needs

Inconsistency
• The proposal acknowledges that some individuals have needs that exceed 40 or 70 hours for health and safety,
BUT
• It does not align those exceptions with 24/7 care needs, even when those needs are already documented and previously approved.

Why this is a problem
• A person who needs continuous supervision or hands-on care cannot have their health and safety met under a hard weekly cap.
• The exception language is written as temporary or emergency-based, not as recognition of

ongoing, permanent high needs.

Contradiction: The proposal admits higher hours are sometimes required, but structures the system so those needs cannot realistically be met long-term.

—

2. Provider Restrictions Conflict With Tolerance, Routine, and Disability Needs

What pages 127–128 do
• Strongly limit who can provide care:
• Live-in family caregivers capped lower
• Greater reliance implied on non-family or agency providers
• Treats family care as something that should be restricted, not individualized

Inconsistency
• The proposal:
• Claims to be person-centered
• References health and safety
• But ignores the reality that:
• Some individuals do not tolerate unfamiliar caregivers
• Routine and trust are medically necessary, not preferences

Conflict: You cannot claim person-centered planning while forcing care from providers the individual cannot safely tolerate.

—

3. Unequal Treatment Based on Provider Type, Not Need

What the proposal does
• Two people with the same assessed needs can receive very different hours depending on:
• Whether care is provided by family
• Whether they can tolerate outside staff

Inconsistency
• The waiver is supposed to be needs-based, yet:
• The cap applies more harshly to family providers
• Individuals who cannot accept outside providers are effectively penalized

Result: The proposal creates artificial scarcity, not based on needs, but on provider category.

—

Option 2

Email to: DHHS.HCBSPublicComments@nebraska.gov
To whom it may concern:

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e. Would Larry the cable guy be willing to help in some way as a Nebraskan with a HUGE

platform? Would Warren Buffett want to help? We could ask some of the wealthiest Nebraskans to step up for those who are disabled in our state.

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Thank you for your time in this critical matter.
Jen M

Yahoo Mail: Search, Organize, Conquer

From: Jennifer Melvin
To: DHHS HCBS Public Comments
Subject: AD Service Hours
Date: Sunday, January 4, 2026 4:56:38 PM

You don't often get email from [redacted]. Learn why this is important

To Governor Pillen, Nebraska DHHS Leadership, and Nebraska Lawmakers
A mother's voice for her child... If Tabitha could talk to you, I like to think this is what she would say.

My name is Tabitha, I have a rare genetic disorder called PCDH-19 epilepsy.
It's a rare genetic condition that causes severe seizures that are difficult to treat and was only discovered in 2008.
I lived the first 15 years of my life battling severe seizure clusters, putting me into the ICU, sometimes even coma to treat before I finally got my diagnosis. By the time I was 2 I'd had thousands of seizures, multiple medical emergencies and surgeries. I have lost a kidney, had an eye biopsy, muscle biopsy, liver biopsy, and brain surgery to separate the 2 halves of my brain, all done without an answer or cure. Then the genetic testing was done and we got the devastating news, PCDH19 incurable rare epilepsy.

I speak with limited words and some signs and rely on my mom to understand my needs-spoken, unspoken and physical. I developed lupus antibodies in 2020 just as covid hit, which caused a blood clot that went from my right hip all the way behind my right knee. We tried for weeks to break it up, with an emergency room visit due to a severe reaction to the coumadin, thankfully my mom drove me daily to get my meds and was hypervigilant in my care or things could've gotten bad. I received my emergency meds and was better, but now I have to have injections every night of lovanox for the rest of my life. This was my second blood clot.

The first one was when I was 17 months and developed a bladder infection. My parents took me to the hospital ER daily for a week and the drs didn't catch it so we headed to Omaha where they found 5 renal abscess's, with one being the size of a pool ball. (The kidney was used as a teaching tool at UNMC)
I was rushed into emergency surgery with only a 30% chance of making it. My parents were there for every moment praying and slowly, with many meds, supplements and lots of care I survived.

I now have to use a wheelchair as walking long distances is hard with that scarred blood clot vein in my leg. I am on multiple medications due to many issues and my mom keeps them all straight for me to take during the day and night. I also require oxygen that my parents have to pay for because insurance wont cover it, even though it's the first thing the ambulance crews and ER staff administer. I have had multiple ER visits and ambulance rides as well as hospital stays in the first few years of my life. My parents educated themselves in my needs and condition so that, with the help of our doctors, they can keep me home, in the safest, most comfortable environment.

My body needs constant, skilled, attentive care. My mom has to check my legs every morning for blood clot symptoms, I still have cramps in my right leg so my mom has to sit with me on the floor to put lotion on my leg and rub the cramps every morning.
I tend to rip off my toe and fingernails due to trichotillomania. So she has to monitor my nails for infection, ingrown or hang nails.
I often pick my arms, face and hands due to OCD and sensory issues so she has to monitor those sores as well.

I can’t tell you when something hurts, I'm in pain, or when a seizure is going to happen or if I feel sick. I have, on average 15-30 seizures a day, monitored by a VNS implant. My safety depends entirely on the people caring for me understanding me and monitoring me. We have a video monitor for at night so they can see me when I make noise to make sure it isn't a seizure. My parents haven't slept in years due to the fact that I do not sleep more than a couple of hours at a time and I often make meses in bed and have

to be changed several times a night. Not to mention the loads of laundry every day from these messes.
My mom is who I am most comfortable with.
She's not just a “family caregiver.” She's my nurse, my emergency response person, my translator, my advocate, and my playmate. My family knows my routines, my cues, my seizure patterns, and the subtle signs that mean, 'I'm ok, or I'm not ok'
I have lots of allergies, so my mom is hypervigilant to my face, eyes, skin for signs of rash. I've also had issues with medication causing liver problems so my mom has to monitor for signs of that as well.
I have incontinence, so my mom has to make sure I'm changed, a lot due to all the fluid intake I have to have because of only having one kidney.
The kind of knowledge my mom has doesn’t come from a handbook. It comes from years of experience, sleepless nights, and loving me fiercely.

With my family and my mom , I am safe. they have prevented wrong medication, over medication and further malpractice.
Without them… well, let’s just say I am at risk of many medical complications
.
Recent policy decisions and proposed changes are putting families like mine in impossible positions. Decisions made without seeing me, without entering my home, and without understanding the reality of my care risk separating me from the people who quite literally keep me alive.
I am asking—respectfully, sincerely, and yes, a little desperately—for grace.
Grace for parents who have already rearranged their entire lives around their child’s survival.
Grace for families whose “informal care” is anything but informal.
Grace for people like me, who do not benefit from unfamiliar hands or constant change. My parents have made their home safe for me, cater to my needs and provide all the tools needed for me to thrive.

This isn’t about convenience.
This isn’t about cutting corners.
This is about safety, dignity, and staying alive.
When policies remove parents from providing care, they don’t replace them with a system—they replace them with risk. Risk of missed cues. Risk of medical error, Risk of fear, Risk of Death. Not to mention an increase in cost, not decrease. And our family has enough going on without adding all that to the list.

When you suggest utilizing family, day programs or other supports you don't understand. THERE IS NONE. There are no programs that take 27 year olds in diapers, with the mentality of a 2 year old and with dozens of seizures. Family have families and medical conditions of their own and the neighbors/church etc are not available, but if they were, they simply do NOT have the medical knowledge or experience to care for me.

So instead of guessing, I’d like to make you an offer.
Please—come into my home. Sit with my parents. Watch my care. See what it actually takes to keep me safe for a single day. Notice how much knowledge, vigilance, and teamwork is required before lunchtime even rolls around. I promise, it will be more informative than any spreadsheet—and you might even leave with a new respect for hypervigilant awareness.
Because I am not a policy.
I am not a budget line.
I am not a theoretical outcome.
I am a person.
And there are many others like me across Nebraska—quietly relying on parents who are doing extraordinary work every single day. The decisions you make will determine whether those families are supported… or stretched past what any human can carry.
Please slow down. Please listen. Please let compassion sit at the table with compliance.
Protect my right to be cared for by the people who know me best, love me most, and have already proven —every single day—that they can.

Thank you for your time,
Tabitha Melvin
(from a mothers heart)

From: Amy Davis
To: DHHS HCBS Public Comments
Cc: Amy Davis; Amy Davis
Subject: AD Waiver - concerns of proposed changes in regards to hours
Date: Thursday, December 18, 2025 2:44:33 PM
Attachments: [redacted]

You don't often get email from [redacted]. Learn why this is important

Good Afternoon,

I am writing to give you some insight on our personal situation and how the loss of hours would deeply impact my son's ability to prosper and progress.

On September 24, 2024 my son, Justin, called me around 4:45 pm stating he had an extreme headache..he asked me to come home because it was like none other he has ever experienced. By the time I got home, he was on the floor in the kitchen surrounded by his vomit. His older brother Michael was trying to clean up the area and support his brother. Once I got there we got him over to the sofa where he eventually vomited again and fell off of the couch. We attempted to take him to the ER but in the process of getting my vehicle ready, my oldest son Michael yelled out… call 911 MOM – he's not breathing! The 7-10 minutes it took for the paramedics and firefighters to arrive my son Michael(23 yrs old), was on the phone with the 911 operator being told how to give CPR and administering it until they arrived. It was the most terrifying moment for both my son Michael and I – as we watched my youngest boy slipping away – white as a ghost and blood trickling down out of the corner of his mouth – It was so surreal and unimaginable.

Once help arrived, we had 10 + firefighters/paramedics in our home and then police as well – while my son was still on my living room floor getting worked on – we began getting questioned as to what happened and if we believed if there was any thought he may have done this to himself (drugs) etc. Then we had the narcotics unit show up – which I opened my home for them to do whatever they needed to do – I was appalled that this was the focus they were pulling both myself and son into while my other boy is getting life saving measures and being loaded into the ambulance – but it is what it is… I do understand that getting a call that a 20 year old male is unconscious in cardiac arrest at his home unfortunately these days they must rule out pill popping and overdoses – it's a sad world we live in these days.

We immediately headed to BryanWest ER and met up with my son Justin – when we arrived – we were ambushed by medical providers saying that my son was rushed to get a CT scan and it was noted he had a substantial brain bleed and that Dr. Gogela was on his way in to do an emergency craniotomy to relieve the pressure on his brain and that time was of the essence.

At 10:30 that evening – my son Justin has a bed in the ICU – we walked in to his head ½ shaved, with 30+ staples in his head with his skull removed – a 7 inch incision/wound in his right side of his stomach – this is where they put Justin's skull to protect it while his brain was swollen. He was intubated as he had gone into pulmonary failure, was on an ungodly amount of blood pressure medication due to cardiac failure and then being told he had a hemorrhagic stroke with the belief that he has an undiagnosed AVM that ruptured. In the coming days/weeks they performed many tests/scans – it was determined by bringing in a 2nd neurosurgeon Dr. Hawkins to do a angiogram that Justin indeed did have an AVM and they (Dr. Gogela and Dr. Hawkins) needed to embolize the feeders in his brain that were bleeding and to stop any other potential bleeds from occurring. They were not able to remove the AVM but were able to embolize all areas they feel would be a risk for him. (As of now, we do know an additional feeder has grown, we are needing to go in for another angiogram to determine if another embolization is necessary but unfortunately we had it scheduled for the first part of December but due to Justin's health – recent 17 day stent in the hospital – they decided to wait to make sure all other underlying health issues were under control and will reschedule most likely this coming January.) Justin was in the ICU at BryanWest for 28 days… during this time, they had to insert a feeding tube, he was given a tracheotomy and battled for his life.

After 28 days in ICU, Justin was transferred to Madonna Hospital – Long Term Acute Care – he stayed there for 5 weeks before being moved down to the Madonna Acute Care area – being that Justin had a stroke and brain injury (ABI- acquired brain injury) the administration was very lost as to where Justin would fit in and where he should go… honestly, they are set up for TBI care and working on ABI…but they are in no way an expert in ABI, I learned this first hand (scary) – and then he wasn't a typical stroke patient… they usually work with more Ischemic stroke patients… he ended up in the general rehab area for a bed, but continued to get PT, OT and SP – I will tell you, this didn't look like what most people think of….when Justin opened his eyes – he woke up to a new world – once a fully functioning young man, who worked, had a normal life and who was planning on becoming a DSP with Mosaic of Lincoln and begin college in Human Services… he woke up to not being able to see without double vision, loss of some vision in left eye, unable to speak, having a trach in his throat to breath, unable to move his body purposefully, his skull in his tummy and attached to machines and someone having to do 100% of all cares on him… oh my heart… but he was 20 and there was/is hope for him to have a purposeful life – every trusted medical provider just kept saying… this will be a marathon not a sprint, he is a young man.. that is on his side – if it was my son, I would do the exact same thing!! With a brain injury there is no time table we can rely on – the brain will heal when it heals but having the proper stimulation, medical team support, family – we can draw him out mentally and slowly as his brain develops new neuro pathways we can continue to help him relearn how to use his body the best he can. The same theory applies… if you let him lay there, no stimulation, only take care of his medical needs.. he will stay the same or deteriorate – this is not an option – nor should it have to be – he has the ability to be home with me and be in a safe, caring, home – his home for his whole life.

While we were inpatient at Madonna, Justin had severe diarrhea.. I expressed that I thought my son was lactose intolerant even though he had never been diagnosed with it just based on his previous comments/habits prior to this event… we then changed his formula to Kate Farms which is lactose free and more organic… we started to notice a change…but he continued to have diarrhea so they added banatrol 3 X a day which is a fiber supplement and incorporated a bowel program (meaning enema in morning to try and slow down the daily diarrhea) still not working… I eventually started talking with a nurse and ask her if there was any other source of lactose which they said no… however, one day when they were giving him banatrol I asked them to look at the packet with them to see what the ingredients were and low and behold it had lactose in it. BOOM – that was HUGE!! We immediately stopped giving him that… and we ended the bowel program and the intense diarrhea stopped – he would and still will have some loose stools but it is not every hour daily – this obviously impacted his ability to do therapies at Madonna – we lost a lot of time (120+ days) of good therapies because he was soiled during the time he was to be in therapy – it was really a sad thing… he really needed those therapies at the early stages …. I am very thankful for what he was able to get but very frustrated that it took ME to determine what was making him physically ill and his medical providers just looked at his chart and assumed it was his brain injury and how his brain was working…

Justin had to go back to BryanWest to get his skull put back in, however, when he went back he came in with a fever and high blood pressures so they did blood work and found his white blood count was elevated – this was a huge concern – IF an infection was present, it could potentially contaminate his skull which was in his tummy – which would mean we couldn't reattach it. After multiple days and neurologists, Infectious Disease, IPA and Neurosurgeons – it was determined that he was not sepsis -they did treat him on broad spectrum antibiotics initially but then were able to stop – they determined he was dealing with the PAID syndrome which is typical for neuro patients to get which can cause the autonomic system to not work property which can cause some crazy things to happen – it was also determined that Madonna had titrated down on one of his meds too quickly and he was put back on the full dose and told not to touch again. After 2 weeks, Justin was discharged from BryanLGH back to Madonna, but this time, was admitted into the A2 floor of the Brain injury part of Madonna. He stayed there until the first week of February – until he was able to find an acceptable skilled nursing facility that would take him, but most importantly, to a place that WANTED him and WANTED to HELP HIM rehab. At this point of the journey, Justin was still considered minimally conscious and part of the "disorders of consciousness" state (COMA stage but awake at times)

Side bar note: We really tried to stay in state – we had been told QLI was an amazing facility and actually I contacted them while Justin was still in the ICU way in the beginning – they said they would consider him but it was too soon and that we could ask them to follow his case – we then worked with Madonna too to see if they could help with a referral to QLI – at the end of the day… they denied him – they said he wasn't at a place where they felt they could help him – this was heartbreaking because he needed more and we didn't know what to do..I couldn't believe there was only ONE place in Nebraska that was a possible option but wasn't an option for my

son. I wondered… why don't they want to help my son? Why isn't he good enough? What are we supposed to do…. Then On With Life became an option… I also visited with some other out of state rehab facilities that were peppered throughout the US… Texas, Colorado, Florida, and some other East coast facilities… but OWL seemed to be the BEST option and they ACCEPTED him and were very excited for him to come… but they warned me upfront… we really would like to have Justin for 5-6 months… that is what he needs but we will do the best we can in the time your insurance will allow him to stay… so we proceeded.

On February 6, 2025 Justin was discharged from Madonna, and was admitted to **On With Life in Ankeny, IA** – this was the biggest blessing!!! Unfortunately, we only could stay here for 58 days due to insurance restrictions (max benefits) and they will not accept Nebraska Medicaid because in a previous situation - they had been given authorization but then they didn't follow thru with paying the claims… which is so unfortunate because ON WITH LIFE is simply an amazing NON-PROFIT organization that provided MORE REHAB then Justin received while being at Madonna – he received more person focused care and they pushed him to his limits and exceeded them – bottom line… they weren't afraid of the situation and they knew what to do…. On With Life specializes in the disorders of consciousness stage – unfortunately they see less and less of this type of individual because the doctors don't know where to refer or simply send individuals like my son to a nursing home to rot or the doctors are recommending families to let their family members go early on in the process and say there is no hope for their family member with this type of brain injury – I know this first hand unfortunately – I had an on-doctor do this while my son was in ICU, I kindly told him, thank you for your opinion, I will be proceeding with our plan with the support of our neurosurgeons, Thank you. At that point, I took my son off of the DONOR list and I didn't hear anything more about that.

While at On With LIFE, Justin emerged!!! What does that mean?? He was able to test out and be considered "Conscience" We determined a system using his eyes – one blink for yes and 2 blinks for no. We were working on an eye gaze system there and if we had more time the speech therapist wanted to get him a trial one and this would've been a game changer as he would be able to use his eyes to say his needs and to be able to talk – he would have a voice while we continued to rehab him to try and swallow, eat, open mouth, make sounds, and eventually talk…. He was able to identify and respond to all of the items in the test and passed with flying colors – It was truly an amazing day! Then they had to do it again a week later to make sure it was a true result and not just a fluke… he passed again – it was so encouraging. We also worked with some hand switches and buttons but those were a struggle with the amount of dystonia my son had/has in his arms and hands – but that didn't stop us from trying. He was learning to use a "people feeder" device while at OWL (to this day none of the therapists in Lincoln have known what that is) We were doing food trials – daily – he was eating apple sauce, pureed fruits..we trialed some hot foods but with him still learning how to swallow consistently. To this day – we do some trials but not as much as we did there – I am hoping to have speech work with me more on this – we learn together a lot I have noticed since we have been home with home health – Justin again is not their typical client which is what I hear every time we have a new agency, new therapist, new doctor, new care giver – so its always trial and error.

While at one with life, I was taught so much! They incorporated me in all the therapies – they asked me to participate as much as possible to learn and because they noticed that he responded better when I was there – I was fortunate to have On With Life allow me to stay in their family housing for free the whole time he was there so I could be there every day with my son and to learn the therapy side as well as be able to communicate his daily care needs – At On with Life I believe their staff ratio for CNA's was like 10-12 patients to 2 CNAs – on a good day – which actually is much better than a typical nursing home which can be 2 CNAs to 18-20 patients.

The biggest struggle with living in a care facility was the lack of time available to take care of my son – he developed redness and sores on his bottom at both Madonna and OWL initially but after a couple of weeks they got better. However, the normal rounding is every 2 hours – but that wasn't sufficient for Justin as he wet himself or poo right after they came in checked and he would be sitting in that until the next check – he doesn't have the ability to hit a call button like most of the other people there so he would get missed or looked over as he wasn't the squeaky wheel – unless I was there… then I could be his advocate and get staff. I realized while I was out of state with my son… that the system we have in place to take care of my son, would not be acceptable conditions and would eventually lead to his death. I knew I needed to be there in person to make sure he was taken care of properly. He already is having to live within himself while we try and rehab him – but to let him rot in his own feces and urine and not having interaction with other people except when they come in to "change him" or "give him meds" was just not enough – it wouldn't be enough for me or anyone to thrive and want to live and part of this whole process for my son is him needing to have a positive attitude internally to give him the drive to want to rehab… to understand we are not giving up and so can't either… If someone doesn't have the will to live… they will eventually give up and that isn't acceptable.

We arrived back in Nebraska on April 5, 2025 – we rented a handicapped accessible van and we drove Justin home to our family home. I have owned the home since 2003, and Justin was born in 2004. It was exciting to bring him home but I was very nervous too – I had learned so much, now was my time to put it all together and be his full time caregiver – doing all parts not just assisting and not just the fun parts. It is A LOT of work!! Initially, we didn't have services in place so for about 3 weeks – there was no source of income and no helpers – about 1 week in we got Tabitha to come out for home health needs – this was a life saver for both Justin and I – just having the support of them initially was great with being so new. We started with one agency initially for caregivers – it was a terrible experience – I was sent individuals that were in the finance world as a background – with a one day training on a hoyer lift… what really? I was under the impression that I would be getting CNAs – that was far from what happened – I ended up having to fire one care giver because he was creepy and I didn't feel comfortable in my own home and another lady was really nice but she had been a secretary for 14 year prior and just needed a quick job to fill in while she found the job she actually wanted – she was mothering which was nice but didn't have the skills either to care for Justin and also only had 1 day of training on a hoyer lift. One day I had to run to the pharmacy quick and the trainer for the company was there and said go ahead, we got this… we will get Justin in his chair and over to

the living room – you can leave, he is safe. I came back, he was in his chair, but his head was down below the head rest and his bottom was about 4 inches from the back of the seat… I was like…oh no…this is not ok… and they trainer got up and starts to put his arms under my sons arms/shoulders and says, oh I will pull him up – and I stopped him in his tracks..that is not proper technique and he could've injured my son by pulling on him – I then showed them the way to do it correctly… again another eye opener… just because they are an agency and they say they know what they are doing…doesn't mean they really do… or that they know how to do it property… I knew from that day… I wasn't going to be able to leave during these hours of help as there was no safe way to transport him back and forth from his chair to his hospital bed safely with just the one staff member who was not experienced. I started working 24 hours free, I moved down to 20 hours paid, then down to
Hours paid – all with having care givers covering the other hours – but still being there about 75% or more of the time to ensure the safety of my son and his care givers. My son is 5'10ish and 240 lbs approximately – if you don't know proper technique and work with him consistently – you could hurt yourself or him as he is considered like a full quadriplegic with the inability to assist with movement.

We ended up changing Agencies in hopes of finding a better source of support as the other company wouldn't even call – they would text and wouldn't send other help if they couldn't find someone – pretty much a joke. The new agency understood our needs and vowed to try and find the matches we needed to suit Justin's needs. We initially went through about 20 different care givers – OMG – one was going to prison for selling fentanyl, living in a half way house (Federal), one had severe mental health issues and just didn't show up, 19-23 year old young ladies – good for age range… but his physical needs were too much for them and honestly not a comfortable situation for a 20 year old young man. Honestly, I am a talker, so I got to know these people coming in to our home – it has to be the right fit or it just doesn't work. The office staff and management came out multiple times to assist – they really wanted to ask for a second helper but were told he wouldn't qualify for that. It truly is odd that while in a facility or any kind, they require 2 people to assist with him with any electric hoyer lift transfers, bed cares, rolling over etc… but when he came home – insurance wanted to send us home with a hydraulic hoyer lift – I was shocked but the OT and I at OWL practiced and tried – we got him in it, but then his butt hit the lever that adjust the lift up and down and he started falling to the ground – we were able to stop that with us both there, but the look in both of our eyes and our facial expressions – was like this will never work! OWL was nervous as well and ended up getting an electric lift donated a couple days later and donated to us – but then miraculously after letters from my personal orthopedic surgeon and the head physician at OWL stating it was unsafe for both my son and a caregiver – we were told we were getting an electric lift – I said how and the DME provider just said – we made it happen. I don't know how, I don't know if they only got paid for the hydraulic and donated the funds for the difference or what (Frontier Home Medical)… but they took care of us and we were very grateful. We were then able to leave the other donated lift at OWL so they could provide for another family in need. Anyhow, after months of trying to sort out caregivers, we finally have a pretty consistent schedule with 4 outside care givers – with one of those being his sister (she would do more but she is a mother of a 3 ½ year old and 18 month old who stays home & does part time hours as an office

manager where she is allowed to bring her children).

Two out of the three care givers have been CNAs in nursing facilities, hospitals and assisted living, the other caregiver was experienced by having a husband she took care of who also had a hospital bed and hoyer lift in the home so I am finally feeling a little relief with having the consistency. I feel like I have individuals now that finally connect with my son and he can be in a thriving environment. The reality is, I know that they are employees and they could eventually move on, but for now they are here and they don't plan on leaving so that gives our family the confidence and continuity of care that Justin needs and deserves. My daughter Michaela, previously was a care giver with Visiting Angels so she had some background but not the extensive experience of what her brother needs now…but she was willing to learn, but as a young person at the age of 24, living with her fiancé, being a homeowner, working part time and being a full time mother to 2, an almost 4 year old and 18 month old – she only has so much time in the day – but she does help as much as she can.

Justin developed encephalitis and in June of 2025, he had a VP brain shunt placed in his skull to drain off the extra cerebral fluid inside his ventricular(s) the drain goes into his abdomen and dissipates there. The hope by adding this would be him to become more cognitive and have more wakefulness – which in turn will help with having to reteach him everything. The neurosurgeons chose to increase his setting after the placement to see if we would get more results but in turn he developed a hematoma and we had to reduce it back and the hematoma reabsorbed and went away – while this was happening – he slowed way down – appeared to be having head pain from having too much suction/pressure from the dial setting on the shunt – he regressed some from where we had been so here we go having to relearn things we had already learned.

In September or 2025, he was discharged from Home Health as he seemed to be ready to go back to full therapies so he was accepted into Madonna's outpatient day program – but around this time he started to have some issues with his eyes.. we thought allergies because he had bad seasonal allergies, he was getting his zyrtek daily, Mucinex daily, allergy eye drops and nose spray – but his eye just wasn't getting better – he also was getting redness on the right side of his face that was running a fever every time it showed up but not always on his forehead – I would bring up to PCP, Madonna nurses, therapists and they really didn't offer much but to continue with what we were doing – I began to notice with all the drainage he was starting to get congestion – more upper respiratory issues – eventually in October I took him to the ER because I just didn't feel good about everything – he had a full work up – his labs came back ok, his CT they did came back as no changes… they ended up doing a cough assist by sticking a tube down his nose and that caused some junk to come up but they just said to keep an eye on him and come back if he got a fever again etc… prior to leaving I asked the ER doc to look at his eye and she ended up giving him some antibiotic eye drops for pink eye and said follow up with an eye doctor or primary care if it doesn't work. The next week we had our team meeting at Madonna and it was discussed that we didn't feel like he was getting what he needed currently since he wasn't able to participate – we also had a few sick days

that pulled him from therapy – it was decided to put it on hold and for Justin to get his eye addressed and get with his neurologist to see if anything had changed since he was so sleepy and not opening his eyes… He had an appointment with the Madonna optometrist to work with him to see how his eyes were doing that same week to help the speech pathologist on if the eye gaze system would make sense at this time with his tracking ability - but when I called and let him know he wouldn't open his eyes and I wasn't sure if he had something going on they said lets reschedule the appointment as Dr. Boles doesn't want to see him if he can't open his eyes as it defeats the purpose of the visit… the following week he still wouldn't open that right eye and didn't want to open his left eye either now – I called my optometrist Dr. Layden at Oculi who is also a neuro-optometrist, like the Madonna doctor and talked to her staff about what was going on and Dr. Layden made an appointment the next day at 8:30 (an appointment before her 1st appointment) to see him to give us some advice – she agreed it was infected and prescribed a different antibiotic but said there is more to this and to reach out to his primary care provider and see if he could get some oral antibiotics – so we did, and they prescribed him augmentin… he developed diarrhea the next day – we assumed this was due to the antibiotic since nothing else had changed – in the next couple days his blood pressures, temperature was not consistently normal and I could tell he didn't feel 100% - Monday night I really started to get concerned and Tuesday morning – he woke up with fever – blood pressures very off and extreme diarrhea – we got him up and going to see if the Tylenol would kick in and if possibly he would improve – he seemed kind of ok but still not great – so at 2 pm when I had a shift change with care givers, I took him to the ER to be checked out. That was November 12th, he wasn't discharged until November 29th – they were unable to figure out what would cause the fevers and where the infection could be – eventually they were able to find an abscess in his bowel that they assumed was the source of infection (which is was part of it) but were still concerned because this infection was in his abdomen and his VP shunt drains into his abdomen that there could be a possibility the infection could reach the tubing in his shunt and go to his brain – so a lot of individuals were involved on his (Infectious Disease, general surgery consults to determine how to remove the abscess, neurosurgeons due to shunt and IPA) while doing this they removed one antibiotic and after 4 days and his WBC continued to go up – they added it back and eventually did a spinal tap which showed increased WBC in his fluid – but because they had already started treating – they assume he had meningitis but it didn't come up on the testing – bottom line – still a lot of unknowns – and there were many days they thought he was at baseline and thought he could maybe go home – which I had to literally pull up videos of my son to show them what his baseline was – they just assumed he was like a vegetable more or less – everyday I had to educate the staff and show them who he is – what he could do prior to coming into the hospital and then showing him the person he was prior to his AVM rupture. Its sad to see your child in this condition as it is, but when people don't know your son – he literally only gets the basic cares necessary and then they are off to the next patient – they don't know if his needs are being met – they just do the checklist and move on. I get it, there is only so many staff (with call ins, sickness, staffing issues etc) I don't blame them, but its definitely a healthcare issue and with my son being in such a unique condition – most people just admit we just don't know how to communicate or how to

help him progress. Justin was finally discharged on a Saturday after not having fevers for 4 days but still had a slightly elevated WBC but the doctors were not worried at this point. However, when I got home, I found out that he had a SEVERE rash on his bottom – with blisters, pus and some with bleeding – I was told that is common with being on so many antibiotics and diarrhea – I took pictures – within 4 days it begin to get better with doing more aggressive measures at home with ointments – fresh air – antifungal meds and also by putting him back on his probiotic he was on and his 2 stomach meds that the hospital took him off of – ugh!

We are now back on home health care – we are working on 2 days in PT (ATP had a evolve sit to stand donated so we can get him up and work with him at home more aggressively) OT – 1 day a week and speech 1 day a week (Saturdays – because the care provider is a full time therapist in the brain unit at Madonna – however… she admitted she has never worked with someone like Justin so it will be trial and error… what???) you work in the specialized A2 unit at Madonna full time – but have experience with an individual like my son – how is that? But it is what it is and I told her to talk to her co -worker at Madonna because she did work with Justin while he was inpatient so maybe she could give her ideas… OMG –

So that is where we are at today…. Our daily routine –

Repositioning nightly every 2 hours
Check BP and Temp
Give water at midnight – Tylenol PRN
Give water at 4 am
6 am he is fully awake
6:30-7 morning meds
7-7:30 breakfast – tube feeding/water
Turn on TV or radio – discuss what is going on today
9 am time to get up – Cares
Bed bath if needed
10 am range of motion – usually takes 1 hour (could take longer if we do upper and lower body) just depends on how well he tolerates and willingness to participate
11:30 am Cares
12 pm lunch – tube feeding – afternoon meds given
1:30 pm Cares
2 pm – 3 pm napping off and on –
3 pm cares if necessary
3 pm – 5 pm upper body range of motion – outdoor activities if possible – go for a walk or go out to the patio and listen to music and enjoy the outside (his favorite place to be)
4 pm meds
4:30pm cares if necessary before feeding
5 pm tube feeding /water
5:30 pm he usually falls asleep in his chair for an hour
6:30 pm Cares if needed
6:30- 8 pm watch a movie or TV show – or if weather nice go outside, try to have dog and cat interact with him –

8 pm he gets evening meds – cares if needed
8:30-9 range – time for bed – transfer into his hospital bed and do cares and get into sleeping attire
9 pm tube feeding
10 pm water flush – reposition – cares if necessary
12 am reposition/water/check BP and temperature- cares if necessary
2 am reposition/check BP/temperature – Cares if necessary
4 am we start all over again

Speech – I add in food trials usually in the evening after dinner when possible - as time allows usually during the day, we try doing some tracking exercises with eyes and try and brush his tongue during oral cares – I like oral cares done about every 3-4 hours – in the hospital they wanted it done every 2 hours but rarely did the CNAs or nurses get that done so I tried to do when I could. (these are done outside of a speech visit)

Occupational Therapy devices – Justin has multiple braces, casts, devices he needs to use or wear but these are depending on how his dystonia is in his body – some times he will need to wear his bi-valves multiple times in the day to help keep his arm straight but then there are days where he will go multiple days in a row without needing it – usually they want him to wear these a couple of hours at a time and then check for skin breakdown – schedules are always good but need to be adjusted as he changes/evolves and his brain continues to heal – its not black and white that is for sure.

I am sure I am missing things we do, but I am hopeful that what I have provided will give you a better idea and understanding of how we got here and what we are doing to try and move forward.

I have a camera on live at all times so I can see/hear him wherever I may be in our home – it's a lot but its my new norm and I am happy I can be here to help him. Prior to this happening to my son, I was a full time Mortgage Loan officer – 100% commission since 2002 – I successfully raised my 3 children as a single mother since 2009 with minimal assistance from their father who lives in Omaha. My children have been very active since day one with dance, cheer, select soccer and select baseball teams prior to high school. My job and my expertise in my field allowed me to be financially capable to take care of my family without support and I also put money away for my retirement. The stress of my job is very intense but very lucrative, when this happened to my son, I was unable to work full time and very limited to be able to help my clients/realtors and referral partners – so therefore that impacted my income immensely. As things continued, I realized that I was the only person who was going to be able to care for my son as we unfortunately do not have any informal supports that are able or willing to provide the extreme cares necessary for me to have a break without having paid care providers. My 73-year-old mother, we just moved her back last month into a 55+ living condo regime to bring her closer, but she can't do cares, she can provide companionship and is great to have around to talk to and with Justin. My daughter, she has a full-time family with children – she comes over as

much as she can to help me out during the week with visiting and bringing his niece and nephew for family time. My oldest son Michael works full time and taking classes at SCC and can be around for a quick run to the store but will not learn how to do cares as its too hard for him – with it being his brother. His dad… he came to the hospital to visit him for 2 hours – on Nov 14th and I haven't heard from him since – out of sight out of mind – its heart wrenching but it's the reality – he also works full time in Omaha and has his own life – he provides primary insurance thru Blue Cross – so he at least does that… I have no other family in Lincoln – I am an only child and my ex-husband's family is dysfunctional and just not around – either out of state, just got out of prison, too old, or just don't care – so it falls back to me – but that's ok… I won't let him fall Justin is my youngest and an old soul – he is fighter and will get his chance the fight for his new normal, if it's the last thing I do – he deserves that!

I am so thankful for having the experience at On with Life, they taught me so much and pointed out resources online and offered open communication after we left. Madonna did a good job at stressing the importance of proper techniques for wheelchair transfers and hoyer lifts – thank God because even at OWL the CNAs were not all trained properly – I actually trained a couple with how to reposition my son and how to transfer him properly, they did appreciate that.

With the changes you are proposing – you would be causing harm to his qualify of life, his ability to prosper and causing a financial strain on our family to take care of him. I legally cannot work the hours necessary for me to be successful as a full time mortgage loan officer – I have always been available 24/7 a day – 7 days a week – no paid vacation or holidays (well I guess I didn't take calls after 11 pm for mortgages lol) because I understand the necessity of this as a fully commissioned employee and needing to put the time and effort into doing the best I can at my job. My employer has been very kind and generous with what we are going thru – they have allowed me to continue to have insurance for myself at this time, but my drastic change in income also impacts them and I am afraid this coming year I may lose my insurance and will have that extra expense to figure out 😵 but I will face that challenge head on when it becomes an issue - The mental stress of my career is a lot as well and I can't let that impact my ability to take care of my son and him moving forward. My new job at 51, has become his full time caregiver, a street nurse, a street CNA, a street PT, OT, and speech therapist – I don't have the degree but I have more experience with working with my son then most therapists (their words not mine) – but really need them to give me the tools and then I make things happen. Is this what I imagined in my retirement years, heck no, am I ok with it, yes, and I WANT to be here for him – that should be huge to you all – I care – I won't take advantage of a system – I actually want to work with him and find the ways to reduce his needed hours – oh my gosh, that would be amazing – how awesome would it be for him to have more independence… any independence at this point – I want him to have the opportunity to get better and I don't believe he will get that chance if he was in a skilled nursing home based on my experiences this past year – please help me keep my son home and in an environment that shows him we care and that we aren't giving up on him – please know… my son got a random headache that caused this all to happen…its not

his fault – he needs us to step up and help him.

I invite you to come visit us in our home, to see our set up – to meet Justin – we continue to find ways to help him, currently I have a therapy bed for us to use that crossroads PT donated to us, we have a sit to stand stander to help keep his weight in line and to help him weight bearing on his legs, I have multiple devices I have purchased online to help with his hands- I have a glove that moves and retrains his fingers on how to move, he has something like this for his legs that he can use in his chair – its like bike pedals – we have a bath chair ready to use – and we are working with ATP on both a bathroom remodel so he can have a shower and bathroom to meet his needs – currently he only gets bed baths as we don't have a bathroom that is accessible, as well as a entrance modification to our garage so he can access the wheel chair accessible vehicle we purchased in August. We have temporary ramps that are removeable at our front entrance which have worked out very well while we wait for these modifications to be completed in our home.
Thank you for your willingness to hear our story.

Kind Regards,

Amy

Amy Davis
Loan Officer, NMLS # 583381
Gershman Mortgage

P: (402) 609-7335
F: (402) 512-1428
E: adavis@gershman.com | **W:** www.gershman.com
A: 8250 Old Cheney Rd., Suite B, Lincoln, NE, 68516

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From: Jennifer Williams
To: DHHS HCBS Public Comments
Subject: AD Waiver
Date: Sunday, January 4, 2026 11:47:40 AM

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Sent from my iPhone

To whom it may concern;

The following are concerns with the proposed changes.

Federal Authority Governing the AD Waiver
Nebraska's AD Waiver operates pursuant to 42 U.S.C. § 1396n(c) and is approved by CMS subject to ongoing compliance with waiver assurances, including but not limited to:
Person-centered service planning
Health and welfare protections
Freedom of choice of qualified providers
Services sufficient in amount, duration, and scope to meet assessed need[1]
Failure to meet these assurances places the waiver at risk of noncompliance and federal corrective action.

II. Freedom of Speech and Retaliation Concerns
Nebraska DHHS policies and practices that discourage, penalize, or chill advocacy, public comment, or complaint-filing by beneficiaries or their caregivers raise serious constitutional and Medicaid compliance concerns.
Medicaid beneficiaries and their representatives retain full First Amendment rights, including the right to speak, petition, and advocate without fear of retaliation[2]. Federal Medicaid regulations further protect the right to due process and grievance without intimidation or adverse consequence[3].
Any reduction, scrutiny, or adverse action taken in response to protected speech or advocacy activity is incompatible with federal Medicaid requirements and constitutional protections.

III. Relationship-Based 40-Hour Cap on Live-In Parent Caregivers
Nebraska DHHS imposes a blanket 40-hour cap on paid caregiving when the caregiver is a live-in parent of an adult AD Waiver participant, without regard to the individual's assessed medical or functional needs.
This policy conflicts with federal HCBS requirements, which mandate that services be:
Determined through person-centered planning4
Based on individual assessed need, not family relationship5
Free from reliance on required unpaid "informal supports"6
Federal law does not permit states to presume that parents of adult beneficiaries must provide uncompensated care as a condition of waiver participation. Such relationship-based limitations function as an impermissible substitute for covered services.

IV. Arbitrary 175% Cap on Caregiver Compensation
Nebraska DHHS further limits caregiver compensation through a 175% cap, applied irrespective of:
Medical complexity

Workforce shortages
Geographic or rural access limitations
Under federal Medicaid law, state payment methodologies must be sufficient to ensure access to covered services comparable to that of the general population7. Payment limitations that render providers unavailable or unwilling to serve waiver participants undermine access, health, and welfare assurances8.
Cost-containment measures may not override federally required access or safety protections.

V. Denial of Meaningful Freedom of Choice of Caregiver
Federal Medicaid law guarantees waiver participants the right to choose among qualified providers, including individual caregivers[9]. Nebraska DHHS policies that make parent caregivers financially or logistically unsustainable effectively eliminate that choice.
A "choice" that cannot be exercised in practice due to hour or compensation caps is not meaningful choice. Federal courts and CMS guidance consistently recognize that constructive denial violates Medicaid's freedom-of-choice protections[1°].

VI. Hour and Pay Caps as Constructive Denial of Services
While Nebraska DHHS may assert that services remain technically available, caps on hours and pay:
Force beneficiaries to abandon their chosen caregiver
Create unsafe gaps in care
Increase turnover and instability
Drive beneficiaries toward institutional placement
Federal regulations require that services be sufficient in amount, duration, and scope to reasonably achieve their purpose[11]. Policies that systematically prevent services from meeting assessed needs violate this standard regardless of nominal availability.

VII. Institutional Bias and ADA/Olmstead Concerns
The combined effect of Nebraska's hour and compensation caps increases the risk of unnecessary institutionalization, in direct conflict with:
Title II of the Americans with Disabilities Act[12]
The Supreme Court's decision in **Olmstead v. L.C.**[13]
Federal regulations requiring services in the most integrated setting appropriate[14]
HCBS waivers exist specifically to prevent institutional bias. Policies that make home-based care unsustainable undermine the waiver's fundamental purpose.

VIII. CMS Oversight and Required Assurances
CMS approval of the AD Waiver is conditioned on Nebraska's ability to demonstrate compliance with waiver assurances under 42 C.F.R. § 441.302. CMS retains authority to require corrective action where state policies violate federal requirements or place beneficiary health, welfare, or rights at risk[15].

IX. Request for Review and Corrective Action
Accordingly, Nebraska DHHS is urged to:
Reevaluate relationship-based hour caps for parent caregivers
Justify any compensation caps with data tied to access and assessed need
Ensure meaningful freedom of choice of caregiver
Protect beneficiaries and caregivers from retaliation for advocacy
Align AD Waiver administration with federal HCBS, Medicaid, ADA, and constitutional requirements

X. Conclusion
Nebraska DHHS AD Waiver policies, as currently administered, raise substantial concerns of noncompliance with federal Medicaid law, HCBS waiver assurances, and civil rights protections. Prompt review and corrective action are necessary to prevent further harm to waiver participants and to ensure continued federal approval.

Footnotes
42 U.S.C. § 1396n(c); 42 C.F.R. § 441.302
U.S. Const. amend. I
42 C.F.R. §§ 431.206, 431.220
42 C.F.R. § 441.301(c)(1)
42 C.F.R. § 441.301(c)(4)
Id.
42 U.S.C. § 1396a(a)(30)(A)
42 C.F.R. § 441.302(a)
42 U.S.C. § 1396a(a)(23); 42 C.F.R. §§ 431.51, 441.301(b)(1)(i)
See id.
42 C.F.R. § 440.230(b)
42 U.S.C. §§ 12131–12134
Olmstead v. L.C., 527 U.S. 581 (1999)
28 C.F.R. § 35.130(d)
42 U.S.C. § 1396n(c)(2)

Thank you for looking into these items during this time period where you are collecting information based on the slideshow that was presented to us and the 238 page documentation of changes to the programs.

Jennifer Lynn Williams

To: DHHS – Division of Developmental Disabilities
Subject: Public Comment on Proposed Amendments to Nebraska Aged & Disabled Waiver

CC: CMS Leadership, Nebraska Legislature's Health and Human Services and Appropriations Committees

January 5, 2026

Dear Nebraska Department of Health and Human Services,

This letter is to provide comments regarding Nebraska's open comment period for the Aged and Disabled (A&D) waiver renewal The comments below reflect the experiences and feedback of members of UNMC/MMI's Community Advisory Board (CAB) and do not necessarily reflect the views of the University or of the UNMC Munroe-Meyer Institute (MMI).

As part of its programming, MMI receives funding for and is designated as a University Center for Excellence in Developmental Disabilities (UCEDD) by the Administration on Intellectual and Developmental Disabilities. In accordance with this designation, the MMI UCEDD convenes a Community Advisory Board (CAB). The CAB serves in an advisory role assisting the UCEDD Director, faculty and staff with the mission, activities and priorities of the UCEDD. The majority of our members are individuals with disabilities or family members who have specific knowledge in how Nebraska's disability programs work. CAB membership represents both the state's geography and ethnicity. The CAB's advisory role helps to ensure that the perspectives of individuals with disabilities and their family members are represented to help guide future UCEDD projects and priorities to ensure the needs of individuals with disabilities and their families across the state are being met. This document is a representation of CAB members thoughts and concerns and does not represent those of the University of Nebraska Medical Center or the Munroe-Meyer Institute.

Thank you for the opportunity to comment on the proposed Aged & Disabled (AD) Waiver renewal and amendment. The CAB appreciates DHHS's ongoing efforts to support Nebraskans who depend on home and community-based services to live safely and independently in their homes. We also appreciate the state's efforts to provide public meetings to explain the waiver changes[1]

[1] Public Comment

However, CAB members are ***deeply concerned*** about the proposed limitations on personal care and companion services and the state's proposal to implement a cap to the A & D Waiver. Limiting personal care and companion services for paid family caregivers to a maximum of 40 hours per week, and a combined total of 70 hours per week for personal care, live-in personal care, and companion services will 1) create health and safety issues for the A&D Waiver participants, 2) create financial instability for these family caregivers and 3.) cost the state more money by placing individuals in facilities which do not have capacity and will ultimately force these individuals into hospitals- which also do not have capacity to serve this population. These limits, without clear exception criteria and processes or individualized flexibility, will have profound negative impacts on the health, safety, and dignity of waiver participants with complex needs.

CAB members request that the state provide more details about how these proposed changes will ensure waiver participant health and safety and/or provide the state with cost savings.

We also have concerns that while the state did hold public meetings to explain the changes to the A & D Waiver, it did not involve public committees (NE DD Advisory Committee[2] and the NE Olmstead Committee[3]) that are **explicitly required by state statute** to provide feedback to programs that involve those with developmental disabilities and their families and changes that could limit access to community living.

The following are comments from members of the UNMC Munroe-Meyer's CAB on the A&D waiver renewal. The themes that are identified below reflect the unanimous support of members of the CAB.

If you should have any questions regarding this letter and the identified themes, please do not hesitate to contact me. Respectfully,

Joe Valenti, Munroe-Meyer Institute Community Advisory Board Chair

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[2] **NE DD Advisory:** "(3) The advisory committee shall advise the department regarding all aspects of the funding and delivery of services to persons with developmental disabilities."
"(5) The department shall inform the advisory committee of proposed systemic changes to services for persons with developmental disabilities at least thirty days prior to implementation of the changes so that the advisory committee may provide for a response to the proposed changes." Source: Nebraska Legislature

[3] **NE Olmstead Advisory:** Strategic plan for providing services; department; duties; advisory committee; analysis and report. (1) "The Department of Health and Human Services shall, in collaboration with the Department of Correctional Services, the Department of Economic Development, the Department of Labor, ... develop a comprehensive strategic plan for providing services to qualified persons with disabilities in the most integrated community-based settings pursuant to the Olmstead decision." Source: Nebraska Legislature

How will the state assure Health and Safety for all Medicaid Waiver participants?

The Problem:

Limits on service hours jeopardize health and safety. Many Nebraskans with disabilities require more than 40 hours per week of personal care support due to medical fragility, mobility limitations, and essential daily living needs. Arbitrary caps will force families to choose between unsafe self-care or costly institutional care. There seems to be a belief by the department that natural supports (families providing unpaid care) can be used to support these individuals. This is not realistic with the structure of today's families as well as the medical needs many of these individuals require.

Please clarify the following:

I. **Please clarify the language from waiver pg 12:** "*When the combined costs of waiver and state plan services exceed the applicable cost limit, the SC will work with the participant to reduce services below the 175% limit, while still ensuring health and safety are met.*"

Concern:

Please make it clear that the state is capping the combination of Medicaid state plan HCBS services and not ALL services under the Medicaid state plan.

II. **Please clarify the language from waiver pg 12:** *"When the participant's needs cannot be met, referrals to other community services, including institutional services, are provided to the participant.* ***The participant is provided with alternative options to meet their needs, including but not limited to nursing facility placement*****."**

Concern:

CAB members are concerned that there are ***no alternative options available in our state including nursing facility placement*****.**

The state has many areas where there are no nursing homes and is also experiencing the closure of many nursing homes across the state. Further, many of these individuals cannot be served in nursing homes because of their complex medical needs and Nebraska's licensing requirements. **Please explain where the state expects to place these individuals who exceed the budget cap?**

Supporting Information:

- Closing of nursing facilities in NE

- **Nebraska nursing home capacity is under significant strain:** With 16 facilities closing in four years due to staffing shortages and funding, leaving 15 counties with no options. Only about 10% of Nebraska homes meet new federal 24/7 RN requirements. Total bed capacity varies by location (e.g., Douglas County Health Center has 254 beds).
- **Declining Capacity:** 16 nursing homes closed in the last four years, resulting in a loss of hundreds of beds, including facilities in Tecumseh (67 beds), Arapahoe (30 beds), and Grant (50 beds).
- **Rural Deserts:** 15 Nebraska counties have zero nursing homes or assisted living facilities.

Source: Nebraska Home Care Association, 2025[4]

Shortage of DSP workers:

- Nebraska is experiencing a critical, statewide caregiver shortage affecting child care, nursing homes, and disability services, causing over $745 million in annual economic impact. Driven by low pay, burnout, and rural gaps, 16 nursing homes closed recently, and 14 counties lack primary care physicians.
- There is a severe shortage of trained in-home, one-on-one support for children with disabilities, particularly in rural areas like North Platte and Scottsbluff.

Healthcare Worker Shortages:

- Nebraska is facing a shortage of approximately 5,000 nurses. 85 rural communities are considered medically underserved for primary care.

1. **What is the <u>exception process</u> for those who exceed the waiver cap?**

Page 26: *" Prior to entrance or post-entrance into a waiver, the Service Coordinator (SC) meets with the participant to complete a high-utilization review and develop a Person-Centered Plan (PCP). When the participant's service needs exceed 150% of the Institutional Cost Limit, the SC will request a clinical review. The clinical review will determine whether the services listed on the high-utilization review are appropriate based on the identified needs of the participant. When the participant's needs exceed 175% of the Institutional Cost Limit, the SC will work with the participant to reduce services below the*

[4] Who Will Care for Nebraska Seniors?

175% limit, while still ensuring health and safety are met. When the participant's health and safety cannot be met within the 175% cost limit, the ***SC will provide the participant with referrals to other community services, including institutional services. The SC will provide the participant with appeal rights.***"

Concern:

The CAB members have concerns that there are **no other options** when an individual's budget exceeds the 175% limit. Many of these individuals will likely initially be forced into hospital care because of their complex needs and the state's shortage of critical complex care facilities. The state's exception process must be clarified so that waiver participants will not be required to move away from families and to ensure that care *continues throughout any transitions.* While the draft waiver mentions exceptions for immediate health and safety needs, it is unclear how often and under what criteria these exceptions will be granted. A robust, transparent exception process is essential to protect participant well-being.

From pg 40: Procedures to Ensure Timely Reevaluations. (Appendix B-6: Evaluation/Reevaluation of Level of Care)

The state updated the procedures to ensure timely reevaluations, changing the face-to-face requirement to person-to-person.

Concern:

The state relies on Services Coordinators to help ensure health and safety. There is a need to clarify the difference between face-to-face meetings to person-to-person meetings. Meeting directly with waiver participants in their natural settings (home, etc) helps to assure health and safety.

2. **The state needs to clarify and revise their HCBS Grievance Processes and Critical Incidents**
    - Students transitioning from school are being offered A & D rather than the DD, which has been historical procedure.

From Pg 163. Grievance Process

1. Service Coordination complaint/grievance process: 1. Service Coordination Agency staff receives a complaint about the provision of services from a participant or participant's representative. The report may be given either verbally or in writing. Service Coordination Agency Staff must begin completing the electronic Local Level Complaint Form once the report is received.

Concern:

Please explain the process if the Services Coordinator is the reason for the complaint and how the individual, family members, and or guardian would make a grievance other than referral to Adult Protective Services.

Concern:

Is this alternative process information provided in an individual's Notice of Rights?

2. Service Coordination Agency staff must complete the investigation and take action to resolve the complaint within 30 working days. If the investigation cannot be completed within 30 working days, Services Coordination Agency must document the reason for the delay.

Concern:

- How is the HCBS recipient being notified of progress in the complaint/grievance process and ensuring care continues?
- Medicaid Access Rule requires that states ensure punitive or retaliatory action is not taken or threatened against beneficiaries who file a Home and Community-Based Services (HCBS) complaint or grievance. Please clarify how the state ensures they have proper processes in place to ensure this.

Page 91: The state needs to clarify how changes suggested in this application are in line with the philosophy and requirements of Person-Centered Care.

Combined limits reduce individualized planning. The proposed combined 70-hour ceiling unduly restricts person-centered care plans that should be based on assessed need rather than a fixed cap. This undermines federal Medicaid HCBS principles, which emphasize individualized, outcome-oriented planning.

Concern:

The state plans to implement Personal Care and LRI Personal Care limits to a combined maximum of 40 hours per week and Personal Care, LRI Personal Care, and Companion services to a combined maximum of 70 hours per week.

- Many Nebraskans with disabilities require more than 40/70 hours per week of personal care support due to medical fragility, mobility limitations, and essential daily living needs. Arbitrary caps will force families to choose between unsafe self-care or costly institutional care.

- Limiting hours without addressing workforce shortages and provider reimbursement rates will further strain Nebraska's direct support workforce, making it harder for participants to find caregivers and maintain stability in services.
- The proposed combined 40/70-hour ceiling unduly restricts person-centered care plans that should be based on assessed need rather than a fixed cap. This undermines federal Medicaid HCBS principles, which emphasize individualized, outcome-oriented planning.
- Allowing family payment reduces provider turnover (which is costly) and supports *continuity of care* — caregivers are more likely to stay long term.
- Even when paying family caregivers *more per hour* than they would earn privately, total program costs remain lower than agency models because Medicaid doesn't pay agency overhead. [5]

Concern:

Pg. 69 The waiver amendment proposes capping budgets with no explanation on the requirements or process to receive the exception funding.

- While the draft waiver mentions exceptions for immediate health and safety needs, it is unclear how often and under what criteria these exceptions will be granted. A robust, transparent exception process is essential to protect participant well-being.

3. **The state needs to clarify their definition of Natural Supports, specifically care provided** *above and beyond what is typically expected for a participant without a disability.*

Pg. 87: Independence Skills Building

This service does not cover natural supports provided by relatives, guardians, or fictive kin living in the home when the support is part of a normal family or household routine, *unless the support is clearly above and beyond what is typically expected for a participant without a disability.* The Service Coordinator verifies natural supports through review of household composition, participant statements, and other available documentation.

Concern:

The state is leaning very heavily on 'natural supports. However, this is not clarified. For example, it is not natural for a grandmother to help toilet her adult grandchild. Further, the state does not explain the grievance process if a waiver participant, their family or guardian disagrees with the state's decision of 'natural supports'.

[5] Brief-2-The-CO-Home-Care-Cost-Model-09-2024.pdf

Page 52 Participants are responsible for understanding allowable service delivery in order to oversee and supervise providers on an ongoing basis.

Concern:

Please clarify what "allowable service delivery" is and how participants are to "oversee or supervise providers."

Home Modifications (pg. 84)

- Specify applicable (if any) limits on the amount, frequency, or duration of this service: Home Modifications have a budget cap of $10,000 per five-year period. If a participant's needs cannot be met within the established budget cap, the participant may request additional funds through DDD Central Office up to a maximum of $20,000.

Concern:

The $10,000 amount for home modifications seems unrealistic given the increasing building and labor costs. Please clarify the exception process and explain how the additional fund request will be reviewed, the timeline for this decision, and who will be involved in the decision-making process.

Again, we thank you for your work on Nebraska's waiver system. If you should have other questions, please direct these to Joe Valenti, CAB Chair at joevalenti1@cox.net

cc: **CMS Leadership**: George Failla, Melissa Harris, Jodie Sumeracki, Jennifer Bowdoin, Curtis Cunningham, and Ryan Shannahan; **DHHS Leadership**: Tony Green, Kristen Smith, Jennifer Clark, and Colin Large; **Nebraska Legislature**: Robert Clements, Christy Armendariz, Machaela Cavanaugh, Myron Dorn, Robert Dover, Loren Lippincott, Jason Prokop, Ashlei Spivey, Paul Strommen, John Arch, Brian Hardin, John Fredrickson, Beau Ballard, Ben Hansen, Glen Meyer, Dan Quick, and Merv Riepe.

From: keepfightingcarson
To: Clark, Jennifer J
Cc: DHHS HCBS Public Comments
Subject: AD Waiver Advocacy -Please Read!!!!
Date: Monday, January 5, 2026 8:23:38 PM

You don't often get email from [redacted] Learn why this is important

Dear CEO Corsi, Director Green, Deputy Director Clark, and Senator.

My name is Ashley Hansen, I once was untouched and honestly unbothered living my life as a busy Mom, until a day in May 2022, my then 15 year old son Carson and my 6 year old daughter Lilly were in a horrific car accident on their way to Vacation Bible School, that day we were no longer that untouched, and unbothered family....we were placed smack dab in the middle of a nightmare making deciaions for our once vibrant, healthy son diagnosed with a devastating Traumatic Brain Injury, maming him forever disabled and us forever Caregivers, just like that, in a blink of an eye. I now am that family reliant if Medicaid, heck Ive waited 6 months to finally get a Waiver approval and Carson has been home for 15 months, but he just turned 19 in October, making him an adult and us not guardians of a fully disabled adult child, so you see why Im writing as a concerned constituent and disability advocate to formally express my strong opposition to the proposed amendments to the Aged and Disabled (A&D) and Traumatic Brain Injury (TBI) waivers, specifically the introduction of utilization thresholds and spending caps.

Let me share the WHY we are truly all so concerned.....
The proposal to initiate a “high utilization review” at $138,657 and impose a hard spending cap of $161,766.50—175% of regular nursing facility costs—poses a serious threat to the independence, safety, and well-being of Nebraskans with disabilities who rely on home- and community-based services.

This policy represents a significant step backward for Nebraska for several reasons:

• It forces institutionalization. By capping home-based care at a percentage of regular nursing facility costs, the state is effectively forcing individuals with complex needs into institutional settings when their care “costs too much” to provide at home. For many of these individuals, there is no appropriate or available skilled nursing facility capable of meeting their needs.

• It unfairly penalizes family caregivers. Families who have worked tirelessly to support their loved ones in their homes and communities are now being told that home is no longer a viable option due to arbitrary financial limits rather than clinical need.

• It lacks transparency and meaningful stakeholder engagement. Announcing these life-altering changes on December 5 with a public comment period ending January 5 does not allow adequate time for impacted individuals, families, and advocates to fully understand or respond to the proposal.

I strongly urge you to remove these spending caps from the final waiver application and instead focus on expanding community-based resources for Nebraskans with disabilities to live in their own homes.

Nebraska must ensure that the safety, rights, dignity, independence, and overall well-being of

people with disabilities are protected.

We are a family of 6, we have 3 other children under 10, but we fully are advocating for our son to have his home be the best place for him and providing the support to his caregivers and environment, without this you will be forcing many families into poverty, forcing the disabled into poor facilities and not equipped to take care of this care group...I have had a hard time finding any support in rural Nebraska! We have been without nursing for over 3 months now, WE are what he has and we are feeling so unseen by our leaders and department of health and human services.

We have shared his story extensively in hopes to advocate for Caregivers and those YBI TBI Survivors, please look at his TikTok @KeepFightingCarson, this shows the fight alot of us parents and survivors living with disabilities endure on a daily basis, please be the one to stand up for us all!!!!!

I look forward to your response and a public commitment to protecting the rights of the disability community.

Sincerely,
Ashley Hansen
[redacted]

Sent from my Galaxy

From: Chelsea Jensen
To: DHHS HCBS Public Comments
Subject: AD waiver amendments
Date: Monday, January 5, 2026 8:46:14 PM

> You don't often get email from [redacted]. Learn why this is important

The proposed changes to the AD waiver have been attributed to a rapid increase in costs for funding participants' services. How much did costs increase after DHHS ended the high utilization review process a couple years ago? Since reviews have been partly reinstated in August 2025, is it reasonable to allow time to demonstrate how high utilization reviews can responsibly impact AD waiver spending before resorting to dramatic caps on service funding?

Please consider capping services based on dollar amounts instead of hours. Independent providers fulfil not only the hands-on caregiving work but also take care of administrative tasks for about $16/hour, while agencies charge from $28 to up to more than $42 per hour. What benefit does having an hourly cap provide versus a straightforward dollar amount?

From: Matthew Rotert
To: DHHS HCBS Public Comments
Subject: AD Waiver changes - Public Comment
Date: Monday, December 29, 2025 6:48:49 PM

You don't often get email from [redacted] Learn why this is important

To whom it may concern,

I am writing today to address the proposed changes to the AD (Adults with Disabilities) Waiver Program as an adult with a disability who stands to be negatively affected by said changes. I am 44 years old, require help with all movement, and am on a ventilator 24/7. Despite these burdens, and because of the AD Waiver Program, I have been able to live independently for 26 years. During that time, I graduated from college in the UNK Honors Program with a BFA, created a freelance graphic design service, enjoyed being active in the Kearney community, and explored many avenues of personal interest, ranging from philosophy to foreign languages. I am not sharing all this to claim I am somehow more deserving, but to illustrate the quality of life also being threatened. Although not readily apparent in a cost analysis, the feelings of purpose, belonging, community, and choice are crucial aspects of staying healthy, the ultimate goal of this vital program. The AD Waiver Program has enabled me to hire the skilled in-home caregivers I need, not only to live independently and achieve these accomplishments, but also to stay healthy and safe. If the proposed cap on funds for individuals (calculated at 175% of the annual average cost of care homes, roughly $162,000) becomes policy, I will not be able to reliably hire enough qualified and capable caregivers to meet all my needs. Compare this to my current requirement of $233,000, and the insufficiency becomes clear. Even in a medium-sized city like Kearney, there are no care homes that can provide the 24-hour one-on-one care that I require to stay safe. Without proper coverage, any minor issue with my ventilator will easily become deadly. EMS simply won't be able to arrive in time. Even if I could find such a facility in Omaha, there are two problems. One, $18.50 per unit hour will not cover the cost. ($162,000 / (24*365) = 18.49) Two, there are not enough openings, let alone facilities, to handle the demand that will be created by the proposed changes. Those who benefit most from the AD Waiver Program cannot simply wait uncovered for the years it would take to build and staff these currently non-existent facilities. My parents are in their 70s and will, in a few years, be unable to assist in my care. I have one sibling, but he has a family of his own to provide for. He can't simply quit his job to become my full-time caregiver. The AD Waiver Program is my, and many others', only viable lifeline.

I have thus far remained objective with this letter, but I now must offer an emotional recrimination. These changes will harm some of the most vulnerable Nebraskans, many of whom cannot advocate for themselves as I can. It is unconscionable to risk the health and lives of the disabled. Please, have no illusions, these proposals are choices that will hurt people. If those in charge of this wish to keep their conscience (and job obligations to all their fellow Nebraskans), please amend any changes to have strictly needs-based exceptions. Unless you spend what life-sustaining 24/7 high-skill care costs, you will not have life-sustaining 24/7 high-skill care. Limits, caps, and percentages of fundamentally different services are not practical or moral approaches. Please, make these decisions ethically as healthcare professionals, not financially as administrators.

Thank you for your time. May you have the courage to do what is right.

Matthew Rotert

From: jessica chatelain
To: DHHS HCBS Public Comments
Subject: AD waiver changes
Date: Sunday, January 4, 2026 8:54:00 AM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

To whom it may concern,

To start I want to say I have copied and pasted the below portion of this email from a friend because it has excellent points and ideas.
Now I will give my opinion…
I have been social media friends with Ashley, mother to Carson #keepfightingcarson, for 3+years. In March of 2023 my 16 year old son was hit by a drunk driver driving at a high speed. He almost lost his life. He was unconscious in his truck when I arrived to the scene. He was kept in a coma for 14 more days. It was a long time after that before I saw a glimpse of my son. He suffered so many injuries, a traumatic brain injury being the scariest one. His accident and injuries mimicked Carson's. I don't know why the outcome has been so different, but my son walks, talks, drives and is now attending his freshman year of college. Carson is not. He is wheelchair bound. He requires 24 hour care, like an infant. He is a full time job. He is someone's child. Someone that his family had to live without for far too long while he was hospitalized. Someone that his family feels so blessed to still have on this earth. Someone they need and that he needs. I understand that better than anyone. My husband and I never left my son's side- 56 days in the hospital. Which is a fraction compared to Carson's story. If the circumstances would have been different I would be doing exactly what Ashley is, fighting for her sons care. For financial help to ensure he has the very best care and the financial assistance to continue that care at home. Home is where he will continue to thrive and I truly believe there will be progress in his recovery. No one plans for life changes like this. Until it happens to you, most think it WON'T happen. Sadly, Ashley and I know it can. As do so many other families who's loved one is living with a disability.
Please consider the options below to help these families.
#keepfightingCarson

Thank you for your consideration,

Jessica Chatelain

On December 5th DHHS released proposed changes to the AD waiver. Part of these changes was to LIMIT live in care giver hours to 40 hours per week. For some of these live-in providers and their clients, this change would be very detrimental. Some of the MOST disabled folks in our state receive the maximum amount of 112 hours per week for their paid care (payment for 16 hours per day of care). Of that group, live-in caregivers provide the majority of those hours. Many of these live-in caregivers are parents or spouses of these disabled people, and many of them have left careers to take care of their loved ones. Some have been caring for their loved ones for 30 years or more. To suddenly cut their hours and income by 72 hours per week is DANGEROUS and very destabilizing for these disabled clients. This could lead to the loss of homes, mental health crises, hospital stays, and possibly death for some of the most medically needy clients.
Families affected by these changes will face severe financial issues. A loss of 72 hours per week at $15.00/hour is a cut of $4320 per month for these households. How will they be able to find jobs that pay that much, as people who have been out of the work force for so long? These families must also balance doctor appointments, hospital stays and the stress of caring for their loved ones, which would make working outside of the home very difficult for them at times. This plan assumes that suddenly, after YEARS of searching, hiring, training and losing paid care givers, that they can find someone to do their jobs. This is further complicated by the fact that these paid caregivers aren't able to administer medications or provide the medical decision-making necessary to ensure proper care for clients at all times, which means our most disabled will be in danger.
This plan will NOT work for the most medically fragile and high needs disabled adults on this waiver. If you are to go forward with limiting live-in care givers to 40 hours per week, you will be forcing people to sell their homes and

put their loved ones into nursing home facilities. The waiver program was created in order to stop this exact situation from happening. Also, moving disabled clients into nursing homes will be further complicated by a current shortage of Medicaid funded beds available.

Instead, we propose that since this waiver has enough funds to make it through this year, that you spend this year meeting with the families of these individuals and create a plan that will actually work. I believe there are solutions available in this situation! The current system that's in place was created for individualized care, and there are already evaluations that were created to determine services and hours. If you want to create caps, please do it moving forward--not retroactively and NOT so suddenly and NOT so drastically. Consider contracting with each family individually (perhaps less agency contracting and more live-in caregiver contracting?), consider a tiered system like DD services use to determine pay rates.

Also please consider seeking out the funds you need:

a. Find an agency or non-profit, or create one, and begin to hold an annual fundraiser that gives average Nebraskans and wealthy Nebraskans a chance to care for the disabled of our state.

b. Perhaps the Huskers could run a fundraiser at one home game a year where they advertise the needs of those who are disabled in our state and give a matching percentage of ticket sales that day.

c. Would the Volleyball team and their fans want to help protect the disabled of our state?

d. Ask the Nebraska legislature to allocate more money for this program, due to the rising number of individuals in this program. I believe this sort of thing happens (for example, asking for raises for state employees, you look at the cost of living and then approve a 3-6% raise for your employee). A request for additional funding seems appropriate

Jessica Chatelain

From: KIM BAINBRIDGE
To: DHHS HCBS Public Comments
Subject: AD waiver changes
Date: Tuesday, December 30, 2025 7:27:55 PM

> You don't often get email from [redacted]. Learn why this is important

Nursing homes in rural areas are not an option as too many clothes and parents would have to drive too far. I cannot believe that the average cost of a nursing home is only is less than $100,000 per year. Where did you come up with that number.

If we are such a pro life state,, are we just a pro or we a pro lifespan state. People will die due to the changes you are making by not letting their parents take care of it. Do you have any idea the amount of time it takes for any parent to raise their child with an intellectual or developmental disability? Why don't you walk in our shoes once

Kim Bainbridge
[redacted]

Sent from Yahoo Mail for iPhone

From: sheri
To: DHHS HCBS Public Comments
Subject: AD waiver changes
Date: Monday, January 5, 2026 9:43:59 AM

> You don't often get email from [redacted] Learn why this is important

Hi,

I guess I was supposed to receive a letter about all the changes, which I DID NOT receive.

Very concerned about the changes effective July 1, 2026. I am only at 15$ hour...at 40 hours a week that will be a decrease in 1,000$/week. Kids at fast food restaurants make more than that! Will my hourly rate at least increase? Will her father be able to take the extra hours in the household since she is 24/7 care??? I am afraid that I will have to take on an extra job outside of the home and not sure where she will go, since I can't even find respite care for her here. I have only been able to find day services for DD here in our town and they do not accept AD waiver people. They have told me they can only do one service and that is DD only. I feel there is a huge flaw in this system for services for AD waiver people. Where do they go for other care needed when the parent is unable to care for them, or has to take on another job??? It seems the focus is on DD services only. Are you trying to get rid of the AD services? So, only DD services are available??? Please help me to understand this.

Parents and caregivers need to be paid for their time for these services when no one else is available. If not, we will be forced to take on other means of income to afford our daily financial needs. If that happens, then our loved ones may be forced to live in nursing homes and other institutions that are crowded and horribly understaffed! Most of these people (our loved ones) are one on one 24/7/365 care. They will not get the quality care that they deserve and are entitled to!

If I am misunderstanding all these coming changes, please give me and others more information to help us understand what is being implemented.

Please consider our loved ones and what the outcome may be with these changes that will be enforced July 1, 2026.

Thank you,

From: Kaitlyn Colvard
To: DHHS HCBS Public Comments
Subject: AD waiver comment
Date: Wednesday, December 17, 2025 1:58:53 PM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Under no circumstances do I , a Nebraska citizen, want these new changes the DHHS are implementing regarding AD waivers. Families should not be forced to care for their severely disabled resident for free, and many do need well over 40hrs weekly of care. This is a inhumane change that will rip families apart by separating disabled ones from their loved ones. Nursing homes are already crowded and often ill-equipped to care for the severely disabled. Please reconsider these changes— we are very unhappy.

Kaitlyn Colvard

From: Kieffer, Laurel
To: DHHS HCBS Public Comments
Subject: AD waiver comment
Date: Friday, January 2, 2026 11:20:07 AM

You don't often get email from [redacted] Learn why this is important

Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers.

These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.

If cost containment is necessary, there are better alternatives:

> Maintain current hour limits for existing participants (grandfathering).
> Remove or revise the 40-hour cap for live-in caregivers.
> Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment.

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From: Aaron Kuecker
To: DHHS HCBS Public Comments
Subject: AD Waiver Comment
Date: Monday, January 5, 2026 8:39:33 PM

> You don't often get email from [redacted] Learn why this is important

In Appendix B: Participant Access and Eligibility, subsection B-7: Freedom of Choice, it says

"Nebraska waiver participants are afforded a choice among waiver services as well as between waiver services and institutional care"

If live-in caregiver hours are capped at 40 per week and those on the AD Waiver are displaced from their home, how is this choice going to be afforded?

Aaron Kuecker
[redacted]

From: Aaron Kuecker
To: DHHS HCBS Public Comments
Subject: AD Waiver Comment
Date: Monday, January 5, 2026 8:39:33 PM

> You don't often get email from [redacted] Learn why this is important

In Appendix B: Participant Access and Eligibility, subsection B-7: Freedom of Choice, it says

"Nebraska waiver participants are afforded a choice among waiver services as well as between waiver services and institutional care"

If live-in caregiver hours are capped at 40 per week and those on the AD Waiver are displaced from their home, how is this choice going to be afforded?

Aaron Kuecker
[redacted]

From: Aaron Kuecker
To: DHHS HCBS Public Comments
Subject: AD Waiver Comment
Date: Monday, January 5, 2026 9:00:16 PM

In section C: Participant Services, subsection C-5: Home and Community Based Services, it says:

"Facilitates individual choice regarding services and supports, and who provides them."

Wouldn't cutting live-in caregiver hours to 40 per week remove the ability for some to choose services and supports? If a caregiver could not sustain themselves on the income from 40 hours per week of caregiver, then they wouldn't be an option for the individual with a disability, therefore eliminating individual choice.

From: Aaron Kuecker
To: DHHS HCBS Public Comments
Subject: AD Waiver Comment
Date: Monday, January 5, 2026 8:58:07 PM

You don't often get email from [redacted]. Learn why this is important

In section C: Participant Services, subsection C-5: Home and Community Based Services, it says:

"Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint."

Does cutting live-in caregiver hours down to 40, causing the individual with a disability to pursue other options cunt as coercion or restraint? As in the state is coercing them to find and utilize more expensive and less trusted caregivers such as nursing or nursing facilities?

From: Aaron Kuecker
To: DHHS HCBS Public Comments
Subject: AD Waiver Comment
Date: Monday, January 5, 2026 8:43:13 PM

You don't often get email from [redacted] Learn why this is important

In Section C: Participant Services, subsection C-1/C-3: Service Specification, it says:

"Personal Care and LRI Personal Care are limited to a combined maximum of 40 hours per week (for live-in caregivers).
Personal Care, LRI Personal Care, and Companion services are limited to a combined maximum of 70 hours per week for non-live-in caregivers.
Exceptions to both limits may be approved by DDD Central Office to meet the immediate health and safety needs of a participant."

What documentation will be required for exceptions? Will exceptions still be capped by the 175% of institutional cost mentioned previously in the document?

From: Aaron Kuecker
To: DHHS HCBS Public Comments
Subject: AD Waiver Comment
Date: Monday, January 5, 2026 9:02:15 PM

In section C: Participant Services, subsection C-5: Home and Community Based Services, it says:

"Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint."

Does cutting live-in caregiver hours down to 40, causing the individual with a disability to pursue other options count as coercion or restraint? As in the state is coercing them to find and utilize more expensive and less trusted caregivers such as nursing or nursing facilities?

From: Chris Stewart
To: DHHS HCBS Public Comments
Subject: AD Waiver Comments
Date: Wednesday, December 10, 2025 6:57:13 PM

You don't often get email from [redacted]. Learn why this is important

I am responding to the proposed changes to the AD Waiver. I have significant concerns regarding the hours being capped for the services my adult son receives. His service coordinator informed us that they were directed to reduce everyone's hours to 70 per week and that supervision would no longer be approved as a covered service. However, during the review on the 10th, this issue was raised and clarified, confirming that supervision is to continue as an approved and provided service. This indicates to me 2 things. 1- the service coordinators need more education on the AD Waiver program 2- they may not be qualified to make the determination of these needs in some situations. My concern is that this remains an essential, authorized service, and any reduction or removal would place my son at substantial risk.

Additionally, I am concerned that the service coordinator is the one determining whether there is a need for supervision. This is where I question the qualifications of the coordinators. My son suffered a brain aneurysm that resulted in cognitive impairments that affect his ability to make safe decisions, along with short-term memory issues and periods of confusion, all of which require ongoing redirection. These cognitive disabilities are not always immediately apparent, unlike his physical limitations. Just because the allotted supervision hours may be capped or used up does not mean the need disappears for the remaining hours he is awake. His need for supervision is continuous and vital to his safety and daily functioning.

I feel that the informal hours being provided for his care are scheduled during the night while he is sleeping. During these hours, it is the family who is actually providing the supervision and care he needs.

I understand that there are budget cuts going on. But I feel that this area that deals with the care of the disabled is not the place to be cutting. This puts their health and safety at risk as well as takes away any sense of independence they may have by being able to remain in their homes instead of an institution. Not to mention the high cost of these institutions that would put more of a strain on the state's budget.
Thank you,
Chris Stewart
Sent from my iPad

From: Brett Williams
To: DHHS HCBS Public Comments
Subject: AD waiver commitment
Date: Sunday, January 4, 2026 12:12:24 PM

You don't often get email from [redacted]. Learn why this is important

To whom it may concern;

Parents (legal guardian)and family members serving as AD Waiver providers are not being paid to parent. They are being reimbursed for delivering Medicaid-authorized services that the state is legally obligated to provide to an adult individual who cannot safely meet those needs independently. Limiting or dismissing family providers does not eliminate the state's responsibility — it simply shifts it onto families without compensation or consent.

Family Providers Are Performing a State-Delegated Role — Not Ordinary Parenting
• Under Nebraska law and Medicaid policy, once an individual reaches adulthood, they are legally responsible for themselves to the extent they are able.
• The State of Nebraska, through Medicaid and the AD Waiver, holds responsibility to ensure:
• Health and safety
• Access to long-term services and supports
• Alternatives to institutionalization
• When a parent or family member becomes a paid AD Waiver provider for an adult child, they are:
• Voluntarily assuming duties that would otherwise be fulfilled by the state
• Performing skilled, time-intensive, and often medically or behaviorally complex care
• Preventing the state from having to fund higher-cost agency or facility services

This is not compensation for parenting — it is reimbursement for delivering Medicaid-authorized services that the state is obligated to provide.

—

The Care Provided Exceeds Normal Parental Duties
• AD Waiver services involve:
• Assistance with multiple ADLs and IADLs
• Continuous supervision to prevent harm
• Behavioral intervention and crisis prevention
• Medical monitoring and hands-on personal care
• These tasks go far beyond what is expected of parents of adult children without disabilities.
• If a parent were not providing this care:
• The state would be required to pay an agency or facility to do so
• The legal obligation would not default back to the parent

—

Payment Recognizes Substitution for Paid Providers, Not Family Status
• Payment under the AD Waiver is based on:
• Authorized services
• Documented need

• Compliance with Medicaid rules
• The relationship of the provider (parent, sibling, spouse) does not change the nature of the service being delivered.
• The only reason parents are present in these roles is because:
• The workforce is insufficient
• The individual tolerates only trusted caregivers
• Families stepped in to prevent institutionalization

—

Denying or Limiting Family Providers Shifts State Responsibility Without Consent
• When family providers are capped or excluded:
• The care requirement does not disappear
• The burden is shifted back onto families without compensation
• This creates an unfunded mandate on families and undermines Medicaid's purpose.

Families did not create the need for these services — the disability did. The AD Waiver exists to meet that need regardless of who delivers the care.

—

Equity and Disability Rights Framing
• Adults without disabilities are not expected to rely on their parents for lifelong personal care.
• Expecting families of people with disabilities to provide extensive unpaid care solely because of family relationship is discriminatory.
• Paying family providers ensures equal access to services, not special treatment.

—

Thank you for reconsidering your perspective of parents (legal guardians)and family members as not parenting but delivering Medicaid-authorized services through agencies with whom we are employed.

Jennifer Lynn Williams
Zane A Williams

From: Wendy Cameron
To: DHHS HCBS Public Comments
Subject: AD waiver cuts
Date: Saturday, January 3, 2026 4:34:46 PM

> You don't often get email from s[redacted]. Learn why this is important

Dear governor Pillen: my name is Katie Cameron and through my mom I would like to react to your proposed changes to cut hours. At 18 months I was diagnosed with leukemia and also suffered a major stroke! I did 6 full months at Children's to complete chemo and learn how to walk, talk, eat, swallow. Without my mom and dad there every single day spending the nights in the room with me I don't think I could have made it. They talked to me constantly, played much, and willed me back to life. They never once left me alone in the hospital. My parents are and always have been my caregivers and I won't settle for less. If you actually go though with this new plan, I will. To survive without my parents: you talk about leaning on outside supports. We have none. Nobody understands the hard work; restless nights staying up with me due to my brains injury: my parents are my only support. In 2023 I was really sick and my mom knew to take me to ER and taken to Childrens Hospital because my heart was failing. I needed a heart transplant to survive. I was transferred to UNC to begin the process to get on the transport list which took a long time: they couldn't stabilize me and I ended on on Ecmo which is life support while waiting for my heart. It took a couple days and on September 7, 2023, I received my new heart. This heart failure was caused by chemo I had to take at 18 months to stay alive. You see, I would not made it without my parents by my side. My dad quit his job at the City of Grand Island to be my caretaker. These proposed changes will devistate families like move and I won't survive without them. How about you come over for a day and observe my parents in action and then tell me we only need 40 hours a week. I am not a stastic or number you need to eliminate to balance the shortfalls the government has. Don't punish us, do what is right and don't cap hours at 40. I promise you you have no clear understanding of what us caregivers are going through. Do the right thing or the sufferage and blood will be forever stained on the decision.

Katie Cameron
[redacted]

Get Outlook for iOS

From: Linda Garcia
To: DHHS HCBS Public Comments
Subject: AD Waiver hours cut
Date: Friday, December 19, 2025 1:12:07 PM

You don't often get email from [redacted] Learn why this is important

I am one of many parents that this proposal will be affecting.
Paying for my daughter to go in to an institution would be the death of her. She is cognitively sound. She has Arthrogryposis Congenita Amyoplasia, Scoliosis, Restrictive Lung Disease, Asthma; all of which causes her chronic respiratory failure. This is also why she needs a trache. Because she is tracheostomy dependent, she requires ACTIVE assistance. Carly's symptomes can fluctuate unpredictably. She is unable to use her arms. She has had 22 back surgeries. She has had her spine fused so she is unable to sit upright for long periods of time. Also because of the spinal fusion, she is in quite a bit of pain during the cold months due to the titanium in her body. She is dependent on a caregiver for about 95% of her needs.
I had to quit working to take care of my daughter. Outside agency care is not always reliable as they are also short staffed. My daughter is considered high skilled care because of her trache. She has stopped breathing on me 6 times. The longest was 2 1/2 hrs. The EMT's arrived and the respiratory therapist and myself took "bagging" her until another ambulance came to take her to where specialists were trained to care for her.
It is hard to find that care now that she is an adult. I have had one doctor tell me she was "chicken", she didn't know how to care for her. I have had others tell me to take her to the Mayo clinic, They have not been able to treat her in the past. HOW is an institution going to care for her??? I volunteered in one of those institutions. It took 3 minutes for a nurse to come and suction the child I was holding. In those 3 minutes, that child could've died!! My daughter can not wait that long to be suctioned. Mucous plugs can cut off her airway and she could die if not immediately taken care of.
Also in institutions, they have call buttons to use. She can't use a call button because she is unable to use her arms. An institution tried putting a big button for her to kick with her foot that did not have an IV in but that button fell to the floor. When she is struggling to breathe, she is not going to be able to call for someone.
PLEASE listen.
Linda Garcia, a concerned mother and caregiver

From: justin smith
To: DHHS HCBS Public Comments
Subject: AD Waiver hours reduced
Date: Monday, January 5, 2026 2:11:32 PM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

I'm writing to you for my concern of the reduced hours for caregivers because it would have a huge impact on my life as well as my mother's who is my live-in caregiver. We live in Shelton and even being 20-30 minutes away from bigger towns like Kearney, Grand Island and Hastings, it is almost impossible to find caregivers that will travel to Shelton. I am a quadriplegic and have my mom and another local caregiver that helps most days of the week but on the weekends it all gets left up to my mother to take care of me. Sometimes one of my sisters comes to help with getting me in and out of bed on the weekends but she has a full time job of her own and the fact is we can't always count on her. I have been in a wheelchair since I was 15 years old and my mother has been my full time caregiver for the last 15 to 20 years. In order to pay taxes, have insurance and other benefits she had to have a job outside our home not to mention pay our house hold bills with at the time I got hurt was $5 an hour in 1993. During that time my sister took care of me most the time. I understand that was over 30 years ago but not even a week ago the pay only went up to $15 an hour. High school kids working at McDonalds make more than that. Honestly I don't believe I know anyone who would work for $15 an hour with the way things cost these days. I'm sure there are things caregivers have to do that some people would not do no matter what you paid them. The only way to get anyone to be a caregiver that I can see is because of the overtime but then you get people who complain about the hours it takes to get that overtime pay. A few years ago my mother needed a back surgery and was unable to work for months. Even asking places like the League of Human Dignity and Caretech we found no help to take her place. We were on our own except for family and friends. To cut the hours to 40 hours a week ends overtime pay and leaves a lot of hours unpaid for the rest of the week. 15 times 40 is $600. Would you do your job for $600 a week? We have lived in our paid for home for almost 45 years and with property taxes and insurance these days we might have to sell our home if these cuts happen. If i didn't live here with my mom I really don't know what I'd do. I've had breathing problems on and off since my accident. For the first few months I needed to be on a ventilator and have had pneumonia several times which means I need to do breathing treatments during the winter often. Even times when I've had to be in the hospital with things like that mom has had to stay with me because the shortage of nurses and in my condition when I'm having breathing problems I need out of bed right now! In the hospital you'll wait for 5 or 10 minutes just to get a nurse to come to your room and the she'll say she'll have to go get help. My mother is 74 years old and can still get me in and out of bed by herself. Even if I'm feeling fine and home I can't be left alone in bed. What if there's a fire? Even with the hours and overtime available now, the overtimes gets paid so rarely we struggle from time to time. Having a live-in caregiver basically means she is my help 24 hours a day. She does a lot she's not paid for, and that's ok but no one else would. I really hope you reconsider these changes. I'm not the only one this would effect but I'm sure other people would have an even harder time than I would finding help.

Justin Smith

12/29/2025

To: all interested and concerned lawmakers
Re: the proposed changes in the AD Waiver program

I am writing to you with great concern and disappointment in our State with regards to the proposed changes coming from DHHS and the AD Waiver program. When a program change as this effects families in Nebraska in such a large scale as this, they need to be heard.

The program currently assists not only families that have children born with severe disabilities, but individuals that may have had traumatic brain injuries from a car accident, stroke, or other disabiltating diseases which in turns means that it could effect anyone and anytime without warning. These cutbacks are targeting the wrong families. These cutbacks could have the reverse effect that you are aiming for financially. These cutbacks scream loud and clear that you feel these individuals are **not worthy of the quality of life** they are currently being able to live.

With so much waste in state spending and our Nebraska Medicaid system …i could go on and on about the abuses and monies that need to be re-evaluated in the medicaid programs as i had witnessed first hand in my own career, when the office i work for accepted medicaid patients… i continually felt we needed to protect the assets of the state while caring for the individuals with dignity and respect…but this grew harder and harder when people assumed that “free services” were their “insurance” and witnessing abuses of these services.

I can tell you from a somewhat “outsider” view point yet with and “insider” look into how the AD Waiver program is NOT the area that you should be choosing to apply the cutbacks to. Let me explain that my sister is one of those in home caregivers to her now 25 year old son. He is easily 250 lbs (or more) who needs 24/7 care. Prior to being on the waiver program i watched my sister and her then husband fight to get his yet undiagnosed condition approved for medical assistance (medicaid) while others were easily accepted. They filed medical bankruptcy including the loss of their home as the medical expenses piled up. My nephew was eventually accepted in the medicaid system and his care involved a team of 9+ doctors, trips to Mayo, Shriners and many visits to Children’s Hospital in Omaha. His mobility decreased to the point of being immobile today.

My sister worked outside the home while her son attended the public school programs as she was soon a single mom with two children and she needed to provide, yet the people that were

able to assist her in any way became very limited due to outbursts and fits of anger and aggression from my nephew. Our parents, and myself on occasion, would care for him and get him on the bus while she was at her job. This was no easy task as he would become violent, scratching or clawing and biting as we struggled to get him out the door and onto the bus. Because of his limited words i would often have to call her to find out what he was asking for before he had a complete meltdown and fit. She would endlessly get called from the school so that she would have to leave her job to go get him because they were unable and unequipped to properly care for him. My nephew was traumatically effected going to those programs at a level that his care was becoming dangerous for my sister and her daughter, yet they never gave less and never gave up.

Once my nephew aged out of the school program and my sister was able to become his full time care provider things began to change for him. They moved into a more suitable home, remodeled a laundry room to provide a wheelchair friendly shower as well as other modifications to make his life more comfortable and not restrict him from being part of his family. Lifts and gadgets, diapers and wipes, his wheel chair van, his feeding tube and medicines are just part of their every day life and things that we take for granted when we take a glimpse into any 24 hour period with him.

Being able to care for him in their home has indeed involved the attempt to use respite providers to give my sister “a break” but inevitably he refuses the “strangers” to provide him with care and it’s MOM that he wants. Her trips to the store are an adventure to leave him behind with his stepdad or his sister (who is now an adult as well) or step siblings….and most certainly cannot happen with an outsider.

Caring for him in his home has allowed him the quality of life that he deserves. He is living with dignity and respect that his mother has provided allowing him to surround himself with things that help him continue to grow….learning new words and being a happy and safe young man. It allows my sister the peace of mind that his needs are met and that he’s not in turn injuring someone through his anger. It allows him a good quality of life that he would not be able to accomplish in a facility, institution or a nursing home that would not meet his needs.

Cutting her in home care provider hours to the point that outside of the home jobs become necessary to sustain his quality of life as well as that of her and the rest of her family, is not the answer. Allowing her the paid hours is far less expensive to the State as would be facility care. I know that the parents and care givers are flooding you (as they should be) with stats and facts

and bullet points of why these cutbacks won't be in anyones best interest, but i am writing to you on a more personal level.

My sister does what i could not do.
My sister lives a life that would exhaust you.
My sister has very few resources to assist her and yet she does not wallow in pity or ask for anything more that what it takes to give her son the quality of life that he deserves.

We as a family have all seen first hand the changes that came with her being able to be his full time provider.

I challenge each of you to spend one week living with her. One day and you would be shaking your heads in disbelief that you would have even considered it be humane and dignified to cut this particular program.

Thank you for your time and attention,

Misty Sullivan (Aunt!)
[redacted]

From: [redacted]
To: DHHS HCBS Public Comments
Cc: [redacted]
Subject: AD Waiver personal care program
Date: Saturday, December 27, 2025 8:52:16 PM

You don't often get email from [redacted] Learn why this is important

Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers.

These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.

If cost containment is necessary, there are better alternatives:

Maintain current hour limits for existing participants (grandfathering).

Remove or revise the 40-hour cap for live-in caregivers.

Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment.

From: Alyssa Nichols
To: DHHS HCBS Public Comments
Subject: AD Waiver personal care program
Date: Sunday, December 28, 2025 1:49:19 PM

You don't often get email from [redacted]. Learn why this is important

Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers. As a registered nurse I have severe concerns of the negative patient outcomes these changes will bring. Current nursing shortages cannot sustain the increase in skilled nursing services these patients would need if the AD Wavier personal care program were to change.

These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs. As a registered nurse I foresee these changes requiring more government spending rather than achieving the desired cost savings.

If cost containment is necessary, there are better alternatives:

Maintain current hour limits for existing participants (grandfathering).

Remove or revise the 40-hour cap for live-in caregivers.

Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment.

Sincerely from a concerned nurse,

Alyssa Nichols BSN, RN

From: Shawnda January
To: DHHS HCBS Public Comments
Subject: AD Waiver Program Changes
Date: Monday, December 29, 2025 11:58:16 AM

You don't often get email from shawndajanuary@gmail.com. Learn why this is important

I am contacting you about the proposed changes to the AD Waiver. The one I am most concerned about is the 40 hours cap for family caregivers. I understand if for people that are under the age of 18 but for over that it will not be a pleasant change. Day service programs aren't open long enough for the caregiver to have a full time job elsewhere.

Do you understand a lot of us have to be with family members 24/7? We cannot just get up and go do whatever we want when we want. We choose to be a caregiver. I think we should get more than 40 hours. If not, I fear a lot of families will be forced to institutionalize their family members in order to be able to get another full time job to pay the bills. That is not only sad for the caregiver but can you imagine the adult that is forced into a strange place. Not to mention these places including day services and agency caregivers are revolving doors of employees. Our family members would not be getting the care they have been used to getting. Leads to depression, and failing health.

I have a 25 year old son, when he was a child I did not get paid for being his caregiver. From my understanding that has now changed. I think if you are going to cut hours anywhere that is where they should be cut. There are places like CRCC that can take them from infant to 21 years old. The "caregiver" can still work a full time job. Day services for adults are mostly 9-2. I do see it says up to 30 additional hours for agency caregivers to come in. My son has never been taken care of by anybody else. I also have 3 dogs. What are they going to do for 30 hours a week so I can work a 20 hour job? (include drive time etc) Most jobs won't hire somebody for 20 hours, and I have heard horror stories about agency caregivers calling in, no replacements available. Sounds like a lot of stress. Who wants a different caregiver coming in all the time to take care of their loved one? I don't want strangers in my house. I cannot afford to live off just 40 hours a week.
All these day services and facilities will not be able to take in all these family members. They will get overwhelmed, waiting lists, and a shortage of employees. It's best if we take care of our loved one. We know what is best for them. We make them happy, they make us happy. This change would be tearing families apart.
--
Shawnda January

From: [redacted]
To: DHHS HCBS Public Comments
Subject: AD Waiver Proposal - Comment
Date: Tuesday, December 30, 2025 1:17:14 PM

You don't often get email from [redacted]. Learn why this is important

Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers.

These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.

If cost containment is necessary, there are better alternatives:

- Maintain current hour limits for existing participants (grandfathering).

- Remove or revise the 40-hour cap for live-in caregivers.
- Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment.

-Benjamin Hamilton

Omaha, NE

From: Jennifer Williams
To: DHHS HCBS Public Comments
Subject: AD waiver proposal
Date: Sunday, January 4, 2026 11:55:38 AM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Sent from my iPhone
Inconsistencies on what is allowed and not on page 127 and 128.

Based specifically on the language on pages 127–128 of the AD Waiver proposal, there are several internal inconsistencies and conflicts when you line up personal care hour caps, exceptions, and who is allowed to provide the care. I'll break this down.

—

1. Conflicting Hour Caps vs. "Health and Safety" Exception Language

What the proposal says
• 40-hour cap for Personal Care + LRI Personal Care when the caregiver is live-in
• 70-hour combined cap for Personal Care + LRI + Companion
• Exceptions may be approved by Central Office to meet immediate health and safety needs

Inconsistency
• The proposal acknowledges that some individuals have needs that exceed 40 or 70 hours for health and safety, BUT
• It does not align those exceptions with 24/7 care needs, even when those needs are already documented and previously approved.

Why this is a problem
• A person who needs continuous supervision or hands-on care cannot have their health and safety met under a hard weekly cap.
• The exception language is written as temporary or emergency-based, not as recognition of ongoing, permanent high needs.

Contradiction: The proposal admits higher hours are sometimes required, but structures the system so those needs cannot realistically be met long-term.

—

2. Provider Restrictions Conflict With Tolerance, Routine, and Disability Needs

What pages 127–128 do
• Strongly limit who can provide care:
• Live-in family caregivers capped lower
• Greater reliance implied on non-family or agency providers
• Treats family care as something that should be restricted, not individualized

Inconsistency
• The proposal:
• Claims to be person-centered
• References health and safety
• But ignores the reality that:
• Some individuals do not tolerate unfamiliar caregivers

• Routine and trust are medically necessary, not preferences

Conflict: You cannot claim person-centered planning while forcing care from providers the individual cannot safely tolerate.

—

3. Unequal Treatment Based on Provider Type, Not Need

What the proposal does
• Two people with the same assessed needs can receive very different hours depending on:
• Whether care is provided by family
• Whether they can tolerate outside staff

Inconsistency
• The waiver is supposed to be needs-based, yet:
• The cap applies more harshly to family providers
• Individuals who cannot accept outside providers are effectively penalized

Result: The proposal creates artificial scarcity, not based on needs, but on provider category.

—

4. Cost-Containment Language Conflicts With Actual Cost Outcomes

What's implied
• Caps are justified as cost control

Inconsistency
• Family caregivers:
• Are paid less than agencies
• Cost far less than institutional care
• Restricting family hours:
• Pushes individuals toward nursing facilities or higher-cost settings
• Violates the stated intent to be fiscally responsible

Contradiction: The proposal limits the least expensive care option while risking the most expensive outcome.

—

5. Olmstead & HCBS Final Settings Rule Conflict (Indirect but Real)

Even though not named directly on pages 127–128, the conflicts are clear:
• Olmstead requires services in the most integrated setting
• Final Settings Rule requires:
• Choice of providers
• Services that support remaining in the community

Inconsistency
• Caps + provider limits:
• Reduce meaningful choice
• Make home care unsustainable for high-need individuals
• Increase risk of institutionalization

This puts the state at odds with federal intent, even if not explicitly acknowledged in the proposal text.

—

6. Summary of Core Inconsistencies (Plain Language)
• The waiver says health and safety matter, but caps make safety impossible for some.
• It says person-centered, but applies blanket limits.
• It says choice of provider, but restricts family care.
• It says cost-effective, but undermines the lowest-cost option.
• It says community-based, but increases institutional risk.

Thank you for considering the inconsistency and coming up with a more concrete proposal that needs the needs of each individual not just a blanket statement.

Thank you
Jennifer Lynn Williams
Zane A Williams

From: Zach Boeka
To: DHHS HCBS Public Comments
Subject: AD Waiver Proposal
Date: Friday, January 2, 2026 3:08:37 PM

You don't often get email from [redacted]. Learn why this is important

Dear Nebraska Department of Health and Human Services:
This letter serves as a formal notice of significant federal compliance concerns regarding Nebraska DHHS's administration of the Aged and Disabled ("AD") Home and Community-Based Services ("HCBS") Waiver authorized under §1915(c) of the Social Security Act. These concerns implicate federal Medicaid statutes, implementing regulations, HCBS waiver assurances, and constitutional and civil rights protections enforced by the Centers for Medicare & Medicaid Services ("CMS").
This correspondence is intended to preserve the record and to request corrective review to ensure Nebraska's continued compliance with federal law.

I. Federal Authority Governing the AD Waiver

Nebraska's AD Waiver operates pursuant to 42 U.S.C. § 1396n(c) and is approved by CMS subject to ongoing compliance with waiver assurances, including but not limited to:
Person-centered service planning
Health and welfare protections
Freedom of choice of qualified providers
Services sufficient in amount, duration, and scope to meet assessed need[1]
Failure to meet these assurances places the waiver at risk of noncompliance and federal corrective action.

II. Freedom of Speech and Retaliation Concerns

Nebraska DHHS policies and practices that discourage, penalize, or chill advocacy, public comment, or complaint-filing by beneficiaries or their caregivers raise serious constitutional and Medicaid compliance concerns.
Medicaid beneficiaries and their representatives retain full First Amendment rights, including the right to speak, petition, and advocate without fear of retaliation[2]. Federal Medicaid regulations further protect the right to due process and grievance without intimidation or adverse consequence[3].
Any reduction, scrutiny, or adverse action taken in response to protected speech or advocacy activity is incompatible with federal Medicaid requirements and constitutional protections.

III. Relationship-Based 40-Hour Cap on Live-In Parent Caregivers

Nebraska DHHS imposes a blanket 40-hour cap on paid caregiving when the caregiver is a live-in parent of an adult AD Waiver participant, without regard to the individual's assessed medical or functional needs.
This policy conflicts with federal HCBS requirements, which mandate that services be:
Determined through person-centered planning4
Based on individual assessed need, not family relationship5
Free from reliance on required unpaid "informal supports"6
Federal law does not permit states to presume that parents of adult beneficiaries must provide uncompensated care as a condition of waiver participation. Such relationship-based limitations function as an impermissible substitute for covered services.

IV. Arbitrary 175% Cap on Caregiver Compensation

Nebraska DHHS further limits caregiver compensation through a 175% cap, applied irrespective of:
Medical complexity
Workforce shortages
Geographic or rural access limitations
Under federal Medicaid law, state payment methodologies must be sufficient to ensure access to covered services comparable to that of the general population7. Payment limitations that render providers unavailable or unwilling to serve waiver participants undermine access, health, and welfare assurances8.
Cost-containment measures may not override federally required access or safety protections.

V. Denial of Meaningful Freedom of Choice of Caregiver
Federal Medicaid law guarantees waiver participants the right to choose among qualified providers, including individual caregivers[9]. Nebraska DHHS policies that make parent caregivers financially or logistically unsustainable effectively eliminate that choice.
A "choice" that cannot be exercised in practice due to hour or compensation caps is not meaningful choice. Federal courts and CMS guidance consistently recognize that constructive denial violates Medicaid's freedom-of-choice protections[1°].

VI. Hour and Pay Caps as Constructive Denial of Services
While Nebraska DHHS may assert that services remain technically available, caps on hours and pay:
Force beneficiaries to abandon their chosen caregiver
Create unsafe gaps in care
Increase turnover and instability
Drive beneficiaries toward institutional placement
Federal regulations require that services be sufficient in amount, duration, and scope to reasonably achieve their purpose[11]. Policies that systematically prevent services from meeting assessed needs violate this standard regardless of nominal availability.

VII. Institutional Bias and ADA/Olmstead Concerns
The combined effect of Nebraska's hour and compensation caps increases the risk of unnecessary institutionalization, in direct conflict with:
Title II of the Americans with Disabilities Act[12]
The Supreme Court's decision in **Olmstead v. L.C.**[13]
Federal regulations requiring services in the most integrated setting appropriate[14]
HCBS waivers exist specifically to prevent institutional bias. Policies that make home-based care unsustainable undermine the waiver's fundamental purpose.

VIII. CMS Oversight and Required Assurances
CMS approval of the AD Waiver is conditioned on Nebraska's ability to demonstrate compliance with waiver assurances under 42 C.F.R. § 441.302. CMS retains authority to require corrective action where state policies violate federal requirements or place beneficiary health, welfare, or rights at risk[15].

IX. Request for Review and Corrective Action
Accordingly, Nebraska DHHS is urged to:
Reevaluate relationship-based hour caps for parent caregivers
Justify any compensation caps with data tied to access and assessed need
Ensure meaningful freedom of choice of caregiver

Protect beneficiaries and caregivers from retaliation for advocacy
Align AD Waiver administration with federal HCBS, Medicaid, ADA, and constitutional requirements

X. Conclusion

Nebraska DHHS AD Waiver policies, as currently administered, raise substantial concerns of noncompliance with federal Medicaid law, HCBS waiver assurances, and civil rights protections. Prompt review and corrective action are necessary to prevent further harm to waiver participants and to ensure continued federal approval.

Respectfully submitted,

Tamara Boeka, Parent and Caregiver

Footnotes

42 U.S.C. § 1396n(c); 42 C.F.R. § 441.302
U.S. Const. amend. I
42 C.F.R. §§ 431.206, 431.220
42 C.F.R. § 441.301(c)(1)
42 C.F.R. § 441.301(c)(4)
Id.
42 U.S.C. § 1396a(a)(30)(A)
42 C.F.R. § 441.302(a)
42 U.S.C. § 1396a(a)(23); 42 C.F.R. §§ 431.51, 441.301(b)(1)(i)
See id.
42 C.F.R. § 440.230(b)
42 U.S.C. §§ 12131–12134
Olmstead v. L.C., 527 U.S. 581 (1999)
28 C.F.R. § 35.130(d)
42 U.S.C. § 1396n(c)(2)

From: Jodi Tolman
To: DHHS HCBS Public Comments
Subject: AD Waiver Proposals Conflict with Purpose and Requirements of the Waiver
Date: Thursday, January 1, 2026 1:48:20 PM

You don't often get email from [redacted] Learn why this is important

Dear DHHS,

I am an independent provider on the AD Waiver for my adult daughter with severe disabilities and complex medical needs, requiring 24 hour/day care. I have major concerns about the proposals presented in the renewal of the AD Waiver, specifically the 40 hour/week limit placed on live-in family caregivers. Below are some inconsistencies found in the AD Waiver application proposal. I urge you to reconsider the changes that have been proposed and maintain compliance with the purpose and goals of the waiver.

SUMMARY OF CORE INCONSISTENCIES

1. **The waiver says health and safety matter, but caps make safety impossible for some.**
2. **It says person-centered, but applies blanket limits.**
3. **It says choice of provider, but restricts family care.**
4. **It says cost-effective, but undermines the lowest-cost option.**
5. **It says community-based, but increases institutional risk.**

1. Conflicting Hour Caps vs. “Health and Safety”

What the proposal says
• 40-hour cap for Personal Care + LRI Personal Care when the caregiver is live-in
• 70-hour combined cap for Personal Care + LRI + Companion
• Exceptions may be approved by Central Office to meet immediate health and safety needs

Inconsistencies:
• The proposal acknowledges that some individuals have needs that exceed 40 or 70 hours for health and safety,
BUT
• It does not align those exceptions with 24/7 care needs, even when those needs are already documented and previously approved.

Why this is a problem:
• A person who needs continuous supervision or hands-on care cannot have their health and safety met under a hard weekly cap.

• The exception language is written as temporary or emergency-based, not as recognition of ongoing, permanent high needs.

Inconsistency: The proposal admits higher hours are sometimes required, but structures the system so those needs cannot realistically be met long-term.

—

2. Provider Restrictions Conflict With Tolerance, Routine, and Disability Needs

The current propsal strongly limits who can provide care:
• Live-in family caregivers capped lower
• Greater reliance implied on non-family or agency providers
• Treats family care as something that should be restricted, not individualized

Inconsistencies
The proposal:
• Claims to be person-centered
• References health and safety
• But ignores the reality that:
- **Some individuals do not tolerate unfamiliar caregivers**
- **Routine and trust are medically necessary, not preferences**

Inconsistency: You cannot claim person-centered planning while forcing care from providers the individual cannot safely tolerate.

—

3. Unequal Treatment Based on Provider Type, Not Need

The proposal says:
• Two people with the same assessed needs can receive very different hours depending on:
- Whether care is provided by family
- Whether they can tolerate outside staff

Inconsistency: The waiver is supposed to be needs-based, yet:
• The cap applies more harshly to family providers
• Individuals who cannot accept outside providers are effectively penalized

Result: The proposal creates artificial scarcity, not based on needs, but on provider category.

—

4. Cost-Containment Language Conflicts With Actual Cost Outcomes

What's implied in the proposal:
• Caps are justified as cost control

Inconsistency:
Family caregivers:
• Are paid less than agencies
• Cost far less than institutional care
Restricting family hours:
• Pushes individuals toward nursing facilities or higher-cost settings
• Violates the stated intent to be fiscally responsible

Result: The proposal limits the least expensive care option while risking the most expensive outcome.
—

5. Olmstead & HCBS Final Settings Rule Conflict

Olmstead requires services in the most integrated setting
Final Settings Rule requires:
• Choice of providers
• Services that support remaining in the community

Inconsistencies:
Caps plus provider limits:
• Reduce meaningful choice
• Make home care unsustainable for high-need individuals
• Increase risk of institutionalization

Result: This puts the state at odds with federal intent, even if not explicitly acknowledged in the proposal text.
—

Live-in family caregivers are a vital resource for the state. Utilize us appropriately! Pay us what we are worth! Don't disrespect us or take advantage of us by assuming we will provide care for free! Continue to compensate us reasonably and equitably, or risk losing a large portion of these family caregivers as they search for jobs outside of the home. Losing live-in family caregivers will only cost the state more to pay for agency providers, or create even bigger financial and logistical problems with a surge of participants suddenly requiring institutional

From: Amy Davis
To: DHHS HCBS Public Comments; Amy Davis; Amy Davis
Subject: AD waiver proposed changes - how will this impact my 21 year old son?
Date: Sunday, January 4, 2026 11:36:56 AM

You don't often get email from [redacted] Learn why this is important

Good Morning -

Under this proposal, is the state's position that adults with 24/7 hands-on care needs either:

1. Receive extensive unpaid care from family members, or

2. Enter an institutional setting to meet their needs?

If neither, what third option does the proposal actually provide in practice?

Looking at things if your person needs hands on 24/7 then that technically excludes them from 30 hours of companion care because they have No hands on written into it. They are totally counting on all families who want their person to live with them only have 40 hours and call the rest of it family provided care.

Please advise - please show me how this is viable? Sounds good on paper for budget cuts - but the reality of this has not been thought out nor has my disabled sons rights been considered

My son - got a headache - a headache for God's sake!! He is now a quadriplegic due to a brain hemorrhage (not spinal - so he could regain functions with therapy)from an undiagnosed AVM that ruptured! He was going to be a human service worker to help developmental disabled individuals have a better quality of life and go to college to get his degree to help make a difference in this world -

WHY do you get to decide he should be cared for by an institution because you think I should lose everything I worked so hard for to support all of my kids and to provide a stable retirement with no government support ever!!!

Until now… when my son is the most vulnerable and NEEDS the most support he will ever need.. and my son still has the ability to improve and he needs all hands on deck to make this happen - I know skilled nursing care costs will surpass your estimates you have provided - I have proof - I have multiple Explanation of benefits from a skilled nursing facility who could meet his needs - he was there for 58 days prior to coming home -

58 days between the following months:all inclusive room/board (please note this does not include the nursing charges and physician charges which are billed separately)

On With Life - Ankeny, IA - brain neuro rehab skilled nursing facility

-February 6-28,2025 submitted - $54,740 with provider discount $35,824.51 paid - coinsurance $915.49 paid by me
-March 2025 submitted - $73,780 with provider discount $48,453 paid
-April 1-4 2025 submitted - $9520 with provider discount paid $6252 paid

This skilled nursing facility was in Iowa as there was no qualified skilled nursing facility that could take on Justin and his needs with a brain injury (Thank God for private insurance otherwise he wouldn't have had this option and I wouldn't have obtained the comfier level to care for him at home because they worked with me as well so I could continue at home with what he was learning and I continued to learn how to care for him appropriately) - our only qualified facility in NE (QLI) would not take him as they said he wouldn't be able to participate at the level they needed him to be there - so sad.

Allowing myself and qualified care givers (which is hard to come by with the skills needed for my son) that I have opened our home up
To has proven to be the BEST option for my son - his physicians, nurses, hospital staff have all praised me on the knowledge and ability to communicate with my son and take care of his needs - they have indeed admitted not having the the experience or ability to be able to gauge or know how to ensure all his needs are being met - unfortunately due to the severity of my sons injuries - we have spent a lot of time in facilities, hospitals and assisted by medical personnel over the past 15 months - I have learned more than most and definitely know my son better then anyone else - I have tried to be able to continue to work in my career but due to the hours and time restraints it has made it extremely difficult - I can't provide the level of service anymore which is devastating to my career and to not be able to take care of my son, is simply unimaginable- I would give up everything for him to be well -

I too worked hard to live the American dream - I didn't squander, I saved, I took care of my family, I own a home, I help others obtain the dream of home ownership - I pay my taxes - I donate my time and money to charities - I just need to be able to take care of my son and make sure he can be the best he can be…someday when my days are up on this earth…someone else will need to help him…I want to make that a transition that won't force him into a world of loneliness and looking up
At a ceiling for hours of a day - can you understand that?

Would you be willing to look at photo albums with me and talk to my kids and mom and see what life was like before? Would you be willing to see what we truly go thru daily? Would you be willing to walk a week in my shoes as his caregiver and mother and see what our life looks like? If you would, it may open your eyes to see we are not the individuals you need to target - not the truly disabled and vulnerable -

I have had multiple conversations with service coordinators within your organization- there is a problem from whomever is doing initial
Assessments - if someone is truly nursing care LEVEL - how do individuals qualify for 7 hours a week only? Give me a break - that is NOT nursing care level that even comes close to what we live -

Maybe you need to look at levels of care - and based on those levels it determines how much funding is necessary rather then clumping us all into one category

Maybe you need to cut out agency providers for parent home givers - and pay the parent caregivers what they make with the agency to avoid the 2x rate you are paying out -

Maybe have the agencies run the outside caregivers since they need to be able to offer employer benefits to them and OT as needed - and need that extra funding for that, but why does an agency get almost the same as I for only submitting hours and paying me as a 1099 self employed person -

There are many things you could look at that is costing you money that wouldn't hurt the ones who need to be there for their loved ones. If I could survive off of love, and not have expenses, and be able to survive - I would but unfortunately- I have a home I need to maintain, my home needs more now than ever with all the extra traffic now with my son home - Ie- caregivers, home health, my utilities are much higher now, my home has much more wear and tear , I work 16 hours daily with no Overtime, during the 8 hours I get to recharge - I am 90% still at home assisting outside caregivers or taking my son to Dr. appts, therapies - PT, OT, speech - my son requires 2 person assist in any facility but that is not something the waiver covers so I need to be within a 15 min radius to assist caregivers either for bed care changes and transporting my son from his hospital bed to his tilt and space wheel chair with a hoyer lift -

I challenge you to visit your disabled citizens you are targeting and help us figure out these "other supports" you refer to - to allow your child or love one to potentially live without the supports they need and see how you would or could handle it -

It is my understanding that my sons' human rights and dignity would be compromised and the ACLU won't stand for that - I will not disappear - my son won't disappear - I understand changes need to occur but we are not just a number in your budget you can slash - it's not right or humane.

May you sleep restfully at night if you continue to put us thru all if this unnecessary stress and ultimately try and destroy what we have accomplished by providing loving and nurturing homes for our loved ones while we put in the time and proper effort necessary for them to thrive.

With much respect,

Amy Davis - mother since 2004/court appointed legal guardian as of 7/1/25

From: Scot Davis
To: DHHS HCBS Public Comments
Subject: AD Waiver Proposed Changes
Date: Sunday, January 4, 2026 7:33:58 PM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Hello,
I would like to voice my thoughts on your proposed cap of 40 hours for live-in care providers. If this proposal goes through this would be a 60% cut in hours that my wife is currently paid to take care of my 22 year old son. My son needs 24/7 care and supervision. Our coordinator who visits every month believes these hours are justified because he would need to be in a nursing home if my wife wasn't able to take care of him.

I can understand a 10-20% cut if finances are bad but a 60% cut is not reasonable. The cost to the state for nursing home care would exceed what my wife is currently being paid to take care on our son. The numbers don't make any sense to me.

My family is better off than others because I am able to work outside of the home but this is not the case for some. These drastic cuts will hurt their only source of income and force them to make hard decisions. Most families would like to be able to care of their family members at home but these cuts might force them to find a nursing home so they can work during the day.

I ask that you reconsider such drastic cuts. Again I do understand that fraud can be rampant but I know that our house is visited every month. She visits with our son and talks to my wife. I would like to think this happens for all families. I max cap does seem reasonable but to say that 40 hours is the limit does not. Each case should be based on the individual needs of the client. A one size fits all is not appropriate in this situation.

Thank you for taking the time to read my comments.

Scot

From: Carly Renken
To: DHHS HCBS Public Comments
Subject: AD Waiver Proposed Changes
Date: Sunday, December 28, 2025 1:07:05 PM

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Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers.

These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.

If cost containment is necessary, there are better alternatives:

Maintain current hour limits for existing participants (grandfathering).

Remove or revise the 40-hour cap for live-in caregivers.

Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment.

Carly Renken, M.Ed. BCBA
Special Musicians
Founder and CEO

From: Amy Davis
To: DHHS HCBS Public Comments; Amy Davis
Subject: Ad waiver proposed cuts - please don't overlook our loved ones
Date: Sunday, January 4, 2026 1:17:12 PM

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I am writing to submit a public comment regarding the proposed changes to the Aged and Disabled (AD) Waiver, specifically the proposed reductions in individual care and services due to an asserted financial shortfall.

As a provider serving aged and disabled individuals in Nebraska, and as someone who works directly with families who depend on these services to remain safe, stable, and in their homes, I am deeply concerned by the direction of these proposed changes.

I would like to formally ask the Department to clearly explain how fiscal responsibility has been exercised over the past five and ten years. Before reducing critical services to individuals who rely on the AD Waiver, it is reasonable and necessary for the public to understand:
- What budgeting and forecasting measures were in place during this time;
- How waiver funds have been allocated and managed;
- What decisions or systemic factors contributed to the current financial shortfall; and
- Why individuals receiving care are now being asked to absorb the consequences of those decisions.

In addition, I respectfully ask DHHS to clearly outline how it plans to exercise fiscal responsibility going forward. What safeguards, oversight measures, or long-term planning strategies will be implemented to ensure that Nebraska does not face similar shortfalls in the future? Providers, families, and individuals receiving services need assurance that better forecasting, accountability, and financial stewardship will prevent repeated cycles of funding crises that place vulnerable populations at risk.

Reducing individual care hours or services does not simply "save money" — it shifts costs elsewhere, often to emergency rooms, hospitals, institutional settings, or family caregivers who are already overwhelmed. These reductions place vulnerable individuals at risk of decline, hospitalization, or loss of independence, which ultimately increases long-term costs to the state.

Nebraska's aged and disabled population did not create this financial situation, yet they are being asked to sacrifice essential care as the solution. I respectfully urge DHHS to demonstrate transparency and accountability regarding past fiscal management and to explore alternatives that do not reduce direct services to individuals who rely on this waiver to live safely in the community.

The AD Waiver exists to prevent institutionalization and promote dignity, stability, and independence. Any changes to it should reflect that mission and should not come at the expense of the very people it was designed to protect.

Thank you for the opportunity to provide public comment and for considering the real-world impact these proposed changes will have on Nebraska's most vulnerable citizens.

From: Scot Davis
To: DHHS HCBS Public Comments
Subject: AD Waiver- Proposed cuts
Date: Monday, January 5, 2026 9:28:23 AM

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I decided to send a few more comments.

My son's disabilities haven't changed and if anything the level of care he needs has only grown since he is no longer in school. Our service coordinator would agree with this assessment. In spite of this my son's hours are being cut by 60% even though ours son's level of need hasn't changed.

Your programed verified and justified these hours for over 18 months but now that has changed? Again if the reason is financial then I would expect a 10-20% cut but not a 60% cut. It seems that there is more at play here. Are you wanting families to put their loved in nursing homes where the level of care is not the same? Being in a loving family environment is best in most situations but these cuts might force families to but them in nursing homes where the cost will be higher to the state.

It just doesn't make any sense to me. If you feel that some individuals are making to much money then put in a cap that is reasonable but my sons hours are justified and my wife is being paid a lot less than a nursing home would cost.

I ask that you make these decisions based on what is best for the adults who need this kinds of support. Resist the urge to believe everyone is taking advantage of this value program. Keep your cuts reasonable if they are needed for financial reasons.

Thank you

From: Catherine Jensen
To: DHHS HCBS Public Comments
Subject: AD Waiver Public Comment
Date: Tuesday, December 16, 2025 11:46:52 AM

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There is a proposed “change” stating, “Extra Care for Children With Developmental Disabilities”.

Why is there no proposed “change” which states, “Extra Care for Adults With Developmental Disabilities”?

Our daughter DEFINITELY requires “Extra Care” as an adult because of her developmental disabilities-as she did as a child.

Sent from Yahoo Mail for iPhone

From: Aaron Kuecker
To: DHHS HCBS Public Comments
Cc: Sen. Megan Hunt; Sen. John Arch
Subject: AD Waiver Public Comment
Date: Tuesday, December 23, 2025 2:48:52 PM

You don't often get email from [redacted]. Learn why this is important

Greetings,

My name is Aaron Kuecker from Omaha, NE, and I would like to leave a public comment on the proposed changes to the AD Waiver personal care program.

In short, I am opposed to the currently proposed changes, but I would like to go into further detail as to why. I will start with my background and connection to the AD Waiver, then describe the problems I see with these changes, and finally offer alternatives for consideration.

Background

My daughter, Chitti Kuecker (age 19), has a severe disability and requires 24/7 care and supervision. She has a rare seizure disorder called Lennox–Gastaut syndrome (LGS). It is a drug-resistant form of epilepsy in which she can have any type of seizure at any time, for any reason. She is currently on four medications and has a medical implant called a vagus nerve stimulator (VNS), yet she still experiences 5–10 seizures per day.

Chitti is non-verbal and requires full care, including assistance with administering medication, diaper changes, feeding, wheelchair mobility, bed turning, teeth brushing, dressing, and nearly every other personal care task. My wife, Katie Kuecker, and I are both caregivers through the AD Waiver, but Katie is her primary caregiver. She recently quit her job to become Chitti's full-time caregiver. Chitti is currently approved for the cap of 112 hours per week through the AD Waiver.

As a side note, Chitti should probably qualify for 24 hours a day, or 168 hours per week, and the cap should be expanded in rare situations where individuals truly require constant care or supervision.

Problems With the Proposed Cuts

These cuts create a discontinuity and degradation of care for those on the AD Waiver, a financial hardship for caregivers, and will be more costly for taxpayers.

Cutting weekly hours from 112 to 70 represents a 37.5% decrease in care and caregiver pay. However, because live-in caregivers are limited to being paid for only 40 of those hours, DHHS is effectively proposing a 64.3% decrease in pay for caregivers like my wife.

Most employers provide cost-of-living adjustments tied to inflation—typically around 2–5% per year. DHHS is not only ignoring inflation but is dramatically reducing caregiver pay. We should be discussing how to increase compensation to keep up with rising costs of living, not cutting it.

For my family, these cuts could mean that my wife can no longer remain a stay-at-home caregiver for our daughter, a choice we made because we knew this program existed. As a special education teacher for Omaha Public Schools, she brought home approximately $4,200 per month. Under the proposed cuts, her income would drop to $2,400 per month (40 hours per week × $15 per hour × 4 weeks). That leaves our family needing to find an additional $1,800 per month in our budget. Can we still afford our mortgage? Can we afford the wheelchair-accessible van we purchased to accommodate our daughter's disability?

If my wife needs to return to work, who will care for our daughter? I believe the best caregivers for Chitti are the people who know her best—my wife and me. We have become quasi-experts in epilepsy due to her needs, and I would argue that we know more about her condition than the average certified nurse, unless that nurse works specifically in epilepsy care. This is not unique to our situation. In general, family caregivers provide the highest-quality care for their loved ones. By cutting hours, you are reducing the quality of care for individuals on the AD Waiver and potentially putting medically fragile individuals at risk for preventable hospitalizations.

This change is also happening far too quickly for families who have come to rely on this level of income. If the cuts are accepted, we have roughly six months to either find an additional $1,800 per month or dramatically alter our budget. Cutting hours is the wrong choice, but if DHHS proceeds anyway, the reduction should at least be staggered to give families adequate time to adjust.

Additionally, these changes will likely increase the overall cost to the state. My daughter requires care for 168 hours per week. Under the proposed cuts, only 40 of those hours could be covered by my wife or me, leaving 128 hours unpaid. Due to Chitti's medical needs, those remaining hours would require a registered nurse (RN) rather than a certified nursing assistant (CNA). At an average RN rate of $32.04 per hour in Nebraska, 128 hours would cost $4,101.12 per week. Combined with the 40 hours of family care, the total weekly cost would be $4,701.12. Currently, at 112 hours per week, the total cost is $1,680. This means the proposed cuts would cost taxpayers an additional $3,021.12 per week, or approximately $157,000 per year.

If skilled nursing assistance cannot be adequately staffed, another option would be institutional care or a nursing home providing 24/7 intensive medical support. These facilities likely do not exist for someone with my daughter's needs, or they lack space or the specialized professionals required to serve her. This is where DHHS's average estimate for

nursing home costs appears misleading. While I do not know the exact cost of such a facility, I am confident it exceeds the approximately $92,000 estimate DHHS is using for 2025. Even if that estimate were accurate, paying my wife to provide 112 hours of care per week would cost $87,360 annually—still roughly $5,000 less than institutional care.

So between the three options, which is most financially responsible? Live-in caregivers provide the highest quality of care at a cost of approximately $87,360 per year under the previous AD Waiver limits. Nursing homes are more expensive and provide lower-quality care, assuming space is even available. Skilled nursing coverage would cost the state approximately $244,360 annually to replace the hours eliminated by the proposed cuts.

So live-in caregivers are both higher quality and less expensive. I know which option I would choose.

I understand that skilled nursing costs may come from a different budget than the AD Waiver, but this still represents a gross misuse of taxpayer funds and negligent stewardship by DHHS leadership. I recognize that the intent behind these cuts may be to prevent a waiver waitlist, but there must be a better approach. In the next section, I offer possible alternatives.

Better Alternatives

It is worth exploring all alternatives, as the proposed cuts represent a lose-lose-lose outcome for individuals with disabilities, caregivers, and taxpayers. Doing nothing is a valid option—DHHS could withdraw the proposal and continue the program as it currently exists. If the AD Waiver budget is strained, DHHS or the state legislature could explore reallocating funds from other programs.

If changes are deemed unavoidable, one option is to grandfather in individuals who are currently approved for higher hours. Anyone newly entering the AD Waiver after July 1, 2025, could be subject to the 70-hour limit. This would protect families who rely on existing income and care levels while gradually establishing a new norm. Additionally, eliminating the 40-hour cap on live-in caregivers would improve continuity of care and reduce unnecessary administrative complexity.

Another issue with the proposed cuts is their one-size-fits-all approach. Individuals with disabilities have widely varying needs. Seventy hours of personal care per week will be insufficient for many people. Instead, the cap could remain at 112 hours, or increase to 168 hours for individuals with extreme needs. DHHS could then conduct audits of service needs assessments to determine appropriate hours. To reduce subjective judgment, a needs-based rubric could be developed, similar to the LRI program. Tasks could be assigned standardized time values—diaper changes at 15 minutes, bathing at 30 minutes, medication administration at 20 minutes, and so on. However, unlike the LRI program,

supervision hours must be included for medically complex individuals whose conditions could rapidly deteriorate without monitoring, such as those with ventilators, tracheostomies, or severe epilepsy like my daughter.

This approach would allow the AD Waiver to serve individuals based on actual need rather than an arbitrary cap. While some individuals' hours might decrease, meeting DHHS's cost-reduction goals, the most vulnerable would still receive the care they require. The best part is that at the end of this process DHHS would have an accurate budget for this program, not estimates or approximations based on nursing home averages or other metrics. You would know exactly how much money is needed to serve all individuals based on their needs. That would carry much more power in our legislature and DHHS would have many advocates, such as myself, in fighting for enough funding if allocations for the waiver were ever short of that amount.

For what it's worth, I would like to rank these alternatives as a parent and caregiver:

1. Continue personal care hours as they exist now. No changes.
2. Re-evaluate every individual on the program using a needs-based rubric without a weekly hour cap.
3. Continue with the proposed changes, but grandfather in those with an approved number of hours per week. But, make no differentiation between live-in and non-live-in caregivers for those new to the waiver.

Summary

In closing, I urge DHHS and our state leaders to step back and consider the human, financial, and ethical consequences of these proposed cuts. The AD Waiver exists to keep individuals with severe disabilities safe, dignified, and cared for in their homes, while also being a responsible use of taxpayer dollars. The current proposal fails on all three fronts. It places families like mine on the brink of financial collapse, reduces the quality and continuity of care for Nebraska's most vulnerable residents, and ultimately costs the state far more through skilled nursing or institutional care.

This is not an abstract policy decision for us. It determines whether my daughter can remain safely at home, cared for by the people who know her, love her, and are best equipped to meet her complex medical needs. I ask you to reject these cuts and pursue thoughtful, needs-based alternatives that protect families, respect caregivers, and uphold the intent of the AD Waiver. Doing so is not only the compassionate choice, but the fiscally

From: Waylon Vajgrt
To: DHHS HCBS Public Comments
Subject: AD waiver public comment
Date: Sunday, January 4, 2026 2:41:08 AM

You don't often get email from [redacted] Learn why this is important

Public Comment on Legal and Ethical Concerns Related to Proposed Cost Controls
1915(c) HCBS A&D Waiver Renewal (NE.018.08.00)

I respectfully submit this comment to raise serious legal and ethical concerns regarding the proposed cost control measures in the Aged and Adults and Children with Disabilities (A&D) HCBS waiver renewal, particularly as they appear to be driven, at least in part, by the State of Nebraska's reported budget shortfall.

While fiscal stewardship is an important responsibility, Medicaid HCBS waivers are not intended to function as budget-balancing tools at the expense of individuals who rely on medically necessary services to live safely in the community. Implementing restrictive cost limits or service reductions that disproportionately affect people with disabilities and medically complex needs raises significant concerns.

Legal concerns

Under Section 1915(c) of the Social Security Act and implementing regulations at 42 CFR §441, HCBS waivers must ensure the health and welfare of participants and be administered in a manner consistent with person-centered planning and medical necessity. Cost neutrality is required to be demonstrated at the waiver level, not enforced in a way that effectively denies necessary services to individuals.

Further, the U.S. Supreme Court's decision in Olmstead v. L.C. requires states to provide services in the most integrated setting appropriate to an individual's needs. Policies that result in insufficient community supports—thereby increasing the risk of unnecessary institutionalization—may place the state at risk of noncompliance with Olmstead obligations.

Ethical concerns

From an ethical standpoint, shifting the burden of fiscal shortfalls onto people with disabilities, older adults, and medically complex children raises concerns of equity and fairness. These populations often have no alternative means to obtain essential care and are uniquely vulnerable to service reductions. Policies that prioritize budget savings over individualized need risk treating community-based services as discretionary rather than essential supports.

Moreover, limiting services for those with the highest needs undermines the foundational purpose of the HCBS program: to promote dignity, autonomy, and community integration. Cost containment strategies that disproportionately impact this population conflict with the ethical principles of justice, nonmaleficence, and respect for persons.

Conclusion

Balancing the state budget should not be achieved by restricting access to medically necessary HCBS services for individuals who depend on them to avoid institutionalization. I urge the Department to reconsider proposals that may compromise legal compliance and ethical responsibility, and to pursue fiscal solutions that do not place disproportionate harm on people with disabilities and medically complex individuals.

Thank you for the opportunity to submit this comment.

sincerely,

Waylon Vajgrt

From: Lisa Hobza
To: DHHS HCBS Public Comments; Green, Tony; Gonshorowski, Drew
Cc: Lisa Hobza
Subject: AD waiver Public comment
Date: Tuesday, January 6, 2026 12:32:28 PM

To whom it may concern:

My daughter was born 22 years ago with multiple congenital anomalies and was not expected to survive birth, let alone dream of living into adulthood. With medical advancements and extraordinary care my daughter Noelle is happy, healthy, and lives a full life that happens to require continuous care. Noelle has a tracheostomy tube for vocal cord paralysis; she was born with an occipital encephalocele that had to be repaired shortly after birth with a VP shunt placed. She has a gbutton, with facial paralysis, anomalies to her hands and feet. Noelle is nonverbal but has good receptive knowledge. Noelle is wheelchair bound with a full rod in her back which limits her movements.

Noelle has received in home private duty nursing care since birth, to allow us to work outside of the home, Noelle to attend school and other typical activities in the community. These services were provided thru the Medicaid Katie Beckett program, Noelle was authorized for 56 hours of work hours per week, 16 hours of respite care per week, and 8 hours of sleep hours at night thru Medicaid. During the school year Noelle would receive reduced hours, as nursing services were covered the public school system. This remained unchanged until Noelle reached the age of 21 and exited the school program. I was instructed by DHHS that I needed to apply for waiver services for Noelle for her to continue to receive services, in which I did. Once approved for the AD waiver, Noelle began to receive a reduction in nursing hours provided by her MCO Nebraska Total Care. Requested hours were denied based on a varied-on reasons, most commonly “not medically necessary” or “duplication of services”. We were able to advocate and make the reduction of hours work for a short time, due to the flexibility of my job. We received a final notice the last few months that we would be limited to 8 hours a day or 56 hours week, in which makes caring for Noelle stressful, while caring for my additional 3 children and holding a fulltime job. We are authorized for 70 hours of personal care thru the AD waiver, but those hours do NOT meet her need for SKILLED CARE and can only be provided by me at the time. Currently waiver service providers are not authorized to provided skilled care services in which Noelle relies on 24/7. These companies are unwilling to train “non nursing” staff to perform such assessments and interventions. Noelle is unable to direct her own medical care due to her intellectual disability and is unable to complete any tasks herself due to her limited use of her body.

These issues with waiver/fee for service and MCO Medicaid are becoming more necessary due to medical advancements. I understand that the current policies were not designed to support adults like my daughter, and I believe that the current changes being made to the AD waiver program did not take into account the small percentage of these high needs individuals that require a high level of 24-hour care. The AD waiver changes do not adequately support the adults requiring the highest level of care that will be required for a lifetime. There is a lot of talk about care being supported by the family/parents, but what people need to realize that this is NOT normal parental care and it does not end at 18 years. I have been providing normal parental care for the past 22 years and on top of that I have been providing skilled medical care that I received no formal schooling on, I have no true breaks in care. It is unreasonable to expect a parent to provide this type of care for a lifetime without being adequately compensated for. Limiting the family care giver to 40hours a week and expecting that the rest of the care to be delivered by a outside party is not reasonable, especially with the current shortage of staff.

I have the following questions and concerns:

1. How was institutional cost figured? I recently called all recommended nursing facilities and not one of them would currently admit my daughter due to the inadequacy of reimbursement for her level of care.
2. How are the proposed changes to the AD waiver, a line with the state of Nebraska's person-centered planning initiatives?
3. Who is going to provide care for my daughter when hours are unstaffed by agencies, what is the emergency plan for these individuals? Tak them to emergency room until care can be arranged.
4. How are we limiting care for those patients that are "stable" at home. Without adequate care and support she will have frequent ER visits, and lengthy hospital stays therefore increasing costs to the state.
5. Why are children supported at home until age 21 Katie Beckett Program, and then policy changes and they suddenly do not need the same level of care thru waiver programs?

Thank you for your time,

Lisa Hobza
Family to Family
Health Information Center Coordinator
Charting the LifeCourse™ Ambassador
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From: Kellie Quinlin
To: DHHS HCBS Public Comments
Subject: Ad waiver public comment
Date: Saturday, January 3, 2026 9:00:36 AM

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Please provide any peer-reviewed data or internal evaluation demonstrating that the current caps (e.g., 40/70 hours) do not create increased unmet needs or health risks compared to needs-based authorizations.

Please provide documentation submitted to CMS that demonstrates how Nebraska's current caps on authorized hours for AD Waiver services protect participant health, safety, and welfare, including any health outcome monitoring, service utilization data, unmet need assessments, or evaluations showing that these limits do not result in harm or increased risk compared to individualized needs-based authorizations. If such documentation does not exist, please explain how the state assures CMS and participants that safety is not compromised.

I'm also concerned with the fact that as it shows written it looks as if it makes it so people who need 24/7 hands on care would not qualify for companion care do to the needs of hands on during the time as well. This plan is written to look good on paper but to squeeze out those who need it most. It will make it so they only fall under the 40 hours and that would even matter if it was out of home providers. There is a huge safety issue and this causes huge gaps in care for these Adults.

Thank you for your time and addressing my concerns.

Kellie Quinlin

From: Lisa Larsen
To: DHHS HCBS Public Comments
Cc: Eddie Larsen
Subject: AD waiver public comments
Date: Sunday, January 4, 2026 2:58:15 PM

You don't often get email from [redacted] why this is important

I am the parent and caregiver for a 28 year old woman. She has Rett syndrome which is a random genetic mutation.

She requires 24/7 care.

The proposed change to the DHHS AD waiver reducing paid caregiver hours to 40/week, and eliminating additional parental care is devastating, gut-wrenching, and heart wrenching.

It does not hold up to the DHHS and HCBS mission statements since it falls way short of providing care for the most vulnerable people in our society:

People who for the most part have been fated to live a life with a disability. People who should be the BASE of ALL that you do.
People who should be able to stay in their homes.
People who should have the choice in who takes care of them.

Finally, if parents cannot take care of these people, institutional care is either non-existent or scarce. What is your answer to where they will go?

Even before this proposed change my biggest nightmare is envisioning where and who will take care of my daughter when I can no longer do so. Will she sit in her own feces all day? Who will brush her teeth every night like I do? Who prepares her favorite foods?

Recently a grandmother tried to commit suicide and take her granddaughter with her because she could not longer care for her. I'm a reasonably sane person, but I fully commiserate with her decision and do not condone it at all. If your proposal is allowed to play out I guarantee you will see more situations such as hers in the news.

As a society how we care for our most vulnerable says who we are. Unfortunately this proposal does not reflect well on any Nebraskan values.

Please do not proceed with this proposal.

Lisa Larsen
Arthur NE

From: Quiring, Hanna
To: DHHS HCBS Public Comments
Subject: AD Waiver Renewal - Remote Supports
Date: Friday, December 12, 2025 11:02:10 AM

My name is Ryan N. I sat in on today's presentation and public comments session for the upcoming changes to the AD Waiver system. My question is, has Nebraska ever taken a serious look at Remote Supports as a way of serving people while keeping them in their homes while not sacrificing that person's safety or support needs? Potentially, I think this could be a way for the state to provide a service that might serve some people better than with traditional in-person supports, cost the state less per person, and address the fears of families who don't want their loved ones to go to an ALF setting but don't see any alternative with the new regulations proposed. Three years ago I spoke with Angie Gonzalez-Dorn who was at the time leading Supported Employment for DD, and she indicated that there was interest at DHHS about such a service, and that there was potentially funding already allocated for a pilot. I did not feel it appropriate to bring this up at the public comments session today.

From: Waylon Vajgrt
To: DHHS HCBS Public Comments
Subject: AD waiver renewal open comment
Date: Sunday, January 4, 2026 2:42:15 AM

You don't often get email from [redacted]. Learn why this is important

Public Comment on Individual Cost Limits and Cost Limit Methodology
1915(c) HCBS Aged and Adults and Children with Disabilities Waiver Renewal
(NE.018.08.00)

I respectfully submit this comment regarding the newly added individual cost limit provisions described in Appendix B-2-a, B-2-b, and B-2-c of the proposed Aged and Adults and Children with Disabilities (A&D) 1915(c) HCBS waiver renewal.

While I recognize the state's obligation to demonstrate cost neutrality and appreciate the inclusion of safeguards and monitoring processes when an individual exceeds the cost limit, I disagree with the underlying cost limit methodology as currently structured. Specifically, the cost limits appear to be based on average institutional cost assumptions that reflect an aged nursing facility population, rather than the actual costs that would be incurred by medically complex individuals requiring specialized care.

Alignment with Appendix B-2-a: Individual Cost Limit in Excess of Institutional Costs

Appendix B-2-a establishes an individual cost limit benchmarked to institutional costs. However, institutional cost averages—particularly those derived from nursing facility utilization among aged adults—do not adequately reflect the level of care required by children and adults with complex medical needs, progressive conditions, or intensive functional support requirements.

Medically complex individuals often require higher levels of in-home nursing, specialized personal care, assistive technology, environmental modifications, and caregiver hours that exceed typical aged-population utilization patterns. Using averaged institutional costs as a proxy for "reasonable" community-based expenditures risks setting an individual cost limit that is artificially low for these participants.

Alignment with Appendix B-2-b: State Implementation of the Individual Cost Limit

Appendix B-2-b describes how the state will implement the individual cost limit through service planning, authorization, and monitoring processes. While implementation steps are outlined, the methodology still constrains person-centered planning by anchoring decisions to a cost framework that does not adequately account for medical complexity.

When service coordinators must plan within a cost limit that is not calibrated to the individual's acuity, the result may be service reductions or denials unrelated to medical necessity or assessed need. This undermines the intent of person-centered planning and places service coordinators in the position of managing budgets rather than ensuring health, welfare, and community stability.

Alignment with Appendix B-2-c: Safeguards When Services Exceed the Cost Limit

Appendix B-2-c outlines safeguards and review processes when an individual's services exceed the cost limit. While the presence of safeguards is important, safeguards alone do not resolve the fundamental issue: the cost limit itself may be misaligned for medically complex participants.

Review processes triggered only after a cost limit is exceeded may create delays, uncertainty, and service disruption for individuals whose needs predictably exceed average cost benchmarks. For participants with known, ongoing medical complexity, reliance on exception or safeguard processes places them in a perpetual state of review rather than establishing an appropriate baseline from the outset.

Impact on Waiver Goals and Risk of Institutionalization

Nebraska's A&D Waiver is explicitly intended to prevent institutionalization and rebalance long-term care toward community-based services. For medically complex individuals, community-based care may appear more expensive on an individual basis but remains the most appropriate and integrated setting—and often avoids far higher long-term institutional and acute care costs.

Cost limits that are not adjusted for complexity risk producing the very outcome the waiver seeks to avoid: unnecessary institutional placement. This concern is particularly relevant in light of Nebraska's obligations under Olmstead v. L.C. to provide services in the most integrated setting appropriate to an individual's needs.

Recommendation

I respectfully urge the Department to revise the cost limit approach in Appendix B-2 to better reflect individual medical complexity. This could include:

Acuity-based or diagnosis-informed adjustments to individual cost limits

Alternative benchmarks for participants with intensive or specialized needs

Proactive identification of individuals likely to exceed average costs, rather than reliance on post-exceedance safeguards

Clear assurance that person-centered planning and medical necessity drive service authorization, not averaged cost assumptions

Aligning the cost limit methodology with the realities of medically complex care will better support Nebraska's waiver goals, uphold person-centered planning requirements, and ensure that cost neutrality mechanisms do not become barriers to community living.

Thank you for the opportunity to comment and for considering the needs of medically complex individuals and families who depend on the A&D Waiver to remain safely in their homes and communities.

Sincerely,

Waylon Vajgrt

From: Katina Russ
To: DHHS HCBS Public Comments
Subject: AD waiver update recommendation
Date: Tuesday, December 23, 2025 10:44:30 AM

> You don't often get email from [redacted]. Learn why this is important

We provide support for an individual with disabilities. The individual uses the bulk of his spending funds from the state to purchase caffeine, soda, and nicotine products. Since families are not allowed to purchase these types of items with SP benefits, I feel that this should also apply to individuals with disabilities who are receiving funds. I especially feel that purchasing nicotine products should not be allowed.

From: Northeastmonk (Northeastmonk)
To: DHHS HCBS Public Comments
Subject: AD Waiver
Date: Friday, December 12, 2025 8:59:45 AM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

To whom it may concern,
I am a parent of a child with a disability. I know first hand how difficult and expensive life can be. Our disabled children, young and old deserve to have the best possible care. If you can make it so parents can afford to give them that life, please do. The amount of money for disabled people should be more because we cannot allow people with disabilities to live a life of disappointment and fear of their rehabilitation and the cost of their care, being reduced or sliced in half.

Please take time to reach out to our leaders and tell them that the funding for disabled people here in America should be a priority. I've witnessed many adults with disabilities live in such poor conditions. They don't have anything and maybe that would have changed had the state given more money to programs and the parents of their disabled child. I am not an expert, but I do know that cutting the budget or funding for programs that help disabled Americans is not the right thing to do.

From:	Justin Tolman
To:	DHHS HCBS Public Comments
Subject:	AD Waiver: Care Categorizations
Date:	Monday, December 29, 2025 10:12:58 AM

You don't often get email from [redacted] Learn why this is important

Dear DHHS,

This email provides comments regarding the Renewal of 1915(c) Medicaid Home and Community Based Services (HCBS) Aged and Adult and Children with Disabilities (NE.0187) Waiver. I am an independent provider and live-in caregiver for a medically complex disabled adult on the AD waiver.

The expectation for "informal care" with the proposed restrictions on "personal care" and "companion care" puts medically complex adults with disabilities at risk. In meetings with DHHS staff, they articulated that the proposed changes to the AD waiver include the expectation that live-in caregivers will provide uncompensated "informal support." ***"Informal support" conflicts with the stated purpose of the waiver to, "…furnish an array of home and community-based services that assist Medicaid beneficiaries to live in the community and avoid institutionalization."***

Additionally, the proposed modifications and comments by DHHS staff seemed contradictory as to how care activities classified (between personal care versus companion care). For medically needy disabled adults, it seems that activities that would be considered as "companion care" would be incredibly limited. The proposed modifications restrict care to 40hrs/week for personal care with up to 30hrs/week additionally for companion care. It is unreasonable to restrict medically complex disabled adults on the AD Waiver to 30 hours per week of companion care where no personal care is allowed.

The possible solution is to eliminate the distinction between personal care and companion care for approved hours. The distinction between personal care and companion care can then be addressed based on an individualized needs assessment.

The proposed modifications to the AD waiver will be detrimental to the care I provide to my medically complex disabled adult child and will necessitate institutionalization for the needed level of care.

Sincerely,

Justin A. Tolman

From: Justin Tolman
To: DHHS HCBS Public Comments
Subject: AD Waiver: Grandfather Exemption
Date: Monday, December 29, 2025 10:13:00 AM

You don't often get email from [redacted] Learn why this is important

Dear DHHS,

This email provides comments regarding the Renewal of 1915(c) Medicaid Home and Community Based Services (HCBS) Aged and Adult and Children with Disabilities (NE.0187) Waiver. I am an independent provider and live-in caregiver for a medically complex disabled adult on the AD waiver.

The proposed changes are arbitrary and capricious for disabled adults who have made long-term plans based on the existing waiver. Many disabled Nebraska adults have planned their living arrangements and care plans based on the current waiver rules and expectations. The proposed modifications fundamentally alter the possibility for community-based and in-home care for these disabled adults. The proposed waiver modifications will force medically needy disabled adults to receive care in institutional settings (nursing homes) because in-home care is no longer feasible.

A possible solution is to exempt currently approved disabled adults from the proposed changes. This would allow disabled adults currently on the AD waiver with approved care plans to receive care under current rules and be exempt from the proposed modifications ("grandfather" in currently approved adults based on existing rules). Allowing an exemption for current enrollees would also manage the expectations for disabled adults and their guardians at a time of transition rather than the proposed July 1, 2026 effective date. There is insufficient time for disabled adults and their caregivers to make such drastic and life-altering care decisions about institutionalization and care agencies, without shocking the currently available resources, institutions, and providers.

The proposed modifications to the AD waiver will be detrimental to the care I provide to my medically complex disabled adult child and will necessitate institutionalization for the needed level of care.

Sincerely,

Justin A. Tolman

From: Justin Tolman
To: DHHS HCBS Public Comments
Subject: AD Waiver: Independent Providers and Cost Savings
Date: Monday, December 29, 2025 10:12:55 AM

You don't often get email from [redacted]. Learn why this is important

Dear DHHS,

This email provides comments regarding the Renewal of 1915(c) Medicaid Home and Community Based Services (HCBS) Aged and Adult and Children with Disabilities (NE.0187) Waiver. I am an independent provider and live-in caregiver for a medically complex disabled adult on the AD waiver.

DHHS can better achieve cost-savings by expanding the use of independent providers rather than agency providers. Independent providers, particularly live-in caregivers, do not require the overhead costs (indirect charges) that agencies require. I am contracted to provide care at a $15/hr rate compared to an average agency rate of $35/hr. Even at this cost-savings, I am able to provide a higher quality of care to my medically complex disabled adult child. As an independent provider, I have received training, updates, and webinars regarding electronic visit verification systems, applications, and billing processes and procedures. I also have the ability to provide care to a medically complex disabled adult according to her needs and within the guidelines and parameters established by DHHS.

Cost-savings for DHHS can be realized by expanding the allowed caregiving hours for independent providers up to 163 hours per week assuming a $15/hr rate for independent providers and $35/hr for agency providers. Specifically, the annual costs to DHHS for an independent provider that is contracted at $15/hr that works 163 hours/week ($127,140) is approximately equivalent to an agency provider $35/hr that only works 70 hours per week ($127,400).

Possible solutions would be to:

- Expand the use of independent providers
- Reduce the mandate to provide care to disabled adults through agencies
- Remove the weekly limit on caregiving hours for independent providers

The proposed hour restrictions for the AD waiver will be detrimental to the care I provide to my medically complex disabled adult child and will necessitate institutionalization for the needed level of care.

Sincerely,

Justin A. Tolman

From:	Justin Tolman
To:	DHHS HCBS Public Comments
Subject:	AD Waiver: Proposed Hour Restrictions
Date:	Monday, December 29, 2025 10:12:58 AM

> You don't often get email from [redacted] Learn why this is important

Dear DHHS,

This email provides comments regarding the Renewal of 1915(c) Medicaid Home and Community Based Services (HCBS) Aged and Adult and Children with Disabilities (NE.0187) Waiver. I am an independent provider and live-in caregiver for a medically complex disabled adult on the AD waiver.

I have fundamental concerns with the proposed hour restrictions. Medically complex adults on the AD waiver cannot have the care necessary to maintain their life when restricted to 40 hours per week, or even 70 hours per week as proposed with an exception. These adults require monitoring and medical intervention throughout a 24 hour per day and 7 day per week (168 hour per week). The proposed hour restrictions would only cover 24% and then 42% of the hours needed for these medically complex adults.

Possible solutions to this would be to:

- Remove the default 40 hour per week limit for live-in caregivers,
- Increase the limit to some number that more reasonably approaches the needed number of hours for medically complex adults, OR
- Require an application and approval process for individuals with documented needs for more hours.

The proposed hour restrictions for the AD waiver will be detrimental to the care I provide to my medically complex disabled adult and will necessitate institutionalization for the needed level of care.

Sincerely,

Justin A. Tolman

From: Justin Tolman
To: DHHS HCBS Public Comments
Subject: AD Waiver: Proposed Limits
Date: Monday, December 29, 2025 10:12:52 AM

You don't often get email from [redacted] Learn why this is important

Dear DHHS,

This email provides comments regarding the Renewal of 1915(c) Medicaid Home and Community Based Services (HCBS) Aged and Adult and Children with Disabilities (NE.0187) Waiver. I am an independent provider and live-in caregiver for a medically complex disabled adult on the AD waiver.

The proposed limitations for both hours and an annual cost limit are inequitable and fiscally irresponsible. As an independent provider, I am contracted to provide care at $15/hr rate which is substantially lower than agency providers with rates in excess of $35/hr. The following table summarizes the cost implications for me and DHHS based on these proposed changes:

	Independent Provider	**Agency Provider**
Contracted Rate	$15/hr	~$35/hr
Proposed Hour Limit	40/week	70/week
Annual Charges *(Based on these rates and limits)*	$31,200	$127,400
Average Annual Institutional Cost	$92,000	
Limit for Annual Cost Range *(150%-175% of Average Institutional Costs)*	$138,000-$161,000	

The proposed imbalance of instituting both weekly caregiving limits and annual cost limits make no sense when comparing how DHHS contracts with independent providers verses agency providers. For example, if the proposed 40 hour/week limit was removed for an independent provider, then **the annual cost for an independent provider giving 24-hour care would still cost DHHS less than the proposed 150% annual limit**. DHHS could still implement cost savings by keeping annual cost limits (e.g. the 150%-175% range based on average annual institutional costs) and removing the caregiving hour limits.

Possible solutions to this would be to:

- Remove weekly caregiving hour limits for live-in caregivers and only keep annual cost limits,
- Allow independent providers to contract for rates comparable to agencies
- Allow normal and usual exceptions to the proposed hour limits based on the needs of medically complex adults with disabilities.

The proposed hour restrictions for the A&D waiver will be detrimental to the care I provide to my medically complex disabled adult and will necessitate institutionalization for the needed level of care.

From: [redacted]
To: DHHS HCBS Public Comments
Subject: Ad waiver
Date: Tuesday, December 23, 2025 3:18:08 AM

> You don't often get email from [redacted]. Learn why this is important

This program was created to keep individuals who meet *nursing home–level of care* living in their homes and communities. Many families are already accomplishing exactly that—by serving as the providers for their loved ones with the most severe needs. These families are not asking the state for more; they are offering the state a cost-effective, humane solution that works.

In our situation, I watched a mother struggle daily—trying to keep a roof over her children's heads while caring for a child with extreme needs. He was required to attend school, not because it benefited him, but because funding structures required it. The school would not acknowledge they could not meet his needs, and therefore would not provide the documentation necessary for change. His condition worsened.

We attempted home health care. It failed completely. Providers could not even get close to him. Physical therapy had to be stopped because it escalated him to the point they could not regain control. After years of deterioration and fighting a broken system, he finally reached an age where a family member could become his provider—and his entire world changed.

I understand there is a belief that people should be able to accept outside caregivers. For some individuals, that may be true. But for many with severe intellectual and behavioral disabilities, it is not that simple.

These are not just adults who are bedridden and need physical assistance. Many function cognitively at the level of a two- or three-year-old—except they grow into 200–250-pound adults. They are rigid in their routines, require constant repetition, and can become unsafe if handled by someone who does not know them well. What they need most is trust, consistency, and caregivers who understand their triggers.

Family providers are what allow these individuals to live, not just exist. They function in the community instead of being placed in institutions where they would likely be overmedicated for convenience rather than supported with dignity. They are happy. They are loved.

Keeping adequate provider hours also allows families to cover **critical needs that Medicaid does not pay for**—yet are essential for safety, health, and quality of life. Dental care is one example. Medicaid may technically cover dental services, but finding a provider willing and able to treat individuals with severe disabilities is often impossible. Families must pay out of pocket to avoid serious health consequences.

Provider income also allows families to make necessary home modifications and maintain adaptive equipment. In our case, we installed a roll-in shower. We are paying for a modified van—vehicles that cost far more than standard cars and are completely unaffordable on a minimal income. We have purchased and installed lifts to allow water therapy in a hot tub

because traditional therapy is not an option. We installed a chair with a track system to safely access the basement during tornado warnings. We purchased a second bed so an emergency sleeping space exists downstairs when needed.

We pay for electronics and sensory items that provide stimulation and regulation—items that Medicaid does not cover, home health does not provide, and institutions would never supply. We purchase wipes, reusable pads, and countless daily-use supplies. The list goes on.

This is more than donating care. Families are structuring their entire lives around keeping their loved ones safe, healthy, and engaged. Provider hours are what make this possible.

This proposal also places families themselves at serious risk. When caregiver hours are reduced, families do not stop providing care—they simply go without necessities. They delay medical care, skip dental care for themselves, fall behind on insurance, and postpone critical home or vehicle maintenance. Some will be forced to drop car insurance, triggering a cascade of legal, financial, and transportation barriers that ultimately cost the state more.

Family caregivers are saving the state enormous sums by preventing institutional placement and avoiding agency overhead. Forcing agencies into situations where they cannot provide effective care wastes money, increases stress on the individual, and destabilizes households that are already functioning.

Importantly, meaningful oversight **can still occur without forcing ineffective outside providers into the home**. There are far less costly and far more effective options that respect both safety and person-centered care. These include:

- Regular service coordinator check-ins via Zoom or phone
- Scheduled virtual visits with the individual and caregiver present
- Routine contact with a designated outside family member or trusted support person
- Additional check-ins during times of transition or increased need

These approaches provide accountability and monitoring while avoiding the disruption and distress caused by unfamiliar caregivers. They also cost significantly less than agency-based staffing that cannot be utilized.

The predictable outcomes of this proposal include:

- Increased reliance on Medicaid for supplies families currently purchase themselves
- Loss of private insurance as caregiver income drops
- Reduced ability to contribute to retirement, increasing future public assistance needs
- Increased risk of injury, liability, and workers' compensation claims
- Agency resources being diverted from individuals who truly have no family able to provide care

Right now, families are caring for individuals whose entire income may be less than $1,000 per month, while households are expected to survive on approximately $31,000 per year. When families are allowed adequate compensated hours, they can maintain stability, invest in necessary adaptations, contribute to retirement, and remain independent of additional state assistance as they age.

We are simply asking that instead of wasting money on services that do not work, those funds be directed to the hours families are already providing—hours that are essential, effective, and still far fewer than what would be required in an institution.

This approach saves the state money, protects individuals, and preserves families who are already doing everything possible to keep their loved ones at home.

Please reconsider these changes and recognize the essential role family providers play in fulfilling the very purpose of this program.

Thank you
Ryan Quinlin

From: Andrea Beisner
To: DHHS HCBS Public Comments
Subject: Ad Waiver
Date: Saturday, December 27, 2025 12:21:15 PM

> You don't often get email from [redacted]. Learn why this is important

Dear whom it may concern,

I am currently taking care of my mother with dementia. The AD waiver allows her to stay in her home with full time care as the hourly cap is now. If the hours are cut, the very possibility that I will have to put my mother in an institution, and that will then cost the state of Nebraska more not less. It would take away any dignity or memory of anything she has left. Please do not allow this change to happen. It would change all our lives forever.

Sincerely,
Andrea Beisner
Patricia Michael

From: Madeline Parker
To: DHHS HCBS Public Comments
Subject: AD Waiver
Date: Sunday, December 28, 2025 11:23:51 AM

You don't often get email from [redacted]. Learn why this is important

Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers.

These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.

If cost containment is necessary, there are better alternatives:

Maintain current hour limits for existing participants (grandfathering).

Remove or revise the 40-hour cap for live-in caregivers.

Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment.

Madeline Parker

From: Allison Wilson
To: DHHS HCBS Public Comments
Subject: AD waiver
Date: Sunday, December 28, 2025 8:32:09 AM

You don't often get email from [redacted] Learn why this is important

Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers. These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable. Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing
or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.
If cost containment is necessary, there are better alternatives:

-Maintain current hour limits for existing participants (grandfathering).

-Remove or revise the 40-hour cap for live-in caregivers.

-Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment

Allie Wilson

From: Aidan Polivka
To: DHHS HCBS Public Comments
Subject: AD Waiver
Date: Sunday, January 4, 2026 3:18:21 PM

> You don't often get email from [redacted] why this is important

To whom it may concern:

On December 5th DHHS released proposed changes to the AD waiver. Part of these changes was to LIMIT live in care giver hours to 40 hours per week. For some of these live-in providers and their clients, this change would be very detrimental. Some of the MOST disabled folks in our state receive the maximum amount of 112 hours per week for their paid care (payment for 16 hours per day of care). Of that group, live-in caregivers provide the majority of those hours. Many of these live-in caregivers are parents or spouses of these disabled people, and many of them have left careers to take care of their loved ones. Some have been caring for their loved ones for 30 years or more. To suddenly cut their hours and income by 72 hours per week is DANGEROUS and very destabilizing for these disabled clients. This could lead to the loss of homes, mental health crises, hospital stays, and possibly death for some of the most medically needy clients.

Families affected by these changes will face severe financial issues. A loss of 72 hours per week at $15.00/hour is a cut of $4320 per month for these households. How will they be able to find jobs that pay that much, as people who have been out of the work force for so long? These families must also balance doctor appointments, hospital stays and the stress of caring for their loved ones, which would make working outside of the home very difficult for them at times. This plan assumes that suddenly, after YEARS of searching, hiring, training and losing paid care givers, that they can find someone to do their jobs. This is further complicated by the fact that these paid caregivers aren't able to administer medications or provide the medical decision-making necessary to ensure proper care for clients at all times, which means our most disabled will be in danger.

This plan will NOT work for the most medically fragile and high needs disabled adults on this waiver. If you are to go forward with limiting live-in care givers to 40 hours per week, you will be forcing people to sell their homes and put their loved ones into nursing home facilities. The waiver program was created in order to stop this exact situation from happening. Also, moving disabled clients into nursing homes will be further complicated by a current shortage of Medicaid funded beds available.

Instead, we propose that since this waiver has enough funds to make it through this year, that you spend this year meeting with the families of these individuals and create a plan that will actually work. I believe there are solutions available in this situation! The current system that's in place was created for individualized care, and there are already evaluations that were created to determine services and hours. If you want to create caps, please do it moving forward--not retroactively and NOT so suddenly and NOT so drastically. Consider contracting with each family individually (perhaps less agency contracting and more live-in caregiver contracting?), consider a tiered system like DD services use to determine pay rates.

Also please consider seeking out the funds you need:

a. Find an agency or non-profit, or create one, and begin to hold an annual fundraiser that

gives average Nebraskans and wealthy Nebraskans a chance to care for the disabled of our state.
b. Perhaps the Huskers could run a fundraiser at one home game a year where they advertise the needs of those who are disabled in our state and give a matching percentage of ticket sales that day.
c. Would the Volleyball team and their fans want to help protect the disabled of our state?
d. Ask the Nebraska legislature to allocate more money for this program, due to the rising number of individuals in this program. I believe this sort of thing happens (for example, asking for raises for state employees, you look at the cost of living and then approve a 3-6% raise for your employees). A request for additional funding seems appropriate in this situation.
i. Or perhaps it would be a GREAT time for the legislators to PAUSE or freeze the corporate tax cuts that are creating some of these budget shortfalls?
e. Would Larry the cable guy be willing to help in some way as a Nebraskan with a HUGE platform? Would Warren Buffett want to help? We could ask some of the wealthiest Nebraskans to step up for those who are disabled in our state.

Please consider solutions that are PEOPLE focused, individualized and caring, not just focused on the dollar signs. Thoughtful policy making will ensure that those who are disabled, as well as their families, can continue receiving the care they need and avoid damaging and life-altering circumstances. This waiver program has blessed a whole lot of Nebraskans and allowed them to flourish. It has helped provide dignity and care for so many people! Please consider that as you move forward and make necessary changes.

Signed: Aidan Polivka

From: Staci G
To: DHHS HCBS Public Comments
Subject: AD waiver
Date: Sunday, January 4, 2026 5:36:34 PM

You don't often get email from [redacted] Learn why this is important

I am writing again after working respite hours this weekend. The 25 year old I work with had a good day, so we went out into the community to spend money and interact with people he lives around. He still needed help with moving his wheelchair, as his TBI keeps him from being able to move himself. I also fed him his food, as that is another task his condition prevents him from doing. This takes around an hour for a small meal, and he needs prompting to chew and swallow, and once we had to stop when he swallowed wrong. He enjoyed interacting with the waitress, who took the time to interact with him, which not everyone does. While we were out, his mother, his primary caretaker, was helping her elderly mother, then spending time with her 2 high schoolers who still live at home. His mother used to work outside the home, but when he came home from his accident, she relied on staff coming to take care of his needs while she worked elsewhere. When they called in sick or had to leave early, there was no back up, and when there are doctor appointments, she also could not work. He currently has 24 hour care, as his condition often keeps him awake for days, and as this takes a toll on his body, he has a lot of anxiety during nighttime hours. I worked overnight this weekend, so his mom could sleep. He did sleep for about 2 hours, though I had to have the recliner beside his bed as he woke if he wasn't holding my hand. The rest of the time his tremors, pain, anger, and boredom kept him asking for something different on his tv, which he again cannot control, needing to be adjusted, asking for help for his CPAP to be on or off, and sitting up to move either from muscle memory or wanting something I'm not understanding. He has not fallen out of bed for a long time, with the vigilance of his mom and staff, and someone being with him at all times. I heard comments from the Zoom meetings last month, that people should not get 24 hour care, as people need to sleep. That is insulting. The amount of days that his mother might get a catnap on top of everything else is also taking a toll on her.

I wrote all this not to complain, as this family means more to me than a regular "job." It is to let you know that these are the people you are cutting hours from and telling them to rely on people helping them for free, or saying they should care for their loved ones for free and go get another job . I invite anyone on this committee to come do what is being done by families for less money than the state would be spending for more Nebraskans to have less quality of life in other facilities, which are closing or understaffed.

I urge you to reconsider taking care from people who need it. If you believe it needs to be cut, please come visit and see why that would be a mistake.

Staci Greunke
[redacted]

From: Rachel Birchett
To: DHHS HCBS Public Comments
Subject: AD Waiver
Date: Thursday, January 1, 2026 4:00:50 PM

You don't often get email from [redacted]. Learn why this is important

To whom it may concern:

On December 5th DHHS released proposed changes to the AD waiver. Part of these changes was to LIMIT live in care giver hours to 40 hours per week. For most live-in providers and their clients, this would be detrimental.

Many of these live-in caregivers are parents or spouses of these disabled people, and many of them have left careers to take care of their loved ones.

Cutting their hours to 40 hours a week will require them to take on other employment to make ends meet. To do that, they will have to hire caregivers. With the lack of caregivers, the high rate of caregiver turnover and the need for caregiver training, these family members will not be ale to maintain the additional employment.

To suddenly cut their hours and income by 72 hours per week is DANGEROUS and very destabilizing for these disabled clients. This could lead to the loss of homes, mental health crises, hospital stays, and possibly death for some of the most medically needy clients.

These families must also balance multiple doctor appointments, hospital stays and the stress of caring for their loved ones, which would make working outside of the home very difficult for them.

This plan assumes that suddenly, after YEARS of searching, hiring, training and losing paid care givers, that they can find someone to do their jobs. This is further complicated by the fact that these paid caregivers aren't able to administer medications or provide the medical decision-making necessary to ensure proper care for clients at all times, which means our most disabled will be in danger.

This plan will NOT work for the most medically fragile and high needs disabled adults on this waiver. Their care will become inconsistent and they are at risk for additional health problems and costs.

Thank you for reconsidering.

Rachel Birchett

From: Fuxa, Amanda
To: DHHS HCBS Public Comments
Cc: Sen. Wendy DeBoer
Subject: AD Waiver
Date: Friday, January 2, 2026 11:17:29 AM

You don't often get email from [redacted]. Learn why this is important

Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers.

These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.

If cost containment is necessary, there are better alternatives:

Maintain current hour limits for existing participants (grandfathering).
Remove or revise the 40-hour cap for live-in caregivers.
Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment.

Amanda Fuxa, OTD, OTR/L
Occupational Therapist | Site Coordinator of Clinical Education
Creighton Pediatric Therapy

T 402.280.2200 | **F** 402.280.2210
17055 Frances Street, Suite 103 Omaha, NE 68130 | amandafuxa@creighton.edu

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From: Katie Novakoski
To: DHHS HCBS Public Comments
Subject: AD wavier proposal question and concern
Date: Saturday, January 3, 2026 1:08:55 PM

Hi,
I am concerned with and oppose these cuts to the AD wavier and the term "informal supports" that is continuing to be used. Once our loved ones are 19, whether they are our children or not, they are legally adults in the state of Nebraska. Nebraska can not force parents and families to provide care or so called "informal supports" to these adults. If they need 168 hours of care (24/7) then that is what they need and it must be provided. You need to explore other places to cut money from. How do you plan to keep our family members safe? How do you explain forcing people into caring for others while remaining unpaid?

Katie Kuecker

From: Katie Novakoski
To: DHHS HCBS Public Comments
Subject: AD wavier Public Comment
Date: Sunday, January 4, 2026 5:47:20 PM
Attachments: [redacted]

Hello,
My husband and I created a petition when the proposal for the ad changes came out. Here are the results in the form of a public comment. Here is the website for your viewing as well.
https://www.change.org/p/urge-dhhs-to-reconsider-the-40-hour-cap-for-live-in-caregivers

There was a total of 2,672 signatures. If a name on the petition is not deemed a public comment, we ask that the DHHS leadership would still consider the vast amount of signatures as public opposition of the changes being proposed on the AD wavier.

Attached is a list of the signatures and the comments that were left on the petition. We are requesting those comments would also be considered for public comment.

Thank you,
Katie Kuecker

From: [redacted]
To: DHHS HCBS Public Comments
Subject: AD Weaver
Date: Monday, December 22, 2025 7:32:48 AM

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Hello

I would like to make a comment about the proposed changes to the DHHS Medicaid waiver program.
I would like to tell you about my son who is going to have his whole life challenged even more if these Medicaid cuts go into effect.
My son‘s name is Christopher. He was 23 when he had a seizure when riding his motorcycle to work. You see my son has worked all the way through high school. He had just started two businesses a landscaping and a tree service. He paid his taxes and donated time and services to people in need. And it all changed on August 19, 2011 when he had his accident.. Christopher now suffers from a traumatic brain injury from lack of oxygen, and he was left with catastrophic injuries. Chris can no longer talk, walk, paralyzed on his left side in a wheelchair, and he’s incontinent has seizures, swallow and his eating is affected, he’s not able to do bed mobility, his cognition is low and he is nonverbal. I have helped Chris go through all the stages of healing. We went from the vent unit to the acute care to long term care wing fighting to come home. You see this is so catastrophic. he had his whole life ahead of him. He feels like he’s lost his dignity, his pride, his future, and now with these cuts, he’s going to lose his home and the opportunity of living the best quality of life in this situation and that would be at home where there’s people that know how to care for him who want to care for him who love him. We have to be able to survive in order to take good care of him and ourselves. I worked several years as an independent contractor for State Nebraska caring for my son and received minimal pay. I can’t help but wonder if the people that are making these decisions, realize how much work the parents or loved ones do without pay. I mean, no one’s looking to get rich. We’re just trying to take care of our children and give them some kind of quality of life. I mean, my son is approved for 140 hours a week I work 85 of them hours through the agency because it’s hard to find help but they do supply help with the remaining 55 hours with a different aide. That’s not including the 28 hours that I work off the clock and the emergency hours from no call no show or they cannot fill the visit since we can only work 16 hours a day on the clock.
I have two College Degrees and I have given that all up to take care of my son

for the last 14 years. I am now 62 years old and in order to go back to work in my field of study I would have to take refresher courses and pass my boards again because I did not keep up with my continuing education classes because again I was caring for my son. And I did not complain. I was there and I did the work. stayed bedside while he was in ICU in Kearney I travel to Lincoln. I stayed with Chris while he was in the vent unit, but he went to acute care when he went to QLI in Omaha in for homebound care. I'm grateful that he is alive and here with me and I can take the best care of him. I can just hear him breath and know if he's struggling, you see my son cannot adjust himself in bed. He cannot lay flat or he could aspirate. My son cannot put his oxygen back on if it falls down which it happens a lot, my son aspirates on his own saliva so he needs suction on a regular basis . Christopher requires a G-tube place in his stomach to dispense his medication's, and his nutrition shakes and water. Chris does eat food orally with thicken liquids. Chris needs assistance with all his personal cares, brush his hair, brushing his teeth, showering toileting, eating dressing, communicating.He needs a lift to be transferred from bed to wheelchair, I have to make all his doctors appointments go to all his doctors appointments on or off the clock, arrange for Transportation to and from doctors appointments, therapy appointments, , talk to his service coordinator. Keep up with all his prescriptions. Apply splits to his arms after range of motion and stretching to his arms and legs because Christopher also suffers from spasticity that is so painful and severe that I have to take him to Omaha to get Botox injections to give any kind of relief for that child. He also has a baclofen pump is placed on his right flank that feeds a muscle relaxer up his spinal cord to help with decreasing spasticity and tightness . And please remember this is all going on to a person that was a upstanding citizen and now he has to feel like when he's at his lowest point in his life and needs taken care of his being throw in the trash and left feeling like he's less than and that just is not right. My son deserves better. I don't understand why the state would be willing to pay an extended family thousands of dollars a month but they complain about the little bit of money I get as his mother who's had him in my home for 14 years by myself I will add. I am a single mother. There is no help. His father died nine years ago of cancer and he didn't come around much anyway. Siblings are not able to help they have kids of their own and work lots of hours themselves due to increased cost of living.

Now let's talk about the modifications. I took care of my boy on little or nothing in an apartment that didn't deserve what I paid because it had nice wide hallways to aide in wheelchair movement. I finally was able to buy a house so Christopher can live at home comfortably and the State paid for modifications

which included a role in shower and a ramp for the entrance in the front door, which cost thousands of dollars. And you're telling me that in July, I will lose my house now. I will have to place my son in a nursing home that's not able to care for his needs. He falls into the category of the most vulnerable population for neglect abuse. And in my home, the state just paid for modifications to put in a roll in shower and a ramp for the entrance into the home which I know cost thousands of dollars. But you don't care about losing that money I mean, I just don't understand the thought process here. In the families that can't find a place for their children they'll have to go to the hospital in the ICU, which will cost three times. If not more for just a couple nights stay then it would at home with the parents or family member that was taken care of them originally with no problems and cheaper. The math is not adding up.
I would like to know the names of the people that's on this panel that's making all these decisions. I feel that the citizens of Nebraska have a right to know its aggressor because they definitely are not working to help us. They're literally killing our children. I'm also curious if there's any members on this so-called panel that has a disabled child is there anybody around this legislature that has any kind of idea what you're expecting out of these family? I ask that the people on this committee please take another look at your proposal and realize that this is unrealistic to do to so many people!!!

Thank you
Michelle Nunnery
[redacted]

From: DOMINIC GILLEN
To: DHHS HCBS Public Comments
Subject: AD/TBI waiver public comment
Date: Wednesday, December 31, 2025 1:22:20 PM

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To Whom It May Concern,

I am writing to express serious concern about the proposed changes to Nebraska DHHS's AD and TBI waivers, both for their impact on families and for the complete lack of clear communication surrounding these changes.

Most individuals served under the AD and TBI waivers require hands-on care 24 hours a day, 365 days a year. Their needs do not stop for nights, weekends, or holidays. Limiting paid caregiving support to 40 hours per week does not reflect this reality and places an unsustainable burden on families who are already providing the majority of care. They can't go find another job and have reliable care for their loved one at the same time.

Families rely on these waivers to keep loved ones at home in the least restrictive environment. When these supports are changed without regard to actual need, families face exhaustion, financial strain, and increased risk of institutional placement—an outcome that is more restrictive for individuals and far more costly for the state.

In addition to the proposed changes, the process has left us deeply distressed and frustrated. Families were given NO meaningful advance notice of these changes. Service providers offered ZERO guidance, education, or outreach to families regarding how these changes would affect their services or care plans, and when specifically asked they said NOTHING. Families were left to piece together information on their own while facing decisions that directly impact their ability to provide care. The summary of changes on the DHHS website NEVER mentioned capping hours. They were presented as simple administrative changes, NOT structural. You had to know that that ONE item would create panic, but it was buried in a 238 page document.

In my own experience, I was told three times by the Director of the League of Human Dignity that each parent in a household could receive 40 hours of paid caregiving, for a total of 80 hours. She told me she had asked that exact same question of DHHS and was told she was correct. This information significantly influenced our planning and understanding. It now appears to be inconsistent with the proposed waiver changes, further highlighting the lack of clarity and reliability in communication provided to families.

If an additional 30 hours of care are available, those hours should be directed to family caregivers. Family members provide consistent, knowledgeable, and dependable care and are already filling the gaps every day. Trying to use these hours through agencies instead of families increases turnover and creates gaps in care. Nebraska is already in a manpower shortage. Smaller agencies may well have to close because of capping hours which will create even more shortages.

Get rid of the agencies and work directly with families to cut the administrative costs of using a middle man. The families should be the priority, NOT the agencies making a healthy profit.

When families are not adequately supported, institutionalization becomes the horrifying reality. Institutional care is far more restrictive and significantly more expensive than home- and community-based services. Supporting family caregivers directly is fiscally responsible and essential to maintaining individuals in their homes and communities.

These proposed waiver changes, combined with zero guidance from service providers and inconsistent communication, undermine trust and place families in an impossible position. I urge DHHS to reconsider these changes, improve transparency and stakeholder communication, and recognize family caregivers as essential partners in providing care in the least restrictive environment.

Sincerely,

Dominic Gillen [redacted]

From: Ellen Smith
To: DHHS HCBS Public Comments
Subject: Against Policy Changes
Date: Saturday, December 27, 2025 4:12:31 PM

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Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers.

These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.

If cost containment is necessary, there are better alternatives:

- Maintain current hour limits for existing participants (grandfathering).
- Remove or revise the 40-hour cap for live-in caregivers.
- Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment.

From: Mary Jo Iwan
To: DHHS HCBS Public Comments
Subject: Aged and Disabled waiver comments
Date: Saturday, January 3, 2026 2:32:14 PM

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ICF vs ICFIID
Philosophy of waivers: I recommend building waiver services based on philosophy applied to populations allowing habilitation along with support services for persons with intellectual disabilities. People should not be forced to abandon habilitation needs just to obtain needed in home supports. Both should be options. Thus:
I recommend including A&D services in DD Waiver in order to allow participants to access the services they NEED and not just services available. Options needed.

Use ICFIDD as offset for persons with intellectual disabilities rather than forcing them to use/choose waiver services designed to offset a custodial model ICF.
Use costs/rates for ICFIID as service measure for persons with intellectual disability rather than ICF. It isn't fair to IDD population to use a custodial model (ICF) to compare service costs. It doesn't take habilitation needs into consideration and doesn't recognize all the years of progress achieved under Special Education system and support from families.

I commend you on using InterRAI tools to standardize the receipt of waiver eligibility and services statewide. However it seems that the interRAI philosophical shift from the former Clinical Assessment Protocol to current Collaborative Action Plan doesn't appear to be reflected in waiver proposal. There still seems to be a budget first then fit in services approach rather than needs identified with client/caregiver/etc and develop plan to meet needs/goals.

Transition plan proposed is not realistic. There aren't volunteers available to fill in gaps in service plans. And still guarantee the client safety mandated under waiver rules and regs. And I don't see facilities being an option for persons with high needs or living in rural areas. So families would be separated from loved ones by many miles. Or maybe another state.
Also the comment stated by Governor Pillan re "grandmas should be grandmas" and not get paid doesn't seem to be a 2026 option. Many Grandmas need to work in order to meet their own obligations. So full time care of grandchildren is not an option for most. It's also not a state philosophy applied to child care subsidies where politicians expect grandmas to provide 40 hrs of child care so it doesn't follow that grandmas would be expected to provide 40 hours of in home services to grandchildren with disabilities. And Nebraska has always supported child care subsidies.
I feel some of these recommendations would address the budget issues you are facing. And still meet the needs of Nebraska's populations.
Thank you for the opportunity to provide comments.

Mary Jo Iwan

From: Angela Gleason
To: DHHS HCBS Public Comments
Subject: Aged and Disabled and TBI Waiver changes
Date: Sunday, January 4, 2026 12:37:43 PM

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Dear Public Official,

I am writing in concern for my neighbors in Nebraska who care for the most significantly disabled individuals in our state. Home and Community Based Services (HCBS) allow families to keep loved ones at home and provide necessary, live saving care which allows for greatest quality of life and at the same time provides the for the best health and safety of participants. The following changes proposed to the waivers concern me for reasons outlined below:

1. The monetary cap on nursing care allowable on the Aged and Disabled and TBI waivers to 175% of an average of some current costs of non-skilled nursing care
2. The limit of respite care to be changed to 'nonpaid caregiver'
3. The limit on hours families will be reimbursed for care provided to 40h/week

The first item concerns me, as the department indicates the number arrived at was found by averaging a small number of individuals who do not receive specialized or skilled nursing care, as is what is needed for many individuals on this waiver, particularly the higher needs individuals who would even possibly need ICU level of care in a facility. To suggest families could simply place loved ones in institutions with the general nursing facility care would negatively affect these individuals health and safety, who currently receive significant 1:1 supervision and care at home, sometimes through the night. Placing high needs individuals in such facilities, if they would even take them, would likely lead to more significant health concerns and even death.

Also, this number is not based on the cost for actually caring for these individuals, placing an extremely low cap on the most needy in our state. This cap essentially would limit the waiver to only a subset of individuals that actually qualify for this waiver. This cap is not needs based, or if it is it is intended to help the more numerous less needy individuals on the waiver to limit support to those who actually need the services as written. Perhaps there are younger children on the waiver who do not need round the clock care, but there are adults who do and children who do who should be served by the state and their families deserve support.

2. Changing the definition of who can receive respite support appears to limit these caregivers from ever receiving any respite. They are paid minimally by the waiver for an already limited amount of time, when they are often providing around the clock care. Preventing the caregivers from accessing respite to only individuals who are non-paid indicate that they are supposed to use their paid time for respite, when they are already providing care. This will significanly impact the health and safety of individuals on the waiver if their caregivers are never able to adequately access respite and rest, as burnout can and does occur when needing to provide such intensive care to loved ones. With out respite, mistakes are more likely to happen, and it is not safe for caregivers to continue to care for their loved ones when they are exhausted and worn out.

3. The limit of paid care hours to 40 per week is harmful to individuals on the waiver when some of the highest needs individuals require around the clock care. These families provide

care all day every day because they love their child/injured loved one. Providing them a 40h week paycheck does nothing to support them when they do not get a break when they go home as normal working adults do. This will impact the health and safety of waiver participants by limiting housing and potentially placing them in unsafe environments because families cannot make ends meet with only 40h of low end pay.

Changes that could be made to these alterations include assessing need of the 40h pay. Perhaps some families with young children in school could get by with only 40h of pay, but families caring for adults or severely disabled children all day every day obviously need more support and should get it. There should be a needs assessment added to this cap to allow individuals with higher need to get the support they need.

The cap on the cost of caregiving should similarly be needs based. I dont believe that limiting and reducing care for our most needy individuals in society is the direction Nebraska needs to head towards. Perhaps individuals and families that would be affected by this monetary cap and encouraged to be placed in nursing homes could instead be grandfathered in to the waiver at their current rate of care, making sure their health and safety is considered and provided for.

I also question how costs are being considered and combined in these calculations. Its not entirely clear how DHHS arrived at the number they are using, and there has been indication they are combining state plan dollars with also waiver money in this change, and these waiver changes should only address the waivers, not the Medicaid state plan which is a separate funding source.

Respite care should be available to all caregivers, as burnout is a real thing and does happen often. It shouldnt be limited to only nonpaid caregivers.

I also encourage DHHS to undertake a longer public comment period for families to truly understand the impact of these changes and to allow them to provide knowledgeable answers as to how this will affect their families.

Thank you for your time and consideration.

Angela Gleason
[redacted]

From: Paula Evans
To: DHHS HCBS Public Comments
Subject: Aged and disabled care waiver cuts
Date: Thursday, January 1, 2026 12:04:43 PM

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My daughter Korinda Evans almost died from being over medicated in Shared living Homes with Abled. Her weight went from 267 to finally 100 pounds as her body shut down. I, Jean Evans, Koris mom , brought her home and became her SLP and got her off the meds and got her a feeding tube and nursed her back to health. She could not walk and had to be lifted to a wheelchair and became incontinent and had to have 24/7 bed care. Her Dr said Kori would have died if I had not brought her home and given her the care I did. Also said she wouldn't last a week in a nursing home.She is now on her feet and able to walk. Families need to be able to get assistance to take care of their loved ones at home and make sure they get loving care. My mother after Covid died of a stroke in a nursing home. No one checked on her from 8 in the morning until noon . Please reconsider this cut.
Paula Jean Evans
[redacted]

From: Katie Rogers
To: DHHS HCBS Public Comments
Subject: Aged and disabled Medicaid waiver change
Date: Sunday, January 4, 2026 11:49:27 AM

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Please do not go forward with the change to the Aged and disabled Medicaid waiver for families from 112 to 40 hours a week. Many unfortunate citizens of Nebraska will be severely hurt by this.

Sincerely,
Kathleen Rogers
[redacted]

From: Ashley Barry
To: DHHS HCBS Public Comments
Subject: Aged and Disabled Waiver Individual Provider
Date: Tuesday, December 30, 2025 7:11:17 PM

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To Whom it May Concern:

I, Ashley Barry, am addressing the proposed changes for A/D Waiver.

I am an Individual Provider for my 24 yr old Angelman Syndrome daughter, Elizabeth. Her care and needs for her entire life has required extensive treatments, as her parent, I learned through obstacles and challenges advocating for her health requirements to be met for 24 years. I currently make $15.01 an hour and am approved at 84 hours a week at an annual wage of $65-$70k.

Elizabeth's care requires a level of nursing that is not manageable at just a Nursing home level of care which is an expense of $125k annually, it is a specialty care but not just limited to, as follow:

Angelman Syndrome (AS) is a neurodevelopmental disorder characterized by severe learning difficulties, ataxia, seizures, and a happy demeanor. Individuals with AS often experience developmental delays, sleep disorders, and feeding difficulties. Effective nursing management is essential to address these challenges and improve the quality of life for affected individuals and their families. (Elizabeth's nickname in high school was Smiles, she carries a beautiful composure that everyone loves, being cared for at home with routine and consistency allows her the appropriate lifestyle. We live on a farm with many animals from pigs, chickens, donkeys, and goats. We do not live near a large community with Adult Day Care, if we did, that care would not be the right environment for her, as Elizabeth requires one on one hygiene, medical supervision, and nutritional care, those facilities are not medically staffed or even professionally staffed.)

Key Nursing Management Strategies

Developmental Support:

Therapeutic Interventions: Engage in physical and occupational therapy to enhance motor skills and daily living activities. Tailored activities can help improve coordination and independence. (After being present and involved in every therapy session for Elizabeth, it has provided the life skills and tools that are tailored to Elizabeth, this care is always changing and required to meet her needs strictly. It requires 24/7 care designed for her alone, not to be managed in any group settings. She had one-on-one care even throughout her school years.)

Communication Strategies: Utilize alternative communication methods, such as sign language or communication devices, to facilitate interaction and expression, as many individuals with AS do not develop functional speech. (Elizabeth is non verbal, throughout her development and age I have had to learn her mannerisms and body language to best meet her level of care. This is 24 years of observations and adjustments to her. I am a licensed massage therapist also and have the proper education to care for not just her needs but the general public, and she cannot be

overlooked in any environment.)

Seizure Management:

Monitoring: Regularly assess for seizure activity, as up to 80% of individuals with AS experience seizures. Maintain a seizure log to track frequency, duration, and type of seizures.

Medication Management: Collaborate with healthcare providers to ensure appropriate antiepileptic medications are prescribed and monitored for effectiveness and side effects. (Elizabeth has been prescribed seven different Seizure medications in 24 yrs, the last medication Elizabeth was on, created Steven Johnson Syndrome, a rare skin reaction of painful swollen epidermis around her face and down to her feet. She required steroids and medical treatment beyond the care she is already receiving by her specialty medical doctors weekly for six months. To take her off her current seizure medication and introduce her new medication and manage her skin condition at the sametime. Elizabeth's 24/7 care is already required but during this time I had to sleep next to her and check that she was still breathing as her throat was swollen and she could have stopped breathing at any moment.)

Feeding and Nutrition:

Feeding Support: Address feeding difficulties by working with a feeding therapist. Monitor for signs of aspiration and consider the use of feeding tubes if necessary, especially in cases of severe feeding challenges. (Elizabeth cannot independently eat, prepare, or organize her meals or any care at that. She only eats her meals with another person hand-over-hand feeding her and managing that she is not malnourished or over eats and chokes. This is again one-on-one care that no institution provides at the level of cost I am paid to provide at $15 an hour when most nurses or nutritionists make $25-$38 an hour. But we are supposed to put our trust into an Adult Day Care facility employees? They are minimum wage employees. I have had the privilege of sitting in a restaurant when an Integrated Life Choices group of special needs individuals came in with three employees. The employees looked and carried themselves more handicapped than the individuals being cared for, and then they sat at their own table not monitoring or supervising; as well as talked about getting drunk and their sex life. How repulsive for these on the clock staff of a supposedly government funded professional facility.)

Nutritional Guidance: Ensure a balanced diet that meets the nutritional needs of the individual, taking into account any specific dietary restrictions or preferences.

Sleep Management:

Sleep Hygiene: Implement strategies to improve sleep quality, such as establishing a consistent bedtime routine and creating a comfortable sleep environment. Monitor for sleep disorders, which are common in individuals with AS. (Elizabeth is incontinent. She requires all bathing and bowel/urinary care at all times. I personally change her six times a day minimally and bathe her and brush her teeth and hair daily. This is a must to continue her best quality of life and meet those needs as any human being should have those rights and needs met. There is no other way to stress concern that those needs will be met at such a high standard in any facility with high risk

requirements such as hers and others like her the same level. Again this is 24/7 care not to be confused as a 40 hour a week career where individuals have different employees offering this intimate and vulnerable care at a standard we ourselves set high. To discuss sleep management more, I have a monitor on overnight and personally wake up three times through my sleep to check in on Elizabeth, I am "off the clock" at this time gladly not needing that compensation, but this program wants to pay an institute for such care? Why change this at a rate currently more feasible than a facility that charges astronomical amounts to provide this and truly at a disconnected random individual that is only there for a paycheck. How scary to be under the care of a corporate institution where employees come and go and never take all the courses that Elizabeth requires for her care, like I have developed for her specifically.)

Family Education and Support:

Education: Provide families with information about Angelman Syndrome, including its characteristics, management strategies, and available resources. Empower families to advocate for their child's needs. (Elizabeth can be upset often and the only way she communicates is through screaming, self harming and crying. I create a safe space for her to go through those emotions and there is no facility that can offer this at the level a family member does and can.)

Support Networks: Encourage families to connect with support groups and organizations focused on Angelman Syndrome to share experiences and resources.

Conclusion

Nursing management for Angelman Syndrome requires a comprehensive and individualized approach that addresses the unique needs of each patient. By focusing on developmental support, seizure management, feeding, sleep, and family education, nurses can play a crucial role in enhancing the quality of life for individuals with AS and their families. Collaboration with a multidisciplinary team is essential to provide holistic care and support.

That is the basic definition for her diagnosis, that is a lot! And there is no way to prepare oneself to be a parent to an Angelman Child and then knowing that care carries through into their adult years at an even higher requirement and need.

It truly is a life lesson to raise an Angelman Syndrome child, and that is not discrediting any other individual's disabilities or diagnosis.

I worked for over 15 years in a top 500 organization where I was making over $30 an hour and 50+ hours a week, I made the decision to leave that and care for Elizabeth because I personally saw groups of individuals like her come through my previous career's location and watched the poor care given and the staff changed daily. There were multiple individuals left alone or forgotten there, and verbal and emotional abuse every time they came through, and every agency mistreated the individuals, Goodwill, ILC, MNIS, etc. That is not quality living and Elizabeth and everyone like her deserves the best always, as you and I do. I took a wage cut to offer her the absolute best care in AD Waiver, and it is minimum wage rate (not a nurses wage), I also only get paid for 84 hours a week when I actually provide 168 hours a week. I was a Director in my previous job, managing budgets and schedules and forming board

meetings and committees, to oversee; I am now an Individual Provider billing and scheduling and sitting through online meetings and learning the multiple platforms this program has introduced to us and I am not getting paid to do that (that alone should be an administrative pay of $40 an hour when I am working in this part of my position. A salary of $40k a year because I dedicate upto 20 hours a week administratively.) There should be more compensation to Independent providers because we take time away from the individual's care even to learn the next phase thrown at us, because it's not a choice, we have to do this for them. We also don't receive health benefits, paid time off, retirement plans, etc. Working with an agency or institute will require administrative expenses and on site medical staff expenses, I don't require that rate.

We do it for our loved ones, we do it for the best quality of life for them, and I have not once pleaded for more money or those other benefits. But knowing that we should be compensated through basic knowledge of healthcare or nursing home care, and we don't demand that pay; and now you want to strip us of minimum wage at 84 hours a week? Where is the true humanity here? So if we are cut back to 40 hours a week, we will be paid $40 an hour, right?(A nurses wage) With benefits? (That's what these adult day care facilities or nursing homes will get $55 an hour.) And then an administrative 20 hours a week at least at $25 an hour for the time spent scheduling, background checks, billing, etc.? (Administrative wage) Elizabeth requires 24/7 care and living at home as she has every right to live at home with loved ones? Like you and I do.

We are humble in our situation, making the best with what our funding gives us, which is not enough even now. But to lessen that substantially is disheartening and goes to say I feel you are inadvertently killing Elizabeth. She will not survive in an institution of disability masses and lacking true humanity and speciality clinical care, because I will be unable to cover her costs of living here and be forced into a fulltime job again. And to offer an out of home provider 70 hours a week, to invade our personal lifestyle, higher wage and more time? You would allow that in your home?

There is a rabbit hole we can go down here with further concerns. My grandma is in a nursing home, she is a fall risk, she fell because there was no supervision and has extensive injuries now; there is a lawsuit on the facility for neglect and abuse. Through documented incidents she has had happen there will be large compensations involved for her health needs as an older adult, these things do happen. But negligent care on someone like Elizabeth is an entire other category, she is young and capable of pregnancy, she is non verbal and cannot speak up for herself, she is strong and healthy because of her care now. But she is vulnerable to abuse because of her speciality care required. We are protecting her and others in her scenario from further incidents like institutional abuse. Again, this is something she can die from, truly. Reducing her care will end up creating more health risks for Elizabeth. The medical field is already lacking enough professional staffing and changing this program will only add more to that. (It is a fact that Elizabeth would have to be sedated in an institution because she requires one professional/medical person to care for her, and an institution will not be able to hire one employee for her at the rate I make now. No more nickname Smiles, she will become a shell, an empty canvas left to decay in her human body.)

I respectfully agree and understand change is needed in A/D Waiver care. Not to cut funds and create more work in the long run, but to give more and offer training and better wages to streamline this care. Yes, CPR and first aid, holistic health classes

such as, energy work, meditation courses and nutrition seminars. Like my LMT requirements of taking CEU courses to upkeep my license, offer these types of opportunities to us in this program. It will provide you a peace of mind knowing we are investing more into this care and program, and us by providing loved and safe care to our family/individuals.

To sum this up in an expense outlook for Elizabeth's care alone. Her base start expense in care at a Skilled Nursing home annually is $125,000, this is just daily living care not including the wage of $80,000 in administrative care; $205,000 annual base pay. My annual wage as of right now is $70,300 as a Individual provider, that is 30% of what her care will cost elsewhere. Then the breakdown of added therapy Elizabeth requires both occupational and physical therapy care, I provide this at no additional costs, in a facility that is an additional $200,000. This has to be included in her care 24/7. And I am sure these employees do get benefits, PTO, retirement, etc.

Thank you for carefully reviewing my case.

Genuinely Concerned.

Ashley D Barry

One last view, I have seen staff of these facilities and the care they provide, it is inadequate to my standards. My family and I have supported these programs through their local businesses, I understand the importance of these facilities for households that care or lack thereof to offer disabled children/adults. But AD Waiver is offered for the households that can and do specialty care, skilled care, truly hard work with patience, we cannot lose sight of them, they are human beings that need all the love we have to give.

From: Samantha Reed
To: DHHS HCBS Public Comments
Subject: Aged and Disabled Waiver Proposed Changes
Date: Friday, December 26, 2025 6:49:32 PM

You don't often get email from [redacted] Learn why this is important

Hello,

My name is Samantha Reed and I'm writing to you regarding the potential changes to the Aged and Disabled Waiver.

I am a Nebraskan that has been utilizing home health services for over 10 years. I became a quadriplegic as a toddler and was cared for by my family until moving out for college like any able bodied person would. I gained independence and was able to live in the UNO dorms, followed by eventually moving into my own apartment after graduating from UNO and beginning my Master's at Bellevue University. I am now 30 and working part time as a mental health therapist in Omaha.

None of this would be possible without having my caregivers in my home 24/7. I rely on them for all of my activities of daily living: getting dressed, eating, bathing, transferring to and from my wheelchair, transporting to and from work, etc. I need a caregiver with me at all times to function.

The proposed changes to the waiver program will eliminate my ability to exist in the community. My parents work full-time jobs. Neither can afford to stop working to take care of me. It's not an option for them to put their lives on hold and, quite frankly, they shouldn't have to.

I'm not going to magically become able bodied when I hit the 70-hour cap if these changes are approved. I will still need around the clock care. What am I supposed to do for the remaining 98 hours of the week? If the hours become capped at 70, I will have to receive that 24-hour care from a nursing home. I have no other options. Thousands of other disabled Nebraskans will be in the exact same predicament.

I'm aware that these proposed changes are because of the cost of our care. I urge you to remember that my fellow disabled Nebraskans and I are more than dollar signs. We're real people. We have lives, families, jobs, and goals. Taking away our care is taking away our dignity. We deserve better than that. Since disability and illness can happen to anyone at any time, you and your loved ones would deserve better too if this were to become your reality.

I strongly request that you reconsider these changes. You're affecting lives here. Please don't take our away.

Thank you for your time,
Samantha Reed

From: stephanie bondi
To: DHHS HCBS Public Comments
Subject: Aged and disabled waivers
Date: Friday, January 2, 2026 9:31:51 PM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Please consider this my public comment in opposition to the changes in the aged and disabled waiver limits.

I oppose these changes because of the significant concerns raised by Nebraskans who rely on these. There's a big uproar about the untenable impact this will have on vulnerable families.

There used to be days when disabled people were sent away to institutions or otherwise discouraged from being in our communities, but we've learned from that. If this is really a budget matter I believe there's ways to increase revenue by cutting subsidies to the wealthy and business owners.

I hope Nebraska will continue to be a place that cares for its neighbors— everyone.

Stephanie Bondi
[redacted]

From: JoAn Swanson
To: DHHS HCBS Public Comments
Cc: [redacted]
Subject: Aged and Disabled Waver
Date: Saturday, January 3, 2026 5:48:33 PM

You don't often get email from [redacted]. Learn why this is important

I am writing to express concerns regarding budget changes in provision for care for the extremely disabled.

My nephew, Austin Stewart, is one of those people. He has been cared for and loved by my sister, Teresa Stewart, in Lincoln for over 30 years. There is no question his care has been exceptional and their relationship is stable and he feels secure.

It would be impossible to match this care in an institution. There is much greater economy for Nebraska, and emotional well-being of Austin to keep him in her care. Austin is on the waiting list at Madonna, which I understand can take years to be accepted. His care needs are such that this is the only facility which has the capacity to care for his extreme disability. (trake, feeding tube, suctioning and overall needs.

It is impossible for the state of Nebraska and devastating for both Austin and Teresa to make a change at this time. I implore you to consider an exception waver and allow her to continue to care for him at their home. I also hope in the future to have your help for Teresa to have a place for him at a qualified facility as she ages. She is currently 61 and has been a champion for her son. Her love and care have without doubt kept him alive for these many years..... it is her life!

Thank you for your consideration. Please place a priority on keeping Austin healthy and smiling with his mother's care.

Respectfully,
JoAn Swanson
(sister to Teresa)
PO box 339
Deerwood, Minnesota 56444
218 830 1931
Feel free to contact me with any questions or advice
cc Teresa Stewart
t.kstewart@yahoo.com

From: Cynthia Wiggins
To: DHHS HCBS Public Comments
Subject: Another point
Date: Thursday, January 1, 2026 2:12:01 PM

If my husband has to get a job and we put our adult kiddos in day services which we will have to do it will increase the cost of what your paying is by 50% or more.
This should not be happening you are causing people that are vulnerable to be neglected by the state support.

Sent from my Verizon, Samsung Galaxy smartphone
Get Outlook for Android

01/01/2026

I am writing as a sibling and informal support to express serious concerns regarding the proposed changes to the AD Waiver standards, particularly the assumption that informal supports will be able to fill gaps in care if formal caregiver hours are reduced.

As a sibling, I care deeply about my family member and want them to be safe, healthy, and supported. Like many siblings, however, I have responsibilities outside the home, including full-time work and/or school commitments, that make it impossible for me to provide consistent, hands-on care—especially at the level required by individuals on the AD Waiver.

Informal supports such as siblings, extended family, and friends are unpaid, untrained, and lack formal accountability. While we may be able to provide emotional support, companionship, or limited help when available, we are not equipped to provide complex medical care, behavioral support, transfers, or continuous supervision, nor can we leave work or school on demand when needs arise.

Under the proposed changes, the reduction of professional caregiver hours creates gaps that siblings like myself cannot realistically or safely fill. This is not due to unwillingness, but to practical limitations. Missing work or school places our own financial stability and future at risk, while attempting to provide care beyond our training places individuals with disabilities at risk of harm.

Suggestions that family members can simply step in overlook the reality that many siblings live separately, work full-time, attend school, or have families of their own. These responsibilities make it impossible to provide the consistency and availability required for high-level care needs.

Research consistently shows that individuals with complex needs thrive best in stable, home-based environments supported by trained caregivers. Limiting live-in caregiver support to 40 hours per week for individuals who require ongoing supervision undermines that stability and shifts responsibility onto siblings and families who are not equipped to absorb it.

There is already a severe shortage of trained caregivers, with waitlists that are years long. Reducing authorized care hours while relying on siblings or other informal supports does not solve this problem—it increases risk and places unfair expectations on families.

Informal supports are meant to supplement professional care, not replace it. The proposed changes create care gaps that siblings with work and school obligations cannot fill and that place individuals with disabilities at risk.

I respectfully urge you to reconsider these proposed changes and ensure that individuals continue to have access to adequate, trained, home-based care that meets their needs.

Thank you for your time and consideration.

Blake Richter

[redacted]

Blake Richter

01/01/2026

With the proposed changes to the AD Waiver standards, there has been repeated public commentary suggesting that informal supports should fill gaps in care. It is critical to clarify what informal supports are and, more importantly, what they are not.

Informal supports are unpaid, voluntary assistance provided by family, friends, neighbors, or community members. They lack training, formal agreements, and accountability, and are intended to complement—not replace—professional services. The level of care required by individuals on the AD Waiver far exceeds what most informal supports are able or willing to provide safely.

I have personally asked my own family and friends if they could assist with the care of the individuals in my home should these changes take effect. All declined due to concerns about lack of training and fear of causing harm. Suggestions that grandparents could fill these gaps are unrealistic and unsafe. My individuals have no living grandparents, and even if they did, expecting elderly individuals to perform transfers or provide intensive supervision creates significant safety risks.

Research consistently shows that individuals thrive better in home-based settings than in medical or institutional environments due to improved social, emotional, and overall well-being. Limiting live-in caregiver support to 40 hours per week for individuals who require round-the-clock care would be detrimental to their health and stability and would force families into impossible choices between employment and safety.

There is already a severe shortage of trained caregivers, with waitlists that are years long. Reducing authorized care hours while recommending informal supports does not solve this problem—it increases risk. When untrained informal supports are used and harm occurs, accountability will fall on families and legal guardians, not the state.

Cost comparisons to facility-based care overlook long waitlists, limited admission criteria, and the documented decline many individuals experience outside of home-based environments. Other state programs recognize that home- and family-based care with trained, paid caregivers is in the best interest of individuals with complex needs. This program should not be treated differently.

These proposed changes place lives at risk in the name of budget savings. Individuals on the AD Waiver are human beings, not line items. I urge DHHS to reconsider these changes and maintain access to adequate, trained, home-based care.

Sincerely,

Bruce Evans [redacted]

01/01/2026

With the proposed changes to the AD Waiver standards, several public comments have suggested that informal supports should be used to fill gaps in care. It is critical to clearly define what informal supports are—and, just as importantly, what they are not.

Informal support is assistance provided by a personal network such as family, friends, neighbors, or community members. This support is unpaid, voluntary, and informal in nature, without contracts, training requirements, or accountability structures. Informal supports can provide emotional connection, companionship, and limited practical help, and are intended to complement professional services—not replace them.

The problem with relying on informal supports under the proposed changes is that the level of care required by individuals on the AD Waiver far exceeds what most informal supports are trained, capable, or comfortable providing.

As a caregiver, I have directly asked my own close family and friends—my informal supports—whether they could help care for the individuals in my home if these changes take effect. All declined. Their response was not a lack of compassion, but an honest recognition that they would not know what to do in a medical or behavioral situation and feared causing unintentional harm due to the complexity of the individuals' needs. That fear is valid.

Another public suggestion has been that grandparents could help fill these gaps. My two individuals have no living grandparents. Even if they did, this proposal creates serious safety risks. Grandparents would likely be in their late 70s or older. One of my individuals weighs over 100 pounds. Even with mechanical lifts, transfers require strength, training, and physical stability. Expecting elderly individuals—many with their own health limitations—to provide this level of care creates an unsafe environment and puts individuals at serious risk of injury or neglect.

There is substantial research showing that individuals thrive better in home-based environments compared to institutional or medical settings. This is largely due to improved social connection, emotional well-being, and overall quality of life. Consider your own experience: even a single night in a medical setting often leaves people eager to return home—to rest, recover, and be in a familiar environment. While individuals with disabilities may not always be able to verbally express this, caregivers who know them well clearly recognize their nonverbal cues, body language, and behavioral indicators of comfort, stress, or distress. These individuals are human beings who deserve dignity, respect, and stability—just like anyone else.

Limiting live-in caregiver hours to 40 hours per week would be incredibly detrimental to the health and well-being of individuals who require round-the-clock care and supervision. As a parent and legal guardian of an adult individual with intensive needs, I have already had to significantly limit my ability to work outside the home to ensure their safety and care. Due to their diagnoses, new environments, unfamiliar people, or disruptions in routine can cause severe distress and destabilization. While we intentionally support social engagement, it must be carefully planned to ensure success and safety.

Reducing caregiver hours would force me to work more outside the home just to meet basic financial needs for my family. Without informal supports who can safely step in, this raises a serious question: Where does that leave my adult individuals and their care needs?

If these changes are enacted, and caregivers follow the state's recommendation to rely on informal supports, who is held accountable when something goes wrong? It is unrealistic to believe the state would accept responsibility. Liability would fall on legal guardians—despite having followed the guidance provided—because care was not delivered by trained professionals. This creates an impossible and unjust position for families.

The state has also failed to address a critical reality: there is already a severe shortage of trained caregivers. Waitlists for services and staffing through agencies are already years long. If these changes go through, hundreds—if not thousands—of individuals will be added to systems that are already overwhelmed. We do not currently have enough nurses, direct support professionals, or agency caregivers to meet existing demand—let alone increased demand created by these proposed cuts.

One report cited the annual cost of a medical facility placement at approximately $93,000 per year and suggested that if in-home care exceeds that cost, individuals may be better served in facility-based settings. This ignores several realities:

- Facility placements also have long waitlists.
- Many facilities cannot accept individuals with higher medical or supervision needs due to staffing limitations.
- Individuals who cannot be left unsupervised, even briefly, do not benefit from these settings.
- Institutional settings often result in declines in emotional health, engagement, and overall quality of life.

Across other state programs that require out-of-home placements, home- and family-based settings are consistently recognized as being in the best interest of the individual, supported by trained and paid caregivers at rates comparable to current AD Waiver

services. Why is this program being treated differently? Why does DHHS strongly advocate for home-based skilled care in some programs, while simultaneously reducing it in this one and suggesting reliance on informal supports?

What must happen for DHHS to truly recognize the level of care required by individuals on the AD Waiver? Does an individual need to be harmed—or worse—before these needs are taken seriously?

I invite decision-makers to spend a full 16-hour day providing this level of care. See the medical management, behavioral supports, transfers, supervision, emotional labor, and constant vigilance required. The reality is that the work far exceeds 16 hours a day—and is dramatically more than the proposed 40 hours per week.

If you had a loved one whose care needs were truly a matter of life or death, would you be comfortable with these proposed changes? These are not abstract policy discussions. These are human lives. You cannot place a dollar amount on dignity, safety, and life itself.

I urge you to reconsider these changes and to see individuals on the AD Waiver not as budget line items, but as human beings who deserve safe, stable, and compassionate care.

Thank you for your time and consideration,

Samantha Evans

[redacted]

01/01/2026

I am writing to express serious concerns regarding the proposed changes to the AD Waiver standards, particularly the repeated suggestion that informal supports should be used to fill gaps in care.

Informal supports—family, friends, neighbors, or community members—are unpaid, voluntary, and lack training, formal agreements, and accountability. They are intended to complement professional services, not replace them. The level of care required by individuals on the AD Waiver far exceeds what most informal supports are capable of providing safely.

In preparation for these proposed changes, I asked my own family and friends whether they could assist with the care of the individuals in my home. All declined due to lack of training and concern about unintentionally causing harm. Suggestions that grandparents could fill these gaps are also unrealistic and unsafe. My individuals have no living grandparents, and even if they did, expecting elderly individuals to perform transfers or provide intensive supervision creates serious safety risks.

Research consistently shows that individuals thrive better in home-based environments than in institutional or medical settings, largely due to improved social, emotional, and overall well-being. Limiting live-in caregiver support to 40 hours per week for individuals who require round-the-clock care would be detrimental to their health and stability and would force families into impossible choices between employment and safety.

There is already a severe shortage of trained caregivers, with waitlists that are years long. Reducing authorized hours while recommending reliance on informal supports does not address this shortage—it increases risk. When harm occurs due to the use of untrained supports, accountability will fall on families and legal guardians, not the state.

Cost comparisons to facility-based care overlook long waitlists, restrictive admission criteria, and the documented decline many individuals experience outside of home-based settings. Other state programs recognize that home- and family-based care with trained, paid caregivers is in the best interest of individuals with complex needs. This program should not be treated differently.

These proposed changes place individuals with significant needs at risk in the name of budget savings. Individuals on the AD Waiver are human beings, not line items. I respectfully urge you to reconsider these changes and to preserve access to adequate, trained, home-based care.

Thank you for your time and consideration.

From: Tammy Fiala
To: DHHS HCBS Public Comments
Subject: Barriers and the Peer Support Service Definition
Date: Monday, December 15, 2025 4:02:20 PM

You don't often get email from [redacted] Learn why this is important

Hello,

I would like to comment on the service definition critria set for becoming a Peer Support staff. I feel that the criteria to meet the required education or work experience would be a barrier to potentially good candidates for peer support work. The most important qualifications are not necessarily education or work experience but rather the ability to connect with peers while drawing upon lived experience with a behavioral health challange while role modeling recovery. That does not require education or work experience. The candidate may have been using services and that gave them the experience needed to advocate for peers and give them real world experience. The criteria set forth in the service definition may serve as a barrier.

I would also consider removing the requirement of supervision to allow supervision to take place with Peer Support managers with supervisory experience in such settings as day rehab.

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SHAPING THE FUTURE OF BRAIN INJURY
NEBRASKA BRAIN INJURY ADVISORY COUNCIL

315 W 60th Street, Suite 400
Kearney, NE 68845-1504
(308) 865-5012
Email: vr.infobiac@nebraska.gov
Website: braininjury.nebraska.gov

January 4, 2026

DHHS - Division of Developmental Disabilities
DHHS.HCBSPublicComments@nebraska.gov

Re: AD Waiver Renewal and TBI Waiver Amendment

To Whom It May Concern:

The Nebraska Brain Injury Advisory Council (BIAC) would like to submit the following comments related to the Aged and Adult and Children with Disability (AD) Waiver Renewal and Traumatic Brain Injury (TBI) Waiver Amendment as individuals with brain injuries are served through both waivers:

First, thank you for adding Legally Responsible Individual (LRI) Personal Care to the TBI Waiver. This addition will help meet the needs of individuals with brain injuries (BI) when there is a lack of available community providers and allows those who know the individual with BI more the opportunity to provide specialized care they may need.

We have several concerns, we would also like to share below:

We are saddened and disheartened that DHHS-DDD would provide notice and request for comments to the AD and TBI Waivers over not one, but two federally/state-recognized holidays. Changes to these waivers will impact the daily lives of individuals with disabilities including brain injuries. These individuals deserve a more appropriate 30-day comment period when they can truly review over 400 pages of applications. We would also encourage DHHS to involve stakeholders much earlier in discussions involving significant changes to services. The State of Nebraska has numerous advisory groups including governor-appointed councils, that would be more than willing to provide insight on how possible changes could affect individuals with disabilities that they represent or brainstorm alternatives that would lessen negative impacts on these individuals.

The new individual cost limits are also very concerning. Has DHHS analyzed the current costs and how the proposed caps will impact individuals receiving AD or TBI Waiver services? Specifically for the TBI Waiver, how many individuals are receiving services under the TBI Waiver? How many of these services will now be affected by the cost limits? The cost limits are based on Medicaid

nursing home rates; however, this comes at a time when there have been numerous nursing home closures in Nebraska due in part to underfunding. If multiple nursing facilities are unable to remain in business due to underfunding, it does not seem appropriate to add cost limits to individuals with disabilities based on those funding amounts. The BIAC does understand that there is a finite amount of money available for Medicaid waiver services; however, we would encourage DHHS to reconsider these cost limits. If these cost limits are implemented, we would recommend DHHS grandfather individuals who are currently receiving services with costs over the proposed limits to prevent negative impacts on these individuals so they can remain living in their community with adequate supports.

Caregiver Training is being removed from the TBI Waiver; however, there is no information provided by DHHS-DDD as to why this service is being eliminated. What is the justification for discontinuing this service? We recognize that DHHS is trying to align the TBI and AD Waivers; however, we feel this service is important to those with brain injuries. Unpaid caregivers who provide informal support to the waiver participant often need additional training in order to be successful in their role of helping to keep the waiver participant out of nursing facilities and in the community setting. There are unique and often complex needs in providing care to individuals with brain injuries thus Caregiver Training is an important waiver service. The BIAC would encourage DHHS-DDD to continue to provide this service.

We are also concerned about limits placed on home and vehicle modifications and assistive technology. These modifications and equipment can often determine if an individual can remain in the community or have to be placed in a nursing facility. They are necessary for some individuals to promote independence and prevent complications that can lead to additional medical care or hospitalizations, thus increasing costs. We encourage DHHS to reconsider implementing these limits or at the very least increasing the limit amounts to better meet person-centered care.

One additional item we would like DHHS to review is the proposed limits on care provided by LRIs and legal guardians. While we understand that waiver services are not meant to provide 24/7 care, there should be provisions in place to fulfill requirements of having a person-centered plan. There are not always enough qualified and available service providers to meet the needs of all individuals with disabilities including those with brain injuries. LRIs and legal guardians are at times able to help bridge the gap in services for these individuals, especially because they know the individual and what needs they have. We would encourage DHHS to reconsider these limits.

The Nebraska Brain Injury Advisory Council appreciates your time in reviewing this letter and addressing the concerns raised. Part of our vision is that Nebraskans with a brain injury, regardless of geographic location or financial situation, will have access to the necessary resources that they require to pursue their recovery journey and we know that both the AD and TBI Waiver have a role in fulfilling that vision. We would be happy to answer any questions you have and are open to future collaboration when changes are considered to waiver services.

Thank you!

Emaly Ball

Emaly Ball
Chair

Tiffany Armstrong

Tiffany Armstrong
Vice Chair/Public Policy Committee Chair

From: Michelle Monson
To: DHHS HCBS Public Comments
Subject: Cap on AD waiver
Date: Monday, January 5, 2026 7:32:20 PM

> You don't often get email from [redacted] Learn why this is important

To the people in charge,

Please do not implement this cap in waivered services. It will be devastating to our family if it is enforced. I understand that there has been a great increase in expenses in caring for the disabled, but I think this is something our state should be proud of-that we value the most vulnerable.

My 27 year old son lives with us and we provide all of his care. My adult daughter and I provide care full time, my adult son provides care on the weekends to give us a break, and my husband takes most of the overnight hours. My son previously was living in a group home in another state that had 24 hour awake staff to care for his high needs. He has severe autism with violent behaviors and frequently goes several days in a row without sleeping. Two years ago he developed Type 1 diabetes and became too much for the group home staff to handle safely. We decided to move him into our home in Nebraska. I've had to significantly reduce my hours at work to 2 days a week. My husband is also looking at going part time because frankly, we are all exhausted. I love my son and I want him to continue living in my home, but cutting his hours would be unsafe and unfair. I do get paid to care for him, but the wages are significantly less than what I was making in my career. I've taken the cut in my pay with a cheerful attitude because I am grateful that I can provide excellent care for my son, but reducing the hours and paying us for only a fraction of the hours that we actually provide for him is unfair and wrong.

It is difficult to find people who are physically capable and willing to provide care for my son. People are afraid to work with him due to his difficult and aggressive behaviors. In the last 2 years we have had only ONE person who provided 4 hours of care so that we could go out and celebrate my daughter's birthday. My husband and I take short vacations separately. We've each had one in the last 2 years.

I invite you to meet our family to understand what our "normal" is. We are in this for the long haul. Please show that you really care for the most vulnerable in our state by removing the cap on services.

Sincerely,
Michelle Monson
[redacted]

From: michael weeks
To: DHHS HCBS Public Comments
Subject: Care giver hours
Date: Monday, January 5, 2026 7:47:22 PM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

I’m writing to you today to ask you to reconsider the proposal to cut the hours of skilled in home care from 112 hours to 70 hours a week. My nephew has muscular dystrophy and is confined to a wheelchair and needs constant attention with breathing treatments and bathing and eating. The proposed reduction would have a very significant impact on his health and wellness. Thank you for listening to my concerns . Best regards Michael Weeks.

From: michael weeks
To: DHHS HCBS Public Comments
Subject: Care giver hours
Date: Monday, January 5, 2026 7:47:22 PM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

I’m writing to you today to ask you to reconsider the proposal to cut the hours of skilled in home care from 112 hours to 70 hours a week. My nephew has muscular dystrophy and is confined to a wheelchair and needs constant attention with breathing treatments and bathing and eating. The proposed reduction would have a very significant impact on his health and wellness. Thank you for listening to my concerns . Best regards Michael Weeks.

[redacted]

Public comment:

I am disappointed that our governor is trying to limit AD/aged wavier companies that support or take care of the disabled people **NEED** this care and the hours currently available are barely enough to cover what disabled individuals can achieve without being assisted by companies like ***caretech,*** ***HOMEINSTEAD*** so I'm publicly concerned that these services are being compromised by Nebraska's Government. I highly recommend reconsidering this adjustment or proposing of cutting hours or in home care companies coverage.

In the Lord's Sight,
Jon Buhlmann

From: Julie Twohig
To: DHHS HCBS Public Comments
Subject: Caregiver comments
Date: Wednesday, December 24, 2025 8:14:27 AM
Attachments: c2bd47f4-e8fe-484e-a460-9c934596646f.png [redacted]

> You don't often get email from jtwohig@vnatoday.org. Learn why this is important

As a caregiver to my 75-year-old father, this new change would literally kill my dad and bankrupt my family.

Dad is on peritoneal dialysis (if unsure what that is, please look it up! It is a game changer!) and nursing facilities do not accept patients on PD. They are REQUIRED to do hemo dialysis. HD transportation is not something that Medicare or supplemental insurance covers. Transportation can cost anywhere from $110 - $300 a day, and HD in is 3 times a week. If paid caregivers are cut their paid hours, this would absolutely bankrupt our family.

As a side note please know, I am NOT a paid caregiver...I am just a 38-year-old, middle class daughter, wife, mother, and caregiver who uprooted her family to move in with her dad to care for him after breaking his hip in 2023. I think about our financial future and worry that if one day my dad were to need 24/7 care, will he be able to survive with us in a homeless shelter, as that will be where we would end up due to the cuts to paid caregiving, assuming shelters are not full due to the ramifications this bill would cause.

Julie Twohig
OPERATIONS COORDINATOR

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vna Visiting Nurse Association
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From: Tobi Davis
To: DHHS HCBS Public Comments
Subject: Caregiver cuts
Date: Wednesday, December 24, 2025 6:37:24 AM

> You don't often get email from [redacted]. Learn why this is important

I am emailing in hopes to ask Dhhs to reconsider cutting the 24/7 caregiver hours. My son is in a vegative state from a severe traumatic brain injury and he is anoxic. For those not knowing what anoxic is , he can't move, walk, talk, eat, drink fluids or anything. I do everything for him . All his cares including baths , briefings changes, dressing him , hoyer lifting him, administer all foods and meds thru a feeding tube and the list goes on and on. He can not be left alone as he can aspirate from vomiting (which when he does that we have to hold him up) . He has to be changed when he goes to the bathroom or else this would lead to bed sores's or even uti's. The two leading things that kill these types of people is pneumonia and or urinary infections. How can this be taken away when it went before a panel for review to approve the 24/7 caregiver hours and now just take it away.? this is against the federal law.

Sent from Yahoo Mail for iPhone

From: Cindy Boeselager
To: DHHS HCBS Public Comments
Subject: Caregiver hours reduced
Date: Saturday, December 20, 2025 9:38:37 AM

You don't often get email from [redacted]. Learn why this is important

I am sending this to urge you to leave care giver hours as they are for disabled people. The changes, cutting hours, will be devastating for many people that choose to take care of their loved ones in their own homes. This devastating step will cut the allotted hours for in home care. It will be a change in level of care, an ultimately result in medical harm to people that are not able to have one on one care for medical issues that do come up.
Families will be torn apart, as levels of care drops with the cuts in hours of income care.
Please rethink this change and work to protect all people's healthcare.
Thank you Cindy Boeselager

From: Joelle Frazer
To: DHHS HCBS Public Comments
Subject: Caregiver payment
Date: Tuesday, December 23, 2025 11:34:58 AM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Do you realize that it would cost the state more to put a medically person in an institution or nursing home? I did my research, if caregiver take care a person at home and get paid it would save the state an average 1.7 million a day. Which would-you want to pay in your taxes? 1.7 million or 1 hundred thousand a day? Do your math?
Sent from my iPhone

From: Tammy Russell
To: DHHS HCBS Public Comments
Subject: Caregiver
Date: Wednesday, December 24, 2025 7:26:10 AM

> You don't often get email from [redacted] Learn why this is important

I believe the hours for a caregiver should be cut or set at a certain dollar amount a week. If they are paid 112 hours out of 168 that leaves 8 hours a day to sleep. I do not believe they are actually working working 112 hours a week.

From: Laura Vajgrt
To: DHHS HCBS Public Comments
Subject: Change this wording
Date: Sunday, January 4, 2026 7:03:18 PM

> You don't often get email from [redacted] why this is important

-Page 53- very last sentence on "Exceptions"

First and foremost I disagree with the percentage caps placed on individuals on the waiver. These numbers are not accurate reflections of complex individuals needs.

On page 53:

It says " Exceptions to both limits may be approved by DDD Central Office to meet the immediate health and safety needs of a participant. "

As currently written, the language on page 53 is overly vague and creates uncertainty regarding the upper limits of exception authority, which raises concerns about inconsistent application and lack of transparency for participants and families. I believe this was added as a safeguard to remain in a "gray area." Giving CMS the impression that additional exceptions could be made. However for a complex individual that normally requires a higher utilization than the 175% cap; there is NO exceptions.

In public hearings and emails by DHHS employees we were told:
"Under no circumstances may exceptions be approved beyond the 175% cost cap."

- **This section needs to be reworded so it is not vague. It should reflect what was said; that there could be exceptions from the 100% cap to the 175% cap. However no exceptions once 175% cap is met.**

- **Laura Vajgrt**

From: Jon Keyzer
To: DHHS HCBS Public Comments
Subject: Changes made to Caregiver Pay in the State of NE
Date: Monday, January 5, 2026 2:42:15 PM

You don't often get email from [redacted] Learn why this is important

To Whom it may Concern,

Hi, my name is Jon Keyzer and I am a Guardian of a disabled individual, Simon Keyzer, who is taken care of primarily by Anna Keyzer in Lincoln. She has been able to utilize the program for paying caregivers and provide amazing care for him for several years. Our family has benefited so much from this financial support, and it has allowed him to live in a home and be surrounded by a loving family. We've been able to take care of him and keep him involved in church programs and out in the community with lots of folks who truly love and care for him as well. This has been life-changing for us!

Hearing the news of upcoming changes to this program has impacted us a great deal as our income will drastically change and providing for Simon will become a far greater challenge. Working with outside caregivers has not gone smoothly at all and we definitely hope to keep him home and surrounded by his family. This program has been an amazing blessing in this area.

I am writing this to let you know that there are lots of families like ours that utilize this program in order to provide great care and keep disabled folks in their homes, surrounded by family. The upcoming caps to hours discussed will cause huge changes in families like ours who will be looking at drastic financial changes as well as questions of how to make the care happen for loved ones. Please consider the impact of this in your policymaking. Our goal is simply to give the best care we can to those we love and help them keep their dignity.

Please consider reducing the cuts so that they are not so drastic and immediate, and please consider allowing live-in providers to provide the full hours of care determined by your evaluations of the clients disabilities (so that they can have their needs met regardless of finding help from caregivers outside the home.) This wouldn't change the budget at all and would provide families with far more flexibility. I have heard that there are legislators that are willing to pass a bill to add more funds if that is what you need to care for the disabled in our state.

We have appreciated so much the support we've received and hope that it can continue in a way that doesn't produce such severe results for those of us impacts by these policies.

I urge you that the lives of those who are disabled are so important!!! And supporting those who care for them enables them to maintain their dignity and experience far better care.

Thank you so much for your consideration in this matter !!

From: Mary McHale
To: DHHS HCBS Public Comments
Subject: Changes to A & D and funding
Date: Monday, January 5, 2026 5:56:10 PM

You don't often get email from [redacted] Learn why this is important

Greetings!

As the parent of an adult child with a disability I am appalled that our governor believes that the answer to having waivers is "to get government out of state issues and go back to the days when the family provided support." I am sure that the governor is aware that in this society, many families do not live by each other, often times both parents/guardians work outside the home, Our son is an only child, my husband and I both work outside the home-- who does the governor expect to help us out? That is not feasible in this society.

When DHHS began getting rid of the waiting list, many people asked how that could be done with no additional funds. DHHS stated everyone who is eligible for either A&D Waiver or the Family Support waiver will receive a waiver. So it is not surprising that now DHHS realizes the expense of taking care of your relative with IDD is costly, and that is even if the family can find a provider who will work with their relative. That is also the reason why a parent/guardian would become the provider. For many of our individuals, staying at home is what is appropriate for that person. Now DHHS is stating that costs have soared. Reducing hours to a 40 hour will dramatically reduce that person's ability. Does the parent use the 40 hours for the member sleeping and then just sit at home all day? Does the parent use the 40 hours during the day and don't provide any monitoring at night? Oh that's right, that family should be doing that having their families take care of that.

In suggesting that members who need more care should go to a nursing home is interesting because many nursing homes are for people of a certain age. Some of our individuals with disabilities are not that certain age and by suggesting that going to a nursing home conflict with the Olmstead ruling requiring states to support competitive and community living- how does that mean community living when the person is living in a nursing home, and not with their peers. The proposed decrease in hours is not in the member's best interest. I called 2 facilities who serve adult individuals with IDD in Omaha. One told me that they don't take people under a certain age. The other facility said that they are full, but that a nursing home in Axtell NE can take younger people. That would mean removing the individual from their home and go to a location which is not familiar to them.

Am curious how the governor and DHHS thought that individuals using the waiver would not drive up costs? Again, where were the funds suppose to come from?

To ask for comments in 30 days during the holiday season almost begs the idea that people are busy with holiday events and they don't respond.

Thank you,

Mary P McHale
[redacted]

From: Tammy Caster
To: DHHS HCBS Public Comments
Subject: Changes to A&D Waiver
Date: Wednesday, December 31, 2025 1:19:40 PM

You don't often get email from [redacted] Learn why this is important

I am the mother and caregiver to my son, a 30 year old man, who is in the final stages of living with Duchenne Muscular Dystrophy. This terminal disease has been slowly taking my son's life since he was born as it is a disease he was born with but not diagnosed with until he was 6. At that time he looked like every other 6 year old, on the outside at least. But inside, this disease was already at work taking away his muscles and his ability to use them the way you and I do. He was using a mobility scooter in elementary school by 5th grade to help him get through the school day because he would fall too much due to his weak legs and trunk muscles. He progressed to an electric wheelchair at the age of 14 when he could no longer walk at all. As this disease has progressed, he has continued to lose use of his arms, meaning he can no longer feed himself or lift his arms to even wipe his eyes or scratch an itch, etc.

In 2020 his biggest muscle, his heart, stopped. He coded. We are blessed that he was brought back to us. But not the same as he was. He is now on a ventilator, has a trach, a feeding tube, and his lungs have been compromised as well. We all know that his time with us is short but we are not going to give up on him. This includes his care. His care is 24/7 and there is no facility that can or will provide what he gets from our family. No nurse will be there for him to move his arm to make him comfortable every 5 minutes, adjust his legs, knees, feet, pillows, sheets, or anything else that he needs. We all know that.

When he was in the hospital, my husband and I stayed with him because we knew that no one could be there for what he needed when he needed it, so we did it all. The only thing the staff at the hospital did was medications.

Our son is not a 9-5, 40 hour commodity. He is a human being who deserves dignity. He has suffered from this disease his entire life and now…now you want to take away from him the last thing he has, his ability to choose who cares for him and his ability to be cared for in his home. That was the point of this waiver, giving Nebraska citizens the right to have their care in their own home with their caregiver of choice. Why would you pay an agency 3 times more than a parent? The agencies cannot keep employees on staff and families cannot afford to not have care.

If cutting paid hours if something that has to be done, it most certainly shouldn't be done like this. You need to work with and learn from the people who are doing the caregiving for their family members before doing such a drastic change that will be detrimental in so many ways to our families. When I think of what my son will go through mentally having to have someone else come into our home to care for him, I fear for his life. Part of the reason I believe he is still with us is because of his positive attitude and energy. If you force an outside caregiver, I believe he will suffer with depression and anxiety. He may not have use of his body, but his mind is strong and completely healthy and he can think for himself. He will not want anyone else to help him with toileting, bathing, or any other personal needs. Again, this is why family is best!!

I would absolutely love the opportunity to bring Derek to meet you in person so you can meet

the people who are impacted by your decisions. For you, it’s numbers, for us, it’s life!!!

Tammy Caster

[redacted]

Sent from Yahoo Mail for iPhone

From: Stephanie Meyer
To: DHHS HCBS Public Comments
Subject: Changes to AD Waiver
Date: Sunday, January 4, 2026 4:46:50 PM

You don't often get email from [redacted]. Learn why this is important

To whom it may concern:

On December 5th DHHS released proposed changes to the AD waiver. Part of these changes was to LIMIT live in care giver hours to 40 hours per week. For some of these live-in providers and their clients, this change would be very detrimental. Some of the MOST disabled folks in our state receive the maximum amount of 112 hours per week for their paid care (payment for 16 hours per day of care). Of that group, live-in caregivers provide the majority of those hours. Many of these live-in caregivers are parents or spouses of these disabled people, and many of them have left careers to take care of their loved ones. Some have been caring for their loved ones for 30 years or more. To suddenly cut their hours and income by 72 hours per week is DANGEROUS and very destabilizing for these disabled clients. This could lead to the loss of homes, mental health crises, hospital stays, and possibly death for some of the most medically needy clients.

Families affected by these changes will face severe financial issues. A loss of 72 hours per week at $15.00/hour is a cut of $4320 per month for these households. How will they be able to find jobs that pay that much, as people who have been out of the work force for so long? These families must also balance doctor appointments, hospital stays and the stress of caring for their loved ones, which would make working outside of the home very difficult for them at times. This plan assumes that suddenly, after YEARS of searching, hiring, training and losing paid care givers, that they can find someone to do their jobs. This is further complicated by the fact that these paid caregivers aren't able to administer medications or provide the medical decision-making necessary to ensure proper care for clients at all times, which means our most disabled will be in danger.

This plan will NOT work for the most medically fragile and high needs disabled adults on this waiver. If you are to go forward with limiting live-in care givers to 40 hours per week, you will be forcing people to sell their homes and put their loved ones into nursing home facilities. The waiver program was created in order to stop this exact situation from happening. Also, moving disabled clients into nursing homes will be further complicated by a current shortage of Medicaid funded beds available.

Instead, we propose that since this waiver has enough funds to make it through this year, that you spend this year meeting with the families of these individuals and create a plan that will actually work. I believe there are solutions available in this situation! The current system that's in place was created for individualized care, and there are already evaluations that were created to determine services and hours. If you want to create caps, please do it moving forward--not retroactively and NOT so suddenly and NOT so drastically. Consider contracting with each family individually (perhaps less agency contracting and more live-in caregiver contracting?), consider a tiered system like DD services use to determine pay rates.

Also please consider seeking out the funds you need:
a. Find an agency or non-profit, or create one, and begin to hold an annual fundraiser that

gives average Nebraskans and wealthy Nebraskans a chance to care for the disabled of our state.
b. Perhaps the Huskers could run a fundraiser at one home game a year where they advertise the needs of those who are disabled in our state and give a matching percentage of ticket sales that day.
c. Would the Volleyball team and their fans want to help protect the disabled of our state?
d. Ask the Nebraska legislature to allocate more money for this program, due to the rising number of individuals in this program. I believe this sort of thing happens (for example, asking for raises for state employees, you look at the cost of living and then approve a 3-6% raise for your employees). A request for additional funding seems appropriate in this situation.
i. Or perhaps it would be a GREAT time for the legislators to PAUSE or freeze the corporate tax cuts that are creating some of these budget shortfalls?
e. Would Larry the cable guy be willing to help in some way as a Nebraskan with a HUGE platform? Would Warren Buffett want to help? We could ask some of the wealthiest Nebraskans to step up for those who are disabled in our state.

Please consider solutions that are PEOPLE focused, individualized and caring, not just focused on the dollar signs. Thoughtful policy making will ensure that those who are disabled, as well as their families, can continue receiving the care they need and avoid damaging and life-altering circumstances. This waiver program has blessed a whole lot of Nebraskans and allowed them to flourish. It has helped provide dignity and care for so many people! Please consider that as you move forward and make necessary changes.

Signed:

Stephanie Meyer
[redacted]

From: KIM BAINBRIDGE
To: DHHS HCBS Public Comments
Subject: Changes to"
Date: Monday, January 5, 2026 9:35:39 AM

You don't often get email from [redacted]t. Learn why this is important

Probably 15 plus years ago, I was attending a presentation by DHHS explaining what the options were for where my son could live after the age of 21. I will never forget the DHHS presenter saying "no one will be able to take care of your adult child like you as his/her parent have". That has always stuck with me and information I have shared with my two neurotypical children who will be taking care of their brother someday.

Why does DHHS now think that some outside provide will or can take care of an adult with complex medical, physical, emotional needs. Nursing homes all across Nebraska have closed due to the low reimbursement rates from Nebraska Medicaid. Let the parents take care of their adult child. Reducing their hours to 40 hours a week is ridiculous. Does DHHS even understand that the care for these individuals is 24/7 - 365 days per week.

Do not reduce parents hours to 40 hours a week.

Kim Bainbridge
[redacted]

From: terry opry
To: DHHS HCBS Public Comments
Subject: Changes
Date: Tuesday, December 23, 2025 1:38:02 PM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

I am here to say the cut in funds for care is a hardship when you have a child that has been kicked out of programs due to behavioral issues and therefore there is not a home that would accept her unless they plan on strapping her to bed (which I wouldn't ever let happen). She is 24/7 care so 67 hours a week is a joke.
Second I do not understand how you will pay a company 33 dollars an hour but will only pay me 15 an hour if I do my own paperwork. The system broken and does not work for disabled adults like my daughter that do not qualify for care in a state home.

From: Mary Buckendahl
To: DHHS HCBS Public Comments
Subject: Changes
Date: Friday, January 2, 2026 9:46:58 AM

> You don't often get email from [redacted] why this is important

Why are we putting our most vulnerable individuals at risk like this? These individuals have a right to have 24/7 care provided thru the AD Waiver which they have qualified for their level of disability.
Why is the state restricting family and guardians from providing care to them? Family is always going to provide better care than others. Guardians and family members follow all the same rules as any other caregiver when applying for these positions.
Why are they being restricted so drastically?
What is the benefit of the restrictions to the individual that is receiving the care? Family clocks in and out just like everyone else. Guardians have always been able to provide care to the adult individual. They know them and the needs better than anyone. I feel it is wrong to limit the involvement in care.

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From: amanda Vick
To: DHHS HCBS Public Comments; Green, Tony; Clark, Jennifer J
Subject: Comment from a caregiver
Date: Saturday, January 3, 2026 2:28:02 AM

You don't often get email from [redacted] Learn why this is important

Please submit for public comment.

Dear CEO Corsi, Director Green, Deputy Director Clark,

I am writing as a concerned mother of an adult child on the waiver, and a disability advocate to formally express my strong opposition to the proposed amendments to the Aged and Disabled (A&D) and Traumatic Brain Injury (TBI) waivers, specifically the introduction of utilization thresholds and spending caps.

The proposal to initiate a "high utilization review" at $138,657 and impose a hard spending cap of $161,766.50—175% of regular nursing facility costs—poses a serious threat to the independence, safety, and well-being of Nebraskans with disabilities who rely on home- and community-based services, including my son.

This policy represents a significant step backward for Nebraska for several reasons:

• It forces institutionalization. By capping home-based care at a percentage of regular nursing facility costs, the state is effectively forcing individuals with complex needs into institutional settings when their care "costs too much" to provide at home. For many of these individuals, there is no appropriate or available skilled nursing facility capable of meeting their needs.

My son has already experienced several times before he moved back home being stuck in a hospital as no nursing home would accept him and insurance wouldn't approve rehabilitation. The two skilled nursing homes he was previously at were great. Unfortunately one was in a different state early on after his accident, and the other was in short term part as a long waiting list on long term care side.
I even had a Medicaid case manager calling nursing homes as my house was not equipped then to bring him home with none found.
My house did get set up for him and he has been home for 8 years while on a waitlist for the long term care home.

• It unfairly penalizes family caregivers. Families who have worked tirelessly to support their loved ones in their homes and communities are now being told that home is no longer a viable option due to arbitrary financial limits rather than clinical need.

• It lacks transparency and meaningful stakeholder engagement. Announcing these life-altering changes on December 5 with a public comment period ending January 5 does not allow adequate time for impacted individuals, families, and advocates to fully understand or respond to the proposal.

I strongly urge you to remove these spending caps from the final waiver application and instead focus on expanding community-based resources for Nebraskans with disabilities to live in their own homes.

Nebraska must ensure that the safety, rights, dignity, independence, and overall well-being of people with disabilities are protected.

These proposed changes will not be safe for my son.

I also have the following questions I would like answers to:

If there are multiple agencies providing caregivers, who is responsible for ensuring that he does not exceed his budget and is not left without services for weeks or months if an annual rate is set (e.g., 150% or 175% instead of hourly rates, especially since agencies are paid at different rates)?

If his hours are cut or his budget is drastically reduced, who is responsible for providing the extensive unpaid care required so that he is not forced into a nursing home or left with an unsafe care plan? What team makes these individualized care plans (petsons doctirs, guardians, family, teachers, service coordinator)? Even at the 175%, my son could be forced to have 12 hours a day alone, with no supports. I don't understand how you think it is safe to go from 4 caregivers plus myself to care for him, to only half the hours when his needs or health have not improved. How is that providing him a safe alternative to being institutionalized?
If many nursing homes would calculate his rate of pay by his needs, how can you pull a number from thin air? When he was out of state at the nursing home his rate was $2,000/day back in 2016. That would be $700,000 a year at a decade old prices. I can't imagine Nebraska is that much cheaper than Iowa. So even if my sons budget is $250,000 that is saving hundreds of thousands of dollars a year having appropriate and safe supports in place to live at home.

My son also does not does not sleep much. At his last appointment, his neurologist stated this is likely due to injury to both sides of his brain, as medications have been ineffective and anesthesia has been the only option to have him not awake.
How can his safety and health be ensured if he does not receive 24/7 care? Examples of ongoing risks also include pulling out G-tubes and suprapubic bladder tubes, seizures, attempts to get out of bed, disoriented, memory issues, aphasia, autonomic instability requiring PRN care and medications, and his inability to call for help or initiate.

Is respite care still going to be available? If so, how does respite fit into the authorized hours or overall budget if changes are made? If part of budget, how can whomever is responsible calculate the hours?

What is the process for appealing any reductions or caps if they occur? How long does the appeal process typically take, and are hours continued or reimbursed while the appeal is under review?

If staff are required to clock out when he is asleep, how does this work given that he sleeps very little and at unpredictable times? When an agency employee clocks out, they are no longer responsible for him and may leave. I have encountered this issue in the past, including a situation where staff left when their ride arrived early while I was not home and only my minor children were present. While that staff member was terminated, it is unrealistic to

expect caregivers to remain on-site without knowing if or when they will be paid.

Currently, his staff use that brief time to clean, organize, prepare his next meals, plan activities, complete laundry, chart, apply and run therapy devices such as leg compression, cpap, assist with temperature regulation during autonomic episodes, and continue monitoring vitals even when he is asleep. Additionally, two of his caregivers live out of town and would not drive in if there is a risk of not being paid. Given that he has no family or friends available to provide unpaid care or volunteer support, how will his health and safety needs be met so that he can realistically have the choice to remain at home?

I look forward to your response and a public commitment to protecting the rights of Nebraska's disability community.

Sincerely,

Amanda Vick
[redacted]

From: Rebekah DeFusco
To: DHHS HCBS Public Comments
Subject: Comment on AD Waiver Proposed Changes
Date: Thursday, January 1, 2026 3:57:02 PM

You don't often get email from [redacted] Learn why this is important

Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers.

These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.

If cost containment is necessary, there are better alternatives:

- Maintain current hour limits for existing participants (grandfathering).
- Remove or revise the 40-hour cap for live-in caregivers.
- Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

I share this with specific heart toward the Kueker Family.

Thank you for considering my comment.

Best, Rebekah DeFusco

From: Carey Wilson
To: DHHS HCBS Public Comments
Subject: Comment on Aged and Disabled Waiver
Date: Monday, January 5, 2026 10:31:23 PM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Dear Tony Green,

I am writing to you today as a mother whose heart is heavy with worry for my daughter's future. My daughter is 20 years old and lives with epilepsy and Dravet syndrome — a severe, lifelong neurological disorder. Her seizures are unpredictable and can be frightening and dangerous. They have put her in the ER more times than we can count. She has also been in the ICU numerous times and has been life flighted to Omaha twice and air ambulanced to Cleveland once. Her seizures are scary, relentless and ultimately life threatening. She is at an increased risk for SUDEP (Sudden Unexpected Death in Epilepsy). SUDEP takes the life of a person with epilepsy every 7-9 minutes. It has been established scientifically, SUDEP is less likely to happen after a seizure if someone is present as SUDEP starts with apnea and later stops the heart. In some cases, simply having someone there to simulate the person has been shown to restart their breathing. She requires constant supervision, patience, and understanding just to stay safe each day. She sleeps in our room next to us, we rarely get a full nights sleep being up with her while she is seizing and waking up with her every move thinking she is having a seizure.

My husband is one of her main caregivers. He is devoted to protecting her, loving her, and making sure she is cared for with dignity and compassion. He understands her medical needs, her seizure triggers, her fears, and the subtle signs that warn when a seizure may be coming, this is something that has been learned over the years. She trusts him completely and that sense of safety means everything to her and to us as a family.

The recent reduction in hours Nebraska is proposing for the Aged and Disabled Waiver that allows parents and caregivers to be compensated for caring for their adult children has placed us in a crisis we never imagined. This support has allowed my husband to care for her in our home and help provide the constant, skilled care our daughter requires. She needs supervision 24/7, holidays, weekends, we cannot take our eyes off of her ever. Reducing the funding (hours) threatens her safety, stability, and quality of life. Typical children move out on their own by the age of 19 and can mostly be independent and support themselves. Our daughter will always rely on us and is completely dependent on us, we will always bear that financial responsibility.

Governor Pillen, our daughter is vulnerable. She cannot advocate for herself. She depends on us entirely and we are doing everything in our power to protect her. But we are afraid of what will happen if hours are reduced and she is no longer able to receive the intensive care she needs. We fear being forced into impossible choices no parent should ever have to make, including placing her with caregivers who may not fully understand the severity and unpredictability of her condition or in a nursing home where they could not possibly give her the one on one care she needs.

Families like ours are not asking for luxuries. We are asking for the ability to continue caring for the children we love, even when they become adults because their needs do not disappear when they turn 19. Dravet syndrome does not disappear. The seizures do not disappear. Our love does not disappear. But the support we desperately rely on is being taken away.

I am begging you, from one human being to another, to please protect and restore funding for caregiver support programs in Nebraska, specifically the Aged and Disabled Waiver. These programs are lifelines. They keep vulnerable adults safe in their homes, surrounded by the people who know and love them most.

Our daughter did not choose this illness. Yet every day, she faces it with courage and innocence. All we want is to continue protecting her and giving her the safest, most loving life possible.

Thank you for listening to my heart and for considering the real, human impact of these funding decisions. Your

compassion and leadership could mean the difference between stability and heartbreak for families like mine.

With hope and gratitude,

Cray and Carey Wilson

[redacted]

From: christine true
To: DHHS HCBS Public Comments
Subject: Comment on Proposed Changes to Reimbursement
Date: Wednesday, December 24, 2025 7:45:54 PM

You don't often get email from [redacted] Learn why this is important

Hello,

As an occasional therapist serving medically complex individuals and their families, and as a family member of multiple individuals with special needs, I am reaching out to comment on the proposed reimbursement cuts DHHS plans to make to from 112 hours to 40 hours a week.

These cuts will put an undue financial burden on families and the entire community. The cost of living increase and the difficulty to find quality care in medical institutions or skilled nursing facilities for medically complex individuals means that Nebraska families will have to choose between the effects of a significant fall in their finances in this recession, or placement in an medical institution or skilled nursing facility with an increase in health care costs to care for the medically complex individual with poorer care than they received at home (poor continuity of care in institutions with staffing shortages and less known/attuned caregivers, etc).

This is a poor fiscal choice for Nebraska. These reimbursement cuts will result in a detrimental impact on Nebraska families and higher overall health care costs. Please amend this proposed change to support all Nebraskans.

Christine True MOT R/L BCP
Occupational Therapist
[redacted]

From: Donna Sandberg
To: DHHS HCBS Public Comments
Subject: Comments as Independent provider
Date: Thursday, December 11, 2025 4:57:57 PM

> You don't often get email from [redacted]. Learn why this is important

My name is Donna Sandberg-Goodner. I am an independent care provider for my disabled adult son.
My son also has other independent providers that help with his care as I am a RN and work 1-2 days a week outside of the home to keep my nursing license active.
I am very active in my son's care. I do all of his providers training, including exercises/ROM, etc. I schedule the other providers and have quarterly meetings with the providers so we can keep open/good communication. I attend all of the DHHS meetings/ trainings as my schedule allows. I have been thinking I would love to be on a Medicaid Advisory committee. My son's care is my number one concern.
The proposed changes will cause many challenges for my son, our family, and many others on AD waiver. Many families are unable to find care for their children in order to have jobs and have to stay home to provide that care. Many are single parents and don't have family/friends or the resources available to assist in their child's care. This puts an emotional/mental and NOW a financial burden on them with the proposed cuts/changes.
Also, many of these clients on AD waiver may have to seek other living arrangements, such as nursing homes. The concern with this is that there is such a shortage of nursing homes in our rural communities and many are closing everyday. The other concern is the elevated cost of nursing homes care is great and how it compares to the cost of allowing the clients on AD waiver to stay in their homes and compensate the independent providers for the care. I see that it should cost less to have a person stay in their home rather than go into a care institution.
I've always believed that was the goal of the healthcare system was to keep people in their homes. As a nurse and looking at this through the eyes of "Person Centered Care", I would hope that DHHS and CMS will take into consideration all the comments and concerns that are submitted.
Thank you,
Donna Goodner
[redacted]

From: Karen Nelson
To: DHHS HCBS Public Comments
Subject: comments concerning TBI Waiver (NE.40199)
Date: Sunday, December 21, 2025 7:06:20 AM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Hello:

I am writing with a specific comment about NE.40199.

On page 56 is a line of particular concern:

"Personal Care and LRI Personal Care are limited to a combined maximum of 40 hours per week (for live-in caregivers)."

When an individual with a TBI can be at home with his family but cannot do anything for himself, this limit is a backbreaking burden for his caregivers, be it paid live-in nonfamily or parents and others who care for him.

Please reconsider this limitation. Families and individuals who choose to live and work in this type of TBI care situation are doing so out of love, in the best interest of the people immediately involved. They should be supported, not limited, by the waiver.

Thank you for your consideration.

Karen Nelson
[redacted]

From: Ronna Hilger
To: DHHS HCBS Public Comments
Subject: comments for consideration
Date: Monday, December 29, 2025 9:07:02 PM

You don't often get email from [redacted] Learn why this is important

Hello,

I am a U.S. citizen and full-time resident of Nebraska. I am writing within the 30-day comment period related to the state's planned changes relating to the renewal of the 1915(c) Medicaid Home and Community Based Services (HCBS) Aged and Adult and Children with Disabilities (NE.0187) waiver and amendments to the Traumatic Brain Injury Waiver (NE.40199)...

I don't have a problem with a high utilization review taking place when waiver spending exceeds **$138,657** and waiver services being limited to no more than **$161,766.50**. But please do NOT cut family care-giver hours to 40 hours per week.

In most cases, the family care-givers aren't charging the state for round-the-clock care. But if the people needing care are institutionalized, that would absolutely result in their care being paid round-the-clock, so Nebraskans would be paying for over 40 hours a week of care anyway. And the cut to family care-giver hours WILL force institutionalization in many cases. For one thing, Nebraska has a workforce problem, so finding help outside of the family won't be possible. And worse as it relates to institutionalization, some Nebraskans don't have nursing homes anywhere near them that could provide the types of care needed, let alone openings in one that accepts Medicaid residents.

Again, please do NOT cut family care-giver hours to 40 hours per week. Thank you for your consideration.

Sincerely,

Ronna Simon
[redacted]

From:	Janet Seelhoff
To:	DHHS HCBS Public Comments; Green, Tony; Clark, Jennifer J; Brunssen, Jeremy
Cc:	Jan Bresnahan; Melissa Vietor; Koch,Shelly; Ryan Beethe; Eric Davis; Robert Lally; Melissa L. Baumert; Evans, Jody M.; Keri Carraher; Kellie Heiman NE-OMAHA; Tim Martens; Kerin Zuger; Andy Gorman; Chuck Chase; Doug Robertson; Jeremy Starkel; Kathleen Horsley; Kerin Zuger; Kristin Starkel; Matt Boever; rebecca.matthews@aplaceathome.com; Rick Perkins; Susie Egr; Tim Martens; Adrian Sanchez
Subject:	Comments from the Nebraska Home Care Association for the Renewal of the Nebraska Medicaid Home and Community-Based Services Aged and Adult and Children with Disabilities Waiver
Date:	Friday, January 2, 2026 8:46:50 AM
Attachments:	Outlook-i05pnqbw.png Nebraska Home Care Association Comments to Proposed AD Waiver Changes.docx

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Dear Nebraska DHHS Division of Developmental Disabilities:

The Nebraska Home Care Association appreciates the opportunity to submit comments on behalf of our members regarding proposed changes to the Nebraska Medicaid Home and Community-Based Services Aged and Adult and Children with Disabilities Waiver. Attached are our comments.

The Nebraska Home Care Association Board and Personal Care Home Care Committee members are cc'd on this email. We welcome a meeting with Tony Green, Jenn Clark, Jeremy Brunssen and other Nebraska DHHS leadership to discuss these recommendations and comments, and partner together to help ensure that Nebraskans can remain safe and independent in their homes and communities.

Thank you for your consideration.

Janet Seelhoff, CAE
Executive Director
Nebraska Home Care Association
3901 Normal Blvd., Suite 100
Lincoln, NE 68506
(402) 423-0718
jseelhoff@assocoffice.net
https://www.nebraskahomecare.org

Nebraska
Home Care Association

From: [redacted]
To: DHHS HCBS Public Comments
Cc: [redacted]
Subject: Comments on Medicaid Waiver
Date: Saturday, December 20, 2025 2:14:29 PM
Attachments: Comments to DHHS 12-17-25.docx

> You don't often get email from [redacted]. Learn why this is important

Attached are my comments on the current Medicaid Waiver.

Comments on Proposed Changes to the Nebraska Aged & Disabled (A&D) Waiver

The participants who will be affected by these proposed changes represent the **most vulnerable individuals in Nebraska**—older adults and people with disabilities who rely on the A&D Waiver for their health, safety, and ability to live with dignity in the community.

Under federal Medicaid law and the **Olmstead v. L.C. decision**, the State of Nebraska has an affirmative obligation to provide services in the **most integrated, least restrictive setting appropriate to the individual's needs**. This responsibility rests with the state—not with unpaid or underpaid family members placed in financially unsustainable caregiving roles.

The proposed changes appear to rely on **unreasonable and unsupported assumptions**, including:

- That families are obligated to provide extensive, often medically complex, care at extremely low reimbursement rates
- That families can absorb the financial and emotional burden of 24/7 caregiving without placing the entire household at risk
- That participants who cannot rely on family caregivers can readily transition to institutional settings, despite:
    - Severe workforce shortages
    - Limited nursing home capacity for waiver participants
    - Few facilities willing or able to accept individuals with high-acuity needs
    - Reduced nursing requirements in nursing facilities, including the lack of guaranteed 24/7 nursing coverage

Given these realities, the proposed changes raise serious concerns about **participant safety, access to care, financial coercion into institutionalization, and compliance with federal disability rights law**.

---

1. Waiver Funding and Fiscal Justification

Please respond to the following:

1. Is there currently a funding shortfall in the A&D Waiver?
    - a. If not, is DHHS projecting a future shortfall? If so, based on what data and timeline?
    - b. What specific budgeting, actuarial, and forecasting methodologies are being used to determine the existence or likelihood of a shortfall?
    - c. Why did the state contract with a company whose primary function is to reduce Medicaid expenditures and allow that entity to make recommendations affecting **HCBS waiver services**, which serve the most vulnerable population in Nebraska?
        - This company has **no accountability** to waiver participants or the disability community.
        - DHHS **does** have legal and ethical accountability to Nebraska residents.
        - Allowing cost-containment recommendations without participant-centered safeguards appears negligent and inconsistent with the intent of HCBS waivers.

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2. Limitation of Personal Care and LRI Personal Care to 40 Hours per Week for Live-In Caregivers

The A&D Waiver exists specifically to **prevent unnecessary institutionalization** and to promote **dignity, stability, and independence** in the community.

It is a demonstrable fact that participants requiring high levels of care **cannot obtain sufficient services** at a limit of 40 hours per week at **$15.00 per hour**, whether through agencies or individual providers.

2. Please explain:
    - a. How does the state justify expecting family members to provide extensive, often round-the-clock care at such a low wage and with such limited authorized hours?
    - b. Why was an **arbitrary 40-hour limit** selected when many participants have **documented 24/7 care needs**?
    - c. The proposed reimbursement rate is far below what medical professionals receive for similar levels of care and places families in severe financial jeopardy.
        - This will inevitably force families to choose institutional care, **removing the participant's right to choose community-based services**.
        - How does the state plan to prevent this outcome and ensure participant needs are actually met?

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3. Combined 70-Hour Weekly Limit for Personal Care, LRI Personal Care, and Companion Services

The proposal allows agencies to provide up to **30 hours per week**, while family caregivers are paid significantly less.

3. Please address:
    - a. How does the state justify the **wage disparity** between agency providers and family caregivers providing the same—or higher—levels of care?
    - b. If the goal is to reduce Medicaid expenditures, why does the state pay **substantially more** for agency staff than for family caregivers who already provide consistent, trusted care?
    - c. Many participants are not comfortable receiving intimate or complex care from strangers.
        - These limits effectively **remove participant choice**, in direct conflict with HCBS principles and disability rights protections.

---

4. Institutional Cost Limit of 175% for Waiver Nursing Home Services

As noted above, the proposed changes will **financially coerce families into institutional placement**, despite clear evidence that:

- High-acuity participants often exceed the care capabilities of standard nursing facilities
- There is an ongoing shortage of qualified staff
- Nursing homes are no longer required to have a nurse on staff 24/7

4. Please explain:
    - How does the state justify pushing participants toward institutional settings that may be **less safe and less appropriate** than their current community-based care?
    - Is the state assuming families will simply "figure it out" and continue providing unpaid or underpaid care, regardless of financial hardship or caregiver burnout?

Additionally:

- a. Will DHHS open or expand institutions capable of providing **high-level medical and personal care** for these individuals?
- b. If so, will these facilities be operational by **July 2026**, when the proposed changes take effect?
- c. If not, where and how will the state ensure participants receive necessary care and services?
- d. What is the state's plan to provide appropriate institutional care in the **least restrictive environment**, given workforce shortages, limited bed availability, and reduced nursing requirements?
- e. What **specific criteria** will DHHS use to determine whether an exception to these limits is warranted?

Closing Statement

These proposed changes appear to prioritize cost reduction over **participant safety, federal compliance, and human dignity**. Without meaningful revision, they risk violating the **Olmstead mandate**, undermining HCBS goals, and placing Nebraska's most vulnerable residents in harm's way.

The state must provide clear justification, transparency, and safeguards before proceeding with any changes that so profoundly affect the lives of A&D Waiver participants and their families.

From: [redacted]
To: DHHS HCBS Public Comments
Subject: Comments on the AD renewal draft
Date: Sunday, December 21, 2025 2:36:54 PM

You don't often get email from [redacted] Learn why this is important

Dear DHHS –

In reference to Appendix C: Participant Services C-1/C-3: Service Specification

The limitation on the number of hours per week for Personal Care services to be provided by a live-in caregiver that are part of the draft for HCBS AD waiver services would be, quite simply, devastating.

I am the live-in caregiver to a severely handicapped adult, who is incapable of performing any activities of daily living. She requires care and supervision 24 hours per day, 7 days per week. Current DHHS guidelines prevent a caregiver being paid while she is sleeping, so that care is currently uncompensated by the state.

The participant is my adult daughter, and we live alone, in a rural community. There is (to my knowledge) no available non-in-home caregivers in the area that are certified for Personal Cares – only Companion; and my daughter requires medication 5 times daily. This precludes my being able to seek external employment, as I would have to leave work to administer medications.

If I were only paid for 40 hours of care per week, even with her SSI – we couldn't afford our home. I honestly don't know that we could afford to live anywhere. This limitation on hours would be absolutely catastrophic to her quality of life.

Please remove these hourly limitations from this draft prior to the renewal going into effect.

Sincerely,

Traci Solarz

From: Donna Sandberg
To: DHHS HCBS Public Comments
Subject: Comments
Date: Friday, December 12, 2025 11:40:13 AM

You don't often get email from [redacted]. Learn why this is important

I'm Donna and an independent provider.
So I am concerned about the clocking in and clocking out so much… It seems very cumbersome for our providers, myself and my son who actually has to sign for everyone. I know that you guys want to be correct on what's actually being done, but this seems like this is very time-consuming and will be very frustrating, may also cause a lot more confusion for the people on your end for reviewing all of this for charges.
I'm not sure if there is a better way… I was just setting down calculating in my head how many hours and what we do for personal care for my son throughout the day and how much of it is companion.
Maybe there's a way to just put in the comments rather than all the clocking in and clocking out so much.
Also, I was wondering like how this is done and if you're at doctors appointments and such… With all the clocking in and out how will that be able to be done? Especially using the EVV system for all the location information.
Thanks,
Donna

From: Donna Sandberg
To: DHHS HCBS Public Comments
Subject: Comments
Date: Friday, December 12, 2025 1:05:04 PM

You don't often get email from s[redacted]. Learn why this is important

From Donna Sandberg-Goodner-

I have concern with the clocking in and out with personal care and companion care…it would be very cumbersome when at a doctor appointment or appointments to have to change the EVV location in order to change from companion to personal care. Providers would have to put in personal care, then click out and back in for the companion care…all while my child is laying on the floor in the bathroom. Don't think that is person centered care!!
Then need to clock out and do EVV location every time for hands on care.
Do you understand that these appointments are exhausting for us, let alone our kids, then we add this "clocking in and out" to the picture?
Please practice this with your own families and let us providers know how easy it is.
Just expressing the real life we live in.

From: Donna Sandberg
To: DHHS HCBS Public Comments
Subject: Comments
Date: Friday, December 12, 2025 1:51:03 PM

You don't often get email from [redacted]. Learn why this is important

Concern from Donna Sandberg-Goodner

How to keep track of personal care and other hours in order to not go over?
Such as my son needs to toilet it takes 7 minutes, he then toilets for 6 more times for different amounts of time….how do you keep track of that in order not to go over the hours? Since he will have other care also that will be given and billed by clocomi g in and out.

Breaking care up this way is going to take so much time and be very cumbersome. Not allowing for what is important here, which is the child.

From: [redacted]
To: DHHS HCBS Public Comments
Subject: Comments
Date: Monday, December 15, 2025 10:36:09 AM

My concern is the care of the clients.
I believe home care is better for the client noting the statistics showing that homes have a higher % of pressure ulcers compared to clients staying at home. Nursing homes range from 2.4-23% compared to home at under 4%.
The cost of institutional care is also higher. It would be nice to get some more funding from CMS to allow clients to stay in their homes.
Thanks,
Donna

From: Jazmine Marie
To: DHHS HCBS Public Comments
Subject: Concern of Community-based Service Plan
Date: Saturday, December 27, 2025 7:15:01 AM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Dear Decision Makers,

I am writing as a concerned member of the public to urge you to stop the proposed caps on home and community-based service hours and the policies that would force people out of their homes and into institutional care.

These changes will not save money. They will cost the state far more.

Adults with severe disabilities who require constant one-on-one care cannot work and cannot live independently. Medicaid-funded home care is not optional for them—it is the only way they can safely live in the community. When adequate in-home care is available, these individuals remain stable, healthier, and out of costly institutions.

High-level care facilities and nursing homes routinely cost the state well over $150,000 per year per person, often much more. In contrast, family-provided in-home care costs a fraction of that amount. Families provide care at lower rates than agencies or institutions, without overhead costs such as buildings, administrative staff, or profit margins. The state saves money while the individual receives better care and quality of life.

Capping hours does not reduce the need for care. It only shifts the cost.

When in-home care hours are cut, families are pushed into crisis. Caregivers lose income and often become eligible for Medicaid, food assistance, and other state-funded programs themselves. Homes become less safe as families can no longer afford upkeep, equipment, or necessary modifications. Hospitalizations increase. Burnout increases. Eventually, many families have no choice but to turn to institutional placement—the most expensive option possible.

Forcing families to use agencies to access additional hours is also fiscally irresponsible. Agency care costs two to three times more per hour than family-provided care, and agencies are already unable to staff the needed hours. This policy increases spending while reducing continuity and quality of care, especially for individuals who cannot tolerate unfamiliar caregivers. Save agency hours for people who truly need agency hours.

Most importantly, these policies take away the only way of life that people with severe disabilities are supposed to be able to count on—the right to live in their homes, with their families, in their communities. These individuals cannot advocate for themselves. We have a responsibility to stand up for them.

I urge you to reject arbitrary caps and forced agency or out-of-home care. Preserve needs-based services. Protect both vulnerable individuals and taxpayer dollars by keeping people safely in their homes.

Please do not pass policies that will increase costs, increase harm, and violate the promise of community-based care.

Thank you for your commitment to hearing the community's concern, and taking care of those you serve.
-Jazmine Rannells

-Jazmine

From: Katie Novakoski
To: DHHS HCBS Public Comments; Green, Tony
Subject: Concern Regarding 40-Hour Cap on Personal Care Services
Date: Saturday, January 3, 2026 1:00:46 PM

Dear DHHS Leadership,

I am writing to express concern that capping personal care services at 40 hours per week for participants who require 24/7 support conflicts with federal Medicaid HCBS requirements, including 42 CFR §441.301(c)(1). I oppose these cuts to the AD wavier personal care hours and want to know how you plan to keep our loved ones safe cutting hours so drastically while following the law.

This regulation requires person-centered planning based on each individual's assessed needs and informed choice. A fixed hourly cap does not account for individuals who need continuous care and effectively limits their ability to live safely in the community, increasing the risk of unnecessary institutional placement.

CMS guidance makes clear that HCBS service plans must be driven by individual need rather than programmatic limits. A 40-hour cap for participants needing 24/7 care undermines these requirements and raises concerns about compliance with federal HCBS standards.

I respectfully request that DHHS reevaluate this policy to ensure alignment with CMS HCBS regulations.

Sincerely,
Katie Kuecker

From: Mark Kuecker
To: DHHS HCBS Public Comments
Subject: Concern Regarding Proposed 40-Hour Cap on Caregiver Services
Date: Wednesday, December 17, 2025 10:05:52 AM
Attachments: [redacted]

You don't often get email from [redacted]g. Learn why this is important

Dear DHHS Leadership,

Thank you for your ongoing efforts to support Nebraska families and individuals with disabilities. I am writing to express my deep concern regarding the proposed 40-hour cap on paid caregiver hours.

As President of Dads Appreciating Down Syndrome (DADS Omaha)—a nonprofit that supports fathers and father figures of individuals with Down syndrome—and as a long-time professional in the care industry, I see firsthand how essential consistent, reliable caregiving is for medically fragile individuals.

Care does not stop at 40 hours, and neither does caregiving. Individuals with complex medical needs require continuous support, and an arbitrary cap introduces serious medical and safety risks.

Consistency in care is critical. Medically fragile individuals depend on caregivers who understand their routines, medications, communication cues, and early warning signs. Caregivers are not interchangeable. Gaps in coverage or frequent staffing changes increase anxiety and significantly raise the risk of preventable medical emergencies.

Reducing paid caregiver hours does not reduce the need for care—it simply shifts that burden onto families who are already providing extensive unpaid support. This leads to caregiver burnout, higher rates of medical error, and increased emergency room visits or institutional placements, outcomes that ultimately increase costs to the state.

This proposal directly affects families like mine. My two special needs granddaughters rely on stable, experienced caregivers to remain safe and healthy at home. Their mother, my daughter-in-law, is their primary caregiver and is unable to work outside the home due to the level of care required.

I respectfully urge DHHS to reconsider implementing a 40-hour cap and to preserve adequate caregiver hours so individuals with disabilities can continue to live safely, with dignity, and within their own communities.

Thank you for your attention and your commitment to the well-being of Nebraska families.

Sincerely,

Mark Kuecker – President
D.A.D.S. -Dads Appreciating Down Syndrome
Cell 402-686-9858 | www.dadsomaha.org | www.facebook.com/dadsomaha

DADS® OMAHA | Dads Appreciating Down Syndrome

D.A.D.S. Omaha is recognized by the IRS as a 501c3 organization

D.A.D.S. mission is to assist and support, through fellowship and action, the fathers and families of individuals with Down syndrome.

From: Leslie Hill
To: DHHS HCBS Public Comments
Subject: Concerning my child
Date: Friday, January 2, 2026 2:15:54 PM

> You don't often get email from [redacted]. Learn why this is important

I am here writing this email to let you know that taking this away from my child is leaving her in this world by herself she has autism severely. She is unable to speak. She is unable to perform any duties by herself and for you guys to decide what is best for her and not even know her is crucial to her well-being. I would really appreciate if you guys reconsider the proposal that you are proposing and give her a chance at a life. I am her mother. I will take care of her forever and ever but now it is forcing me to return back to work full-time and get a part-time job as well. I do not know why my child would be in this world without these benefits. I would really really appreciate if y'all take her into consideration and amongst other families like mine thank you.

From: Katie Novakoski
To: DHHS HCBS Public Comments
Subject: Concerns About Proposed Aged & Disabled (AD) Waiver Changes
Date: Thursday, January 1, 2026 3:13:50 PM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Dear Director Green and DHHS Leadership,

I write to submit formal comments and opposition regarding the Nebraska DHHS proposed changes to the Aged & Disabled (AD) Medicaid waiver, particularly the reduction of reimbursable caregiver hours and proposed service caps. While I understand the state's desire to pursue fiscal sustainability, I am deeply concerned that the proposed revisions contradict the goals and findings of the most recent Nebraska Medicaid Annual Report (December 2025) and risk undermining long-term care outcomes for vulnerable Nebraskans.

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1. Commitment to Community-Based Care Versus Restrictive Waiver Changes

According to DHHS's Medicaid Annual Report (Dec. 2025), the Division of Medicaid and Long-Term Care continues to emphasize home and community-based services as an alternative to institutional care and is actively working toward a "gradual rebalancing of long-term care expenditures" — meaning support for people to remain in their homes rather than in nursing facilities.

Yet, the proposed AD waiver changes would reduce reimbursable caregiver hours, limiting in-home support — including family caregiver compensation — and setting hard caps tied to institutional cost metrics rather than individual clinical need. This approach directly diminishes support intended to keep Nebraskans safely in their communities, which the annual report identifies as an ongoing and stated Medicaid priority.

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2. Person-Centered Planning and Actual Needs

The Annual Report emphasizes not only the continuation of community care but also person-centered planning, coordination, and support for individuals living in their homes. Service coordination is designed to help individuals identify and access the services they actually need to live independently.

Contrary to this, the proposed waiver changes would:
- Cap paid caregiver hours (e.g., reducing from 112 weekly hours to a core 40 hours for family caregivers; additional outside caregiver hours limited), and
- Tie maximum reimbursable costs to annual nursing home rates, requiring administrative exception reviews for significantly higher needs.

By imposing such arbitrary caps and bureaucratic thresholds, the proposed changes risk undermining true person-centered care — particularly for beneficiaries whose clinical needs exceed those caps. That runs counter to the function of service coordination outlined in the Annual Report.

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3. Long-Term Sustainability Should Include Quality of Care, Not Just Cost Containment

DHHS has framed the waiver amendments in part as necessary to preserve the waiver's sustainability over time. However, the Annual Report's framing of long-term care success is not limited to financial sustainability alone — it highlights Medicaid's role in enabling Nebraskans of all ages and abilities to live independently and with dignity in

their communities.

Quality and continuity of care are core Medicaid goals — goals that cannot be upheld by reduced support. Cutting caregiver hours and limiting flexibility will likely:
- Increase unmet care needs,
- Shift costs to emergency and institutional care settings,
- Degrade beneficiary outcomes, and
- Discourage the very home-based care the state's own report embraces.

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4. Aligning Policy With Reported Priorities

Given what the Medicaid Annual Report reveals about the state's ongoing commitment to home and community-based services and community living, I respectfully urge DHHS to reconsider or revise the proposed AD waiver changes to better align with the following principles:

1. Maintain adequate caregiver hours tied to individualized clinical needs rather than arbitrary formulas based on institutional cost averages.
2. Preserve the foundational principle of person-centered planning by ensuring waiver limits do not undercut care plans developed through comprehensive assessment.
3. Ensure any cost containment strategies protect access and quality for Nebraskans with the most intensive long-term support needs.
4. Include clear safeguards and appeal rights for beneficiaries who exceed proposed limits due to medically necessary care requirements.

Conclusion

The proposed AD waiver revisions, as currently drafted, stand in stark contrast to the Medicaid Annual Report's emphasis on supporting home and community-based care, person-centered planning, and continuous access to long-term services. I encourage DHHS to integrate the insights from the Annual Report directly into policy outcomes so that fiscal goals and care quality goals are not at odds.

Thank you for your attention to these concerns and for your service to Nebraskans.

Sincerely,
Katie Kuecker

From: Katie Rodenbaugh
To: DHHS HCBS Public Comments
Subject: CONCERNS REGARDING AD WAIVER CHANGES
Date: Monday, January 5, 2026 9:25:17 PM

You don't often get email from [redacted]. Learn why this is important

To whom it may concern,

My name is Katie. I am reaching out to you today in regards to a family member who is on the AD Waiver. With everything that has been discussed recently with families and DHHS changes, I have some concerns.

I have a brother-in-law who is severely disabled with cerebral palsy. He cannot walk, talk, feed, or bathe himself etc.. As much I would love to come take care of him when his parents cannot, I live 2 hours away. I have a full-time job; I have a child and family of my own which restricts me from being able to help take care of him when needed. I think it's unreasonable for the state to ask family members of these disabled children and adults to come take care of them when they do not have the capacity to do so. The care should be with the parents who know the child/adult the best and know their needs and who are right there with them every single day. Parents of these children/adults have lived this life with them day in and day out. They know their exact needs. They know what type of behaviors, movements, mannerisms their child/loved one has and what they mean and what to do about them. They know when they are having a seizure. They know when something isn't right.

I would like to also mention, I myself had an older brother that had cerebral palsy as well. He passed away at a care facility. Had he been able to stay with my parents and not go to a care facility, they could have taken care of him from our home; and he may still be alive today. Placing children or adults who have disabilities in a care facility or with others who do not know the magnitude of the knowledge that it takes to care for them, could lead to crisis situations. My brother was not cared for the way he should have been. He was sick for 3 days before anyone at that care facility even alerted my parents and/or took him to the hospital. By the time he got to the hospital, it was too late and he passed away of a bowel obstruction. It was absolute negligence on their part and again

if he had been with my parents who knew him and his needs and could recognize immediately what was wrong with him, he may still be alive today.

Please take the time to strongly consider what it means for families and the children/adults with disabilities to be taken care of the way they deserve.

Sincerely,

Katie

From: Eli Barry
To: DHHS HCBS Public Comments
Cc: Ashley Barry
Subject: Concerns
Date: Saturday, January 3, 2026 1:31:28 PM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

I am writing in concerns to the preposed changes to the assistance hours for the at home care providers. My wife provides care for our special needs daughter who is legally an adult. Elizabeth, our daughter, needs assistance with all every day tasks that we take for granted. She is in capable of getting out of bed, using the restroom on her own behalf. She cannot dress her self, make her own meals or even a simple drink. She is nonverbal so not only can she not do these things for her self she can not verbally express her wants, needs, concerns, or complications or desires. The list of tasks she needs assistance with continues on and on. I know the purposed bill is not cut and dry and does not meet the needs of everyone's best interest. That being said we would please like to know how to appeal this request or awareness of the documentation needed to provide. Elizabeth's quality and quantity of care far supersedes the 40 hours. Thank you for you attention to this extremely sensitive subject and look forward to hearing back from you on this matter.
Thanks in advance,
Eli K. Barry
Sent from my iPhone

From: Kara Covrig
To: DHHS HCBS Public Comments
Subject: Consider changes to this decision, more hours and do not effect these vulnerable lives
Date: Tuesday, December 23, 2025 12:51:29 PM

You don't often get email from [redacted] Learn why this is important

Please consider working with our elected officials to change this. This is beyond devastating for so many who will go from 128 hours a week for support/staff/nursing to 40 hours. And this is just ONE example from a family we know.

We personally are working through loosing all our nursing hours that we should have, we are fighting insurance to cover more than ONE diaper a day and waiting for an "assessment" of my sister Lisa's needs that will take place sometime next year.

These cuts will cost the lives of those who are so vulnerable, the family and those who care around the clock for individuals and more effects than we will ever know right now. Devastating.

So many people need 24/7 care and will not be able to receive that care if these cuts happen and we can all sign, email, call and contact our representatives..

We can do better. We NEED to do better.

From: [redacted]
To: DHHS HCBS Public Comments
Subject: Consider changes to this decision, more hours and do not effect these vulnerable lives
Date: Tuesday, December 23, 2025 12:51:27 PM
Attachments: [redacted]

You don't often get email from [redacted] Learn why this is important

Please consider working with our elected officials to change this. This is beyond devastating for so many who will go from 128 hours a week for support/staff/nursing to 40 hours. And this is just ONE example from a family we know.

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So many people need 24/7 care and will not be able to receive that care if these cuts happen and we can all sign, email, call and contact our representatives..

We can do better. We NEED to do better.

Kara Covrig

CLARK CREATIVE GROUP

From: Melissa Cook
To: DHHS HCBS Public Comments
Subject: Cook, Kaden
Date: Monday, January 5, 2026 5:04:39 PM

You don't often get email from [redacted]. Learn why this is important

Hello,

My name is Melissa Cook. I am Kaden Cook's Mom and Guardian. Life has been so difficult with all the personal changes throughout our lives. Now, when life keeps moving forward and improving mentally, physically, and medically; Kaden has not been in the hospital for Christmas in two years because of seizures, or a shunt malfunction. He is blossoming at 22 years old. He started communicating with me on his eye gazing Dynvox. He is improving more and more with family and friends. We finally have life going pretty good for us. He's going to start Hetra soon. Insurance doesn't cover this. We did the math and can afford Kaden to go twice a week. Our support and daily life will change drastically if our combined maximum 40 hours per week between Personal Care and LRI Personal Care changes. We are getting 90 hours per week now. Going down to 40 hours….we will not be able to keep our modified vehicle we still have 10,000 we owe. We rent an apartment in Greenwood Nebraska. Since we are in Cass County, we have not been able to find an agency to come and help us because two nurses need to be available for a client; for back up. When we did live in an area that we could receive outside help other than family and friends, when I worked 12 hour shifts as a med aide and cna…I had to switch my 8 hour days to 12 hour days so it would be worth the RN's time to come and replace me while I worked. I had a loveseat full of all different kinds of toys, activities, books for them to engage with Kaden while I was working. Nothing seemed to be touch very often. So I spoke with the Head Nurse that visited us every three months to see how everything was working out. Told her I wanted to set up a video camera. She thought that was a great idea. I was irate at what I was seeing!!!! I requested 6 of the RN's that was not welcome back in our home, and I had documentation to show and did. I have worked in the nursing field since 1999, the year I graduated. I can't fathom putting my son in an institution. Both of my boys were born with X-Link Recessive Congenital Hydrocephalus due to a pathogenic variant in the LICAM gene inherited by me.

1. X-linked recessive congential hydrocephalus (s/p VP shunt) due to a pathogenic variant in the LICAM gene inherited….
   This genetic change accounts for the findings in Kaden. A maternal half-brother, now deceased, and a maternal great-uncle were also affected.
2. Spastic quadriplegia
3. History of seizures
4. Profound intellectual disability
5. Non-verbal, although does utilize some signs for communication
6. Non-ambulatory, wheelchair dependent
7. Neuromuscular scoliosis
8. Ulcerative colitis

Genetic Counseling:
We again reviewed the X-linked inheritance pattern in X-linked hydrocephalus. His mother is a carrier, meaning that she has the L1CAM pathogenic variant on one of her X chromosomes, and a working copy of the L1CAM gene on the oth Female carriers for X-linked hvdrocenhalus

My boy is total dependent and has to have supervision at all times. He thrives off of all the activities and places we do and go!!

Please don't ruin our lives. It's been so hard, don't make it harder again. We have our vehicle that needs to be payed off before July of this year or we will loose it. We live paycheck to paycheck. The more money I make the more my health insurance is. So I purposely didn't want to increase my wages from $15.00 an hour because of that. I went to Southeast Community College years ago and couldn't get days care because they didn't have a full time nurse available.

Melissa

From: Teresa Lombard
To: DHHS HCBS Public Comments
Subject: Cuts to caregiver hours for family caretakers of medically needy Nebraskans
Date: Wednesday, December 31, 2025 8:22:00 AM

> You don't often get email from [redacted] Learn why this is important

Please do not make cuts to caregiver hours as proposed. There are many reasons why this change would be harmful to individuals and families in Nebraska. In particular, round the clock care would become more expensive when an individual can no longer be cared for in their home, and is instead institutionalized. This would be a greater monetary cost to Nebraskans, while also greatly increasing the likelihood that the individual's health would decline.

The State of Nebraska has a responsibility to her citizens, and this proposed reduction in caregiver hours is irresponsible.

Teresa Lombard

From: gladys popham
To: DHHS HCBS Public Comments
Subject: Cuts to caregivers hours
Date: Tuesday, December 23, 2025 9:36:10 PM

You don't often get email from [redacted]. Learn why this is important

My daughter is 31years old. She's total care. She is considered skill care. She is fed by a G button in her tummy. She needs her meds every three hours around the clock. She requires a wheel chair. She is blind, has cerebral palsy, seizures, is diabetic . She is unable to position herself. Needs to be turned every two hours. Is completely dependent on Mom and Dad for all her cares. Is unable to verbalize or communicate. This cut to only 40 hours would be devastating. A lot of our money goes towards expenses for our daughter's needs. One example is gas for our 100 mile trip to Omaha for her physicians visits

From: gladys popham
To: DHHS HCBS Public Comments
Subject: Cuts to caregivers
Date: Tuesday, December 23, 2025 11:50:59 PM

You don't often get email from [redacted]. Learn why this is important

Our daughter is 31years old. She was born premature. She functions at a new born level. She is total care. She is fed thru a G button and requires meds every three hours around the clock. She has cerebral palsy, is blind, has a shunt, is a severe diabetic, has seizures. She is unable to position herself. Needs turned every two hours. Unable to ambulatate or communicate. She dependents on Mom and Dad for all her cares. These cuts would be devastating. We as her parents use our money to cover expenses for our daughter. One example, is gas money for our van, for our daughter 's 100 mile trips to Omaha for all her physicians visits. She gets excellent care by a family that adores her.

From: Rachel Uhrenholdt
To: DHHS HCBS Public Comments
Subject: Cuts to Family Caregiver Hours
Date: Thursday, December 25, 2025 8:09:00 PM

> You don't often get email from [redacted]. Learn why this is important

The recent proposal to cut family caregiver hours from 112 per week to 40 hours per week is short-sighted at best, and will lead to the death of many medically complex individuals at worst. There are not enough outside care providers available to staff these individuals, especially in rural areas of the state. I was a primary caregiver for my disabled uncle for a couple years prior to his death in 2023. We did have some outside care, but many times the companies we worked with were unable to provide staff for the hours he needed, in which case I had to step in. Weeks would go by without adequate outside staff to cover the hours. We even ended up with staff that brought bedbugs into my uncle's home. For some families, outside care is not possible. Not to mention, the wage given to family caregivers is minimum wage or just slightly above. Often, the family caregivers are forced to quit better paying jobs to take care of their disabled family member. The wage provided by the state, at 40 hours per week, is not enough for them to live on, nor does it reflect the care level they are providing.

Rachel Uhrenholdt
[redacted]

Sent from my Verizon, Samsung Galaxy smartphone
Get Outlook for Android

From: Courtney Gentle
To: DHHS HCBS Public Comments
Subject: Cuts to Medicaid waiver in Home services
Date: Wednesday, December 17, 2025 9:49:02 AM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

To whom it may concern:

I am writing to strongly encourage you to rethink cuts to Medicaid Waiver in home services.

My understanding is that DHHS is proposing to cut benefits to Medicaid Waiver recipients receiving in home care services. These cuts could be as drastic as going from 112+ hours a week to 40 hours a week. This is not acceptable. If a family is utilizing these hours to go to work, how would you propose they get their family member to the location of care, get to work and work 40 hours a week and get back to pick up said family member in the time allotted? Let alone get a hair cut or go to the doctor. If the family is providing care themselves for income? How would you suggest they live on 40 hours at 10-12$/hour?
There have been planned town halls to discuss this and propose "alternative care" options to families. These alternative options will include family care, volunteer care, and facility care. These alternatives are truly insulting. If capable, most parents want their children or parents/grandparents at home. Their Children or parents/grandparents also want to be at home. Institutionalization increases mental health issues, bed sores, infections, hospitalizations….i could go on. In addition, Nebraska care facilities already have waiting lists for Medicaid admissions because Medicaid beds are limited due to poor reimbursement. Family care is already happening with every call in causing a change of plans, a call in to work, a lack of sleep. Some of us already have rearranged our lives to be the paid care provider due to lack of staff availability at the cost of a better paycheck elsewhere. And please God tell me who these volunteers are? In the 24 years that I have lived in this state, I have been unsuccessful in locating them.
Medicaid waiver programs include the Developmental Disabilities Waiver, the Family Support Waiver, and the Aged and Disabled Waiver. Take a peek at who those waivers serve and you will see that these are exactly the people that Medicaid was intended to serve. Disabled children and adults and the elderly are the only people who qualify for these programs. These programs are intended to keep our most vulnerable safe and in a "least restrictive environment". Which is often their own home. These waivers provide services to disabled Nebraskan residents who are citizens of the United States of America. These waivers keep disabled children and adults in their homes with people who love them. These waivers assist clients with personal hygiene, medication administration, nutrition (to include feeding orally and tube feedings), teach care, catheter care, incontinence care. On top of all of that they help recipients participate in their communities by providing supported outings. They also prevent caregiver burnout by providing families time away from caring for their loved one.
Services provided by these programs are the quintessential spirit of the Medicaid program. Our Nebraska Leaders promised Medicaid cuts would only be for fraud, waste, and abuse. That is certainly not the case with these proposed cuts.
These proposed cuts will not only affect recipients, they will also affect the income of health care workers and parents/children/guardians of recipients as well as Nebraska owned businesses negatively. These businesses have already taken blow after blow from policies that create barriers to timely payment for care. No one working with Nebraska Medicaid waiver programs is doing it to get rich. The companies are poorly reimbursed, which in turn means the employees providing care are poorly paid. They do it because they care.

I know that there is a budget issue but there has to be a better way than taking care from our most vulnerable.

I personally am a special needs mom, a hospice nurse, a mental health nurse, and a Medicaid waiver provider.

My daughter is a special needs adult child of a military veteran who receives Medicaid waiver in home services. I'm not sure what we would do without the help we are getting. Between other jobs, caring for our other daughter, caring for our special needs daughter, doctors appointments and so on, it's already difficult to ever get a day off. Trying to make up for both the time and income that will be decreased by these cuts will make it pretty much

From: Monica Kittrell
To: DHHS HCBS Public Comments
Subject: Cutting back the hours
Date: Tuesday, December 23, 2025 5:22:03 PM

> You don't often get email from [redacted]. Learn why this is important

Hello my name is Monica Kittrell. My fiance is a newly Quadriplegic on April 22 2025. I am is sole caregiver as we are in an area that does not have any home health care agency in our area to help relieve me when I need to time off to go get food, Dr appointments for our 2 children 15 (with bipolar issue on medication), and 5 yr (level 1 Autism). I am everyone sole caregiver at this time. If the hours where to be cut back to 40 hours as the proposal states it would take away from the care he needs which right now is 24/7 care. He has several medical issues associated with being a Quadriplegic. He also has a tracheostomy that needs some one to be here for him so they can suction his secretions or he will choke to death. We have asked for help from a few places and because of the amount of care he needs they can not even begin to allow there aid to do. Please dont cut the hours for family members that take cares of their loved ones. We do not have enough care facility to take care of family. It cost much more for care facility than it does for family member to be paid for. It costs roughly 6k to 8k in a nursing home. With many residents, some of the residents not being very well taken care of.

December 8, 2025

Mr. Colin Large, Policy Administrator
Nebraska Department of Health and Human Services
via – e-mail to Colin.Large@nebraska.gov

RE: Proposed changes to HCBS (AD) Waiver (NE.0187)

Good Morning Mr. Large:

I tried calling but discovered you were in meetings today until noon. I decided to just summarize my comments and concerns regarding the above captioned topic so that you may have an opportunity to consider them.

You may recall that we conversed in September 2024 concerning the proposed issuance of Directive 24-05. Following consideration of my concerns that such a directive would have a negative impact upon individuals living near the Nebraska border with other states, you e-mailed me on September 27, 2024 to let me know that DHHS would be withdrawing that directive before its implementation date. I appreciated your rapid response and quick decision.

I recently received notification from Stacey Boss that the proposed changes to the AD Waiver program to be implemented next July will be addressed in four ZOOM meetings beginning later this week. I took time to download the 238 page document that contains those proposed changes. As I reviewed the document I developed several questions and concerns. While I spent time with those portions that covered the AD Waiver, I will state up front that I did not complete an exhaustive review of the document. It may very well be possible that my questions and concerns were answered somewhere else in the document. As the policy administrator, I decided to just ask you for your opinion instead of going through the entire document line by line.

While I intend to be in attendance in at least one of these meetings, I thought I would share my questions and concerns with you in advance to give you an opportunity to consider and if possible respond either by telephone or e-mail or if not by clarifying my questions during the ZOOM meetings. That way, my questions won't detract from the overall presentation you have planned.

The topics I have questions about are as follows. (The page reference is where they appeared on the PDF copy I downloaded):

- Institutional Costs (page 25). The document states that the State may refuse admission to the program if the costs for the individual are at a *level higher than 175% of the institutional average.*

Can you tell me what the current "institutional average" is? With that knowledge I will be able to reduce the number of hours of paid caregivers if that becomes necessary so that my ward can remain in her current home. While I have not worried about that for a number of years, this item caused me to recall when my Ward was first placed in the program, the Service Coordinator told us that while she was authorized for a specified number of hours per week, we were advised to underbill by several hours as that differential could be picked up by the Service Coordinator's agency and used to offset their office expenses. He further indicated that while they couldn't require we underbill, failure to do so could cause the Ward to be rejected from the program at a later date and institutionalized. I have consistently underbilled the entire time the Ward has been in the program and I would like to make certain that I stay under the 175 percent of institutional average by a reasonable amount.

- Legal Guardian vs. Legally Responsible Individual (LRI) (pages 53 and 109). My understanding of the difference between a Legal Guardian and a LRI is that a Legal Guardian is required to be appointed such by the Court whereas a LRI is the parent who is legally empowered to act on behalf of a minor child. In fact, page 109 states, "A Legally Responsible Individual (LRI) is defined as the natural or adoptive parents of a minor child or spouse of the waiver participant." My concern is the language on page 53 which states, "Personal Care services may be provided by a relative or legal guardian, but not by a legally responsible individual."

  In my case, the "Ward" is my 35 year old daughter who has multiple disabilities that require her to have 24/7 care. I was declared her co-guardian when she was initially adjudicated to be a protected individual in 2008 and was subsequently declared her sole guardian upon the death of the other co-guardian (her mother) in 2017. It is my assertion that I may qualify for payment for Personal Care under the AD Waiver program since the Ward is over the age of 18 and I have been appointed as her Guardian by the Court. Do you concur that the definition of Legal Guardian applies and that I should NOT be considered the LRI in this case?

- Relative Legal Guardian – page 111. This page defines a "Relative legal Guardian" as a, "court appointed legal guardian of a participant who is also the spouse, adult child, parent, or other relative of the participant." Based upon the above discussion, I believe I qualify as this individual. The end of the first paragraph of page 111 states, "Payment may only be made to relatives who are not legally responsible for the participant." I am confused by this statement as it seems to indicate that a Guardian who by definition of Guardian, is responsible for the participant is thus ineligible to provide paid services for the participant.

  The remainder of this page provides more clarification as to when and how Relative Legal Guardians may be paid for services provided which again seems inconsistent with the earlier statement that, "Payment may only be made to relatives who are not legally responsible for the participant." Can you indicate whether the proposed changes to be enacted next July will affect me as the Relative Legal Guardian for a 35 year old Ward to receive payment for

Personal Care service provided to the Ward. Specifically, will the proposed changes make me ineligible to receive payment for Personal Care services after the changes go into effect?

- No Restraints – page 171. This pages states, "The State does not permit the use of restraints by any provider of any waiver service." The section continues and later states, "In addition, the use of mechanical restraints is not allowed."

  In my case the Ward is transported in a handicapped lift van while she is in her wheelchair. The lap belt of the wheelchair and the chest strap are attached to keep her in the chair. The wheels are locked and the frame of the chair is attached to tie downs on the floor. A shoulder strap crosses over her body. All of these restraints are provided to ensure her safety while being transported. The above language appears to prohibit that.

  In order to make certain I was on solid footing, I inquired of the local law enforcement agency and was informed that anyone in a motor vehicle is expected to comply with the appropriate statutes involving the use of seatbelts and other restraints.

  While I certainly understand and support that disabled individuals are not to be unduly restrained, I believe that while being transported, these individuals should be afforded the same protections required for others. Can you tell me if an exception to the 'no restraints' is or can be included to allow individuals in wheelchairs to be secured while being transported?

Thank you in advance for taking the time to look through this letter. I will be available after 1:00 this afternoon if you care to call me (402) 480-2705. Or – if you prefer to e-mail that would also be fine.

Sincerely,

Dale Rawson
[redacted]

From: Teresa Spurgeon
To: DHHS HCBS Public Comments
Subject: Decrease caregiver hours
Date: Sunday, January 4, 2026 10:01:24 PM

You don't often get email from [redacted] Learn why this is important

To Whom It May Concern:

I am writing with my concerns on the cuts that are proposed for the number of hours allowed for caregivers in the state of Nebraska. There are many families in our state that depend on the income from the hours as caregiver to be able to make ends meet and provide the needed care for their loved ones. With the proposed cut in hours these caregivers will have to find work outside of the house in order to provide adequate housing and food for their families. The wages that they are able to obtain outside of the house will not offset the cost that they will have to pay for the needed supervision and care for their loved ones that they were able to provide previously. Forcing these families into this situation will not only cause undue stress to both the individuals that are providing the care but also to the family members that are being cared for.

Many families are trying to care for their family members without relying on help outside of the family and keep their family members out of care facilities. By reducing the amount of hours that they will be compensated for is increasing the odds that they will have to enroll their loved ones into such facilities or utilizing such programs as ‘Home Instead’. This will increase the financial burden double or even triple on these families as they will now have to find additional funds in order to pay for this care. I have personally seen the care that is provided at these facilities and with the amount of patients within the facility, your loved ones don’t always get the attention and care that is needed. With having your loved ones at home, you can always make sure that their needs are met in a timely fashion.

My opinion, which I am sure is shared by many, is that care within the home by a loved one is the best path for these individuals. With the decrease in the number of hours that these caregivers are allowed you are taking that option away from many families.

Sincerely,

Teresa Spurgeon

From: Darin Spurgeon
To: DHHS HCBS Public Comments
Subject: Decreased caregiver hours in the State of Nebraska
Date: Sunday, January 4, 2026 9:24:34 PM

You don't often get email from [redacted] Learn why this is important

Darin Spurgeon
[redacted]
[redacted]

To Whom It May Concern:

I am writing with my concerns on the cuts that are proposed for the number of hours allowed for caregivers in the state of Nebraska. There are many families in our state that depend on the income from the hours as caregiver to be able to make ends meet and provide the needed care for their loved ones. With the proposed cut in hours these caregivers will have to find work outside of the house in order to provide adequate housing and food for their families. The wages that they are able to obtain outside of the house will not offset the cost that they will have to pay for the needed supervision and care for their loved ones that they were able to provide previously. Forcing these families into this situation will not only cause undue stress to both the individuals that are providing the care but also to the family members that are being cared for.

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My opinion, which I am sure is shared by many, is that care within the home by a loved one is the best path for these individuals. With the decrease in the number of hours that these caregivers are allowed you are taking that option away from many families.

Sincerely,

From: [redacted]
To: DHHS HCBS Public Comments
Subject: Desperately urging you to change
Date: Tuesday, December 23, 2025 12:45:00 PM

> You don't often get email from [redacted]. Learn why this is important

This is beyond devastating for so many who will go from 128 hours a week for support/staff/nursing to 40 hours. And this is just ONE example.

These cuts will cost the lives of those who are so vulnerable, the family and those who care around the clock for individuals and more affects than we will ever know right now. Devastating.

You can do better, those in Nebraska deserve better. You can be the change.

Kara Covrig

From: Jarod & Emily Heady
To: DHHS HCBS Public Comments
Subject: DHHS – Division of Developmental Disabilities. 42 C.F.R. §441.304(f)
Date: Monday, January 5, 2026 6:11:56 PM

You don't often get email from [redacted]. Learn why this is important

As parents of a special needs adult we are shocked and saddened by the proposal to severely cut the hours of caregivers pursuant to 42 C.F.R. §441.304(f).

If this were to go into effect, we literally have no idea what we would do. Our 20yr old son requires around the clock supervision and care. Our family and many others like ours do not have the resources to provide this care outside of the AD Waiver.

We would ask whoever it is that is proposing this legislation that they first walk a mile in the shoes of those whom these cuts will affect. I think it's easy for lawmakers and department secretarys to just look at numbers and not look at the people behind those numbers.

Maybe if they actually talked to some of these families that are doing there best, trying to cover their bills and keep food on the table, in addition to the extra stress and costs that come with taking care of a special needs child or adult. Then these decision makers would see the terrible and drastic ramifications that would result from this careless legislation.

Up to this point our family has been in favor of most of this administrations policies and we believe that the president and his cabinet generally want to help and do what's right for the American people. However, I can unequivocally say that it is a grave mistake to strip away funding and benefits from the most needy and vulnerable in our society.

If this administration is looking to cut costs they should start by targeting those in MN and CA that have defrauded the system for Billions of dollars and seek reparations there. Not by cutting the benefits of honest, hard working, tax paying families.

December 29, 2025

Thank you for the opportunity to provide public comment.

My Name is Heather Rask. I am the mother and legal guardian of an adult son, Tristan Urwin with special needs who has Angelman Syndrome and is on the Autistic Scale as he is non-verbal. Angelman Syndrome is a rare neurogenetic disorder characterized by severe developmental delays, intellectual disability, lack of functional speech, seizures, sleep disturbances, and significant challenges with motor coordination and balance. As a result of his condition, my son requires continuous, 24-hour supervision and hands-on assistance with all basic activities of daily living, including eating, toileting, bathing, dressing, mobility, and safety monitoring. He is unable to live independently in any way.

Tristan currently receives essential services through the AD waiver program. These services are not a luxury; they are what allow him to remain safely in his home and to have any meaningful quality of life. I am deeply concerned about the proposed revisions to this program which, as currently described, would impose a cap of 70 hours per week on in-home care. Furthermore, live-in legal guardian caregivers—like myself—would be limited to 40 of those hours, with the remaining 30 hours required to be provided by an unrelated caregiver. These proposed constraints do not accurately reflect the intensity, complexity, and continuity of care that my son requires.

While I recognize and respect the state's intent to align total in-home care hours with the cost of nursing facility placement, this framework fails to account for families such as mine, for whom the home environment is the only appropriate and humane setting. For my son, a nursing facility is not simply "another option"; it is not an option at all if we care about his emotional well-being, his ability to connect with those who know him best, and his ability to live with dignity. He can truly thrive only at home. He experiences his highest quality of life here, supported by someone who knows him intimately, understands his non-verbal communication, and can anticipate his needs and triggers before they become crises.

I cannot discern any sound rationale for mandating that the authorized hours be divided between a family caregiver and an unrelated provider, particularly when this requirement does not appear to yield any financial savings for the state. The cost to the state remains the same whether the hours are provided by me or by an outside caregiver. The only "difference" is that the proposal forces families to bring in additional individuals—even when this is clinically unwise, logistically unworkable, or emotionally harmful. Policy should be driven by what is best for the person receiving care, not by arbitrary limits that separate care into "family" and "non-family" buckets without any demonstrated benefit.

Any policy changes in this area should carefully consider the individual's quality of life and the critical importance of stable, continuous, family-based care. For individuals like my son, change in caregivers is not a small inconvenience; it can be frightening, confusing, and destabilizing. He does not have the ability to explain if he is afraid, if he has been mistreated, or if he feels unsafe. The continuity, familiarity, and trust that exist between him and me as his mother and caregiver are core components of his care, not optional extras.

Our family has previously undergone the difficult process of attempting to secure an appropriate caregiver in Western Nebraska. It has been extraordinarily challenging to identify individuals who are both capable of meeting my son's complex needs and reliably trustworthy. The pool of potential caregivers in our region is very small. Many individuals are not trained, not comfortable with the level of care required, or simply not reliable enough to be entrusted with the life of a vulnerable adult who cannot speak for himself. Turnover is high, burnout is common, and the reality on the ground does not match the assumption that there are plenty of qualified unrelated caregivers available.

In 2018, I assumed the role of my son's full-time caregiver after we discovered that the caregiver we had employed was physically abusing him by hitting him with a hanger. That individual was subsequently criminally charged. This traumatic experience has had a profound and lasting impact on our family. It is impossible to fully describe what it feels like to learn that the person you hired and trusted to care for your vulnerable child has instead harmed him. As a result, I am resolute that my son will never again be placed in a situation where he may be abused or neglected. I have very limited trust in outside caregivers, and for good reason. When you combine this history with the documented shortage of qualified providers in Western Nebraska, it becomes clear that requiring us to bring in additional unrelated caregivers is not simply a policy detail—it is a direct threat to my son's safety and stability.

My son would not fare well in a nursing facility. He would lose the familiarity of his home, his routines, his community, and the constant presence of family. His current, comfortable quality of life is possible only because he remains in his own home, where I can respond quickly to his needs, monitor his health, and provide the emotional security and loving environment that he requires. Removing or restricting my ability to provide this level of care does not simply "shift" responsibility; it would diminish his quality of life and increase his risk of harm.

It is also deeply troubling that, while these reductions are being proposed, families are being informed in Zoom sessions that it is their responsibility to care for, or to find care for, their disabled loved ones. On the one hand, we are told that we are responsible; on the

other hand, we are being told that the state will only compensate a small fraction of the actual care that is required. For someone in my position—as the legal guardian and full-time caregiver for my son—the proposed reduction to 40 hours per week is simply untenable.

To put this into perspective: 40 per week equates to less than 2 full days of paid care each week, approximately 8 days per month, and less than 1 month of paid support over an entire year. In practical terms, this means that I would be expected to provide the equivalent of eleven months of full-time care every year with no compensation whatsoever, while still somehow maintaining a household, covering basic living expenses, support my son and his needs financially, and attending to my own health. This is not sustainable, and it is not feasible.

Many caregivers, myself included, have already made substantial sacrifices, including career advancement, and financial security in order to fulfill these caregiving responsibilities. We did so because the system recognized that the care we provide is essential and because programs like the AD waiver made it possible for us to continue caring for our loved ones at home. We rely on this income not only to pay for housing, food, utilities, and transportation, but also to provide our disabled family members with access to appropriate medical care, therapies, adaptive equipment, and meaningful activities. Removing or drastically reducing this support threatens both the caregivers' stability and the well-being of the individuals they care for.

I believe these proposals unfairly target and disadvantage family and legal-guardian caregivers. By reducing my authorized hours simply because I am a live-in legal guardian, the system is effectively penalizing me for choosing to keep my son at home rather than placing him in an institutional setting. It sends the message that the care of a mother and legal guardian is worth less than the care of a stranger, despite the fact that the cost to the state is the same. This is, in effect, a form of discrimination against family caregivers.

If implemented, given our previous experience with abuse by a paid caregiver, this is not an abstract fear; it is a reality we have already lived through. No one can safeguard him to the same extent, or provide the same level of individualized care and quality of life, as his own mother and family. These changes would likely force me to seek full-time employment outside the home just to survive financially, and to entrust my adult son to another caregiver, thereby exposing him to risks that I have devoted myself to preventing.

For these reasons, I respectfully and strongly urge you to:

1. **Reconsider and withdraw the proposed limitation that caps live-in legal guardian caregivers at 40 hours per week.**

2. **Allow families the flexibility to use the full 70 or more authorized hours or more with a family caregiver and the legal guardian, if that is what best meets the individual's needs**, rather than forcing the use of unrelated providers when they are not available, not appropriate, or not trusted.
3. **Engage directly with families and caregivers**—especially those in rural areas like Western Nebraska—to understand the real availability of qualified caregivers and the real impact these changes would have.
4. **Prioritize policies that keep individuals with significant disabilities safely in their homes and communities**, supported by the caregivers who know them best, rather than pushing them toward institutional settings or forcing families into impossible financial and caregiving situations.

My son, and many others like him, cannot advocate for themselves. They depend on us as parents, guardians, and caregivers to speak for them. I hope you will hear this comment not as a complaint, but as a plea to craft policy that is humane, realistic, and truly centered on the needs and rights of the individuals you serve.

Thank you very much for your time, your attention, and your consideration of my comments.

Sincerely,

Mother and Legal Guardian of Tristan Urwin

Heather Rask

[redacted]

Nebraska Department of Health and Human Services (DHHS),

I am writing today as an implication of the 30-day public comment period for amendments to the AD - Aged and Disabled Waiver. The changes that are being proposed on the waiver would potentially put many families in strenuous situations and create unsafe environments for participants of the AD waiver.

As a sibling of a special needs individual who is currently on the AD waiver- the proposed changes not only to hours, implied institutionalization and lack of calculated care plans if respective amendments are made could be detrimental to families. After sitting through a majority of public comment sessions and reading the proposed changes there is an underlying assumption for families to or parties responsible to rely on other family members or friends with a reduction of hours. Living and understanding how it is to care for a special needs individual that is not a choice or reliable option for many.

My family only has one other qualified individual that can care for my sister for extended periods of time. Which is me, but I am a full-time student and have a full time job where I cannot provide ample support time or resources to my family anymore. Many other families are in the same boat with not having assistance and my family will be one of them. Aside from myself my 72 year old grandmother has been the only other help moderately, which is not feasible, she no longer can pick-up my sister or provide the same attentiveness needed. Other members of the family do not want the responsibility if something were to happen and that leaves just my parents. Relying on a family for care is not the solution, neighbors, friends, family ‘others’ within the community do not truly understand what it is like to take care of a special needs individual. It makes them uncomfortable and responsible- things the state will also be with these drastic changes. Everything is on a clock, including the proposed changes to the AD waiver. Something that does not have a solidified plan for individuals across the state.

Throughout the amended/proposed changes there are many grey areas to exceptions,evaluations and solutions for care of individuals who are medically fragile. These changes should be more clear as just assuming family and other assistance can be provided is not the answer. I hope during the reevaluation period of these waiver amendments there is a humanistic approach to the proposed changes. The DD waiver in early 2025 made beneficial changes to the developmentally disabled yet not even 12 months later you are stripping needed care for more challenging disabled individuals. Rework the care, economic and workforce push in the state before cutting the only hours and resources thousands are relying on. Understand the families and dynamics of those on the AD waiver. There was a lack of process to these changes and it shows a lack of awareness and preparation. I urge better evaluation of disabled individuals to happen before amendments are made to potentially create hazardous situations for many.

Kindly, Aidia

From: Sarah Lounsbury
To: DHHS HCBS Public Comments
Subject: DHHS CAREGIVER CHANGES
Date: Friday, January 2, 2026 2:07:35 PM

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To whom it may concern:
On December 5th DHHS released proposed changes to the AD waiver. Part of these changes was to LIMIT live in care giver hours to 40 hours per week. For some of these live-in providers and their clients, this change would be very detrimental. Some of the MOST disabled folks in our state receive the maximum amount of 112 hours per week for their paid care (payment for 16 hours per day of care). Of that group, live-in caregivers provide the majority of those hours. Many of these live-in caregivers are parents or spouses of these disabled people, and many of them have left careers to take care of their loved ones. Some have been caring for their loved ones for 30 years or more. To suddenly cut their hours and income by 72 hours per week is DANGEROUS and very destabilizing for these disabled clients. This could lead to the loss of homes, mental health crises, hospital stays, and possibly death for some of the most medically needy clients.

Families affected by these changes will face severe financial issues. A loss of 72 hours per week at $15.00/hour is a cut of $4320 per month for these households. How will they be able to find jobs that pay that much, as people who have been out of the work force for so long? These families must also balance doctor appointments, hospital stays and the stress of caring for their loved ones, which would make working outside of the home very difficult for them at times. This plan assumes that suddenly, after YEARS of searching, hiring, training and losing paid care givers, that they can find someone to do their jobs. This is further complicated by the fact that these paid caregivers aren't able to administer medications or provide the medical decision-making necessary to ensure proper care for clients at all times, which means our most disabled will be in danger.

This plan will NOT work for the most medically fragile and high needs disabled adults on this waiver. If you are to go forward with limiting live-in care givers to 40 hours per week, you will be forcing people to sell their homes and put their loved ones into nursing home facilities. The waiver program was created in order to stop this exact situation from happening. Also, moving disabled clients into nursing homes will be further complicated by a current shortage of Medicaid funded beds available.

Instead, we propose that since this waiver has enough funds to make it through this year, that you spend this year meeting with the families of these individuals and create a plan that will actually work. I believe there are solutions available in this situation! The current system that's in place was created for individualized care, and there are already evaluations that were created to determine services and hours. If you want to create caps, please do it moving forward--not retroactively and NOT so suddenly and NOT so drastically. Consider contracting with each family individually (perhaps less agency contracting and more live-in caregiver contracting?), consider a tiered system like DD services use to determine pay rates.

Also please consider seeking out the funds you need:
a. Find an agency or non-profit, or create one, and begin to hold an annual fundraiser that gives average Nebraskans and wealthy Nebraskans a chance to care for the disabled of our state.
b. Perhaps the Huskers could run a fundraiser at one home game a year where they advertise the needs of those who are disabled in our state and give a matching percentage of ticket sales that day.
c. Would the Volleyball team and their fans want to help protect the disabled of our state?
d. Ask the Nebraska legislature to allocate more money for this program, due to the rising number of individuals in this program. I believe this sort of thing happens (for example, asking for raises for state employees, you look at the cost of living and then approve a 3-6% raise for your employees). A request for additional funding seems appropriate in this situation.
i. Or perhaps it would be a GREAT time for the legislators to PAUSE or freeze the corporate tax cuts that are creating some of these budget shortfalls?
e. Would Larry the cable guy be willing to help in some way as a Nebraskan with a HUGE platform? Would

Warren Buffett want to help? We could ask some of the wealthiest Nebraskans to step up for those who are disabled in our state.

Please consider solutions that are PEOPLE focused, individualized and caring, not just focused on the dollar signs. Thoughtful policy making will ensure that those who are disabled, as well as their families, can continue receiving the care they need and avoid damaging and life-altering circumstances. This waiver program has blessed a whole lot of Nebraskans and allowed them to flourish. It has helped provide dignity and care for so many people! Please consider that as you move forward and make necessary changes.

Signed:
Sarah Lounsbury
[redacted]

Sent from my iPhone

From: Brenda Johnson
To: DHHS HCBS Public Comments
Subject: DHHS changes to the AD waiver.
Date: Thursday, January 1, 2026 2:00:07 PM

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Sent from my iPhone

To whom it may concern:

On December 5th DHHS released proposed changes to the AD waiver. Part of these changes was to LIMIT live in care giver hours to 40 hours per week. For some of these live-in providers and their clients, this change would be very detrimental. Some of the MOST disabled folks in our state receive the maximum amount of 112 hours per week for their paid care (payment for 16 hours per day of care). Of that group, live-in caregivers provide the majority of those hours. Many of these live-in caregivers are parents or spouses of these disabled people, and many of them have left careers to take care of their loved ones. Some have been caring for their loved ones for 30 years or more. To suddenly cut their hours and income by 72 hours per week is DANGEROUS and very destabilizing for these disabled clients. This could lead to the loss of homes, mental health crises, hospital stays, and possibly death for some of the most medically needy clients.

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Also please consider seeking out the funds you need:

a. Find an agency or non-profit, or create one, and begin to hold an annual fundraiser that gives average Nebraskans and wealthy Nebraskans a chance to care for the disabled of our state.

b. Perhaps the Huskers could run a fundraiser at one home game a year where they advertise the needs of those who are disabled in our state and give a matching percentage of ticket sales that day.

c. Would the Volleyball team and their fans want to help protect the disabled of our state?

d. Ask the Nebraska legislature to allocate more money for this program, due to the rising number of individuals in this program. I believe this sort of thing happens (for example, asking for raises for state employees, you look at the cost of living and then approve a 3-6% raise for your employee). A request for additional funding seems appropriate.

Thank you in advance for reconsidering and looking at different options.

Brenda Johnson

From: Cori Watkins
To: DHHS HCBS Public Comments
Subject: DHHS CUTS TO FUNDING
Date: Monday, December 29, 2025 5:06:42 PM

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> To whom it may concern : Here in Nebraska they have proposed deep cuts to all services for disabled people , in home , caregivers , reducing hours and pay for all involved , also breaking the law while at it , drastic funding cuts and staff cuts when we are already managing on a skeleton crew everywhere in this state with Caregivers , at all skill levels and after our DHHS dept here in Lincoln Nebraska lost somewhere between 30-40 million according to our state auditor , with inflation , prices going up , we need more help not less and this is putting the disabled population at great risk , danger and harm , Our Governors proposal to put these people in nursing homes , takes them away from their families , support systems , Consistency the list goes on ,plus the cost of a nursing home is outrageous , our nursing homes cannot absorb this , I am a special needs Mom of a severely disabled daughter who is 28 now and I'm a nurse of 36 and we already have dangerously understaffed skilled care homes , I know I've worked at them , almost all
> Of them in and around lincoln as an agency nurse , this is a very serious matter and it's quite clear our leadership or lack thereof is targeting the most vulnerable of our community , this is intolerable and unacceptable to discriminate against them this way by making them suffer , families suffer , letters , complaints emails and calls have been not been enough for the powers that be to change course , we the parents of special needs children whether they be adults or still minors need help , this is not an acceptable solution to just lock them away , far from society , it's evil and inhumane , the test of how healthy a Society is , is how well we treat our elderly and disabled populations , and this is a disgrace , ask them where the money is , ask them why we need to cut services from the disabled ? Because they can't fight back , but we the parents will not stop fighting this , there is no way this is going to work anyway , this is ludicrous to think this is even feasible , especially when the lawsuits start flying against this state and I can assure you they will if this inhumane nonsense continues , I hope that you can be of some kind of assistance in this situation , we are reaching out to everyone and anyone who might be able to help , Thank you for your time and attention to this very important matter , I can provide more details if needed , Cori L Watkins [redacted]

Email: DHHS.HCBSPublicComments@nebraska.gov

Fax: (402) 471-8792.

Mail: DHHS – Division of Developmental Disabilities, 301 Centennial Mall South, P.O. Box 95026, Lincoln, NE 68509-5026.

DHHS HCBS Public Comments,

My name is Lisa Goodman and I am the in-home caregiver for my 26-year-old daughter, who is on the A and D waiver. She has autism and I have been a home caregiver to her for 3 years. I quit my job at a law firm to stay home with her. As her safety was violated.

We attempted to have independent providers come to our house and this became a huge issue. Most days we had 4 caregivers splitting an 8-hour shift. She couldn't deal with that many people who she didn't know coming in and out of our home. It got totally out of hand having strangers coming in and out of our home. The turnover is high and this is not a safe environment for anyone.

We also toured day services and we did not feel this was an appropriate fix. There were kids unattended while employees were on their phones. Not the environment we want our daughter in.

She was in a group environment and was molested by another special needs person (as have many of our special needs adult women friends) nothing was ever done as the person who did this was special needs as well. She does not have the ability to tell people not to touch her as this became a huge safety issue, I had to quit my job and stay home to keep her safe. I will not put her in harms way again. You need to consider this as it does happen more than you know. Background checks give a false sense of security as it only shows up if one has been caught and charged.

Her care does not stop at 8 hours a day. She needs supervision at all times; due to her disability and the way her mind functions. The hours that we get to take care of her help us give her as good of a life that any person deserves. We do our best to make sure she gets to experience as much of life that any person would get to who did not have her condition. Sitting in a nursing home, or having someone come take care of her in home does not facilitate these needs. The restrictions that these changes have made on this waiver has been nothing but obstacles for parents and caregivers to give this kind of care for these individuals. This includes the highly restrictive clock in clock out locations that are required from the last changes. I would ask any of you to look at your day and tell me that life does not throw you a curve when it comes to scheduling things. These persons have every right to be able to go out and enjoy our

world and DHHS has done everything it can to lock them in their homes with these restrictions. Now with these hours cuts this will also make it to where extra-curricular activities are almost impossible.

These cuts will now make it to where we will have to look at some kind of other service so that I can get a full-time job on top of her care with the limited 40 hrs. With only the possibility of having someone come in for an additional 30hrs that limits my options to a part time job that will also affect the quality of life she gets and deserves. Bringing in an outside agency does not do anything but increase cost for the state and decrease her care. DHHS is trying to make it out that families will cover these hours voluntarily, which is not the case. A lot of us have no outside help that would be consistent for these adults. Other family members have their own families to care for and cannot be consistent on the help they provide if willing to help at all. How many of you have to take care of your adult son or daughter full time? The care is also not a Monday-Friday affair, these caregivers are there all week long. 24-7-365.

I believe this violates many provisions put in place to protect our children against these outrageous new policies being implemented without any thought as to how this will affect families and end up costing the state far more money. Why wasn't our input asked for before you came to these conclusions? I strongly oppose these changes!

Thank you for your time.

Lisa Goodman

From: Donna - Sky Blue Aussies
To: DHHS HCBS Public Comments
Subject: DHHS in-home caregiver proposed cuts.
Date: Friday, December 19, 2025 8:39:05 AM

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Shame on you! Taking advantage of Nebraska's most vulnerable citizens by making cuts that will not only drastically affect their daily life, but potentially result in death and sickness. If you think putting someone in a facility is going to save Nebraska money, think again! being in a facility is going to result in more of these medically complex individuals getting sick, going to the emergency room and having huge hospital bills . in-home care is a consistent and valuable resource that in the long run is saving DHHS millions of dollars in hospital bills. An in-home caregiver should 100% still be allowed to have 112 paid hours or even increase that , because most of these people require 24 /seven care that cannot be put on a time clock. I protest this cut in hours and I will do everything in my power to get the word out to every single Nebraskan about what DHHS is trying to slip under the rug. Taking advantage of the disabled and medically complicated adult adults and children in the state as a budget line. Again shame on you.

January 5, 2026

DHHS.HCBSPublicComments@nebraska.gov

To whom it may concern:

I am writing as a constituent to express my firm opposition to the Department of Health and Human Services proposal to impose a cap on hours for live-in caregivers or in our case family on family care. This proposal is deeply concerning and if implemented it would place vulnerable Nebraskans at serious risk while undermining the very purpose of community-based care.

Live-in-caregiving or parents who take care of their loved ones is not shift work. Although we are required to use the clock-in system, which rarely works correctly in our rural area is a problem in and of itself. While I have no problem with using the clock-in system it needs to be understood that rural areas do not always have service. Individuals who depend on family to care for them often require continuous supervision, immediate assistance and constant support that cannot be reduced to an hourly calculation. An arbitrary cap ignores medical realities and places health, safety and dignity secondary to administrative convenience. The result will be predictable and preventable harm.

As a matter of fact, the unpredictable has happened on several occasions for my daughter. I came home to see a daughter, who is paralyzed and has a brain injury, very confused, had completely undressed herself and trying to stand up out of her wheelchair because a severe UTI spread throughout her body. I know exactly what signs to look for in caring for my own daughter and ironically not only all her drs, but the nursing staff have noticed that she has never had a major breakdown of her skin. My point is that we may clock in and out, but our shifts never end and we don't clock out and go home for the night. She also suffers from moderate to severe anxiety that requires me to be up with her at night, so therefore we are always here to help with or take care of her needs. Over the course of 14 years, we have developed a system that works for her and the family taking care of her.

This proposal also threatens to destabilize an already fragile caregiving workforce. I used to work for Mercy and gave up my career choice to take care of my daughter after having different caregivers in the home fail to care and fulfill her needs. My daughter has told me that in the past one of her caregivers got her up, made breakfast and then would lay on the couch and sleep the remainder of her shift. Another occurrence was a caregiver that put her in the shower only to leave her in the shower with no way out, no towels to dry off with and me coming home to her hollering for help. No caregiver anywhere to be found as she had left my daughter in the shower while she ran to Sioux City to pick up her paycheck from

Melissa at LiveWell. I not only came home to that but had her out of shower, hair dried and put back to bed so I could dress her and had her back in her chair before the caregiver on duty got back to the house. Shortly after that I became her caregiver full-time because of the abuse and neglect from the caregivers that were supposed to be here and not giving the care that was required of them and the constant no-shows. I would have to leave my job to come home to get her up for the day. Also, due to a no-show she had fallen down the stairs in her wheelchair. Luckily, she had her phone on her and was able to call her stepdad to come home-result of that incident as a fractured hand.

As live-in caregivers we accept these roles knowing the demands are continuous. Limiting hours will reduce compensation, discourage skilled caregivers from remaining in or entering the field and dramatically increase turnover. Nebraska cannot afford policies that drive caregivers away while demand for care continues to rise.

Equally troubling are the fiscal consequences. Capping live-in caregivers' hours will not reduce costs but will shift and increase them. Families will be forced to coordinate multiple caregivers to fill gaps, increasing administrative overhead and an inconsistency of care. We as caregivers haven't seen a raise in a very long time and the current company we work for hasn't seen a raise in over 4 years. Worse than that, some individuals will inevitably be pushed into institutional settings due to lack of adequate in-home support resulting in significantly higher cost to the state and poor outcomes for those receiving care.

This proposal runs counter to Nebraska's commitment to keeping people safely in their homes and communities. It represents a step backward and not forward in long-term care policy.

I urge you to oppose this proposal and to demand that DHHS and Governor Pillen reconsider any policy changes that fail to reflect real-world caregiving conditions and concerns. Meaningful stakeholder input, flexibility based on individual needs and legislative oversight are essential before any such changes are advanced.

Nebraska's most vulnerable residents and the families and caregivers who support them deserve policies grounded in reality, compassion and fiscal responsibility.

Thank you for your attention to this critical issue. Please feel free to contact us if you have any questions at [redacted]

Sincerely,

Kimberly and Fred Denker

CC: jim.pillen@nebraska.gov

[redacted]

Steve.Corsi@nebraska.gov

Currently my wife and I earn $15.00 per hour when caring for our 29-year-old daughter. We do not receive any benefits in addition to that wage, which also happens to be the minimum wage in Nebraska for 2026. Our daughter requires near constant attention as she suffers from irretractable epilepsy and delayed mental development. Status epilepticus is common with our daughter, requiring immediate intervention with rescue medicines, oxygen, and sometimes ER visits. Most of her seizures occur during sleep, requiring 24/7 supervision. She is mostly nonverbal and is unstable on her feet. She lacks the capacity to perform some of life's most basic tasks on her own, going to the bathroom and personal hygiene. In many aspects she is at the mental level of a two-year-old.

Would you be willing to come to our home and provide care for our daughter beyond the proposed 40 hours that we will be limited to? Your primary duty is to provide immediate attention in the event of seizures of any degree. An understanding of seizure behaviors and knowledge of lifesaving medications and when to administer is required. Other duties include constant attention of our daughter at all times. Step by step assistance is required when walking. Food preparation and meal planning is required. Bathroom assistance is necessary including cleansing, this includes personal care during monthly menstruation. Administering showers is required three times per week. Any accidental bowel movements outside the bathroom must be cleaned up to pre-incident conditions. You are required to administer medicines as prescribed by doctors. Transportation to and from the jobsite will be your responsibility. Compensation is $15.00 per hour with no other benefits. Any additional compensation is considered above and beyond what is currently being paid for this level of care.

We have no family to help us and none of our friends are willing to step up. This is a huge responsibility that no one is willing to do for minimum wage. A nursing home would cost astronomically more and we would never put her in one because she would not get the care we give her. My mother died in a nursing home in Nebraska due to neglect. Our daughter gets the best care available from us, at considerably less than outside care would cost. No one would ever care for her like her parents. Why we can't be paid for that, but others can, it makes no sense.

From: jared grauer
To: DHHS HCBS Public Comments
Subject: DHHS proposed caregiver hours cap comment
Date: Tuesday, December 30, 2025 4:46:31 AM

> You don't often get email from [redacted]. Learn why this is important

I am writing to speak against the DHHS proposal on Nebraska's Aged and disabled waiver. Reducing the cap number reimbursed caregiver hours From 112 to 70 would be absolutely devastating for families that depend on the current level of caregiver hours. Reducing the cap number of hours is not viable as the disabled population of Nebraska would suffer with this type of change. Please do not implement the DHHS proposal.

Thanks,

Jared Grauer
Hickman, NE

From: Megan Linse
To: DHHS HCBS Public Comments
Subject: DHHS Proposed Cuts to AD and TBI waivers
Date: Friday, January 2, 2026 10:49:51 AM

You don't often get email from [redacted]. Learn why this is important

I am writing with deep concern and urgency regarding the proposed DHHS cuts to Nebraska's Aged and Disabled (AD) and Traumatic Brain Injury (TBI) waivers. For many families, these services are not optional or supplemental — they are the difference between safety and crisis, stability and burnout. These waivers allow loved ones with disabilities or brain injuries to remain in their homes, surrounded by family, instead of being forced into institutions. Cutting this support would place an overwhelming and heartbreaking burden on families who are already giving everything they have to care for those they love.

The emotional and financial toll of these cuts would be devastating. Parents, spouses, and caregivers would be forced to choose between their jobs and the safety of their family members, pushing many to the brink. Beyond the human cost, these cuts will ultimately cost the state more through emergency care, hospitalizations, and institutional placements. I ask you, with sincerity and hope, to stand with Nebraska families and protect the AD and TBI waivers. Our most vulnerable residents deserve compassion, dignity, and the support they need to live full lives in their communities.

My brother is severely disabled and suffers from seizures everyday. This would DRASTICALLY affect his life. He is 23 years old, but functions at a one to two year old level. He depends on my family for eating, bathing, dressing, hygiene and just about every daily task that we take for granted. I am begging you to please not make the cut to 40 hours, he is the most vulnerable in our state and these cuts would fail him horribly.

-Megan Linse

From:	James Summers
To:	DHHS HCBS Public Comments
Subject:	DHHS.HCBSPublicComments@nebraska.gov TOPIC: state"s plan to renew the 1915(c) Medicaid Home and Community Based Services (HCBS) Aged and Adult and Children with Disabilities (NE.0187) waiver and amend the Traumatic Brain Injury Waiver (NE.40199). The ...
Date:	Thursday, December 25, 2025 4:35:31 PM

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Sent from my iPhone

I am asking all involved in the proposed changes to deny them. You passing these changes is going to have a severely negative impact on families that sacrifice there lives to take care of their loved ones. I know of personal friends that will be effected.

Please vote no.

Thank you for your time.

From: Deborah Perry
To: DHHS HCBS Public Comments
Subject: DHHS
Date: Monday, December 29, 2025 5:45:42 PM

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I strongly urge the Nebraska DHHS to NOT proceed with the proposal to a Medicaid waiver which would limit need-determined reimbursable hours for caregivers. For a government that is pro family and a society that truly cares about people and their families this proposal would destroy and harm many families. Please reconsider
Thank you,
Deborah Perry MD

From: Mike Kinkade
To: DHHS HCBS Public Comments
Subject: Disabled and elderly cuts
Date: Tuesday, December 23, 2025 8:42:41 PM

> You don't often get email from [redacted] Learn why this is important

My step son is in a vegative state and has to have 24/7 hour cares. He can not do anything on his own. He was diagnosed with severe traumatic brain injury and is anoxic. With that being said he literally relies on us for every single thing. Cutting hours not only puts people in dangerous also leaves them without cares and forces them into institutions which is against federal law. There are so many people that have had to modify their homes to accommodate basic needs which also have bills to pay to provide for their loved ones. He also has had to go thru a lot of paperwork and the review panel for the approval already that put him at the 24/7 care.

Michael

From: Melissa Davis
To: DHHS HCBS Public Comments
Subject: disapproval of Proposed changes to Medicaid waiver
Date: Monday, January 5, 2026 8:00:45 AM

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January 5th, 2026

Nebraska Department of Health and Human Services
Division of Developmental Disabilities
301 Centennial Mall South
PO Box 95026
Lincoln, NE 68509-5026
Dhhs.HCBSPublicComments@Nebraska.gov

Dear Committee Members:

I am writing to inform you of my disapproval of the proposed changes to the Medicaid waiver program for 2026-2027 and 2027-2028 fiscal year. My name is Melissa Davis. I have been a proud professional caregiver working for Caring For All/ Caring For People Services for the past seven and ½ years. I have been mostly taking care of my mother that is on their roster in that time.

I believe that the proposed changes that are being made are very very detrimental to not only my mother but to other care providers and the recipients of those that are on the Medicaid AD wavier program. Including myself, as the primary care provider for my mother.

I believe that the proposed changes will also be detrimental to Nebraska's economy because the work is plenty for those who want to work in the field, but the workers are few. This is only because of the fact that back in the seventy's and eighty's the baby boomers, those that are in my mother's generation, were encouraged to limit the number of children that they had because it was harmful to the environment. Which dropped the amount of babies most families had in the 1940's, 1950s, and 1960s from at least 2 to 3 children down to the dismal average number of children of one to maybe two children today. Which explains why the amount of the baby boomers that are getting older are on the Medicaid AD waiver. Without having the tax benefits of the payees from the following generations of Generation X, the millennials or Gen Y and Generation Z. With the beginning of Generation Alpha starting to enter the working world within the next 5 to 10 years.

We also have to face facts when it comes to the worker shortage in this state. There are already 3 jobs for every person that is eligible for working in this state. I feel that with the cuts of time down to 40 hours a week. That job to eligible worker ration will increase to 4 or 5 jobs per eligible worker. Which then would increase the need for wages to go higher because companies need to keep up with the pace of paying better to entice their people to stay or encourage others that are not on their staffs to leave their current job to come and work for them.

I have often wanted to take a day off for different events or activities that would

require me to leave my mother in someone else's care. I have often told Caring for All/ Caring for People services of these events months in advance only to find that there is nobody that would be available to take the open shift, either that week of the event or the week before the event. Which then means that I would have to pull in extended family and friends to help me out. Not only losing my salary but then I have to turn around and pay those extended family members and friends for their efforts to help me out. As I have no brothers or sisters, therefore, I do not have any informal support to pick up the additional hours while I work a second job. And let's be honest, if I continually ask for help from my extended family and friends will wane on them and at some point they will have had enough with helping me out, because they would be putting their lives on hold for my mother and I.

I have lots of trust issues with strangers to ensure that my mother gets the quality of care that she requires. I believe that I am the only one that has the care and strength to be able to ensure that she gets that quality of care that she needs. I have had a few times in the past seven and ½ years had to have my mother spend time in the hospital and the nursing home. And while I find the hospitals in the Omaha Metro area are the finest in order to provide the quality of care, the opposite can be said of the nursing homes in the Omaha Metro area.

Only because they are so understaffed that it is pitiful. Because there are people that do not want to work in the nursing homes, changing dirty diapers, getting food or hot liquids thrown at them, and have to endure with the verbal abuse when the resident is sick because the resident doesn't know any better or the family, because they don't understand nor care with what is going on.

In addition I feel that should my hours be cut down to 40 hours per week, I would not be able to pay for my bills and would have to pick up a second job to ensure that my excessive amount of student loan debt and credit card debt is not only paid off, but paid off on time. Plus I feel that it would decimate what little savings I have, which then would put my ability to retire at the current age of retirement of age 67 which is unfortunately for me is, in twenty-three and ½ years, in jeopardy. I am very well aware that I will not be able to count on Social Security and am planning for the unfortunate possibility of that fund drying up before I retire.

My mother is currently on Hospice care and has been living at home mostly in great spirits for the last 18 months. I feel that if I have to give her care over to a nursing home that would charge far greater the amount of money that I would ever make in a fiscal year that she would most likely die within 6 to 8 weeks. She is my rock and we have been through everything together through thick and thin. She is the last family member that I have that actually loves me for who I am unconditionally as all mothers should. I have no other family that will be there for me when she does go.

I am asking. No Actually I am begging you to find the money to cover the deficit that the state of Nebraska has put themselves in, from somewhere else. Even if that means going back to the rich buddies of the state and telling them look, we cannot give you your tax breaks. Because it is fiscally irresponsible. Trickle-down economics does not work. It never has and it never will. It does not take a pure genius who spent a small fortune on a college education to tell people that. I am a strong believer in everyone paying 20 percent in taxes across the board. It does not matter whether you make two dollars a year or one trillion dollars per year. Think about this if a rich person makes one trillion dollars per year and has to pay 20 percent taxes, they

are **STILL RICH**.

I am going to close with this: The last time I checked the preamble of the US Constitution it did not say “We the people of the upper income bracket”. It says, “We the People of The United States, in order to inform a more perfect union, establish Justice, Insure Domestic Tranquility, provide for the common defense, promote the general Welfare, and secure the Blessing of Liberty to ourselves and our Posterity, do ordain and establish this Constitution for the United States of America.” PERIOD. This doesn’t mean that you do not get to cut important programs like the waiver program in order to give tax breaks to the rich.

If you feel compelled to visit my home and look into the situation that I and my mother live in please contact me at the information below. Thank you for taking the time out of your day to read this letter and I pray that you will respond accordingly.

Sincerely,

Melissa K. Davis

Melissa K. Davis
[redacted]

From: Beckey Ivey
To: DHHS HCBS Public Comments
Subject: disapproval of proposed changes to Medicaid wavier program
Date: Monday, January 5, 2026 8:00:58 AM

You don't often get email from [redacted] Learn why this is important

January 5, 2026

DHHS - Division of Developmental Disabilities
301 Centennial Mall South
P.O. Box 95026
Lincoln, NE 68509-5026
DHHS.HCBSPublicComments@Nebraska.gov

Dear Committee Members:

I am writing to express my disapproval of the proposed changes to the Medicaid waiver program for the 2026/2027 and the 2027/2028 fiscal years. My name is Beckey Sue Ivey and I have been a client of Caring for All/Caring for People Services for nearly eight years. My daughter has taken care of me for 7 and ½ of those years through this company.

Before my daughter began to work for them in July of 2018, I had been assigned at least four different caregivers from February of 2018 until my daughter began in July. These caregivers left their position for various reasons including better pay, better hours, or better duties. One just never showed up for her shift and left Caring for All/Caring for People Services scrambling to find someone to take me to my doctor's appointment and cover her shift.

As I said before, my daughter has worked 7 and ½ years for Caring for All/Caring for People Services. In that time she has had approximately four vacation days off, simply because there was no one to cover for her. Her first vacation day off was three years after she began working for them. Usually she has had to find someone, either a friend or relative, to take care of me if she wanted to attend an event such as a funeral or wedding, and pay them out of her own pocket to do so. In essence she has no informal support to pick up additional hours while she works a second job to recoup her losses and be able to pay her bills, such as the student loans she took out to attend state colleges for her three degrees she cannot use in this position.

The companies who supply these caregivers are already short staffed and now you want to hinder their services or possibly put them out of business by not allowing them to pay overtime. Do you really think they want to pay their employees overtime? No they do not. They do it because they have to. Let me give you an example based on my experience. Caring for All/Caring for People Services is paid $35.00 and some change per hour for my care. Of that $35.00, they pay my daughter $18.00 an hour up to 40 hours per week. Overtime after 40

hours is $27.00 per hour and this is not including benefits such as health, vision, dental, disability insurance, their portion of social security and medicare taxes, a 401k, and workman's compensation. What is left goes for administrative costs. Believe me they are not making money.

As I mentioned before they are short staffed, the reason being is people do not want to become caregivers because of the duties involved. Some people do not want to change a baby's dirty diaper, let alone someone who is 69 years old, can't roll over by themselves, is bedridden, and has a catheter to contend with. Working at Aldi's running a cash register for $21.00 an hour is much more appealing.

Now let's get back to finances, my point here is two-fold. Would you rather pay a nursing home/assisted living facility between $95,000.00 to $138,000.00 a year or my daughter $66,606.60 per year for better care 24 hours a day, 7 days a week. 365 days a year? I have been in such a facility and believe me, I have much better care at home. The lack of care at the facility and the prospect of dying at home were just two of the reasons I went into hospice.

One last thing, I would like to invite you to our home to answer any questions you may have or to actually see how our living arrangements work. Please contact my daughter, [redacted] to schedule a home visit.

Thank you for taking the time to read this email and here is hoping that you understand you are not only hurting people, you are hurting the state's tax base as well.

Sincerely,

Beckey S. Ivey

Beckey S. Ivey
[redacted]

From: Jas Montez
To: DHHS HCBS Public Comments
Subject: Draft of HCBS Waiver
Date: Tuesday, December 16, 2025 4:15:17 PM
Attachments: image001.png

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Hello,
I sat in on the Zoom presentation today and first off, thank you for handling all of the questions with compassion and grace.
I work for a facility that provides rehab and helps to secure AD or TBI waiver services after our program, if needed. I am looking for clarification on a comment toward the beginning when I was first joining. Did I hear you correctly when you mentioned that there will be a waiting list for these waivers? I ask only because I thought the point of combining the waivers was to eliminate the waiting list. I do understand budget concerns so just wanted to see if I heard you correctly.
Thank you again for hosting these listening sessions.

QLI
Brain and Spinal Cord Injury Specialists

Jas Montez, she/her
Benefits Advisor
D: (402) 573-3754 F: (402) 573-3780
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From: Holly Steidlmayer
To: info@arc-nebraska.org; DHHS HCBS Public Comments
Subject: Exceptions
Date: Monday, January 5, 2026 11:11:33 PM

> You don't often get email from [redacted]. Learn why this is important

Hello,

I am writing to oppose the exception language in the personal care service definition.

Under **Olmstead v. L.C.** and DOJ enforcement:

States must provide community services sufficient to allow people to live outside institutions **on an ongoing basis**, not only when a crisis occurs.

Restricting exceptions to **immediate** needs: (see page 53 of the application bottom sentence in box)

- Forces individuals to deteriorate until a crisis
- Implies it is temporary
- Creates a predictable risk of unnecessary institutionalization

Courts and DOJ have repeatedly rejected policies that require people to be unsafe *first* before receiving adequate services.

We request that this be rewritten to comply with Federal HCBS requirements, and to expand and normalize exception pathways, not emergency only.

Thank you for the opportunity to comment.

Holly Steidlmayer

From: Jennifer Williams
To: DHHS HCBS Public Comments
Subject: Fiscal responsibility
Date: Sunday, January 4, 2026 12:22:11 PM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Dear Nebraska DHHS Leadership,

I am writing to submit a public comment regarding the proposed changes to the Aged and Disabled (AD) Waiver, specifically the proposed reductions in individual care and services due to an asserted financial shortfall.

As a provider serving aged and disabled individuals in Nebraska, and as someone who works directly with families who depend on these services to remain safe, stable, and in their homes, I am deeply concerned by the direction of these proposed changes.

I would like to formally ask the Department to clearly explain how fiscal responsibility has been exercised over the past five and ten years. Before reducing critical services to individuals who rely on the AD Waiver, it is reasonable and necessary for the public to understand:
- What budgeting and forecasting measures were in place during this time;
- How waiver funds have been allocated and managed;
- What decisions or systemic factors contributed to the current financial shortfall; and
- Why individuals receiving care are now being asked to absorb the consequences of those decisions.

Reducing individual care hours or services does not simply "save money" — it shifts costs elsewhere, often to emergency rooms, hospitals, institutional settings, or family caregivers who are already overwhelmed. These reductions place vulnerable individuals at risk of decline, hospitalization, or loss of independence, which ultimately increases long-term costs to the state.

Nebraska's aged and disabled population did not create this financial situation, yet they are being asked to sacrifice essential care as the solution. I respectfully urge DHHS to demonstrate transparency and accountability regarding past fiscal management and to explore alternatives that do not reduce direct services to individuals who rely on this waiver to live safely in the community.

The AD Waiver exists to prevent institutionalization and promote dignity, stability, and independence. Any changes to it should reflect that mission and should not come at the expense of the very people it was designed to protect.

Thank you for the opportunity to provide public comment and for considering the real-world impact these proposed changes will have on Nebraska's most vulnerable citizens.

Sincerely,
Jennifer Williams
Speak Life LLC
Aged & Disabled Provider
Nebraska

From: Sarah Kuhlmann
To: DHHS HCBS Public Comments
Subject: Formal Objection to AD Waiver Changes
Date: Monday, December 29, 2025 5:47:17 PM

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Dear Nebraska Department of Health and Human Services,

I am writing to formally object to the proposed changes to the Nebraska Aged and Disabled (AD) Waiver Program. I submit this objection as a sibling of an adult individual who relies on the AD Waiver to meet his daily medical and personal care needs.

My brother is an adult with significant medical and physical needs. He depends on AD Waiver services to remain safely in his home and out of an institutional setting. Reducing his authorized hours would directly jeopardize his health, safety, and quality of life. Our family does not have informal supports who are willing and able to step in to replace these medically necessary services. I am unable to provide this level of care, and my parents do not have informal supports available to care for him either.

Nebraska law is clear regarding the age of majority. Once an individual reaches age 19, parents are no longer legally or financially responsible for that individual's care. The State of Nebraska already recognizes this distinction through its administration of Medicaid waiver services for adults. Any policy that assumes or relies upon parents, siblings, or other family members to provide unpaid care to adults directly conflicts with this legal framework.

Equally important, informal supports—by definition—must be voluntary. They cannot be required, presumed, or used to replace authorized Medicaid services. Family members, including siblings and parents, are not voluntarily providing this level of care for free, nor can they be expected to do so. The apparent expectation that families will absorb the loss of paid services through uncompensated labor misrepresents both the intent of informal supports and the realities faced by families like mine.

The AD Waiver exists to provide medically necessary services that allow individuals with complex needs to remain safely in their homes rather than being placed in institutional care. These services include tasks such as mechanical transfers, lifting, incontinence care, suctioning, tube feedings, oxygen management, and medication administration. This is not casual assistance—it is intensive, hands-on medical and personal care that requires consistency and reliability.

Federal Medicaid waiver principles require that services be based on assessed need and that they function as a true alternative to institutional placement. Reducing hours while assuming unpaid family labor undermines the waiver's role as an institutional diversion program. When services are insufficient to meet assessed needs in the home, the waiver fails its intended purpose.

The proposal also ignores economic reality. Family members work full-time, have their own households, and must earn an income to survive. Most cannot afford to provide daily or around-the-clock care without compensation. This is not a matter of unwillingness—it is a matter of impossibility. Reducing paid hours does not eliminate need; it simply shifts an unsustainable burden onto families who have no legal obligation and no practical ability to absorb it.

Additionally, the assumption that reduced hours can be offset by "outside help" is unsupported. Nebraska is experiencing a severe shortage of direct care workers. Agencies are understaffed, and there is no available workforce to replace lost paid caregiving hours. Authorizing fewer hours—or shifting reliance away from paid family caregivers—will not result in alternate care being provided.

Many individuals on the AD Waiver require care well beyond 40 hours per week, with some needing continuous support. Arbitrary hour reductions and the elimination of paid family caregiving do not reduce need—they create unsafe conditions and increase the risk of hospitalization or institutional placement. This outcome directly contradicts the purpose of the AD Waiver.

DHHS has a legal and ethical obligation to administer the AD Waiver in a manner consistent with Nebraska law, federal Medicaid requirements, and the actual assessed needs of waiver participants. Policies that rely on unpaid, involuntary labor from individuals with no legal duty to provide care are neither lawful nor sustainable.

I strongly urge DHHS to withdraw these proposed changes and to preserve adequate authorized hours and the ability for qualified caregivers to be compensated for the care they provide. Reducing my brother's hours would have devastating consequences for him and for our family, and it would undermine the integrity of Nebraska's Medicaid waiver system.

Sincerely,
Sarah Kuhlmann

From: Katie Novakoski
To: Green, Tony
Subject: FORMAL OBJECTION to the AD wavier changes NEBRASKA
Date: Sunday, December 28, 2025 11:12:27 AM

Some people who received this message don't often get email from [redacted] Learn why this is important

Dear Nebraska Department of Health and Human Services and other interested parties,

I am writing to formally object to the proposed changes to the Nebraska Aged and Disabled (AD) Waiver Program, including reductions in authorized service hours, limits on compensation for live-in caregivers, and the increased reliance on unpaid "informal supports." These changes are contrary to Nebraska law, inconsistent with the purpose and structure of the AD Waiver, and incompatible with fundamental Medicaid waiver principles. If implemented, they will significantly reduce the safety, continuity, and quality of care for adults with severe disabilities while shifting unsustainable financial and caregiving burdens onto families.

Nebraska law is explicit regarding the age of majority. Once an individual reaches age 19, parents are no longer legally or financially responsible for that individual's care. The State of Nebraska already recognizes this distinction through its administration of Medicaid waiver services for adults. Any policy that assumes or relies upon parents, grandparents, or other family members to provide unpaid care to adults directly contradicts this established legal framework. Not only that, but many families do not have these informal supports to rely on, perpetuating the unsafe conditions these changes would force upon families.

Equally important, informal supports, by definition, must be voluntary. They cannot be mandated, presumed, or relied upon to replace authorized Medicaid services. Parents, family members, and friends are not voluntarily providing this level of care for free, nor can they reasonably be expected to do so. The Department's apparent expectation that families will step in to provide uncompensated care fundamentally mischaracterizes both the nature of informal supports and the realities faced by families supporting adults with significant disabilities.

The AD Waiver exists for a specific and essential purpose: to provide medically necessary services that allow individuals with significant disabilities and complex medical needs to remain safely in their homes rather than being placed in institutional settings. Services authorized under the AD Waiver include mechanical transfers and lifting, incontinence care, suctioning, tube feedings, oxygen management, medication administration, and constant supervision. These tasks are skilled, hands-on medical and personal care. They are not casual assistance, and they are not acts of voluntary goodwill. They are labor.

Federal Medicaid waiver requirements mandate that services be based on assessed need and

that they function as a true alternative to institutional care. Arbitrary reductions in authorized hours—while presuming unpaid labor from family members—undermine the waiver's role as an institutional diversion program. When services are insufficient to meet assessed needs in the home, the waiver fails its intended purpose and increases the risk of hospitalization or placement in more costly institutional settings.

For many individuals on the AD Waiver, 70 hours of care per week is not sufficient to meet even basic daily needs, let alone ensure safety for medically complex conditions that require constant or near-constant supervision. Many participants require care far exceeding 40 hours per week, with some needing continuous, 24-hour support. Hour caps and limits on paid family or live-in caregivers do not reduce need—they create unsafe gaps in care and place vulnerable adults at serious risk.

The expectation that family members will provide this care without compensation also ignores economic reality. Many parents and family caregivers work full-time, have their own households, and must earn income to survive. Most cannot afford to provide daily or round-the-clock care for free. This is not a matter of unwillingness; it is a matter of impossibility. When paid hours are reduced, caregivers are forced to seek employment outside the home, leaving adults with disabilities without necessary care during critical hours. It is unfair to expect families to take such drastic cuts in hours that they use to care for their loved ones while cost of living continues to rise every day.

The proposal further assumes that reduced hours can be offset by "outside help." This assumption is unsupported by current workforce conditions. Nebraska is experiencing a severe and ongoing shortage of direct care workers. Agencies are understaffed, and in many areas there is no available workforce to replace lost paid family caregiving hours. Authorizing services that cannot realistically be delivered does not meet the State's obligations under the waiver.

Family and live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes and reduces overall Medicaid expenditures. Cutting hours and limiting compensation will force many families to pursue skilled nursing or institutional care, which is far more expensive for the State and often results in poorer outcomes. These proposed changes risk increasing hospitalizations, institutional placements, and total taxpayer costs—outcomes that directly contradict the purpose of the AD Waiver.

If cost containment is necessary, there are more responsible and lawful alternatives that would preserve safety and continuity of care, including:

- Maintaining current authorized hour levels for existing participants through grandfathering provisions.
- Removing or revising the 40-hour compensation cap for live-in caregivers.
- Implementing individualized, needs-based assessments rather than one-size-fits-

all hour caps, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable adults, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. DHHS has both a legal and ethical obligation to administer the AD Waiver in a manner consistent with Nebraska law, federal Medicaid requirements, and the actual assessed needs of waiver participants.

I urge DHHS to withdraw these proposed changes or significantly revise them to preserve adequate authorized hours and the ability for qualified family members to serve as paid caregivers. Failure to do so will place vulnerable adults at serious risk and undermine the integrity and purpose of Nebraska's Medicaid waiver system.

Thank you for considering my comment and protecting some of the most vulnerable adults in our communities.

Katherine Kuecker

From: Katie Novakoski
To: DHHS HCBS Public Comments
Subject: FORMAL OBJECTION to the AD wavier changes
Date: Sunday, December 28, 2025 10:28:07 AM

You don't often get email from [redacted]. Learn why this is important

Dear Nebraska Department of Health and Human Services and other interested parties,

I am writing to formally object to the proposed changes to the Nebraska Aged and Disabled (AD) Waiver Program, including reductions in authorized service hours, limits on compensation for live-in caregivers, and the increased reliance on unpaid "informal supports." These changes are contrary to Nebraska law, inconsistent with the purpose and structure of the AD Waiver, and incompatible with fundamental Medicaid waiver principles. If implemented, they will significantly reduce the safety, continuity, and quality of care for adults with severe disabilities while shifting unsustainable financial and caregiving burdens onto families.

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that they function as a true alternative to institutional care. Arbitrary reductions in authorized hours—while presuming unpaid labor from family members—undermine the waiver's role as an institutional diversion program. When services are insufficient to meet assessed needs in the home, the waiver fails its intended purpose and increases the risk of hospitalization or placement in more costly institutional settings.

For many individuals on the AD Waiver, 70 hours of care per week is not sufficient to meet even basic daily needs, let alone ensure safety for medically complex conditions that require constant or near-constant supervision. Many participants require care far exceeding 40 hours per week, with some needing continuous, 24-hour support. Hour caps and limits on paid family or live-in caregivers do not reduce need—they create unsafe gaps in care and place vulnerable adults at serious risk.

The expectation that family members will provide this care without compensation also ignores economic reality. Many parents and family caregivers work full-time, have their own households, and must earn income to survive. Most cannot afford to provide daily or round-the-clock care for free. This is not a matter of unwillingness; it is a matter of impossibility. When paid hours are reduced, caregivers are forced to seek employment outside the home, leaving adults with disabilities without necessary care during critical hours. It is unfair to expect families to take such drastic cuts in hours that they use to care for their loved ones while cost of living continues to rise every day.

The proposal further assumes that reduced hours can be offset by "outside help." This assumption is unsupported by current workforce conditions. Nebraska is experiencing a severe and ongoing shortage of direct care workers. Agencies are understaffed, and in many areas there is no available workforce to replace lost paid family caregiving hours. Authorizing services that cannot realistically be delivered does not meet the State's obligations under the waiver.

Family and live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes and reduces overall Medicaid expenditures. Cutting hours and limiting compensation will force many families to pursue skilled nursing or institutional care, which is far more expensive for the State and often results in poorer outcomes. These proposed changes risk increasing hospitalizations, institutional placements, and total taxpayer costs—outcomes that directly contradict the purpose of the AD Waiver.

If cost containment is necessary, there are more responsible and lawful alternatives that would preserve safety and continuity of care, including:

- Maintaining current authorized hour levels for existing participants through grandfathering provisions.
- Removing or revising the 40-hour compensation cap for live-in caregivers.
- Implementing individualized, needs-based assessments rather than one-size-fits-

all hour caps, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable adults, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. DHHS has both a legal and ethical obligation to administer the AD Waiver in a manner consistent with Nebraska law, federal Medicaid requirements, and the actual assessed needs of waiver participants.

I urge DHHS to withdraw these proposed changes or significantly revise them to preserve adequate authorized hours and the ability for qualified family members to serve as paid caregivers. Failure to do so will place vulnerable adults at serious risk and undermine the integrity and purpose of Nebraska's Medicaid waiver system.

Thank you for considering my comment and protecting some of the most vulnerable adults in our communities.

Katherine Kuecker

From: Joshua Nichols
To: DHHS HCBS Public Comments
Subject: Formal Opposition to Proposed AD Waiver Changes
Date: Saturday, December 27, 2025 9:37:30 PM

> You don't often get email from [redacted]. Learn why this is important

To Whom It May Concern,

I am submitting this comment to formally oppose the proposed updates to the AD Waiver personal care program. I am specifically concerned about the reduction in weekly service hours and the new pay limits for live-in caregivers.

These cuts threaten the health and safety of people living with severe disabilities. For many individuals with complex medical needs, 70 hours of care a week isn't enough to cover basic daily requirements or ensure they are never left in a dangerous situation. Furthermore, limiting live-in caregivers to only 40 hours of pay makes it financially impossible for many of them to continue providing this essential support.

Family and live-in caregivers offer a level of dedicated, cost-efficient care that allows people to stay in their own homes. If these hours are cut and pay is capped, many families will have no choice but to turn to nursing homes or institutional care. This is not only a worse outcome for the individuals involved, but it is also much more expensive for the state. Reducing home-based support will likely lead to more hospital visits and higher costs for taxpayers in the long run.

If the department needs to manage costs, I suggest looking at a more balanced solution around individual assessments. Use a needs-based system rather than a universal cap so that those who require constant supervision can still get the help they need.

The AD Waiver is supposed to protect vulnerable people and support the caregivers who look after them. This proposal works against those goals. I ask that DHHS reconsider these changes and focus on solutions that prioritize the actual needs of the community.

Thank you for your time and for reviewing my concerns

Joshua Nichols
Bellevue Nebraska

From: Duran, Diana
To: DHHS HCBS Public Comments
Subject: FW: 40 hour week limit in home caregivers
Date: Monday, December 29, 2025 9:50:04 AM

Diana Duran | DHHS Advocate
OFFICE OF COMMUNICATIONS
Nebraska Department of Health and Human Services
OFFICE: 402-471-6035 | FAX: 402-471-3996
DHHS.ne.gov

-----Original Message-----
From: Jeanne Brown <jeanne.brown01@cox.net>
Sent: Friday, December 26, 2025 9:07 AM
To: DHHS Webmaster <DHHS.Webmaster@Nebraska.gov>
Subject: 40 hour week limit in home caregivers

[Some people who received this message don't often get email from jeanne.brown01@cox.net. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Regarding, upcoming legislation re: above the 40 hours a week.
I have been caring for my son for the past 26 years in my home. Who dreams up these ridiculous things, this is 24/7 on call care 7 days a week, we get paid for approximately 1/3 in a weeks time. Has anyone done the math for institutional care for the same time period! Thousands of dollars. You are asking we open up our home to strangers while we are here to care for our loved ones, how does that make sense?
Regards,
Jeanne Brown

From: Large, Colin
To: DHHS HCBS Public Comments
Subject: Fw: A and D waiver renewal
Date: Wednesday, December 17, 2025 1:21:22 PM

Colin Large | *Policy Administrator II*
Executive Green Belt
he/him
DEVELOPMENTAL DISABILITIES & HOME AND COMMUNITY-BASED SERVICES

Nebraska Department of Health and Human Services
CELL: 402.853.1452 | WEB: DHHS.ne.gov

From: [redacted]
Sent: Wednesday, December 17, 2025 10:58 AM
To: Green, Tony <Tony.Green@nebraska.gov>
Cc: Large, Colin <Colin.Large@nebraska.gov>; Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>
Subject: A and D waiver renewal

I am reaching out to you out of concern for the changes in the waiver which seem to be affecting families in a very dramatic manner. I also admit, I am in no way totally familiar with this waiver nor the details of how it is and has been utilized.
I do fear though that possibly overall budget considerations are a factor in these changes. I only hope that there is a way to help these families to take care of their loved ones as they have been accustomed too.
The stories and tears I am feeling on the calls are heartbreaking. I sincerely hope there will be some viable options for the individuals and their caregivers.

I compliment Colin and Jennifer in their presentation of the information and trying to answer questions as well as being exposed to personal attacks! I know it's their jobs,BUT. Thank you both!

Joe

Joe Valenti
President of Family and Friends of the Beatrice State Developmental Center
Parent Advocate for Developmentally Disabled Individuals
[redacted]

From: Smith, Kristen
To: DHHS HCBS Public Comments
Cc: Large, Colin; Clark, Jennifer J
Subject: FW: A Personal Appeal to Protect Nebraska's Medicaid Waivers
Date: Friday, January 2, 2026 10:07:43 AM

Good morning,

Here is another one.

Kristen Smith | *Deputy Director of Eligibility, Policy, and Quality*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-8704

DHHS.ne.gov | **Facebook** | **Twitter** | **LinkedIn**

From: [redacted]
Sent: Sunday, December 28, 2025 7:34 PM
To: Green, Tony <Tony.Green@nebraska.gov>; Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>; Smith, Kristen <Kristen.Smith@nebraska.gov>; Boss, Stacey <Stacey.Boss@nebraska.gov>; Dan Quick <dquick@leg.ne.gov>; Sen. John Fredrickson <jfredrickson@leg.ne.gov>; Sen. Ben Hansen, B. <bhansen@leg.ne.gov>; Sen. Beau Ballard <bballard@leg.ne.gov>; Sen. Brian Hardin <bhardin@leg.ne.gov>; Merv Riepe <mriepe@leg.ne.gov>; dlonowski@leg.ne.gov; vrountree@leg.ne.gov; Sen. Dave Murman <dmurman@leg.ne.gov>; Houseman, Karen <Karen.Houseman@nebraska.gov>
Subject: A Personal Appeal to Protect Nebraska's Medicaid Waivers

> You don't often get email from [redacted] Learn why this is important

Dear Senator/Representatives,

I truly hope you all had a wonderful, safe and relaxing holiday.

I am writing to you not only as a Nebraska resident, but as someone whose life was permanently changed by sudden disability.

Until I was 35 years old, I never imagined Medicaid would affect my family. I was not a caregiver. I was not connected to disability services. Then my twin sister experienced a sudden cardiac arrest that left her with a severe anoxic brain injury. Overnight, she lost the ability to speak, walk, eat independently, or care for herself in any way. Overnight, our family became caregivers.

Like most families, we did not plan for this. We did not prepare for it. And we quickly learned that without Medicaid Home- and Community-Based Services waivers,eventually our only options would have been institutionalization or collapse.

I have other family members who were blessed with Medicaid waivers, which made it possible for them to live with dignity at home, and for our family to survive

emotionally, physically, and financially. One of them included an adult male named David Menusek who lived in the Beatrice Institutions for 30 years. While there, he was abused and forgotten; they ripped his teeth out of his mouth as a toddler so he would not bite the crib he was left in. He was released and connected with ENCOR (now called DUET) where he met my father, who worked for the company for over 40 years. David eventually moved in with our family. He was at-risk living by himself (he was often robbed). David was always afraid of the sound of keys being rattled because it reminded him of institution workers coming into his room to abuse him. Despite his trauma, he was a beautiful human being. So loving, and a devout follower of God. He was the JOY of lives for many years until he passed away in 2010. David was part of our family. More on Beatrice history here: https://www.youtube.com/watch?v=aWzaJdHh99g

My aunt Shari who has Prader Willi Syndrome was also institutionalized for years- abused, silienced, traumatized. At one point she needed to leave the state to find a place to live...and that was the most traumatic time ever for her. Today she is in her late 70s and did not get the waiver until a few years ago. These last few years of Shared Living for my Aunt Shari- who lives in Ralston- have been some of the best of her entire life. It has given our family comfort knowing she is finally happy and being cared for by amazing people with the support of our family. Which she deserved much earlier in life. These services are not a luxury; they were the difference between safety and crisis. She deserves no more crisis on top of what she already deals with in her life due to her condition, and neither does our family. Or other families. It is a CONSTANT fight for life and dignity.

I am deeply concerned about proposed changes to Nebraska's Medicaid waivers, particularly reductions to caregiver hours or access. These changes may look administrative on paper, but in real life they force families into impossible decisions: quitting jobs, leaving loved ones unsafe, or institutionalizing them against their will. If you do not know about Beatrice, please look here. I know what nursing homes are like; some get lucky, many do not. However I do know of an extended family member who built a brand new lake house after they invested in a nursing home, and it makes me so incredibly disappointed.

Caregivers are already stretched thin; often caring around the clock while working, parenting, and grieving. I know this personally as a family caregiver who struggled and was experiencing C-PTSD for 3.5 years before my sister died...and that grief/trauma does not end. Caregiving has a lifelong cost, mostly due to lack of services. Due to isolation that changes you forever.

I know many Nebraskans, like I once did, assume this issue does not affect them. But disability and caregiving are not rare. They arrive suddenly and without warning. Any one of us is one accident, one illness, or one aging parent away from needing these exact services.

I respectfully urge you to protect Medicaid HCBS waivers and to consider the real human cost of reducing them. Supporting community-based care is compassionate, fiscally responsible, and reflects the values of dignity and responsibility that Nebraska

stands for. This is what my family members deserved, along with ALL people in our state. Nebraska is a special place, so please ensure it does not change in that way.

Thank you for your time and for your service to our state.

Sincerely,
Sarah Rasby, former family caregiver & PhD scholar

Lincoln, NE 68512

From: Large, Colin
To: DHHS HCBS Public Comments; Ingabire, Yvonne; Newtson, Miranda D
Subject: Fw: A&D waiver change clarification
Date: Monday, January 5, 2026 1:46:11 PM
Attachments: image001.png

Colin Large | *Policy Administrator II*
Executive Green Belt
he/him
DEVELOPMENTAL DISABILITIES & HOME AND COMMUNITY-BASED SERVICES

Nebraska Department of Health and Human Services
CELL: 402.853.1452 | WEB: DHHS.ne.gov

From: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>
Sent: Thursday, December 11, 2025 4:57 PM
To: 'Hansen, Jennifer L' <jenniferl.hansen@unmc.edu>; Large, Colin <Colin.Large@nebraska.gov>
Cc: Swanson, Sarah R <sarah.swanson@unmc.edu>; DHHS HCBS Public Comments <DHHS.HCBSPublicComments@nebraska.gov>
Subject: RE: A&D waiver change clarification

In this case it would be personal care hours.

Jenn Clark, LIMHP | *Deputy Director of Community Services*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-7909

From: Hansen, Jennifer L <jenniferl.hansen@unmc.edu>
Sent: Thursday, December 11, 2025 4:53 PM
To: Large, Colin <Colin.Large@nebraska.gov>; Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>
Cc: Swanson, Sarah R <sarah.swanson@unmc.edu>; DHHS HCBS Public Comments <DHHS.HCBSPublicComments@nebraska.gov>
Subject: RE: A&D waiver change clarification

Thank you both for the prompt replies! Please forgive me, what do you mean when you refer to “hours” (as in “state plan (MCO) hours and the waiver hours combined”)--hours of therapies, nursing care, personal care services, etc.? I appreciate the clarification!

Jennifer Hansen
Parent Resource Navigator
Munroe-Meyer Institute for Genetics and Rehabilitation

University of Nebraska Medical Center
985450 Nebraska Medical Center | Omaha, NE 68198-5450
402.559.5759 | fax 402.559.5737
Jenniferl.hansen@unmc.edu

UNMC | Facebook | Twitter | Instagram | YouTube | Flickr

From: Large, Colin <Colin.Large@nebraska.gov>
Sent: Thursday, December 11, 2025 2:21 PM
To: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>; Hansen, Jennifer L <jenniferl.hansen@unmc.edu>
Cc: Swanson, Sarah R <sarah.swanson@unmc.edu>; DHHS HCBS Public Comments <DHHS.HCBSPublicComments@nebraska.gov>
Subject: Re: A&D waiver change clarification

Non-UNMC email

Jenn is correct.

We will consider this email as a Public Comment and will look to see if clarifying language is needed prior to CMS submission.

Thank you for bringing this to our attention.

Colin

Colin Large | *Policy Administrator II*
Executive Green Belt
he/him
DEVELOPMENTAL DISABILITIES & HOME AND COMMUNITY-BASED SERVICES
Nebraska Department of Health and Human Services
CELL: 402.853.1452 | WEB: DHHS.ne.gov

From: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>
Sent: Thursday, December 11, 2025 1:07 PM
To: 'Hansen, Jennifer L' <jenniferl.hansen@unmc.edu>; Large, Colin <Colin.Large@nebraska.gov>
Cc: Swanson, Sarah R <sarah.swanson@unmc.edu>
Subject: RE: A&D waiver change clarification

Colin can correct me if I am wrong.

I believe this means that whatever hours the state plan (MCO) hours and the waiver hours combined exceed the cost limit. For us it would really mean the waiver hours as we are not

taking the hours that the MCO pays for/provides into consideration of the waiver cap.

Thanks.

Jenn Clark, LIMHP | *Deputy Director of Community Services*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-7909

From: Hansen, Jennifer L <jenniferl.hansen@unmc.edu>
Sent: Thursday, December 11, 2025 11:42 AM
To: Large, Colin <Colin.Large@nebraska.gov>
Cc: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>; Swanson, Sarah R <sarah.swanson@unmc.edu>
Subject: A&D waiver change clarification

Good morning!
Firstly, I just want to thank you and Jenn for hosting the listening session yesterday and want to give you both so much credit for taking some not-so-positive feedback as the messengers. Please know that both of your dedication to the disability community is noticed and very, very much appreciated!

I was the one who asked the question regarding the **combination** of HCBS services and Medicaid state plan included in the individual's budget of 150%/175%, as noted below:

Page 12: "*All current waiver participants will continue to receive the services as outlined on their person-centered plan (PCP). Prior to the participant's next eligibility year, the Service Coordinator (SC) will meet with the participant to complete the high-utilization review. When the combined costs of waiver and state plan services exceed the applicable cost limit, the SC will work with the participant to reduce services below the 175% limit, while still ensuring health and safety are met. When the participant's needs cannot be met, referrals to other community services, including institutional services, are provided to the participant. The participant is provided with alternative options to meet their needs, including but not limited to nursing facility placement.*"

If I am misinterpreting this, could you please explain what the highlighted section does mean? Thank you, again!

Best,
Jennifer Hansen
Parent Resource Navigator
Munroe-Meyer Institute for Genetics and Rehabilitation
UNMC
BREAKTHROUGHS FOR LIFE.®

University of Nebraska Medical Center

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The information in this e-mail may be privileged and confidential, intended only for the use of the addressee(s) above. Any unauthorized use or disclosure of this information is prohibited. If you have received this e-mail by mistake, please delete it and immediately contact the sender.

From: Houseman, Karen
To: DHHS HCBS Public Comments
Subject: FW: A/D Medicaid Waiver Proposal Changes
Date: Tuesday, January 6, 2026 9:45:57 AM

Hello – this was received before the deadline

Karen Houseman | *DHHS Program Manager II, AD and TBI Waiver Service Coordination*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-9329 | CELL: 402-840-0869

From: lkhegg@cox.net <lkhegg@cox.net>
Sent: Friday, January 2, 2026 3:51 PM
To: Houseman, Karen <Karen.Houseman@nebraska.gov>
Subject: A/D Medicaid Waiver Proposal Changes

You don't often get email from [redacted] Learn why this is important

Dear Karen Houseman,

I am writing in response to the proposed changes to the A/D Medicaid waiver.

Our son is 28 years old and needs 24/7 care. He has multiple cognitive and physical disabilities, uses a wheelchair, and is blind. He also has unique medical issues that need constant monitoring for extra lifesaving medication given through a g-tube or injection.

The deep cuts being proposed would greatly reduce his quality of life by reducing or eliminating the care he receives from his live-in sister. We are currently getting 112 hours per week of paid caregiver time split between Peter's sister and me. The cuts would reduce this to 40 hours per week. Our family has worked hard and sacrificed much to care for Peter and are very thankful for what the waiver has provided. But the cap on hours for live-in caregivers is unrealistic and strongly limits who can provide quality care. Our loved ones should be able to choose their caregivers! We have no "informal supports" and live a very isolated life due to Peters fragile health. We do not have friends or family that are available or qualified to care for him the way he needs or would be comfortable with. Comfort and consistency are extremely important for Peter's health and well-being. Our primary goal has always been to keep him healthy, safe and happy. Reducing hours would cause a complete strain on our lives, affecting those we care for and the life we have taken years to build for Pete. We want to continue to give him the quality of life and purpose that he deserves.

Thank you for considering this,

Lissa K. Hegg- Peter's mother and loving caregiver

he’s going to lose his home and the opportunity of living the best quality of life in this situation and that would be at home where there’s people that know how to care for him, who want to care for him, who love him. We have to be able to survive in order to take good care of him and ourselves. I worked several years as an independent contractor for State Nebraska caring for my son and received minimal pay. I can’t help but wonder if the people that are making these decisions, realize how much work the parents or loved ones do without pay. I mean, no one’s looking to get rich. We’re just trying to take care of our children and give them some kind of quality of life. I mean, my son is approved for 140 hours a week I work 85 of them hours through the agency because it’s hard to find help but they do supply help with the remaining 55 hours with a different aide. That’s not including the 28 hours that I work off the clock and the emergency hours from no call no show or they cannot fill the visit since we can only work 16 hours a day on the clock. I also hope that the people that are making these decisions realize that we have based our bills on our income and they’re taking that all the way, so I personally will be losing my house in Chris’s home!

I have two College Degrees and I have given that all up to take care of my son for the last 14 years. I am now 62 years old and in order to go back to work in my field of study I would have to take refresher courses and pass my boards again because I did not keep up with my continuing education classes because again I am my son’s primary caregiver. I did not complain I was there and I did the work. I stayed bedside while he was in ICU in Kearney I travel to Lincoln. I stayed with Chris while he was in Madonna’s vent unit, then he went to acute care in Madonna Rehab Hospital followed by QLI in Omaha for homebound care. I’m grateful that he is alive and here with me and I can take the best care of him. I can just hear him breath and know if he’s struggling, you see my son cannot adjust himself in bed. He cannot lay flat or he could aspirate. My son cannot put his oxygen back on if it falls down which it happens a lot, my son aspirates on his own saliva so he needs suction on a regular basis . Christopher requires a G-tube place in his stomach to dispense his medication‘s, and his nutrition shakes and water. Chris does eat pureed food orally with thicken liquids. Chris needs assistance with all his personal cares, brush his hair, brushing his teeth, showering toileting, eating, dressing, communicating. He needs a lift to be transferred from bed to wheelchair, I have to make all his doctors appointments go to all his doctors appointments on or off the clock, arrange for Transportation to and from doctors appointments, therapy appointments, , talk to his service coordinator. Keep up with all his prescriptions. Apply splits to his arms after range of motion and stretching to

his arms and legs because Christopher also suffers from spasticity that is so painful and severe that I have to take him to Omaha to get Botox injections to give any kind of relief for that child. He also has a baclofen pump is placed on his right flank that feeds a muscle relaxer up his spinal cord to help with decreasing spasticity and tightness . And please remember this is all going on to a person that was a upstanding citizen and now he has to feel like when he's at his lowest point in his life and needs taken care of his being throw in the trash and left feeling like he's less than and that just is not right. My son deserves better. I don't understand why the state would be willing to pay an extended family or Home health agencies thousands of dollars a month but they complain about the little bit of money I get as his mother who's had him in my home for 14 years by myself I will add. I am a single mother. There is no help. His father died nine years ago of cancer and he didn't come around much anyway. Siblings are not able to help they have kids of their own and work lots of hours themselves due to increased cost of living.

Now let's talk about the modifications. I took care of my boy on little or nothing in an apartment that didn't deserve what I paid because it had nice wide hallways to aide in wheelchair movement. I finally was able to buy a house so Christopher can live at home comfortably and the State paid for modifications which included a role in shower and a ramp for the entrance in the front door along with doorways being widened, which cost thousands of dollars. And you're telling me that in July everything changes. I will lose my house now. I will have to place my son Who is only 39 years old in a nursing home that's not able to care for his needs. He falls into the category of the most vulnerable population for neglect/abuse. But the Committee/state don't seem to worry about losing that money. I mean, I just don't understand the thought process here. In the families that can't find a place for their children they'll have to go to the hospital in the ICU, which will cost three times. If not more for just a couple nights stay then it would at home with the parents or family member that was taken care of them originally with no problems and cheaper. The math is not adding up.

I would like to know the names of the people that's on this panel that's making all these decisions. I feel that the citizens of Nebraska have a right to know its aggressor because they definitely are not working to help us. They're literally killing our children. I'm also curious if there's any members on this so-called panel that has a disabled child is there anybody around this legislature that has any kind of idea what you're expecting out of these family?

Family Providers Are Performing a State-Delegated Role — Not Ordinary Parenting

• Under Nebraska law and Medicaid policy, once an individual reaches adulthood, they are legally responsible for themselves to the extent they are able.
• The State of Nebraska, through Medicaid and the AD Waiver, holds responsibility to ensure:
• Health and safety
• Access to long-term services and supports
• Alternatives to institutionalization
• When a parent or family member becomes a paid AD Waiver provider for an adult child, they are:
• Voluntarily assuming duties that would otherwise be fulfilled by the state
• Performing skilled, time-intensive, and often medically or behaviorally complex care
• Preventing the state from having to fund higher-cost agency or facility services

This is not compensation for parenting — it is reimbursement for delivering Medicaid-authorized services that the state is obligated to provide.

3M

The Care Provided Exceeds Normal Parental Duties
• AD Waiver services involve:
• Assistance with multiple ADLs and IADLs
• Continuous supervision to prevent harm
• Behavioral intervention and crisis prevention
• Medical monitoring and hands-on personal care
• These tasks go far beyond what is expected of parents of adult children without disabilities.
• If a parent were not providing this care:
• The state would be required to pay an agency or facility to do so
• The legal obligation would not default back to the parent

3M

Payment Recognizes Substitution for Paid Providers, Not Family Status
• Payment under the AD Waiver is based on:
• Authorized services
• Documented need

• Compliance with Medicaid rules
• The relationship of the provider (parent, sibling, spouse) does not change the nature of the service being delivered.
• The only reason parents are present in these roles is because:
• The workforce is insufficient
• The individual tolerates only trusted caregivers
• Families stepped in to prevent institutionalization

3M

Denying or Limiting Family Providers Shifts State Responsibility Without Consent
• When family providers are capped or excluded:
• The care requirement does not disappear
• The burden is shifted back onto families without compensation
• This creates an unfunded mandate on families and undermines Medicaid's purpose.

Families did not create the need for these services — the disability did. The AD Waiver exists to meet that need regardless of who delivers the care.

3M

Equity and Disability Rights Framing
• Adults without disabilities are not expected to rely on their parents for lifelong personal care.
• Expecting families of people with disabilities to provide extensive unpaid care solely because of family relationship is discriminatory.
• Paying family providers ensures equal access to services, not special treatment.

Parents and family members serving as AD Waiver providers are not being paid to parent. Parents are doing extraordinary cares. They are being reimbursed for delivering Medicaid-authorized services that the state is legally obligated to provide to an adult individual who cannot safely meet those needs independently. Limiting or dismissing family providers does not eliminate the state's responsibility — it simply shifts it onto families without compensation or consent.

Please help me
Michelle Nunnery
[redacted]

Sent from Yahoo Mail for iPhone

From: Smith, Kristen
To: DHHS HCBS Public Comments
Subject: FW: AD Waiver cuts
Date: Monday, January 5, 2026 8:28:15 AM

Please see below. Thank you!

Kristen Smith | *Deputy Director of Eligibility, Policy, and Quality*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-8704

DHHS.ne.gov | **Facebook** | **Twitter** | **LinkedIn**

From: [redacted]
Sent: Sunday, January 4, 2026 5:01 PM
To: Smith, Kristen <Kristen.Smith@nebraska.gov>
Subject: AD Waiver cuts

> You don't often get email from [redacted] Learn why this is important

To Governor Pillen, Nebraska DHHS Leadership, and Nebraska Lawmakers
A mother's voice for her child... If Tabitha could talk to you, I like to think this is what she would say.

My name is Tabitha, I have a rare genetic disorder called PCDH-19 epilepsy.
It's a rare genetic condition that causes severe seizures that are difficult to treat and was only discovered in 2008.
I lived the first 15 years of my life battling severe seizure clusters, putting me into the ICU, sometimes even coma to treat before I finally got my diagnosis. By the time I was 2 I'd had thousands of seizures, multiple medical emergencies and surgeries. I have lost a kidney, had an eye biopsy, muscle biopsy, liver biopsy, and brain surgery to separate the 2 halves of my brain, all done without an answer or cure. Then the genetic testing was done and we got the devastating news, PCDH19 incurable rare epilepsy.

I speak with limited words and some signs and rely on my mom to understand my needs-spoken, unspoken and physical. I developed lupus antibodies in 2020 just as covid hit, which caused a blood clot that went from my right hip all the way behind my right knee. We tried for weeks to break it up, with an emergency room visit due to a severe reaction to the coumadin, thankfully my mom drove me daily to get my meds and was hypervigilant in my care or things could've gotten bad. I received my emergency meds and was better, but now I have to have injections every night of lovanox for the rest of my life. This was my second blood clot.

The first one was when I was 17 months and developed a bladder infection. My parents took me to the hospital ER daily for a week and the drs didn't catch it so we headed to Omaha where they found 5 renal abscess's, with one being the size of a pool ball. (The kidney was used as a teaching tool at UNMC)
I was rushed into emergency surgery with only a 30% chance of making it. My parents were there for every moment praying and slowly, with many meds, supplements and lots of care I survived.

I now have to use a wheelchair as walking long distances is hard with that scarred blood clot vein in my leg. I am on multiple medications due to many issues and my mom keeps them all straight for me to take during the day and night. I also require oxygen that my parents have to pay for because insurance wont cover it, even though it's the first thing the ambulance crews and ER staff administer. I have had multiple ER visits and ambulance rides as well as hospital stays in the first few years of my life. My parents educated themselves in my needs and condition so that, with the help of our doctors, they can keep me home, in the safest, most comfortable environment.

My body needs constant, skilled, attentive care. My mom has to check my legs every morning for blood clot symptoms, I still have cramps in my right leg so my mom has to sit with me on the floor to put lotion on my leg and rub the cramps every morning.
I tend to rip off my toe and fingernails due to trichotillomania. So she has to monitor my nails for infection, ingrown or hang nails.
I often pick my arms, face and hands due to OCD and sensory issues so she has to monitor those sores as well.

I can't tell you when something hurts, I'm in pain, or when a seizure is going to happen or if I feel sick. I have, on average 15-30 seizures a day, monitored by a VNS implant. My safety depends entirely on the people caring for me understanding me and monitoring me. We have a video monitor for at night so they can see me when I make noise to make sure it isn't a seizure. My parents haven't slept in years due to the fact that I do not sleep more than a couple of hours at a time and I often make meses in bed and have to be changed several times a night. Not to mention the loads of laundry every day from these messes.
My mom is who I am most comfortable with.
She's not just a "family caregiver." She's my nurse, my emergency response person, my translator, my advocate, and my playmate. My family knows my routines, my cues, my seizure patterns, and the subtle signs that mean, 'I'm ok, or I'm not ok'
I have lots of allergies, so my mom is hypervigilant to my face, eyes, skin for signs of rash. I've also had issues with medication causing liver problems so my mom has to monitor for signs of that as well.
I have incontinence, so my mom has to make sure I'm changed, a lot due to all the fluid intake I have to have because of only having one kidney.
The kind of knowledge my mom has doesn't come from a handbook. It comes from years of experience, sleepless nights, and loving me fiercely.

With my family and my mom , I am safe. they have prevented wrong medication, over medication and further malpractice.
Without them… well, let's just say I am at risk of many medical complications
.
Recent policy decisions and proposed changes are putting families like mine in impossible positions. Decisions made without seeing me, without entering my home, and without understanding the reality of my care risk separating me from the people who quite literally keep me alive.
I am asking—respectfully, sincerely, and yes, a little desperately—for grace.
Grace for parents who have already rearranged their entire lives around their child's survival.
Grace for families whose "informal care" is anything but informal.
Grace for people like me, who do not benefit from unfamiliar hands or constant change. My parents have made their home safe for me, cater to my needs and provide all the tools needed for me to thrive.

This isn't about convenience.
This isn't about cutting corners.
This is about safety, dignity, and staying alive.
When policies remove parents from providing care, they don't replace them with a system—they replace them with risk. Risk of missed cues. Risk of medical error, Risk of fear, Risk of Death. Not to mention an increase in cost, not decrease. And our family has enough going on without adding all that to the list.

When you suggest utilizing family, day programs or other supports you don't understand. THERE IS NONE. There are no programs that take 27 year olds in diapers, with the mentality of a 2 year old and with dozens of seizures. Family have families and medical conditions of their own and the neighbors/church etc are not available, but if they were, they simply do NOT have the medical knowledge or experience to care for me.

So instead of guessing, I'd like to make you an offer.
Please—come into my home. Sit with my parents. Watch my care. See what it actually takes to keep me safe for a single day. Notice how much knowledge, vigilance, and teamwork is required before lunchtime even rolls around. I promise, it will be more informative than any spreadsheet—and you might even leave with a new respect for hypervigilant awareness.
Because I am not a policy.
I am not a budget line.
I am not a theoretical outcome.

I am a person.
And there are many others like me across Nebraska—quietly relying on parents who are doing extraordinary work every single day. The decisions you make will determine whether those families are supported… or stretched past what any human can carry.
Please slow down. Please listen. Please let compassion sit at the table with compliance.
Protect my right to be cared for by the people who know me best, love me most, and have already proven—every single day—that they can.

Thank you for your time,
Tabitha Melvin
(from a mothers heart)

Yahoo Mail: Search, Organize, Conquer

From: Green, Tony
To: DHHS HCBS Public Comments
Subject: FW: AD Waiver
Date: Monday, January 5, 2026 7:44:57 AM

Tony Green | *Director*
DEVELOPMENTAL DISABILITIES AND AGING
SUPPORTING DIGNITY AND CHOICE THROUGH COMMUNITY CONNECTIONS
Nebraska Department of Health and Human Services
OFFICE: 402-471-6038
DHHS.ne.gov | Facebook | Twitter | LinkedIn

From: [redacted]
Sent: Thursday, December 25, 2025 6:13 PM
To: Green, Tony <Tony.Green@nebraska.gov>
Subject: AD Waiver

> You don't often get email from [redacted] Learn why this is important

Please don't cut hours for live-in care because I'm trying to live paycheck to paycheck.

Sent from my T-Mobile 5G Device
Get Outlook for Android

From: Green, Tony
To: DHHS HCBS Public Comments
Subject: FW: AD waiver
Date: Monday, January 5, 2026 7:07:07 AM

Tony Green | Director
DEVELOPMENTAL DISABILITIES AND AGING
SUPPORTING DIGNITY AND CHOICE THROUGH COMMUNITY CONNECTIONS
Nebraska Department of Health and Human Services
OFFICE: 402-471-6038
DHHS.ne.gov | Facebook | Twitter | LinkedIn

-----Original Message-----
From: Susan Lunkwitz <susanlunkwitz@yahoo.com>
Sent: Thursday, January 1, 2026 11:44 AM
To: Green, Tony <Tony.Green@nebraska.gov>
Subject: AD waiver

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

I'm writing in regard to the AD waiver. I take care of my sister who is a double amputee and requires around the clock care. She would not get this care in an already understaffed nursing home and besides I wouldn't allow her to even go to one. This waiver helps get the hours needed to take care of her. We travel a lot to numerous doctor appointments and other appointments. I ask that you do whatever you can to keep this AD waiver in effect. Taking this away would hurt me financially and hurt the needs of taking care of my sister and all the traveling we do for appointments and other things.
Thank you for your time,
Susan Lunkwitz

From: Clark, Jennifer J
To: DHHS HCBS Public Comments
Cc: Green, Tony
Subject: FW: AD Wiaver changes
Date: Sunday, January 4, 2026 7:08:58 PM

HI,

Tony also received this email separately, so not sure if he passed it along. Sending just in case.

Thanks.

Jenn Clark, LIMHP | *Deputy Director of Community Services*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-7909

From: Robert Kier [redacted]
Sent: Saturday, January 3, 2026 3:47 PM
To: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>
Subject: Fw: AD Wiaver changes

> You don't often get email from [redacted]. Learn why this is important

Yahoo Mail: Search, Organize, Conquer

> ----- Forwarded Message -----
> **From:** "[redacted]"
> **To:** "Tony.Green@nebraska.gov" <Tony.Green@nebraska.gov>
> **Cc:**
> **Sent:** Sat, Jan 3, 2026 at 3:43 PM
> **Subject:** AD Wiaver changes
>
> I am writing to express serious concerns that the AD Waiver changes will increase costs to the state, rely on harmful misconceptions about family caregiving & shift unavoidable expenses onto families.
> Family provided care remains significantly cheaper than institutional care. Family caregivers provide high-acuity care at a fraction of the cost of nursing facilities and agency based services. Even at higher authorized in-home hours this approach saves the state substantial money compared to institutional placement.
> Family caregivers are not just living a normal life and getting paid. Family caregivers are performing skilled, around the clock work that would otherwise require paid staff or licensed facilities. This care goes far beyond typical family

duties and simply cannot be absorbed without compensation or support. Many disabled individuals cannot tolerate outside providers. Forcing unfamiliar caregivers into the home often leads to trauma, behavioral escalation and failed staffing.

In summary: The AD Waiver Proposal does not eliminate costs- it shifts them:

*From Medicaid to Families

*From Prevention to Crisis

*From home-based care to Hospitals and Institutions.

Families are absorbing enormous financial, physical and emotional burdens to keep adults with disabilities safely at home. Policies should support not penalize this commitment!

I respectfully urge you to oppose AD Waiver changes that reduce hours, restrict family caregivers or eliminate individualized exceptions.
Thank you for your time and consideration.

Robert and Karen Kier

Yahoo Mail: Search, Organize, Conquer

From: Clark, Jennifer J
To: DHHS HCBS Public Comments
Subject: FW: AD/Waiver Cuts
Date: Sunday, January 4, 2026 7:19:36 PM

Hello

Another one for public comment.

Thanks.

Jenn Clark, LIMHP | *Deputy Director of Community Services*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-7909

From: Jennifer Melvin [redacted]
Sent: Sunday, January 4, 2026 4:59 PM
To: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>
Subject: AD/Waiver Cuts

> You don't often get email from [redacted] Learn why this is important

To Governor Pillen, Nebraska DHHS Leadership, and Nebraska Lawmakers
A mother's voice for her child... If Tabitha could talk to you, I like to think this is what she would say.

My name is Tabitha, I have a rare genetic disorder called PCDH-19 epilepsy.
It's a rare genetic condition that causes severe seizures that are difficult to treat and was only discovered in 2008.
I lived the first 15 years of my life battling severe seizure clusters, putting me into the ICU, sometimes even coma to treat before I finally got my diagnosis. By the time I was 2 I'd had thousands of seizures, multiple medical emergencies and surgeries. I have lost a kidney, had an eye biopsy, muscle biopsy, liver biopsy, and brain surgery to separate the 2 halves of my brain, all done without an answer or cure. Then the genetic testing was done and we got the devastating news, PCDH19 incurable rare epilepsy.

I speak with limited words and some signs and rely on my mom to understand my needs-spoken, unspoken and physical. I developed lupus antibodies in 2020 just as covid hit, which caused a blood clot that went from my right hip all the way behind my right knee. We tried for weeks to break it up, with an emergency room visit due to a severe reaction to the coumadin, thankfully my mom drove me daily to get my meds and was hypervigilant in my care or things could've gotten bad. I received my emergency meds and was better, but now I have to have injections every night of lovanox for the rest of my life. This was my second blood clot.

The first one was when I was 17 months and developed a bladder infection. My parents took me to the hospital ER daily for a week and the drs didn't catch it so we headed to Omaha where they found 5 renal abscess's, with one being the size of a pool ball. (The kidney was used as a teaching tool at UNMC)
I was rushed into emergency surgery with only a 30% chance of making it. My parents were there for every moment praying and slowly, with many meds, supplements and lots of care I survived.

I now have to use a wheelchair as walking long distances is hard with that scarred blood clot vein in my leg. I am on multiple medications due to many issues and my mom keeps them all straight for me to take during the day and night. I also require oxygen that my parents have to pay for because insurance wont cover it, even though it's the first thing the ambulance crews and ER staff administer. I have had multiple ER visits and ambulance rides as well as hospital stays in the first few years of my life. My parents educated themselves in my needs and condition so that, with the help of our doctors, they can keep me home, in the safest, most comfortable environment.

My body needs constant, skilled, attentive care. My mom has to check my legs every morning for blood clot symptoms, I still have cramps in my right leg so my mom has to sit with me on the floor to put lotion on my leg and rub the cramps every morning.
I tend to rip off my toe and fingernails due to trichotillomania. So she has to monitor my nails for infection, ingrown or hang nails.
I often pick my arms, face and hands due to OCD and sensory issues so she has to monitor those sores as well.

I can't tell you when something hurts, I'm in pain, or when a seizure is going to happen or if I feel sick. I have, on average 15-30 seizures a day, monitored by a VNS implant. My safety depends entirely on the people caring for me understanding me and monitoring me. We have a video monitor for at night so they can see me when I make noise to make sure it isn't a seizure. My parents haven't slept in years due to the fact that I do not sleep more than a couple of hours at a time and I often make meses in bed and have to be changed several times a night. Not to mention the loads of laundry every day from these messes.
My mom is who I am most comfortable with.
She's not just a "family caregiver." She's my nurse, my emergency response person, my translator, my advocate, and my playmate. My family knows my routines, my cues, my seizure patterns, and the subtle signs that mean, 'I'm ok, or I'm not ok'
I have lots of allergies, so my mom is hypervigilant to my face, eyes, skin for signs of rash. I've also had issues with medication causing liver problems so my mom has to monitor for signs of that as well.
I have incontinence, so my mom has to make sure I'm changed, a lot due to all the fluid intake I have to have because of only having one kidney.
The kind of knowledge my mom has doesn't come from a handbook. It comes from years of experience, sleepless nights, and loving me fiercely.

With my family and my mom , I am safe. they have prevented wrong medication, over medication and further malpractice.
Without them… well, let's just say I am at risk of many medical complications
.
Recent policy decisions and proposed changes are putting families like mine in impossible positions. Decisions made without seeing me, without entering my home, and without understanding the reality of my care risk separating me from the people who quite literally keep me alive.
I am asking—respectfully, sincerely, and yes, a little desperately—for grace.
Grace for parents who have already rearranged their entire lives around their child's survival.
Grace for families whose "informal care" is anything but informal.
Grace for people like me, who do not benefit from unfamiliar hands or constant change. My parents have made their home safe for me, cater to my needs and provide all the tools needed for me to thrive.

This isn't about convenience.
This isn't about cutting corners.
This is about safety, dignity, and staying alive.
When policies remove parents from providing care, they don't replace them with a system—they replace them with risk. Risk of missed cues. Risk of medical error, Risk of fear, Risk of Death. Not to mention an increase in cost, not decrease. And our family has enough going on without adding all that to the list.

When you suggest utilizing family, day programs or other supports you don't understand. THERE IS NONE. There are no programs that take 27 year olds in diapers, with the mentality of a 2 year old and with dozens of seizures. Family have families and medical conditions of their own and the neighbors/church etc are not available, but if they were, they simply do NOT have the medical knowledge

or experience to care for me.

So instead of guessing, I'd like to make you an offer.
Please—come into my home. Sit with my parents. Watch my care. See what it actually takes to keep me safe for a single day. Notice how much knowledge, vigilance, and teamwork is required before lunchtime even rolls around. I promise, it will be more informative than any spreadsheet—and you might even leave with a new respect for hypervigilant awareness.
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And there are many others like me across Nebraska—quietly relying on parents who are doing extraordinary work every single day. The decisions you make will determine whether those families are supported… or stretched past what any human can carry.
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Thank you for your time,
Tabitha Melvin
(from a mothers heart)

Yahoo Mail: Search, Organize, Conquer

From: Green, Tony
To: DHHS HCBS Public Comments
Subject: FW: AD/Waiver Cuts
Date: Monday, January 5, 2026 6:47:53 AM

Tony Green | *Director*
DEVELOPMENTAL DISABILITIES AND AGING
SUPPORTING DIGNITY AND CHOICE THROUGH COMMUNITY CONNECTIONS
Nebraska Department of Health and Human Services
OFFICE: 402-471-6038
DHHS.ne.gov | Facebook | Twitter | LinkedIn

From: Jennifer Melvin [redacted]
Sent: Sunday, January 4, 2026 4:59 PM
To: Green, Tony <Tony.Green@nebraska.gov>
Subject: AD/Waiver Cuts

> You don't often get email from [redacted] Learn why this is important

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Tabitha Melvin
(from a mothers heart)

Yahoo Mail: Search, Organize, Conquer

From: Clark, Jennifer J
To: DHHS HCBS Public Comments
Subject: FW: Aged and Disabled Waiver - Due by January 5, 2026 - Public Comment
Date: Sunday, January 4, 2026 6:34:17 PM

Hello

Below is for public comment.

Thanks

Jenn Clark, LIMHP | *Deputy Director of Community Services*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-7909

From: Brad Thompson [redacted]
Sent: Friday, January 2, 2026 8:49 AM
To: Green, Tony <Tony.Green@nebraska.gov>; Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>; Houseman, Karen <Karen.Houseman@nebraska.gov>; Smith, Kristen <Kristen.Smith@nebraska.gov>; Boss, Stacey <Stacey.Boss@nebraska.gov>; Dan Quick <dquick@leg.ne.gov>; gmeyer@leg.ne.gov; Sen. John Fredrickson <jfredrickson@leg.ne.gov>; Sen. Ben Hansen, B. <bhansen@leg.ne.gov>; Sen. Beau Ballard <bballard@leg.ne.gov>; Sen. Brian Hardin <bhardin@leg.ne.gov>; Merv Riepe <mriepe@leg.ne.gov>; dlonowski@leg.ne.gov; vrountree@leg.ne.gov; Sen. Dave Murman <dmurman@leg.ne.gov>; Sen. Myron Dorn <mdorn@leg.ne.gov>
Subject: Aged and Disabled Waiver - Due by January 5, 2026 - Public Comment

> You don't often get email from [redacted]m. Learn why this is important

Bradley and Debra Thompson
[redacted]

Subject: Aged and Disabled Waiver- 40 hour cap for live-in caregivers

Dear Nebraska Representatives,

This email is in response to the open public comment period for the proposed changes to the Aged and Disabled Waiver due by January 5, 2026.

President Ronald Reagan said it best when he said the most terrifying words you'll ever hear is "I'm from the government and I'm here to help." If Nebraska HHS implements the proposals set forth, we will become a nanny state similar to the

mandatory mandates during Covid-19 pandemic. These proposals would be like Dr. Fauci saying, take the shot it will protect you, stand 6-feet away to prevent spread, we here to protect the vulnerable, if implemented these proposals would also be a future case study of the failure of Nebraska leaders mandating a one size fits all which will be disastrous to the families of Nebraska.

Brad has experience working at the state level with the Autism Council in Wisconsin, appointed by Governor Jim Doyle (D) and Governor Scott Walker (R) from 2004 to 2008 when the insurance mandate was implemented and the "waitlist" was removed. With appropriate representation at the state level, these proposals would never be adopted as written without parental input from state councils or advocates, and from public comment period. These proposals also fail to follow guidance in the Olmstead Act (1999) and from Supreme Court instruction, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life" and "confinement in an institution severely diminishes the everyday life activities of individuals, social interactions, work options, economic independence, educational advancement, and cultural enrichment."

It's obvious these heavy handed top down type proposals have the intentional effect of destroying the only reliable safety net our severely disabled son has in place:
- By capping live-in caregiver hours at 40 hour, while restricting non-family providers the remaining hours up to 70 hours per week. What drives these changes?
- In this waiver, the state specifies 175% of the institutional average cost as the cost limit threshold. Limiting and capping resources.
- Intent of removing self-centered or individually directed care from the home to state institutions. Removing the parents and/or court appointed guardians.

Note: a recent 7th Circuit Court of Appeals decision affirmed a preliminary injunction on similar proposals in Indiana. Recognizing that the children deserve to live at home with their families, not being forced into institutions. The decision reinforces the understanding that children with complex medical needs are best served when they can remain in the home and that there are steps that must be taken to help ensure these children remain safely in their families homes.

Our son is 33 years old and successfully living at home. His complex needs are being met at home with his family. He is non-verbal autistic, has Graves Disease, PICA, severe GI issues with specific diet, extensive medication routine and requires 24/7 supervision, and one on one supervision in all community settings including transportation. Our son does not understand safety risks and is an elopement risk. Our son deserves to have input to the self-directed in-home care he receives, whether family or non-family. His behavior is evident when providers are not attentive or are haphazard when providing care, it directly affects his well-being.

Nebraska HHS needs to train their moderators during public comment to be respectful and not have condescending attitudes and speak in a professional manner to those parents and organizational managers on the zoom calls. I've never heard so much disrespectful tone and unprofessional language towards parents.

It is our recommendation that Nebraska HHS keep in place the currently paid 112 hours to family members and keep in place language that would be flexible with managing these hours based on provider and respite availability as there are currently no agencies that we've contacted available to assist us. The written language should give the parents the ability to be paid and to use those hours when appropriate to pay non-family providers. Our son deserves to have input in his self directed care.

Thank you for your attention.

Respectfully,

Brad and Deb Thompson
Lincoln, Nebraska

From: DHHS Regulations
To: DHHS HCBS Public Comments
Cc: DHHS Regulations
Subject: FW: Caps hurt communities of care
Date: Tuesday, December 23, 2025 9:18:45 AM

Good morning!

The email below was received in the regulation's mailbox regarding capping 40 hours a week.

Thank you!

Marge Bauerly | Regulations, Legislature, & Compliance Paralegal I
LEGAL SERVICES – NEBRASKA STATE OFFICE BUILDING, 3RD FLOOR
Nebraska Department of Health and Human Services
OFFICE: 402-471-8417 | FAX: 402-742-2374
DHHS.ne.gov | Facebook | Twitter | LinkedIn

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-----Original Message-----
From: Megan Volz [redacted]
Sent: Sunday, December 21, 2025 8:53 AM
To: DHHS Regulations <DHHS.Regulations@nebraska.gov>
Subject: Caps hurt communities of care

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Morning,

My sister-in-law's mom shared with me last night at a Christmas concert about her son's care will be impacted by this proposed hour cap. We don't understand when someone in our community that requires more extensive care beyond the 40 hour work week, would be deprived of that care. Having all people cared and provided for by us, the community of Nebraska, helps us all. We all know the cost of healthcare and the lack of support those who may have complex medical and developmental needs have in general. When those people who have family and communities are cared for by state and federal funds (which effectively minimize the financial impact for all) to have the burden of cost of care or finding resources is removed, it means those people surrounding that individual can also then be able to work and support their families and communities with less stress and more time than without that support.

To propose to save money by targeting groups who are at highest risk in our society is criminal and unchristian.

Shame on the DHHS for even considering to do this.

Megan Volz
[redacted]

Sent from my iPhone

From: Large, Colin
To: DHHS HCBS Public Comments
Subject: Fw: Clarification
Date: Friday, January 2, 2026 11:39:30 AM

Colin Large | *Policy Administrator II*
Executive Green Belt
he/him
DEVELOPMENTAL DISABILITIES & HOME AND COMMUNITY-BASED SERVICES

Nebraska Department of Health and Human Services
CELL: 402.853.1452 | WEB: DHHS.ne.gov

From: Large, Colin <Colin.Large@nebraska.gov>
Sent: Friday, January 2, 2026 11:39 AM
To: Laura Vajgrt [redacted]
Subject: Re: Clarification

You may not receive an authorization for a waiver service and personal care under the State Plan at the same time. For example, if you are authorized for Personal Care under the waiver from 8 am to 12 pm, you may not receive an authorization for Personal Care under the State Plan between the hours of 8 and noon but may utilize those State Plan services at other times of the day as appropriate.

This is a current requirement and was not a change made in this renewal cycle.

Please let me know if you have further questions.

Colin

Colin Large | *Policy Administrator II*
Executive Green Belt
he/him
DEVELOPMENTAL DISABILITIES & HOME AND COMMUNITY-BASED SERVICES

Nebraska Department of Health and Human Services
CELL: 402.853.1452 | WEB: DHHS.ne.gov

From: Laura Vajgrt [redacted]
Sent: Thursday, January 1, 2026 3:42 PM
To: Large, Colin <Colin.Large@nebraska.gov>
Subject: Clarification

Colin,
Could you provide clarification on this- I would like Information prior to public comment if you could.

Page 53- paragraph 3-

-Personal care under the waiver differs in scope and nature from Personal care offered under the State Plan. A participant cannot be authorized to receive both waiver and State Plan personal care at the same time.

So my daughter is ventilator dependent. I can not find a nurse. As of now I receive 56 personal care and a extra 56 skilled care / personal care- (the hours my nurse would get if I had one) is this saying you will no longer be able to get those nursing hours?

If not compensated for the what I call skilled hours my nurse would provide. Is the plan to be..stop providing that care- go to the ER constantly or call an ambulance all the time. If we are just to do personal care- I would suspect the outcome would be more damaging to the budget- but I wanted to check and make sure that is what it is saying in the paragraph- that you will not be compensated for what your nurse would provide- and do?
Thanks
Lori-

From:	Smith, Kristen
To:	DHHS HCBS Public Comments
Cc:	Clark, Jennifer J
Subject:	FW: Concerning the proposed changes to the AD Waiver
Date:	Monday, January 5, 2026 2:12:17 PM

Sharing. Please see below.

Kristen Smith | *Deputy Director of Eligibility, Policy, and Quality*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-8704

DHHS.ne.gov | **Facebook** | **Twitter** | **LinkedIn**

From: Sarah Hegg [redacted]
Sent: Monday, January 5, 2026 2:03 PM
To: Green, Tony <Tony.Green@nebraska.gov>; Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>; Houseman, Karen <Karen.Houseman@nebraska.gov>; Smith, Kristen <Kristen.Smith@nebraska.gov>; Dan Quick <dquick@leg.ne.gov>; gmeyer@leg.ne.gov; Sen. John Fredrickson <jfredrickson@leg.ne.gov>; Sen. Ben Hansen, B. <bhansen@leg.ne.gov>; Sen. Beau Ballard <bballard@leg.ne.gov>; Sen. Brian Hardin <bhardin@leg.ne.gov>; Merv Riepe <mriepe@leg.ne.gov>; vrountree@leg.ne.gov
Subject: Concerning the proposed changes to the AD Waiver

> You don't often get email from [redacted] Learn why this is important

To whom it may concern:

This email is concerning a proposed amendment to the AD Waiver, specifically Appendix C, Section C-1/C-3: Service Specifications. I ask that you reconsider imposing a 40 hour-a-week limit for live-in caregivers providing Personal Care services. This could be devastating to both the caregivers and the vulnerable people they care for.

I live with and care for my severely disabled 28-year-old brother, Peter. My mom and I split our allotted hours to continually supervise, give medications, provide personal hygiene care, plan activities, etc. His needs do not end after 40 hours a week. He doesn't just take the evenings or weekends off from living. This is not a normal job! I quit my full-time job several years ago to help my mom with his constant care. We both need to earn money to contribute to the household and limiting us to 40 combined hours a week just won't cut it. This is true for many other families as well. If I have to get another job, that greatly decreases the time I have to help care for Peter. He will have to give up the activities we do every day that have helped him to expand his skills and his life. Without these extra hours, many families may not be able to afford to keep their disabled loved one at home anymore. And putting them in a nursing home or assisted living facility will only end up with them receiving a lower level of care and costing the government even more money.

A recent news release from DHHS (November 24, 2025) stated "Family Caregivers Strengthen Nebraska Homes and Communities." This is so true! Who could give better care for an aging or disabled person than someone who already loves them and is invested in their well-being? The news release goes on to state that many caregivers feel "overwhelmed" because they

have to work another job while also caring for a loved one. DHHS claims to want to alleviate this problem, but it will only be exacerbated if hours are limited as more caregivers will be forced to get second jobs to be able to pay their bills. The news release also acknowledges that "Easing the burden for caregivers will improve the overall quality of care." Limiting hours for live-in caregivers will only *increase* the burden and *decrease* the quality of care. DHHS claims to support these family caregivers, but a cap on hours seems instead like a targeted punishment.

DHHS also claims to encourage "Person-centered planning" where waiver participants can choose their type of care and be involved in making a plan for their lives. According to the DHHS website, Nebraska's Olmstead Plan is committed to providing care and services according to each participant's "needs and preferences." I can assure you that the majority of these participants prefer that their families, not strangers, care for them when possible. I know that's what my brother wants. A stranger coming into our home to provide a lesser level of care would be extremely disruptive. And having to move to a nursing home or assisted living facility would cause extreme anxiety and stress, which could lead to medical complications and even death. This is the reality for many other families as well.

Families know their elderly/disabled loved ones and know the kind of care they need. These live-in caregivers should be properly compensated for their important work, work that is actually saving the government money by preventing the mass institutionalization of vulnerable people. The proposed 40-hour cap on paid hours is an insult to these hard-working Nebraskans. I ask that you do all that you can to prevent this change in the AD Waiver from being implemented.

Thank you for reading!

Sincerely,

Sarah Hegg

From: Clark, Jennifer J
To: DHHS HCBS Public Comments
Subject: Fw: FORMAL OBJECTION to the AD wavier changes NEBRASKA
Date: Monday, December 29, 2025 8:27:41 AM

Hi
For public comment.
Thanks
Jenn

Get Outlook for iOS

From: Katie Novakoski [redacted]
Sent: Sunday, December 28, 2025 11:12:18 AM
To: Green, Tony <Tony.Green@nebraska.gov>
Subject: FORMAL OBJECTION to the AD wavier changes NEBRASKA

> Some people who received this message don't often get email from katie_novakoski@alumni.baylor.edu. Learn why this is important

Dear Nebraska Department of Health and Human Services and other interested parties,

I am writing to formally object to the proposed changes to the Nebraska Aged and Disabled (AD) Waiver Program, including reductions in authorized service hours, limits on compensation for live-in caregivers, and the increased reliance on unpaid "informal supports." These changes are contrary to Nebraska law, inconsistent with the purpose and structure of the AD Waiver, and incompatible with fundamental Medicaid waiver principles. If implemented, they will significantly reduce the safety, continuity, and quality of care for adults with severe disabilities while shifting unsustainable financial and caregiving burdens onto families.

Nebraska law is explicit regarding the age of majority. Once an individual reaches age 19, parents are no longer legally or financially responsible for that individual's care. The State of Nebraska already recognizes this distinction through its administration of Medicaid waiver services for adults. Any policy that assumes or relies upon parents, grandparents, or other family members to provide unpaid care to adults directly contradicts this established legal framework. Not only that, but many families do not have these informal supports to rely on, perpetuating the unsafe conditions these changes would force upon families.

Equally important, informal supports, by definition, must be voluntary. They cannot be mandated, presumed, or relied upon to replace authorized Medicaid services. Parents, family members, and friends are not voluntarily providing this level of care for free, nor can they reasonably be expected to do so. The Department's apparent expectation that families will step in to provide uncompensated care fundamentally mischaracterizes both the nature of informal supports and the realities faced by families supporting adults with significant

disabilities.

The AD Waiver exists for a specific and essential purpose: to provide medically necessary services that allow individuals with significant disabilities and complex medical needs to remain safely in their homes rather than being placed in institutional settings. Services authorized under the AD Waiver include mechanical transfers and lifting, incontinence care, suctioning, tube feedings, oxygen management, medication administration, and constant supervision. These tasks are skilled, hands-on medical and personal care. They are not casual assistance, and they are not acts of voluntary goodwill. They are labor.

Federal Medicaid waiver requirements mandate that services be based on assessed need and that they function as a true alternative to institutional care. Arbitrary reductions in authorized hours—while presuming unpaid labor from family members—undermine the waiver's role as an institutional diversion program. When services are insufficient to meet assessed needs in the home, the waiver fails its intended purpose and increases the risk of hospitalization or placement in more costly institutional settings.

For many individuals on the AD Waiver, 70 hours of care per week is not sufficient to meet even basic daily needs, let alone ensure safety for medically complex conditions that require constant or near-constant supervision. Many participants require care far exceeding 40 hours per week, with some needing continuous, 24-hour support. Hour caps and limits on paid family or live-in caregivers do not reduce need—they create unsafe gaps in care and place vulnerable adults at serious risk.

The expectation that family members will provide this care without compensation also ignores economic reality. Many parents and family caregivers work full-time, have their own households, and must earn income to survive. Most cannot afford to provide daily or round-the-clock care for free. This is not a matter of unwillingness; it is a matter of impossibility. When paid hours are reduced, caregivers are forced to seek employment outside the home, leaving adults with disabilities without necessary care during critical hours. It is unfair to expect families to take such drastic cuts in hours that they use to care for their loved ones while cost of living continues to rise every day.

The proposal further assumes that reduced hours can be offset by "outside help." This assumption is unsupported by current workforce conditions. Nebraska is experiencing a severe and ongoing shortage of direct care workers. Agencies are understaffed, and in many areas there is no available workforce to replace lost paid family caregiving hours. Authorizing services that cannot realistically be delivered does not meet the State's obligations under the waiver.

Family and live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes and reduces overall Medicaid expenditures. Cutting hours and limiting compensation will force many families to pursue skilled nursing or institutional care, which is

far more expensive for the State and often results in poorer outcomes. These proposed changes risk increasing hospitalizations, institutional placements, and total taxpayer costs—outcomes that directly contradict the purpose of the AD Waiver.

If cost containment is necessary, there are more responsible and lawful alternatives that would preserve safety and continuity of care, including:

- Maintaining current authorized hour levels for existing participants through grandfathering provisions.
- Removing or revising the 40-hour compensation cap for live-in caregivers.
- Implementing individualized, needs-based assessments rather than one-size-fits-all hour caps, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable adults, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. DHHS has both a legal and ethical obligation to administer the AD Waiver in a manner consistent with Nebraska law, federal Medicaid requirements, and the actual assessed needs of waiver participants.

I urge DHHS to withdraw these proposed changes or significantly revise them to preserve adequate authorized hours and the ability for qualified family members to serve as paid caregivers. Failure to do so will place vulnerable adults at serious risk and undermine the integrity and purpose of Nebraska's Medicaid waiver system.

Thank you for considering my comment and protecting some of the most vulnerable adults in our communities.

Katherine Kuecker

From:	Large, Colin
To:	DHHS HCBS Public Comments
Subject:	Fw: HCBS waivers
Date:	Monday, December 29, 2025 10:16:48 AM

Colin Large | *Policy Administrator II*
Executive Green Belt
he/him
DEVELOPMENTAL DISABILITIES & HOME AND COMMUNITY-BASED SERVICES

Nebraska Department of Health and Human Services
CELL: 402.853.1452 | WEB: DHHS.ne.gov

From: Smith, Kristen <Kristen.Smith@nebraska.gov>
Sent: Monday, December 29, 2025 8:24 AM
To: Large, Colin <Colin.Large@nebraska.gov>
Cc: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>
Subject: FW: HCBS waivers

Sharing for public comment.

Kristen Smith | *Deputy Director of Eligibility, Policy, and Quality*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-8704

DHHS.ne.gov | Facebook | Twitter | LinkedIn

From: nikki mann [redacted]
Sent: Sunday, December 28, 2025 8:27 PM
To: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>; Smith, Kristen <Kristen.Smith@nebraska.gov>
Subject: HCBS waivers

You don't often get email from [redacted] Learn why this is important

Dear Deputy Director,

I am writing as a Nebraska resident to express my concern regarding proposed changes to Medicaid Home- and Community-Based Services (HCBS) waivers.

Medicaid waivers are a critical part of our state's care infrastructure. They allow children, adults, seniors, and veterans with disabilities or serious medical needs to receive care in their homes and communities, rather than in institutional settings. These services support not only individuals with

disabilities, but also the family caregivers who make it possible for loved ones to remain safely at home.

Any reduction in caregiver hours or access to services places families in impossible positions, forcing them to leave the workforce, risk the safety of loved ones, or consider institutional care against their wishes. Caregivers are already under significant strain, and further reductions would increase isolation, burnout, and long-term costs to the state.

I respectfully urge you to protect Medicaid HCBS waivers and to carefully consider the real-life impact these changes will have on families across Nebraska. Supporting community-based care is not only compassionate policy; it is fiscally responsible and reflects our shared values.

Thank you for your time and service to our state. I appreciate your consideration of this important issue.

Sincerely,
Nikki Mann
[redacted]

Sent from Yahoo Mail for iPhone

From: Clark, Jennifer J
To: DHHS HCBS Public Comments
Subject: FW: Inconsistent proposal's Concerns
Date: Thursday, January 1, 2026 5:45:04 PM

Hi
I think this also goes with public comment.

Thanks.

Jenn Clark, LIMHP | Deputy Director of Community Services
DEVELOPMENTAL DISABILITIES
Nebraska Department of Health and Human Services
OFFICE: 402-471-7909

-----Original Message-----
From: Abbey Morgan <abbeyannebach@outlook.com>
Sent: Thursday, January 1, 2026 6:48 AM
To: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>
Subject: Inconsistent proposal's Concerns

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

1. Conflicting Hour Caps vs. "Health and Safety" Exception Language

What the proposal says
• 40-hour cap for Personal Care + LRI Personal Care when the caregiver is live-in • 70-hour combined cap for Personal Care + LRI + Companion • Exceptions may be approved by Central Office to meet immediate health and safety needs

Inconsistency
• The proposal acknowledges that some individuals have needs that exceed 40 or 70 hours for health and safety, BUT • It does not align those exceptions with 24/7 care needs, even when those needs are already documented and previously approved.

Why this is a problem
• A person who needs continuous supervision or hands-on care cannot have their health and safety met under a hard weekly cap.
• The exception language is written as temporary or emergency-based, not as recognition of ongoing, permanent high needs.

Contradiction: The proposal admits higher hours are sometimes required, but structures the system so those needs cannot realistically be met long-term.

—

2. Provider Restrictions Conflict With Tolerance, Routine, and Disability Needs

What pages 127–128 do
• Strongly limit who can provide care:
• Live-in family caregivers capped lower • Greater reliance implied on non-family or agency providers • Treats family care as something that should be restricted, not individualized

Inconsistency
• The proposal:
• Claims to be person-centered
• References health and safety
• But ignores the reality that:
• Some individuals do not tolerate unfamiliar caregivers • Routine and trust are medically necessary, not preferences

Conflict: You cannot claim person-centered planning while forcing care from providers the individual cannot safely tolerate.

—

3. Unequal Treatment Based on Provider Type, Not Need

What the proposal does
• Two people with the same assessed needs can receive very different hours depending on:
• Whether care is provided by family
• Whether they can tolerate outside staff

Inconsistency
• The waiver is supposed to be needs-based, yet:
• The cap applies more harshly to family providers • Individuals who cannot accept outside providers are effectively penalized

Result: The proposal creates artificial scarcity, not based on needs, but on provider category.

—

4. Cost-Containment Language Conflicts With Actual Cost Outcomes

What's implied
• Caps are justified as cost control

Inconsistency
• Family caregivers:
• Are paid less than agencies
• Cost far less than institutional care
• Restricting family hours:
• Pushes individuals toward nursing facilities or higher-cost settings • Violates the stated intent to be fiscally responsible

Contradiction: The proposal limits the least expensive care option while risking the most expensive outcome.

—

5. Olmstead & HCBS Final Settings Rule Conflict (Indirect but Real)

Even though not named directly on pages 127–128, the conflicts are clear:
• Olmstead requires services in the most integrated setting • Final Settings Rule requires:
• Choice of providers
• Services that support remaining in the community

Inconsistency
• Caps + provider limits:
• Reduce meaningful choice
• Make home care unsustainable for high-need individuals • Increase risk of institutionalization

This puts the state at odds with federal intent, even if not explicitly acknowledged in the proposal text.

—

6. Summary of Core Inconsistencies (Plain Language) • The waiver says health and safety matter, but caps make safety impossible for some.
• It says person-centered, but applies blanket limits.
• It says choice of provider, but restricts family care.
• It says cost-effective, but undermines the lowest-cost option.
• It says community-based, but increases institutional risk.

Thank you for your time to read through found inconsistencies and detrimental conflicts. These impact wellbeing and safety In the most immeasurable ways.

From: Cynthia Wiggins
To: DHHS HCBS Public Comments
Subject: Fw: Money cuts
Date: Thursday, January 1, 2026 9:37:12 PM

Sent from my Verizon, Samsung Galaxy smartphone
Get Outlook for Android

From: Cynthia Wiggins [redacted]
Sent: Thursday, January 1, 2026 6:39:25 AM
To: DHHS.HCBSPublicComments@nebraska.gov <DHHS.HCBSPublicComments@nebraska.gov>
Subject: Money cuts

Cutting the amount of money private providers is putting the care of our client family members at risk if we have to find outside employment to supplement the funding cuts. The people/clients we care for are very vulnerable and will suffer deeply from the changes. If the state wouldn't have made the billing so hard for some people you wouldn't have had to hire and contract with all the home health companies which is sucking the funding Revo their contracts and leave private providers alone.
DO BUDGET CUTS AT YOUR OFFICE XUT THEIR 2AGES IN HÀLF AND LEAVE US ALONE.

RANDALL W.

Sent from my Verizon, Samsung Galaxy smartphone
Get Outlook for Android

From:	Green, Tony
To:	DHHS HCBS Public Comments
Subject:	FW: My Concern of Caregiver Hours Cut:
Date:	Monday, January 5, 2026 6:49:40 AM

Tony Green | *Director*
DEVELOPMENTAL DISABILITIES AND AGING
SUPPORTING DIGNITY AND CHOICE THROUGH COMMUNITY CONNECTIONS
Nebraska Department of Health and Human Services
OFFICE: 402-471-6038
DHHS.ne.gov | **Facebook** | **Twitter** | **LinkedIn**

From: Cindy Padgett [redacted]
Sent: Friday, January 2, 2026 5:01 PM
To: Green, Tony <Tony.Green@nebraska.gov>
Subject: My Concern of Caregiver Hours Cut:

> You don't often get email from [redacted]. Learn why this is important

I'm writing to express my concerns about the proposed cuts to caregivers hours for family members like my brother Gary L Padgett as his primary caregiver. I provide personally care that meets his unique needs, allowing him to live comfortably at home. My brother is a disabled veteran who served our country with honors. He's been living with Parkinson's and Dementia and I've been his primary caregiver since June 2020 providing care in our home. With his conditions, my brother thrives in his own home surrounded by family and memories. He needs help getting help getting ready for bed help into bed and assist to the restroom and his showers it's hard for him to get around cause of his Parkinson's and directing with his bathroom and with his meals and I administer all his medication and I drive him to all his Dr appointments. By cutting hours would force him into an institutional care, that would impacting his quality of life and strain to the system. As my brother caregiver I've seen significant process and stability. Please consider the value of family caregivers and the benefits of home based care for veterans like my brother is. I have worked many Nursing homes and some of the care that was given was not like the care these residents could of gotten in their own homes! I know my brothers care here at home that I'm giving him the best care and I know he's safe living in his own home and happy around his environment that' he's used to in his own home!
Sincerely,
Cindy L Padgett

From: Smith, Kristen
To: DHHS HCBS Public Comments
Subject: FW: Please Reconsider the Proposed 40 hour Restriction under the AD Waiver
Date: Monday, January 5, 2026 11:01:21 AM

Sharing.

Kristen Smith | *Deputy Director of Eligibility, Policy, and Quality*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-8704

DHHS.ne.gov | **Facebook** | **Twitter** | **LinkedIn**

From: Steve Volz [redacted]
Sent: Monday, January 5, 2026 10:33 AM
Subject: Please Reconsider the Proposed 40 hour Restriction under the AD Waiver

> You don't often get email from [redacted]. Learn why this is important

To Whom It May Concern,

As a Nebraska resident, voter, and relative of an individual with disabilities, **I am writing to say that Nebraska DHHS would reconsider their proposed 40-hour cap on live-in caregivers under the Aged & Disabled Waiver.**

This proposal will have a direct impact on my brother-in-law, Peter Hegg, as well as our family. He depends on continuous, live-in support in order to safely remain at home—a necessity for his health and well-being. Imposing a strict limit on caregiving hours threatens to interrupt his care, increase risk factors, jeopardize years of progress, and force difficult decisions for our family, which counters the intent of the waiver program.

For nearly thirty years, my In-Laws have made significant physical, emotional, and financial commitments to care for Pete. Their dedication reflects the resilience required of families in similar situations. Implementing this cap would impose undue strain on families already facing considerable challenges.

The current home-based care plan ensures stability, security, and effective support for Pete, preventing institutionalization and promoting dignity. Enforcing a 40-hour cap disregards the ongoing nature of disability and the practical realities families encounter—disability care cannot be confined to a standard work schedule.

The Health and Human Services department has a responsibility to protect vulnerable individuals in Nebraska and to make policy decisions grounded in sound judgment, compassion, and fiscal responsibility. I believe this proposal does not meet these standards as it imposes unreasonable burdens, introduces safety risks for those with complex medical needs, and may drive up long-term costs through increased reliance on institutions or emergency services.

This policy affects real people and families, including my own, and countless others. The proposed limit could destabilize established care for the sake of an arbitrary constraint rather than actual needs.

I respectfully urge you to reconsider this proposal and to advocate for Nebraska families who rely on the Aged & Disabled Waiver to preserve safety and dignity. Please consult with those impacted and utilize your authority to develop policies that safeguard, rather than compromise, vulnerable populations.

I request a response clarifying your position on this proposal and outlining the committee's plans to address the concerns raised by affected families.

Sincerely,

Steve Volz

[redacted]

[redacted]

From: Green, Tony
To: DHHS HCBS Public Comments
Subject: FW: Proposal for A/D Waiver Changes
Date: Monday, January 5, 2026 6:49:58 AM

Tony Green | *Director*
DEVELOPMENTAL DISABILITIES AND AGING
SUPPORTING DIGNITY AND CHOICE THROUGH COMMUNITY CONNECTIONS
Nebraska Department of Health and Human Services
OFFICE: 402-471-6038
DHHS.ne.gov | Facebook | Twitter | LinkedIn

From: lkhegg@cox.net [redacted]
Sent: Friday, January 2, 2026 3:52 PM
To: Green, Tony <Tony.Green@nebraska.gov>
Subject: Proposal for A/D Waiver Changes

> You don't often get email from [redacted]. Learn why this is important

Dear Tony Green,

I am writing in response to the proposed changes to the A/D Medicaid waiver.

Our son is 28 years old and needs 24/7 care. He has multiple cognitive and physical disabilities, uses a wheelchair, and is blind. He also has unique medical issues that need constant monitoring for extra lifesaving medication given through a g-tube or injection.

The deep cuts being proposed would greatly reduce his quality of life by reducing or eliminating the care he receives from his live-in sister. We are currently getting 112 hours per week of paid caregiver time split between Peter's sister and me. The cuts would reduce this to 40 hours per week. Our family has worked hard and sacrificed much to care for Peter and are very thankful for what the waiver has provided. But the cap on hours for live-in caregivers is unrealistic and strongly limits who can provide quality care. Our loved ones should be able to choose their caregivers! We have no "informal supports" and live a very isolated life due to Peters fragile health. We do not have friends or family that are available or qualified to care for him the way he needs or would be comfortable with. Comfort and consistency are extremely important for Peter's health and well-being. Our primary goal has always been to keep him healthy, safe and happy. Reducing hours would cause a complete strain on our lives, affecting those we care for and the life we have taken years to build for Pete. We want to continue to give him the quality of life and purpose that he deserves.

Thank you for considering this,

Lissa K. Hegg- Peter's mother and loving caregiver

From:	Clark, Jennifer J
To:	DHHS HCBS Public Comments
Subject:	FW: Proposed Amendment cuts to the Nebraska Medicaid Home and Community-Based Services (HCBS) Aged and Disabled (AD) Waiver
Date:	Thursday, January 1, 2026 5:40:54 PM
Importance:	High

HI
Here is one to add.

Thanks.

Jenn Clark, LIMHP | *Deputy Director of Community Services*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-7909

From: Mitch Hegg [redacted]
Sent: Thursday, January 1, 2026 3:52 PM
To: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>
Subject: Proposed Amendment cuts to the Nebraska Medicaid Home and Community-Based Services (HCBS) Aged and Disabled (AD) Waiver
Importance: High

> You don't often get email from [redacted]. Learn why this is important

Dear Jennifer Clark,

I felt it imperative that I voice my strong concern and opposition for the proposed cuts to the Nebraska Medicaid Home and Community-Based Services (HCBS) Aged and Disabled (AD) Waiver service hours for the care of our most vulnerable people. These proposed draconian cuts reducing service hours to just 40 hours per week for live-in family members will be devastating and possibly life-threatening to the disabled persons and a significant financial burden on the family caregivers that care for these family members. These are our Sons, Daughters, Parents, Brothers, Sisters, Aunts and Uncles. How have we come to this, that we would introduce and move forward on budget cuts that adversely affect the already difficult lives that aged and disabled loved ones live? It's downright shameful.

I understand that budgets need to make sense, but to cut care hours for people that can't care for themselves. How can you convince yourself that is the right way to balance your budget. I'm sure their other areas that can be cut that don't affect the lives of people that can't take care of themselves.

I sincerely ask you to re-look at what is being proposed, close your eyes and imagine you are doing this to one of your loved ones to save a few dollars in the grand scheme of an entire budget where cuts can be made to things that don't affect the

care of our most vulnerable people.

Every aged or disabled persons care is different; some require a lot of hours spent caring for and helping them to enjoy life and others require less hours. Lumping them all together and setting a maximum number of hours (the propose 40 hours) for all, is just not very caring or loving and frankly it's an easy way to make a cut without providing diligence to truly support and care for all involved, the aged, disabled and caregiver alike.

Our son is 28 years old and has many disabilities that would prevent him from surviving in a nursing home or a group home. He is blind, does not take anything by mouth (he is tube fed), he is incontinent, has cerebral palsy and is on life-saving medications. He requires 24/7 monitoring and care just to survive. Because of our diligent care we have kept him safe and out of the hospital. Bringing "outsiders" in to care for him would be devastating to his emotional state and his physical health and would be drastically more expensive then to just continue to provide the current 112 hours of in-home family care he receives now.

One DHHS employee is stated as saying "You'll be paid for a 40-hour work week, just like other working people" Our son and other aged and disabled people receiving care, don't just stop being disabled or needing care at the close of a 40-hour work week!

If this is all about the budget – what are you doing? How are you convincing yourself that this is somehow the right and prudent course of action?

Due to his emotional anxiety, routine and his life-saving medications he would never survive outside our care, we know him best and understand his unique medical condition that if not monitored throughout the day constantly, he would slip into a medical crisis and not survive. Because we are diligent and know him and his medical crisis signs, we have avoided many hospital stays and emergency room visits over the last 28 years.

Please reconsider the proposed cuts to the A&D care hours! As you can see, we spend way more than 40 hours a week caring for our son. The loss of hours would be a financial burden to all his care givers and a strain on the health of those caring for him by requiring employment outside of caring for our son.

Being leaders requires you to not only evaluate and make decisions but to do it with compassion, care and what is right and not just easy and budget line cuts.

Thank you for taking the time to read and understand our concerns.

Sincerely,
Mitchell Hegg
Father and caregiver for Peter Hegg

From: Clark, Jennifer J
To: DHHS HCBS Public Comments
Subject: FW: Proposed changes to the AD waiver
Date: Monday, December 22, 2025 8:06:25 AM

See below for public comment.
Thanks

Jenn Clark, LIMHP | *Deputy Director of Community Services*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-7909

From: Staci G [redacted]
Sent: Sunday, December 21, 2025 12:51:22 AM
To: Green, Tony <Tony.Green@nebraska.gov>
Subject: Proposed changes to the AD waiver

You don't often get email from [redacted]. Learn why this is important

I am a current respite worker for a 25 year old on the AD waiver. I cannot work there full time, as my full time job offers benefits and more money. His mother is always on the lookout for help, so she can take care of her other children and aging mother, as well as catch some sleep. With his medical complexities, leaving him alone is not an option, as his TBI often keeps him up for days, with tremors, cramps, pain, anger issues, body temperature control issues, and more. This family and others like her need more help, not cuts. Caring for their loved ones at home is cheaper than a nursing home, and more loving for quality of life. As I write this, I just got done reinserting his gtube that was pulled out for the 8th time in the last 24 hours because of pain. In a facility, this would have been a trip to the ER, and at home it is done by family and staff. The things being proposed will hurt Nebraskans, the most vulnerable among us, and those families who love them. We can't let that happen.

Staci Greunke
[redacted]

Get Outlook for Android

From: Clark, Jennifer J
To: DHHS HCBS Public Comments
Subject: FW: Public Comment Opposing the Proposed Changes to AD Waiver Service Limits
Date: Tuesday, December 30, 2025 6:14:01 PM

Hello

Here is an email for public comment.

Jenn Clark, LIMHP | Deputy Director of Community Services
DEVELOPMENTAL DISABILITIES
Nebraska Department of Health and Human Services
OFFICE: 402-471-7909

-----Original Message-----
From: Abbey Morgan [redacted]
Sent: Tuesday, December 30, 2025 7:57 AM
To: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>
Subject: Public Comment Opposing the Proposed Changes to AD Waiver Service Limits

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

I strongly oppose this proposal and the assertion that it does not violate the HCBS Final Settings Rule.

While the proposal may technically allow individuals to remain in their homes on paper, it undermines the actual ability of people with the highest needs to live in the community in a meaningful, sustainable way. The HCBS Final Settings Rule is not satisfied by a mailing address alone. It is measured by real-life outcomes: autonomy, choice, control, and the ability to avoid unnecessary institutionalization.

This proposal restricts those outcomes in several critical ways.

First, the Final Settings Rule requires meaningful choice of providers and respect for individual needs identified through person-centered planning. Many individuals—particularly those with complex medical, behavioral, or sensory needs—do not tolerate unfamiliar caregivers. For these individuals, trusted family providers are not a preference; they are a necessity for health and safety. Eliminating or severely limiting family-provided care ignores individualized assessments and replaces person-centered planning with rigid caps.

Second, the proposal creates a predictable risk of institutionalization, which directly conflicts with the Olmstead decision. When home-based services are insufficient to meet 24/7 needs, families are left with no realistic option other than nursing facilities or congregate settings—despite the fact that family-provided home care is significantly less costly to the state. A policy that forces people out of their homes due to service limits is not neutral; it is structurally institutional.

Third, the Final Settings Rule requires that individuals have control over their daily lives and who enters their home. Forcing unwanted or intolerable outside staff into a person's home is a restriction on autonomy, privacy, and dignity. This is especially harmful for individuals with disabilities who rely on consistency, routine, and trust to function safely.

Fourth, applying hard service caps without adequate exceptions for extraordinary needs overrides person-centered planning, which is a core requirement of HCBS compliance. High-needs individuals cannot be treated the same as individuals with minimal support needs without causing harm. Equity requires flexibility, not uniform limits.

You cannot claim compliance with a rule designed to prevent institutionalization while implementing policies that make community living impossible for those who need support the most. The Final Settings Rule and Olmstead both require that services be sufficient to allow individuals to remain in the most integrated setting appropriate to their needs. This proposal fails that test.

I urge the state to:
• Maintain adequate service hours for individuals with 24/7 needs • Preserve family-provided care as a valid and supported option • Expand, not restrict, exceptions based on individual assessments • Ensure cost-effective home care is prioritized over institutional placement

Policies should support families who are keeping loved ones safely at home—not penalize them for doing so.

From: cale thompson
To: DHHS HCBS Public Comments
Subject: Fw: Public Comment to AD Waiver proposed caps on hours-Strongly urge a pause and update
Date: Tuesday, January 6, 2026 4:49:14 PM

You don't often get email from [redacted]. Learn why this is important

I agree with the thorough comments from my sister-in-law and brother. See below:

Dear Fellow Nebraskans and NE DHHS Team,

I am writing as a Nebraskan, a family member, and a caregiver to urge you to pause and reconsider the proposed cuts to the Nebraska Aged & Disabled (A&D) Waiver, specifically the plan to cap waiver services at 70 hours per week, down from the current allowance of up to 168 hours for individuals with complex needs.

These proposed cuts come on the heels of more than $400 million in tax cuts, followed now by a declared budget shortfall. I am deeply concerned that, rather than addressing this shortfall with care and foresight, the state is proposing a change that would fundamentally dismantle home- and community-based services (HCBS) for Nebraska's most vulnerable citizens; without a viable alternative plan.

Real families, real consequences
Two of my family members currently rely on the A&D Waiver to remain safely in their homes.
One is 91 years old, has advanced dementia, is wheelchair-bound, and requires 24-hour care. Her waiver services cover essential needs: feeding, toileting, bathing, medication administration, transfers, fall prevention, and overnight supervision. Under the proposed cap, she would immediately lose 98 hours per week of essential care. There has been no explanation from policymakers as to how those hours would be replaced; or whether her safety would simply be compromised.
My second family member, age 68, would lose 35 hours per week of critical care under the same proposal.
Both individuals would technically qualify for institutional placement if these cuts proceed. But qualifying for a nursing facility does not mean it is appropriate, humane, or fiscally responsible; nor does it reflect the intent of the A&D Waiver program, which was created to support independence and keep Nebraskans in their homes whenever possible.

The flawed cost assumptions behind this proposal
State discussions have cited an "average" nursing home cost of approximately $92,438 per year, with a proposed cap of 175% of that amount. This framing is deeply misleading.
That average does not reflect:

- Patients with advanced dementia
- Individuals requiring round-the-clock supervision
- High fall risk or total assistance with activities of daily living

These are not "average" patients; and Nebraska does not have sufficient nursing facility capacity, staffing, or specialized care options to absorb a forced influx of high-acuity residents. Pushing people out of their homes does not save money; it shifts costs to more expensive and less appropriate settings, often resulting in higher Medicaid expenditures through institutional care or avoidable hospitalizations.

Workforce and safety realities
Caregiving is already a strained workforce. My family members rely on multiple caregivers, and recruiting and retaining staff is increasingly difficult. While a 70-hour cap might be technically "staffable," it would be unsafe. Caregivers have already indicated they would leave under these conditions, compounding instability and risk.

Federal policy and legal implications
Federal Medicaid policy has long encouraged home- and community-based services over institutionalization, recognizing both the cost-effectiveness and the human dignity of keeping people integrated in their communities.
This proposal appears to violate the spirit, and potentially the letter, of federal HCBS policy, as well as the principles established under the Americans with Disabilities Act and the Olmstead decision. Federally, states are required to provide services in the most integrated setting appropriate to an individual's needs.
Moving forward without individualized assessments, transition planning, or exceptions for complex cases exposes Nebraska to federal scrutiny, compliance risk, and potential legal challenge.

What I am asking
I respectfully but urgently ask that you:

1. **Pause any action** on the proposed A&D Waiver hour caps
2. **Conduct a formal impact assessment**, particularly for individuals with complex medical and cognitive needs
3. **Meet with affected families and caregivers** before advancing policy changes
4. **Create clear exceptions or alternative pathways** for those who cannot safely survive under a one-size-fits-all cap

Nebraska can, and must, balance fiscal responsibility with compassion, legality, and common sense. Cutting life-sustaining home care without a plan does not solve a budget problem; it creates a humanitarian one.

Thank you for your time and for your service to our state. I would welcome the opportunity to discuss this further or share additional detail about how these changes would affect real Nebraskan families.

Sincerely,

Kathryn (Katie) & Tyler (Ty) Thompson
Lincoln, NE

Get Outlook for iOS

From: Cynthia Wiggins
To: DHHS HCBS Public Comments
Subject: Fw: urgent read before January 5th.
Date: Tuesday, December 30, 2025 7:58:39 AM

You don't often get email from [redacted]. Learn why this is important

Sent from my Verizon, Samsung Galaxy smartphone
Get Outlook for Android

From: Cynthia Wiggins [redacted]
Sent: Monday, December 29, 2025 5:44:03 AM
To: DHHS.HCBSPublicComments@nebraska.gov <DHHS.HCBSPublicComments@nebraska.gov>
Subject: urgent read before January 5th.

Budget cuts that affect vulnerable adults should be illegal. It is neglect and dishonor of the most vulnerable people in the state

I am writing in regard to the proposed changes from the state to lessen the amount of money paid ***to in home private providers*** on the AD and DD waiver.

For many people including my husband and myself we quit our jobs, stopped going to school, rearranged our lives to care for our adult disabled children. Knowing that we were relying on the state funding that has helped us for the last 20 years.

We never had an issue of getting paid or fulfilling the obligations of the job and in turn ensured our loved ones were well cared for all while saving the state of Nebraska thousands and thousands of dollars.

The proposed changes will force us to look for work to supplement to help provide for our family. The question is who is going to care for the 1 to 1 people we care for during the hours we are not home. Who is going to diaper our kids, cook their meals during the hours we are off or having to work at a outside job?.

There were no issues with the waiver program until you made everyone get back round checked through Maximus which is costly. Then the last couple of years we started with Tellus and therap(EVV) all which is overhead coming out of the money designed to fund care for our loved ones with special need, not pencil pushers. Then the state went on to hire and sign sizable contracts with various companies because the billing was too difficult for some individuals. **All money being spent should be spent on care for the people we serve, not corporations doing other people's paperwork.** Corporations like these need to be having to suffer from the cutbacks not the private providers. We have already sacrificed our careers and lives for our to care for the ones we love.

I know all this was done to prevent fraud but in reality, all it did was get the people cheating on the system other ways to lie and steal. You're not hurting them you're hurting the people who loved their individuals enough to make the sacrifices needed to be able to care of their loved ones in their homes to keep them safe and out of group homes and nursing homes for as long as we can. **All while saving the state money.**

I would ask you how you and the others at the state level if someone told you in six months your pay is going to be cut by 65% or more, .how would you feel. Think about it how would you and the other congress people feel.

Also, so many people that are qualifying for AD waiver should have to be nursing home level of care not some of the ones approved recently. I have heard from providers that are shocked people are being put on waiver.

My son had a stroke with the effects still evident and a heart transplant he qualifies because without me he will have to live out his days in a nursing home. If you were 38 would you want to live in a nursing home.

Budget cut somewhere else not with the most vulnerable people in Nebraska.

Cynthhia and Randall Wiggins [redacted]

From: Cynthia Wiggins
To: DHHS HCBS Public Comments
Subject: Fw: urgent
Date: Sunday, December 28, 2025 7:33:24 PM

> You don't often get email from [redacted]. Learn why this is important

Sent from my Verizon, Samsung Galaxy smartphone
Get Outlook for Android

From: Cynthia Wiggins [redacted]
Sent: Sunday, December 28, 2025 6:08:18 PM
To: Cynthia Wiggins [redacted]
Subject: Fw:

From: Cynthia Wiggins [redacted]
Sent: Sunday, December 28, 2025 6:06 PM
To: Cyndi Wiggins [redacted]
Subject:

Budget cuts that affect vulnerable adults should be illegal. It is neglect and dishonor of the most vulnerable people in the state

I am writing in regard to the proposed changes from the state to lessen the amount of money paid ***to in home private providers*** on the AD and DD waiver.

For many people including my husband and myself we quit our jobs, stopped going to school, rearranged our lives to care for our adult disabled children. Knowing that we were relying on the state funding that has helped us for the last 20 years.

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Budget cut somewhere else not with the most vulnerable people in Nebraska.

From: Clark, Jennifer J
To: DHHS HCBS Public Comments
Subject: FW: Yesterdays ZOOM meeting
Date: Thursday, December 18, 2025 2:57:58 PM

Hi
Add below email please.

Thanks

Jenn Clark, LIMHP | *Deputy Director of Community Services*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-7909

From: Charlotte and Kevin Endorf [redacted]
Sent: Thursday, December 18, 2025 2:54 PM
To: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>
Subject: Yesterdays ZOOM meeting

> You don't often get email from [redacted] Learn why this is important

I attended the meeting via Zoom yesterday. I also head up the Brain Injury Awareness group of Northeast NE. The numbers keep increasing but last I saw, in NE alone there are about 16,000 new brain injuries per year from falls, car and motor cycle accidents, strokes, aneurysm, etc

At some point nearly every sufferer I know has needed a caregiver. I feel more thought needs to go into the cuts being made. When I was hurt eight years ago, help in the well known facilities in NE wasn't available. We checked out of state also and since I could walk (holding onto walls), I couldn't get help in the well known places desired. Instead I spent 90 days in Omaha being shuttled by Uber and a long term hotel to three therapies three times weekly. I was nursing home material. However, I worked in a nursing home in the 80's. My siblings chose to place our parents there. Did I see improvement or even a decent quality of life for them? No, not like I saw in my own healing. I can tell you true horror stories of nursing home life. They are basically a place to go to die. Not many ever return home. So many have closed causing even more work for each nurse/CNA. When I worked myself through college as a CNA it wasn't uncommon to lift triple your weight. It wasn't uncommon to be responsible for over 30 people each eight hour shift. This obviously is worse care than being at home with living caregivers who know you well.

Double check the numbers. They do not add up. It's cheaper and better to keep the sufferer home. Add PTSD which many of us also suffer to the mix and this mass shift of living circumstances combined with the obvious stress of the parent/family caregivers is going to end in lots of sedation to simply mask the problems.

I am grateful on the progress I have made. I am one of the lucky or I call it blessed. I am speaking for a group from Yankton SD to Madison NE (North and South). ONeill to Oakland NE (East to West). The many abbreviations and small print on the screens yesterday were hard for both me and my caregiver husband who is fine. Not to mention how fast the leaders talked, the inability to type in chat and the dozen or so of us who had our hands up but we're not given any opportunity to talk.

Add the Medicaid volunteer and work changes to this mix and you have about the worst poverty guarantee Christmas gifts for many Nebraskans who worked their tails off before injury and are not asking for handouts but only fairness at a lesser cost.

In my writing and speaking interviews I worked with many who lived WWII and the Holocaust. Hitler chose to eliminate the handicapped. History is repeating itself. This is just a different tactic. It's not a good decision. Please reevaluate and forward this note to all making decisions on this.

Nebraskans are struggling. Many have been forced to get food from emergency shelters due to lack of funds and employment after the brain injury. My house taxes tripled this year after moving to a tiny house when our forever home became too expensive without me working. We should have contested it but I had horrible head pain at the time of the meeting to do so and just couldn't go.

I just took on a two hour a day job, six days a week. Some days are good but days like today with the high winds, the neuro fatigue is unbearable. I have worked for Humanities NE over two decades. I just received their newsletter and see our talks will be cut in half in 2026. Before injury I did 150 plus talks a year myself. My husband helps me now, but what we have worked back up to will be only about $7,000 next year if they don't decide to eliminate the speakers bureau completely like they have done twice in the past. My husband now commutes an hour a day to work and our vehicles have many miles on them. I take Cedar County Transit mostly when I need to go out of town. They just released new, higher rates because of the cuts they are enduring.

Something has to give! Please help.

Charlotte Endorf
Magnet NE

From: janell epp
To: DHHS HCBS Public Comments
Subject: Fwd: A/D Waiver
Date: Tuesday, December 30, 2025 4:10:32 PM

You don't often get email from [redacted] Learn why this is important

---------- Forwarded message ---------
From: **janell epp** <[redacted]
Date: Tue, Dec 30, 2025, 4:09 PM
Subject: Re: A/D Waiver
To: <DHHS.HCBSPublicComments@nebraska.go>,
<DHHS.HCBSPUBLICCOMMENTS@nebraska.gov>

On Tue, Dec 30, 2025, 3:07 PM [redacted] wrote:

> To whom it may concern
>
> I am a individual Provider for my Grand daughter for several years now and I'm concerned about the proposed changes to reduce the amount of hours for her care.
> How can anyone dictate that all handicapped or special needs people will only require 40 hours of care? Each individual requires different types of care and quantity of care. Only a medical professional after testing and a full exam can determine what is needed for each individual. I understand that each individual medical history had to be submitted in order to qualify for DHHS assistance so is that information going to be considered to determine amount of care needed?
> The medical field has been severely under staffed for years so by forcing more handicapped individuals into nursing homes and such facilities is increasing the strain which affects the care they receive. Forcing these individuals to leave their homes and families is inhumane.
> When I asked a retired nurse how a facility would likely care for a person that is non verbal, needs to be fed, dressed, assisted with toiletries and with walking. She said they would more than likely heavily medicate that person. They don't have the staffing to give that kind of individual care.
> Imagine a family member of yours needing this kind of care. What would you want for them? Would you want them cared for by loving family members or in a facility that just can't give them the care they need. They deserve our best care from the time they wake in the morning till bed time. That's more than 40 hours a week.
>
> A concerned care giver and grandmother of a very special person.
>
> Janell Epp

From: Karen Al-Shemmeri
To: DHHS HCBS Public Comments
Subject: Fwd: Changes in AD waiver
Date: Friday, January 2, 2026 10:21:10 AM

> You don't often get email from k[redacted] Learn why this is important

---------- Forwarded message ---------
From: **Karen Al-Shemmeri** [redacted]
Date: Thu, Jan 1, 2026, 10:58 AM
Subject: Changes in AD waiver
To: <DHHD.HCBSPublicComments@nebraska.gov>

To whom it may concern:
On December 5th DHHS released proposed changes to the AD waiver. Part of these changes was to LIMIT live in care giver hours to 40 hours per week. For some of these live-in providers and their clients, this change would be very detrimental. Some of the MOST disabled folks in our state receive the maximum amount of 112 hours per week for their paid care (payment for 16 hours per day of care). Of that group, live-in caregivers provide the majority of those hours. Many of these live-in caregivers are parents or spouses of these disabled people, and many of them have left careers to take care of their loved ones. Some have been caring for their loved ones for 30 years or more. To suddenly cut their hours and income by 72 hours per week is DANGEROUS and very destabilizing for these disabled clients. This could lead to the loss of homes, mental health crises, hospital stays, and possibly death for some of the most medically needy clients.
Families affected by these changes will face severe financial issues. A loss of 72 hours per week at $15.00/hour is a cut of $4320 per month for these households. How will they be able to find jobs that pay that much, as people who have been out of the work force for so long? These families must also balance doctor appointments, hospital stays and the stress of caring for their loved ones, which would make working outside of the home very difficult for them at times. This plan assumes that suddenly, after YEARS of searching, hiring, training and losing paid care givers, that they can find someone to do their jobs. This is further complicated by the fact that these paid caregivers aren't able to administer medications or provide the medical decision-making necessary to ensure proper care for clients at all times, which means our most disabled will be in danger.
This plan will NOT work for the most medically fragile and high needs disabled adults on this waiver. If you are to go forward with limiting live-in care givers to 40 hours per week, you will be forcing people to sell their homes and put their loved ones into nursing home facilities. The waiver program was created in order to stop this exact situation from happening. Also, moving disabled clients into nursing homes will be further complicated by a current shortage of Medicaid funded beds available.
Instead, we propose that since this waiver has enough funds to make it through this year, that you spend this year meeting with the families of these individuals and create a plan that will actually work. I believe there are solutions available in this situation! The current system that's in place was created for individualized care, and there are already evaluations that were created to determine services and hours. If you want to create caps, please do it moving forward--not retroactively and NOT so suddenly and NOT so drastically. Consider

contracting with each family individually (perhaps less agency contracting and more live-in caregiver contracting?), consider a tiered system like DD services use to determine pay rates. Also please consider seeking out the funds you need:
a. Find an agency or non-profit, or create one, and begin to hold an annual fundraiser that gives average Nebraskans and wealthy Nebraskans a chance to care for the disabled of our state.
b. Perhaps the Huskers could run a fundraiser at one home game a year where they advertise the needs of those who are disabled in our state and give a matching percentage of ticket sales that day.
c. Would the Volleyball team and their fans want to help protect the disabled of our state?
d. Ask the Nebraska legislature to allocate more money for this program, due to the rising number of individuals in this program. I believe this sort of thing happens (for example, asking for raises for state employees, you look at the cost of living and then approve a 3-6% raise for your employees). A request for additional funding seems appropriate in this situation.
i. Or perhaps it would be a GREAT time for the legislators to PAUSE or freeze the corporate tax cuts that are creating some of these budget shortfalls?
e. Would Larry the cable guy be willing to help in some way as a Nebraskan with a HUGE platform? Would Warren Buffett want to help? We could ask some of the wealthiest Nebraskans to step up for those who are disabled in our state.

Please consider solutions that are PEOPLE focused, individualized and caring, not just focused on the dollar signs. Thoughtful policy making will ensure that those who are disabled, as well as their families, can continue receiving the care they need and avoid damaging and life-altering circumstances. This waiver program has blessed a whole lot of Nebraskans and allowed them to flourish. It has helped provide dignity and care for so many people! Please consider that as you move forward and make necessary changes.

Signed:
Karen Al-Shemmeri

From: Abbey Morgan
To: DHHS HCBS Public Comments
Subject: Fwd: Inconsistent proposal's Concerns
Date: Thursday, January 1, 2026 6:52:35 AM

You don't often get email from [redacted]. Learn why this is important

Sent from my iPhone

Begin forwarded message:

From: Abbey Morgan [redacted]
Date: January 1, 2026 at 6:47:42 AM CST
To: jennifer.j.clark@nebraska.gov
Subject: Inconsistent proposal's Concerns

1. Conflicting Hour Caps vs. "Health and Safety" Exception Language

What the proposal says
• 40-hour cap for Personal Care + LRI Personal Care when the caregiver is live-in
• 70-hour combined cap for Personal Care + LRI + Companion
• Exceptions may be approved by Central Office to meet immediate health and safety needs

Inconsistency
• The proposal acknowledges that some individuals have needs that exceed 40 or 70 hours for health and safety,
BUT
• It does not align those exceptions with 24/7 care needs, even when those needs are already documented and previously approved.

Why this is a problem
• A person who needs continuous supervision or hands-on care cannot have their health and safety met under a hard weekly cap.
• The exception language is written as temporary or emergency-based, not as recognition of ongoing, permanent high needs.

Contradiction: The proposal admits higher hours are sometimes required, but structures the system so those needs cannot realistically be met long-term.

—

2. Provider Restrictions Conflict With Tolerance, Routine, and Disability Needs

What pages 127–128 do

• Strongly limit who can provide care:
• Live-in family caregivers capped lower
• Greater reliance implied on non-family or agency providers
• Treats family care as something that should be restricted, not individualized

Inconsistency
• The proposal:
• Claims to be person-centered
• References health and safety
• But ignores the reality that:
• Some individuals do not tolerate unfamiliar caregivers
• Routine and trust are medically necessary, not preferences

Conflict: You cannot claim person-centered planning while forcing care from providers the individual cannot safely tolerate.

—

3. Unequal Treatment Based on Provider Type, Not Need

What the proposal does
• Two people with the same assessed needs can receive very different hours depending on:
• Whether care is provided by family
• Whether they can tolerate outside staff

Inconsistency
• The waiver is supposed to be needs-based, yet:
• The cap applies more harshly to family providers
• Individuals who cannot accept outside providers are effectively penalized

Result: The proposal creates artificial scarcity, not based on needs, but on provider category.

—

4. Cost-Containment Language Conflicts With Actual Cost Outcomes

What's implied
• Caps are justified as cost control

Inconsistency
• Family caregivers:
• Are paid less than agencies
• Cost far less than institutional care
• Restricting family hours:
• Pushes individuals toward nursing facilities or higher-cost settings
• Violates the stated intent to be fiscally responsible

Contradiction: The proposal limits the least expensive care option while risking

the most expensive outcome.

—

5. Olmstead & HCBS Final Settings Rule Conflict (Indirect but Real)

Even though not named directly on pages 127–128, the conflicts are clear:
• Olmstead requires services in the most integrated setting
• Final Settings Rule requires:
• Choice of providers
• Services that support remaining in the community

Inconsistency
• Caps + provider limits:
• Reduce meaningful choice
• Make home care unsustainable for high-need individuals
• Increase risk of institutionalization

This puts the state at odds with federal intent, even if not explicitly acknowledged in the proposal text.

—

6. Summary of Core Inconsistencies (Plain Language)
• The waiver says health and safety matter, but caps make safety impossible for some.
• It says person-centered, but applies blanket limits.
• It says choice of provider, but restricts family care.
• It says cost-effective, but undermines the lowest-cost option.
• It says community-based, but increases institutional risk.

Thank you for your time to read through found inconsistencies and detrimental conflicts. These impact wellbeing and safety In the most immeasurable ways.

From: A Downs
To: DHHS HCBS Public Comments
Subject: Fwd: InterRAI appeals, all denied
Date: Monday, January 5, 2026 1:25:42 PM

You don't often get email from [redacted] Learn why this is important

Please address this situation:

---------- Forwarded message ---------
From: **A Downs** [redacted]
Date: Mon, 5 Jan 2026 at 10:47
Subject: InterRAI appeals, all denied
To: <dhhs.DDDCommunityBasedServices@nebraska.gov>

I received this email from DHHS this morning:

_____

RE: Records Request Reference # R065807-121525

Good morning,

Thank you for your public records request dated 12/15/2025 8:00:00 AM seeking:

I am submitting this formal public records request for the total number of InterRAI DI funding appeals related to the Division of Developmental Disabilities that were denied, including the number of administrative hearings held and their outcomes, from the beginning of its implementation July 1, 2025 to the present date.

The program provided the following information, which is responsive to your request:

- There have been 152 DD InterRAI appeals. Of those, 44 have been affirmed and zero reversed. 108 are still in process as of December 30, 2025.

Please be advised that public records law allows for a charge for the actual cost of collecting, reproducing, and mailing the records you have requested; however, there is no cost for this request.

Sincerely,

Nebraska DHHS Public Records

_____

Can we please address the fact that ALL 44 appeals have been denied? Something is not right. This is not "Person Centered Planning" and definitely not "Helping people live better lives".

From: Jodi Tolman
To: DHHS HCBS Public Comments
Subject: Grandfather in current participants at current levels (below 175% institutional cost level)
Date: Saturday, December 27, 2025 10:23:42 AM

> You don't often get email from [redacted] Learn why this is important

Dear DHHS,

I am an independent provider on the AD Waiver for my adult daughter with severe disabilities and complex medical needs, requiring 24 hour/day care. I have major concerns about the proposals presented in the renewal of the AD Waiver, specifically the 40 hour/week limit placed on live-in family caregivers.

GRANDFATHER IN CURRENT PARTICIPANTS AT THEIR CURRENT LEVEL OF HOURS FOR LIVE-IN FAMILY CAREGIVERS

I understand and recognize the need for budget management as more partcipants are served by the waiver. I strongly recommend and request that instead of cutting hours so significantly to current participants, that you **grandfather these participants in** and allow us to keep our current number of hours as live-in family caregivers. I plead with you to please allow existing participants to keep the number of hours they currently have for live-in family caregivers, and only place the 40 hour/week restriction on new in-coming participants moving forward.

Grandfathering in current partcipants, exempting them from the proposed changes, will allow you to control future spending, without causing such severe hardship to current live-in caregivers who have already quit other careers to work full-time caring for their loved one. These live-in family caregivers are a critical and valuable part of reducing care costs at the state level and should continue to receive support from the state as they have been receiving.

I understand that a small percentage of participants are currently above the proposed 175% of institutional care cost limit. **I urge you to bring down those participants to that 150-175% level, and allow all other participants already below the 150-175% level to maintain their current number of hours approved for live-in family caregivers.**

Live-in family caregivers are a valuable resource for the state. Utilize us appropriately! Pay us what we are worth! Don't disrespect us or take advantage of us by assuming we will provide care for free! Continue to compensate us reasonably and equitably, or risk losing a large portion of these family caregivers. Losing live-in family caregivers will only cost the state more to pay for agency providers, or create even bigger financial and logistical problems with a surge of participants suddenly requiring institutional care.

I plead with you to grandfather in live-in family caregivers, and exempt us from the new weekly limits proposed in the AD Waiver renewal.

Respectfully,

Jodi Ann Tolman

From: Jodi Tolman
To: DHHS HCBS Public Comments
Subject: Grandfathering in of current participants at current hours, and other considerations
Date: Saturday, December 20, 2025 2:28:05 PM

> You don't often get email from [redacted]. Learn why this is important

Dear DHHS,

I am an independent provider on the AD Waiver for my adult daughter with severe disabilities and complex medical needs, requiring 24 hour/day care. I have major concerns about the proposals presented in the renewal of the AD Waiver, specifically the 40 hour/week limit placed on live-in family caregivers.

GRANDFATHER IN CURRENT PARTICIPANTS AT THEIR CURRENT LEVEL OF HOURS FOR LIVE-IN FAMILY CAREGIVERS

I understand and recognize the need for budget management as more partcipants are served by the waiver. I strongly recommend and request that instead of cutting hours so significantly to current participants, that you **grandfather these participants in** and allow us to keep our current number of hours as live-in family caregivers. I plead with you to please allow existing participants to keep the number of hours they currently have for live-in family caregivers, and only place the 40 hour/week restriction on new in-coming participants moving forward.

Grandfathering in current partcipants, exempting them from the proposed changes, will allow you to control future spending, without causing such severe hardship to current live-in caregivers who have already quit other careers to work full-time caring for their loved one. These live-in family caregivers are a critical and valuable part of reducing care costs at the state level and should continue to receive support from the state as they have been receiving.

I understand that a small percentage of participants are currently above the proposed 175% of institutional care cost limit. **I urge you to bring down those participants to that 150-175% level, and allow all other participants already below the 150% level to maintain their current number of hours approved for live-in family caregivers.**

AGENCY PROVIDERS COST THE STATE MORE THAN TWICE THE COST OF INDEPENDENT PROVIDERS

The AD Waiver renewal proposes that additional hours given to the participant beyond the 40 hour/week live-in caregiver limit must be provided by an outside agency provider. I urge you to consider the additional cost this puts on the state! As an independent provider, I am paid

$13.93/hr (increasing to the minimum wage requirement of just $15/hr in January 2026.) Compare that to how much it costs the state to pay for an agency provider to work those same hours:

Cost to provide just 30 additional hours per week:

Independent provider (family live-in caregiver): $15/hr x 30 hrs/wk x 52 weeks = **$23,400/year**

Agency provider (outside caregiver): $35/hr x 30 hrs/wk x 52 weeks = **$54,600/year**

By paying an independent provider (live-in family caregiver) instead of an agency, the **state will save $31,200/year on just ONE participant!** Multiply those savings by hundreds of partipants and that is huge savings for the state.

Those savings are magnified even further when you consider that my daughter, as well as many others on the AD waiver, will most likely qualify for more than 70 hours/week based on their level of medical complexity and their need for 24 hour/day care.

It makes no financial sense to require additional hours to be worked by agency providers who cost the state far more money than independent providers.

You have already grandfathered in parents like me who are parent independent providers, exempting us from the new policy that requires new parent caregivers to work through an agency. Use this to your advantage as a way to save even more money by paying us instead of more expensive agency providers for additional hours.

The other issue with requiring additional hours to be worked by agency providers is that most agencies do not have the providers to support the huge need that these waiver proposals will suddenly create, leaving huge gaps in care and increasing the need for institutional placement.

IF A PARTICIPANT, BASED ON NEED, QUALIFIES FOR MORE THAN 40-70 HOURS/WEEK IT IS IRRELEVANT WHO WORKS THOSE HOURS.

If a participant is evaluated based on need and is determined to qualify for additional hours up to the 150% or 175% institutional cost limit, why does it matter who works those hours?! If you are willing to pay that money to agencies, why not save money by paying the live-in family caregivers at an even lower wage?! **It is inconsistent, contridictory, and discriminatory to determine that a participant requires a certain number of care hours per week, but restrict**

who is allowed to work those hours.

Live-in family caregivers should receive AT LEAST the average cost of institutional care at a MINIMUM! That is the whole purpose of the waiver—to provide a COST-NEUTRAL alternative to institutional care. You are proposing that live-in family caregivers receive just $31,200/year ($15/hr x 40 hrs/wk x 52 weeks)—only ONE-THIRD of the average cost of institutional care! That is unreasonable and unacceptable.

Live-in family caregivers are a valuable resource for the state. Utilize us appropriately! Pay us what we are worth! Don't disrespect us or take advantage of us by assuming we will provide care for free! Continue to compensate us reasonably and equitably, or risk losing a large portion of these family caregivers. Losing live-in family caregivers will only cost the state more to pay for agency providers, or create even bigger financial and logistical problems with a surge of participants suddenly requiring institutional care.

I plead with you to grandfather in live-in family caregivers, and exempt us from the new hourly limits proposed in the AD Waiver renewal.

Respectfully,

Jodi Ann Tolman

From: Waylon Vajgrt
To: DHHS HCBS Public Comments
Subject: HCBS A & D Waiver open comment
Date: Monday, January 5, 2026 3:18:21 PM

You don't often get email from [redacted]. Learn why this is important

I respectfully submit this comment to express deep concern about the ethical implications of the proposed cost controls in the Aged and Adults and Children with Disabilities (A&D) HCBS waiver renewal, particularly in the context of efforts to address the state's budget shortfall.

Home and Community-Based Services exist because Nebraska, like the rest of the nation, recognized a fundamental truth: people with disabilities, older adults, and medically complex children deserve the opportunity to live in their homes and communities with dignity, safety, and meaningful choice. These services are not optional conveniences. They are essential supports that allow individuals to survive, participate in family life, and remain connected to their communities.

Balancing a budget by limiting access to these supports raises serious questions about whose well-being is being prioritized. When fiscal pressures are resolved by placing greater constraints on those with the highest needs—and the fewest alternatives—it shifts the cost of public shortfalls onto individuals who are least able to absorb them. This approach conflicts with widely held values of fairness, shared responsibility, and compassion.

For many participants, reduced services do not simply mean inconvenience; they mean unsafe living conditions, caregiver burnout, preventable medical crises, or forced entry into institutional settings. These outcomes are inconsistent with the stated purpose of the A&D Waiver and with Nebraska's longstanding commitment to community-based care.

Ethically, policies should be evaluated not only by their fiscal impact, but by their human impact. A system that preserves budget stability by eroding independence, dignity, and stability for people with disabilities risks losing sight of the values that underpin public service. Community-based care reflects a collective decision that we are stronger—and more just—when we support people where they live rather than isolating them in institutions.

I urge the Department to reconsider proposals that place a disproportionate burden on vulnerable populations and to pursue solutions that uphold Nebraska's values of inclusion, respect, and shared responsibility. Fiscal challenges should be addressed in ways that do not compromise the health, dignity, and community participation of those who rely on HCBS services.

Thank you for the opportunity to share these concerns and for considering the human impact of these proposed changes.

Sincerely,
Waylon Vajgrt

From: M Hare
To: DHHS HCBS Public Comments
Subject: HCBS Public Comments
Date: Friday, January 2, 2026 5:53:00 PM

You don't often get email from [redacted] Learn why this is important

Mr. Matthew G. Hare
Mrs. Jennifer J. Hare
[redacted]

December 31, 2025

Nebraska Department of Health and Human Services
Division of Developmental Disabilities

Re: Public Comment on Draft HCBS Waiver NE.018.08.00 – Impact of 40-Hour Cap and Program Design on My Disabled Daughter's Care

To Whom It May Concern:

I am writing as the parent and primary caregiver of my disabled daughter, who is certified as disabled by Social Security, Medicaid, and Nebraska DHHS, and who receives services under the [Aged and Adults and Children with Disabilities] Home and Community-Based Services (HCBS) waiver. I currently provide approximately 12 hours per day (about 84 hours per week) of in-home care and am an authorized paid caregiver under this waiver.

The draft HCBS waiver renewal (NE.018.08.00), effective July 1, 2026, proposes major changes to service limits, including a combined 40-hour per week cap on Personal Care and LRI Personal Care for live-in caregivers, with a 70-hour combined maximum for certain non-live-in services. I am deeply concerned about the impact these changes will have on my daughter's health, safety, and quality of life, and I respectfully submit the following comments.

A 40-hour weekly cap for a live-in legally responsible caregiver completely ignores the certified hours necessary to fully support my daughter. Her current authorization for approximately 84 hours per week was not created casually. It reflects her documented medical, behavioral, and functional needs as evaluated by Social Security, Medicaid, and DHHS.

Reducing paid caregiving time to 40 hours per week would create a large, obvious gap between what is clinically required and what is funded. In practice, this would either leave critical care needs unmet, or push me, as her parent, to provide the remaining hours entirely unpaid. Neither outcome is consistent with the purpose of HCBS waivers, which is to provide

sufficient supports to allow people to remain safely in their homes and avoid institutionalization.

To make up the difference between the 40-hour cap and my daughter's true needs, the draft waiver appears to assume that additional hours can simply be covered by hiring other caregivers, up to a 70-hour combined total for certain services. This looks straightforward in policy, but it does not reflect reality for my daughter or many others.

The additional 30 hours per week (or more, in high-need cases) effectively mandates bringing strangers into a very intimate and vulnerable setting. For my daughter, whose disability already causes significant distress and anxiety, the introduction of unfamiliar people into her home would almost certainly amplify that distress. The presence of multiple rotating caregivers can undermine her sense of safety, erode trust, and trigger behavioral and emotional crises. Continuity of care and the consistent presence of a trusted caregiver are not luxuries for her – they are essential components of her ability to function and remain stable.

The assumption that additional hours can easily be covered by outside providers also ignores the severe workforce shortages we are facing. In our community, particularly as a rural area, there is a profound lack of qualified para in-home health care providers. It is would be challenging to find and retain individuals who are willing and able to provide the level of complex, intensive care that my daughter requires.

Even if potential workers existed, the process of recruiting, vetting, training, scheduling, and paying them is complex and burdensome, especially for families already stretched thin by caregiving demands. At the same time, our rural area lacks local facilities or realistic institutional alternatives. For us, and many families like ours, in-home care by a family caregiver is not only the preferred option; it is often the only humane and feasible option.

If the draft waiver is approved and implemented as written, it will likely force many high-need individuals into institutional settings because their families simply cannot cover the unfunded hours of care. For families who cannot safely maintain care at home within a 40-hour paid cap, institutionalization may become the only option, even when the individual strongly prefers to remain at home.

This outcome would separate disabled individuals from the caregivers they trust most, disrupt critical family bonds, and expose them to the risks and trauma associated with institutional environments. It would also be significantly more expensive for the state. The cost of institutional care routinely exceeds the cost of supporting intensive, familial in-home care, particularly when considering long-term outcomes and quality of life. From both a human and a financial perspective, maintaining robust support for family caregivers at home is far more aligned with the goals of HCBS and sound public policy.

The waiver text references the possibility of exceptions to the 40-hour cap for live-in legally responsible individuals, but does not provide enough detail about how those exceptions would work. The criteria, process, timelines, and standards for approval are not clearly defined in the

publicly available draft.

Without this level of detail, it is impossible for the public to fully understand how the proposed policy would function in practice or to offer truly informed comments. Families like mine cannot tell whether our loved ones would realistically qualify for an exception, how stable those exceptions would be over time, or whether they would be subject to frequent review and potential reduction.

For public comment to be meaningful, stakeholders must be able to see not only the headline caps, but also the specific mechanisms that might mitigate their impact in exceptional cases. I strongly urge DHHS to publish clear, detailed guidelines for exceptions to the 40-hour cap and to allow additional public comment once those details are available.

While I understand that funding constraints may be a major driving force behind the new waiver proposal, I believe some recent program history is important to consider in evaluating the current situation.

In the last couple of years, numerous individuals who qualified for the waiver program were determined eligible through the Developmental Disabilities (DD) process but were then moved over to the Aged and Disabled (AD) side of the ledger. This administrative decision significantly increased the overall cost of the AD program, because participants who could have been served under DD were instead counted against AD capacity and costs.

Communications from DHHS and other decision makers have framed this waiver renewal and the proposed hour caps as necessary to keep the AD program "solvent." However, the prior decision to shift many participants from DD to AD substantially contributed to the current cost escalation on the AD side. It feels disingenuous to move a large number of people to the AD waiver, thereby driving up its expenses, and then cite those elevated costs as a reason to impose harsh new caps on family caregivers or to declare financial stress and "insolvency."

If program design and cross-program shifting contributed to the current cost profile, that should be acknowledged openly. The solution should not be to restrict essential care for the very individuals whose needs have not changed, simply because they are now counted in a different category on the state's ledger.

Given these concerns, I respectfully request that DHHS and the Division of Developmental Disabilities:

- Re-examine the rigid 40-hour cap for live-in legally responsible caregivers in light of individuals whose documented needs significantly exceed that limit.
- Ensure that, at a minimum, the exception process is clearly defined, transparent, timely, and realistically accessible, with criteria that fully recognize the lack of provider availability and the importance of continuity of care.

- Consider the real-world impact of these changes in rural and frontier areas, where there are few or no alternative providers or facilities, and where institutionalization would be both traumatic and far more expensive than sustaining family care.

- Acknowledge and address the role that prior administrative decisions — such as shifting participants from DD to AD — have played in driving current AD cost concerns, rather than placing the primary burden of cost control on disabled individuals and their families.

- I further, respectfully ask DHHS and state leaders to also consider alternative funding strategies rather than primarily cutting supports to disabled individuals and their families. Specifically, I urge you to examine broader state-level revenue and policy options that could help stabilize and sustain the waiver program.

    - This should include reconsidering the recently enacted graduating income tax reduction, which reduces the resources available for vital services like HCBS;

    - Exploring a dedicated funding mechanism linked to new large-scale economic developments in Nebraska, such as the Elk Creek Minerals Project (Niocorp's Elk Creek Project); and

    - Incorporating the recently announced hundreds of millions of dollars Nebraska is set to receive from the Rural Health Transformation Program authorized in the 2025 Big Beautiful Bill Act. A small, targeted share of these new or enhanced revenue streams could be directed to support long-term care and disability services, helping keep the waiver program solvent without shifting the burden onto the most vulnerable Nebraskans.

I appreciate the state's efforts to maintain and improve HCBS programs and to ensure fiscal responsibility. At the same time, I urge you to prioritize the health, safety, stability, and preferences of disabled Nebraskans like my daughter, who depend on consistent, trusted, family-based care to remain in their homes and communities.

Thank you for considering these comments. I would welcome the opportunity to provide more specific information about my daughter's situation and the real impact these proposed changes would have on her daily life.

Sincerely,

Matthew G. Hare, M. Ed
Jennifer J. Hare
[redacted]
Parents and Legally Responsible Individual for Disabled Daughter

From: Sarah Henderson
To: DHHS HCBS Public Comments
Subject: HCBS Waiver Changes
Date: Thursday, January 1, 2026 9:44:04 PM

You don't often get email from [redacted] Learn why this is important

HCBS Waiver Decision-Makers

I am writing because we heard about the proposed changes to the AD waiver and while we have seen many changes over the last few years, none were detrimental to the care and well-being of the patients - it just made providing care more tedious, time-consuming and finicky for the providers. The changes proposed at this point would significantly reduce the care AD waiver clients would receive in many ways. In our eldest son's case, it could be fatal to himself or others around him.

We live in an extremely rural area. We have done foster care for over 20 years. Our eldest son, who is now 28, was adopted from foster care at age 8. He was, and still is, severely disabled. He functions around a 10 month age level, even lower in some areas! He was exposed to meth and alcohol prenatally, he has epilepsy, non-verbal, autism, severe mental retardation, cerebral palsy, hydrocephalus, has a VP shunt, missing a part of his brain, incontinent, severe food allergies/intolerances...and these are just the main diagnoses. He requires 24 hour care and is a danger to himself if left unattended. He only sleeps about 4 hours per night, and requires multiple bad checks through the night. He is incapable of doing any of his ADLs on his own - teeth brushing, bathrooming, showering, shaving, diapering, laundry, dressing, etc. Literally everything must be done for him. He does not like to wear clothes, so he can pull on clothes hard enough to tear them off. Then he is sitting naked. We dress him multiple times an hour to keep clothes on him. He tears his diapers off so we go through a tremendous amount of diapers - that we provide at our own expense. He is incontinent and has multiple sets of bedding - which can sometimes be changed multiple times per night. We then in the morning start the routine of washing all his bedding - at least two loads per day of just bedding, plus more loads of his clothes each day that must be washed daily to prevent odor from the urine and /or feces on them. He also will smear feces if we don't catch it instantly and change his diaper. We have manufactured many different types of clothing modifications to try and keep him dressed and socially acceptable. This is also at our expense. If he didn't have us sitting with him non-stop he would sit there naked. He has seizures with little to no notice. He must have somebody with him at all times because he doesn't understand what is happening to know he needs to get himself somewhere safe when he falls. More than once we have caught him and laid him down and kept him safe until the seizure stopped. He would be unable to tell us he was going to have a seizure, had a seizure or needs medication. This requires someone to be by his side at all times. He has very lax muscles and stiff joints - this means that his joints lock and he falls VERY easily. He cannot stand straight up and is very sway backed - we have done extensive PT with him to get him able to stand - when he came he was barely able to hold himself upright sitting. All his PT exercises are things we do FOR him. When he does walk he is an absolute fall risk and the smallest thing will trip him. He must have somebody walk by him and go through all transitions - sitting to standing, standing to sitting,etc. He knows how to turn water on and REALLY likes water. Without somebody supervising him he would flood a house in a heartbeat and then be unattended with slippery water wherever it may have been spilled. He has severe food allergies and intolerances that must be monitored. We shop for, prepare, and feed him all of his food. If he had no supervision he would eat anything he wanted that is within sight. He will pick up an apple and put the ENTIRE thing in his

mouth. His food must be presented to him in a non-choking way and in moderation so he doesn't eat himself into sickness. He is obsessed with heat. He cannot be alone near furnaces, fireplaces, space heaters - he will push buttons and touch hot things. He has no understanding of what safety is, even when having an injury or negative consequence - he also doesn't learn to make a better choice either. If he would burn himself on a space heater, he would not know to not do that again. He loves water and has tried jumping off a cliff before to get into the river. He has tried leaving hotel rooms to get to a pool. Anywhere there is water, there is danger for him. There are many more things that I am sure we do on a regular basis because we have modified and done them for so long that we don't think about them.

I point out all the above things so that you can see he is a full-needs, 24-hour care disabled adult. He MUST have somebody with him at all times. If we would place him in a nursing home, any mobility would be taken from him due to the fall risk. He would require a nurse to be by his side 24-7. I have to assume that his own parents who know him best and share his care is better for him than strangers in a facility setting. If the new rule is put into place that only one caregiver inside the home could be paid for 40 hours, then he will be left without a caregiver. We have tried since he was young to find respite and have never been successful. It is not a fun job to change a feces filled diaper of an adult, let alone for the $15/hour that the waiver provides. We are so rural that anybody coming to help care for him would likely be driving 90 miles ONE way to get to him to provide care. We got one agency, ONE time to get a caregiver to come out ONE time - EVER - in 10 years! My husband and I are his two main care providers. We have a couple family caregivers who step in to help occasionally but they are not able to provide care after one of us hits 40 hours. He will be left without a caregiver. Since we qualified for the AD waiver our family has been able to provide the best care for him. If his hours are taken away - we will still have to provide the care - because there is NOBODY who will do it in our area. If we are forced to place him in a nursing home it will not be best for him and it will cost the state more than his care if he remains at home on the AD waiver. Why not remove the overtime for in-home caregivers then the state can save money - as I assume this is all about funding and obviously nothing to do with quality of life or patient care, and the patients will still have the best care from people who love them.

At one point, if I understand correctly, I saw an email about TBI waiver getting a monthly stipend for their participants care. Why not consider that with these waiver participants who require over 40 hours and are able to live at home. Then you could eliminate the overtime cost and still save money, but the participant care would remain the same. There is a tremendous amount of money paid to agencies to send caregivers out to patient homes- what about family in-home caregivers receiving a small portion of that instead- many costs would be eliminated for the state, much oversight would not be needed, EVV would be unnecessary.

I feel like while the states attempt to save money, they are putting many different types of disabled adults into one box with what they see as a solution and it's not a one-size fits all solution. Our son must have constant supervision and care - that is not possible when the 40 hour limit for one caregiver is put into place. Who will take care of him? I could see if a patient has caregivers come into their home that a 40 hour limit would make sense....they could rotate caregivers who come to them, because they obviously already live somewhere they can obtain care. But when they live at home with their caregiver (or in our case 2) - it just doesn't make any sense. I also believe the cost savings with this plan will cause more expenses to arise in medical bills and nursing home costs, which of course defeats the purpose of placing these cost saving measures into place in the first place.

Please allow us to continue caring for our adult son while we can. At this time we give him the best chance at the fullest, happiest, safest life possible!

Thank you for your time,

Sarah Henderson

From:	Sue
To:	Corsi, Steve; Abbott, Melinda; Clark, Jennifer J
Cc:	Scully, Jena; makayla@arc-nebraska.org; Green, Tony; Houseman, Karen; Ashli.Clark@cms.hhs.gov; sberan@leg.ne.gov; Sen. Ben Hansen, B.; Sen. Brian Hardin; Quintero, Katie; ombud@leg.ne.gov; sclouse@leg.ne.gov; Dan Quick; gmeyer@leg.ne.gov; Merv Riepe; Sen. Terrell McKinney; Mark Kolterman; DHHS HCBS Public Comments; OEOCR@cms.hhs.gov; bernice.denbow@cms.hhs.gov; Barbara.Cotterman@cms.hhs.gov
Subject:	HELP fight NE DHHS
Date:	Monday, December 22, 2025 3:16:18 PM

Nebraska DHHS is trying to force severely handicapped into alzheimer units and take them out of family homes. They are wanting to pay only $600 to $700 a week for families to live on. Health insurance would take 2 weeks paycheck for just health insurance. People can't live on 40 to 70 hours at almost minimum wage. DHHS isn't even paying the rates determined by the rate study. Families shouldn't have to volunteer more than the 56 hours. DHHS is trying to punish people who keep these individuals in their home. Why does Nebraska want to lock these individuals up? What have they done wrong. For a severely handicapped person, care without benefits should be $25-$30 an hour for the 70 hours. Each individual in the home should be able to get that at $25-$30 hour. We don't even get sick time, retirement holiday pay, vac etc. We give up alot to care for these individuals. Now Nebraska wants us to choose between bankruptcy or putting the individuals into an institution!!!

The state said 40 hours is full time, yet the want 3 people to share the 40 hours, which is only 13 hours per week per person, to live on. How can people live on 13 hrs per week? Then the state is expecting non parents to even volunteer hours if they live in household. When we already volunteer 56 hours a week, why do they even expect us to volunteer more hours than this? They expect us to pay a lot of their expenses to the special needs person, in addition to the 56 hours we are expected to volunteer now.

We need to get a class action law suit for the state to try and force individuals into institutions and not allow them to live in homes and not able to choose their own caregivers.
They need to be able to choose whomever they want to care for them. They should not be punished for living with their family. The Supreme Court has already ruled that it is their legal right as an individual!

The State of Nebraska, DHHS, needs to be stopped!!

Sent from Proton Mail for Android.

-------- Original Message --------
On Monday, 12/22/25 at 14:10 Sue <farmgirl2016@protonmail.com> wrote:

> The clients have a set amount of hours of care that they need. How can DHHS say they will not pay for the hours a severely handicapped person requires?
>
> When the states says they will only pay 40 or 70 hrs a week when the individual requires 24 hr care, no family homes will be able to keep individuals the family home. They would have to go to an alzheimer unit for that amount of care. This would be the same as locking up in an institution with absolutely no quality of

life!!!

Aren't clients supposed to be able to choose their caregivers? Why is DHHS taking those rights away? Why does DHHS want to lock them up in an alzheimer unit away from their family and friends. That is what would happen if they lower hours to 40 or 70. Families not only have to pay the expenses of their household, but also pay the majority of expenses for the disable person also.

By being a full time caregiver, we are giving up paid health insurance, paid holidays, paid vacation, paid sick time, retirement benefits etc. They are also giving up their quality of life being able to do a lot of things.

When you consider how much it costs for all of those benefits a lot employees get, DHHS is not over paying live in caregivers. Consider how much it costs the state for employee benefits per person.

Sent from Proton Mail for Android.

-------- Original Message --------
On Monday, 12/22/25 at 13:46 Sue [redacted]

> Other questions,
>
> When limiting hours to people that live in household, I was able to get my daughter Kristina, from Florida, to move in with us to help me out. This would mean that she would have to move because she would lose her income.
>
> Even if it went to 70 hours, the income would drastically affect families. Now families have to pay alot of a clients expenses to enjoy life. For example traveling to Florida. DHHS would be preventing Tiffany from traveling because we could no longer afford it and DHHS would not pay expenses for others to take her.
>
> When a client is profoundly handicapped and needs 24 hr care, you are already making parents volunteer some of their time each day.
>
> It is also expected that parents have to cover a lot of expenses for the person they are caring for. How does putting parents at poverty levels of benefit for anyone?
>
> Without enough pay to live, how does forcing a client into a alzheimer unit give them any quality of life. Hasn't the Supreme Court already ruled you can't do that? Yet if parents can't afford their adult individual to live in their home, isn't that what you are going to do?

When a client has been determined to need 24 hr care, why does it matter who provides the care? It is based on needs of the client.

How can DHHS stop individuals from enjoying life and doing g things with family and out in the community? That is what will happen if you take away the families income. Families will no longer be able to afford caring for their adult client. This is a lose lose situation. I took over a 50 percent cut in pay and lost all of my benefits by caring for my daughter. She was in and out of the hospital so much, that I couldn't work the hours needed and to keep her safe.

When individuals work full time jobs, most aren't minimum wage. To hire an agency in my area to help out, the wages would be over $50 and Hour and the want overtime for weekends, holidays and over 40 hrs a week. It is cheaper to pay the parent than an agency. Tiffany needs the same the same hours. Parents shouldn't have to go to work for an agency.

DHHS is already paying much less an hour for parents than what the pays rate in our state should be. If DHHS is going to require agencies to come into the home for those hours, it will cost the state 2 to 3 times money than what they pay currently.

What will happen if I have to get outside job and use an agency and there is not enough people to cover all of the hours?

You say 40 hours is full time for one person, but you want 3 people to share those 40 hours, that isn't full time for anyone.

Sent from Proton Mail for Android.

-------- Original Message --------
On Sunday, 12/21/25 at 12:30 Sue [redacted] wrote:

> Didn't mean send yet.
>
> When client is traveling with provider instead of with family. So if going to Omaha and 8 hrs will be up, who

is going to pay other caregiver to travel along in their vehicle until their time starts. Does that mean that client may not be able to sit with family to eat at restaurants?

So that the provider, who has gotten loans based on their income, does not go bankrupt, are you going tobat least double the pay rate? A family can't live on $600 a week take home pay.

Clients are suppose to be able to choose their own caregivers. How can you limit the hours of most qualified providers because of money and then you create safety issues for individuals with medical issues?

This is all the questions I have for next meeting. After I hear these responses I will probably have more questions.

Sue Coles

Sent from Proton Mail for Android.

-------- Original Message --------
On Sunday, 12/21/25 at 12:04 Sue [redacted]:

> Good morning,
>
> Please read these questions for next meeting and tell us if you have come up with a plan to address these issues yet, or if you are still working on it. We feel that DHHS in restricting a clients rights to travel, spend time family, etc. This is against the law. A Disabled person is allowed to travel and do things the same as you and I.
>
> 1. How are you going to address limiting the clients rights to spend time with family, if you are saying a stranger has to take them. I believe that a disabled person has a right to do things with their family and is the State trying to prevent that when there isn't enough room, for example in the car while

traveling, for an additional person. Isn't the individual allowed to travel with the family?

2. When traveling for up to 3 months, who is going to pay the additional expenses of the providers such as mileage, motel, food, cost to get into zoos parks etc?

3. If DHHS is not going to pay these expenses, you are restricting the clients rights to travel. The client has a legal right to travel and i would guess an outside individual isn't going to want to pay all of the travel expenses to take the client. These clients are poor and don't have the money to pay for it themselves.

4. If my retired husband doesn't want strangers in house with him all day, is provder to sit it car with them? A man doesn't want to be alone with a strange woman all day, including while he's showering.

5. A family can't live o $600 a week income. It wouldn't even be enough to cover health insurance and house payment each month. How about car payments, home and auto insurance, food, utilities, cable, car gas, entertainment, travel expenses etc?

6. There is no way to find as qualified individuals to care for client as someone with decades of experience caring for them. Is DHHS mandating that the client hire less qualified individuals? If so, is DHHS willing to accept responsibility of injury or death to the client. What if the client can't find as qualified individual?

Sent from Proton Mail for Android.

-------- Original Message --------

On Friday, 12/19/25 at 12:58 Sue [redacted]

It is obvious that besides limiting the travel of the client and restricting their rights to choose their caregivers, you are trying to BANKRUPT FAMILIES.

This needs to be stopped now!!!

Also, it needs to be addressed that a parent, caring for their disabled child, can not live on 40 hours a week. It would take two weeks paycheck to just cover health insurance. Their would be no money left to even pay the house payent. There would be no money for car payment, health insurance, food, gas, electricity etc. This doesn't even cover dental or vision insurance.

What you are doing when you want to reduce hours to 40 hours, it would make it impossible for parents to keep their children out of institutions. I took more than a 50 percent pay cut. I lost retirement, paid holidays, health insurance, life insuance, dental insurance and would be at 4 weeks paid vacation.

Sue Coles

Sent from Proton Mail for Android.

-------- Original Message --------
On Friday, 12/19/25 at 07:29 Sue

<[redacted]>
wrote:

Another question

When you are married and your spouse is retired, if they don't want strangers in his home. If he feels uncomfortable showering and hanging out in our home with someone else. He does not want to be accused of doing something in appropriate with another woman in the house.

Also is DHHS willing to be responsible for theft in the house?

What if you can't find a caregiver more qualified than current caregiver. Is DHHS saying that we have to hire less qualified individuals? If less qualified individual is hired, will DHHS willing to accept responsibility for injury or death?

Sue Coles

Sent from Proton Mail for Android.

-------- Original Message --------
On Friday, 12/19/25 at 05:41 Sue <[redacted]> wrote:

PLEASE RESPOND WITH AN ANSWER.

Also, besides figuring out how you will pay for 2 additional caregivers travel time, lodging expenses, (we can't all travel in same vehicle) so gas and car rental, and their time away from home for up to 3 months at a time. It is the

law
that
you
can't
prohibit
the
client
from
traveling.
You
and not
considering
the law
that
allows
the
client
to have
the
choice
of
caregivers.
When
you
want to
allow
only
40 hrs,
that
will
not be
enough
money to
live on
and
pay
health
insurance for
a
family
member
who
has no
benefits.
Next,
we
refuse
to
allow
outside

people
to
come
into
our
home
and
invade
our
privacy.
DHHS
has no
legal
reason
to
restrict
the
hours
of
CERTAIN
caregivers.
Is DHHS
willing
to
except
legal
responsibility
if
DHHS
is
trying
to
force
the
client
to hire
less
qualified
caregivers
and the
client
gets
injured
or
dies?
When
traveling
for
months
at a

time,
what if
there
are no
caregivers
willing
to be
gone
away
from
home
that
long
even if
DHHS
pays
all of
their
lodging,
food
and
pay for
their
idle
time
sitting
in a
motel.
We
also
need to
have
DHHS
pay for
all
tickets
to
places
like
Disney
for any
other
caregivers.
Tiffany
is
broke
and on
Medicaid.
She
can't

afford
to pay
these
expenses
for
other
people.
She
should
not be
expected
to have
to stay
inside
their
home
like
their
life has
no
meaning,
as the
Supreme
Court
has
already
ruled.
When I
take
Tiffany
and
travel
and go
to
theme
parks, I
pay my
own
way.
We
can't
afford
to pay
for
additional
caregivers
expenses.
The
caregivers
will be

expected
to pay
all of
the
own
expenses.

PLEASE
EXPLAIN
WHAT
DHHS
HAS
PLANNED
SO
THAT
THEY
DON'T
PROHIBT
THE
CLIENTS
RIGHTS
TO
TRAVEL
AND
ENJOY
LIFE.
IF
CLIENT
DOESN'T
HAVE
THE
MONEY
TO
PAY
THE
CAREGIVERS
EXPENSES?

SUE
COLES

Sent
from
Proton
Mail
for
Android.

Original
Message

On
Monday,
12/15/25
at
14:29
Sue
[redacted]
wrote:

Hello,

I
am
hearing
that
DHahS
is
considering
limiting
family
providers
to
40
hours.

Tiffany
has
the
legal
right
to
choose
her
own
providers.
When
she
lives
with
me,
is
the
state
going

to
pay
travel
expenses
for
additional
people
to
travel
with
us.
If
we
go
to
Omaha,
are
you
paying
someone
else
to
be
with
us
until
our
8
hours
is
up?
We
are
traveling
to
Florida
again
this
month.
Will
you
pay
additional
people
to
drive
their
car
the
24

hours
and
follow
us
to
help
watch
Tiffany?
Will
you
pay
for
their
room
and
board
in
Florida
to
be
available
for
them
to
be
able
to
watch
Tiffany.

What
are
the
rules
when
we
can't
find
individuals
to
provide
Tiffany
care, when
they
don't
want
to
pay
their
own

expenses
when
traveling
in
or
out
of
the
state?

Do
you
know
of
providers
that
are
available
24
hrs
day
for
when
our our
plans
change?

What
do
we
do
if
we
can't
find
individuals
to
provide
the
level
of
care
required,
in
our
area?

I
was
thinking

about
fighting
the
16
hour
rule
but
I
could
understand
that
sometimes
going
over
16
hrs
a
day
might
not
be
safe
for
some
individuals.
I
now
feel
that
limiting
providers
to
16
hours
goes
against
the
rights
of
individuals
to
pick
their
own
providers.
If
the
individual
feels
that

the provider isn't providing them safe care, then the client has the right to schedule another provider.

Also if the State wants us to higher agencies for partial days, the rate is twice as high at least if, I can even find a qualified individual to watch her.

Also,
families
have
a
right
to
some
privacy
in
their
own
homes.

Additionally,
if
you
are
wanting
to
limit
it
to
16
hours,
change
it
to
billing
limitvof
16
hrs
a
day.
That
way
if
someone
works
16
hrs
and
1
minute,
the
billing
will
still
go
though
because

of
rounding.

Please
let
me
know
of
other
changes
you
are
wanting
to
make
that
takes
away
individual
rights.

Sue
Coles

Sent
from
Proton
Mail
for
Android.

From: Kevin Kajdasz
To: DHHS HCBS Public Comments
Subject: Help us help Zach Kajdasz
Date: Monday, January 5, 2026 10:10:20 PM

You don't often get email from [redacted] Learn why this is important

My son Zachary Kajdasz was diagnosed with Duchenne Muscular Dystrophy in 2004 when he was 4 Yrs old. My wife & I were devastated with the news. We both had great jobs to help support our family of four. My wife & I researched what Duchenne Muscular Dystrophy consisted of. It is a rare progressive genetic incurable disease that primarily affecting boys. DMD is caused by a mutation in the DMD gene, located on the X chromosome, which prevents the body from producing Dystrophy. First detection is between ages 2 & 5. Trouble running, jumping & using the Gowers sign which consists of the child using there own hands to walk up there legs to get up off the ground. The Gower's Sign is how my son Zach was first discovered of having DMD. After a physical therapist seen my son get off the ground, he was diagnosed. We made an appointment with his pediatrician & the blood results revealed he had DMD. The calf muscles appear unusually large because the muscles are being replaced by fat & scar tissue. My son lost his ability to walk at the age of 10 & was forced to use a wheelchair full time. Next Zach started losing strength in his upper extremities. It was hard for him to hold utensils & a tooth brush, things we take for granted. Zach's spine was starting to get compromised from his inability hold himself upright so he needed to get his spine fused. This was a very difficult surgery to perform on a child with DMD. The final stage of DMD is loss of respiratory which inevitably leads to death. This is a horrible disease to live with as a parent to watch. Once Zach was confined to a wheelchair my wife & I decided that she would quit her full time job to care for our son. It was a very difficult decision since we needed her income. When we were introduced to the Age & Disabled Wavier where a parent could get paid to take care of their loved one. It was a miracle! We & many people we know need the hours & help that DHHS offers us. It would be devastating to not only our family but all the families that use this great service. There would be an overwhelming amount of loved ones that would need to be in a full time facility. It would cost the state more money in the long run. Please reconsider lowering our hours. Keep our loved ones home where they are safe! My son would die in a nursing home. I thought we voted on a government that was going to make America great again! There is nothing great about putting your loved one in a nursing home when they can stay in the care of people that will care for them the best in there remaining years. Please help us & do not lower our hours!

Thanks!

Kevin Kajdasz
[redacted]

Sent from Yahoo Mail for iPhone

From: Toni Kajdasz
To: DHHS HCBS Public Comments
Subject: HELP
Date: Monday, January 5, 2026 5:01:59 PM

You don't often get email from [redacted] Learn why this is important

My son Zachary Kajdasz “age 25” has Duchenne muscular dystrophy and needs 24/7 care. I’m Zachary’s mom “Toni Kajdasz” and I take care of him 7 days a week along with his father “Kevin Kajdasz”
If I can’t continue to get paid my hours to take care of Zach, I will have to get another job and Zach will have to go to a skilled nursing facility. What are the skilled nursing facilities to choose from for his Medicaid and is there a list to choose from and get him on a waiting list? Zach needs 24/7 care and I’m scared he would be neglected in such a facility and end up with bed sores etc, for I have to turn him every hour through out the night to prevent them since he can’t use his arms or leg muscles anymore. Zach has to be fed 5 times a day, he can’t lift his arms. I heard nursing homes are short staffed and Zach will be neglected. Why would the state want to pay someone else to take care of him when I’m his mom and he doesn’t want some stranger doing it. Please, I beg of you to reconsider taking my hours away, he will die in a nursing home and having. Someone else come in to our home makes no sense, since I’m his mom and can take the best care of him.

Sincerely,
Toni Kajdasz

From: Kathleen Core
To: DHHS HCBS Public Comments
Subject: Home Care Cuts
Date: Wednesday, December 31, 2025 4:55:27 PM

> You don't often get email from [redacted]. Learn why this is important

To whom it may concern,
I understand public comments are currently being solicited for budget cuts for in home services for the aged and disabled. My 89 year old mother is able to stay in her home instead of going to a long term care facility only because of the inhome care she receives. If/when she is admitted to a long term care facility, she will qualify for Medicaid. The cost of long term care is upwards of $10,000/ month. She is receiving far superior care in a much safer, more comfortable environment than can be provided in a facility.
If the funds are cut, you will place a heavier burden on a very fragile component of our health care system. As a nurse practitioner, I make visits on long term care patients on a regular basis. I see food trays placed in front of patients unable to feed themselves, I see call lights unanswered, I place calls to facilities and no one answers the phone, I see deep wounds caused by pts remaining in the same position too long, I see staff talking to clients harshly. The state pays top dollar for what I certainly consider to be widespread neglect.
My dad was in a long term care facility. He was afraid of some of the staff, had personal items stolen, and because his call lights went unanswered for hours, he frequently soiled himself.
I do not wish to see any of my patients or family members have to go to a care facility. I am pleading with you to keep current funding in place for in home care.
Respectfully,
Kathleen M. Core, ARNP

From: Sage Parra
To: DHHS HCBS Public Comments
Subject: Hour limit
Date: Saturday, December 27, 2025 10:42:16 AM

You don't often get email from [redacted]. Learn why this is important

Dear Nebraska Department of Health and Human Services Waiver Review Team,

I am writing during the public comment period to express serious concerns regarding the proposed changes to the Nebraska Aged and Disabled (AD) Waiver, specifically the proposal to reduce allowable paid caregiver hours from up to 112 hours per week to 40 hours per week.

This proposed reduction is not only unrealistic—it is dangerous for many individuals who rely on the AD Waiver to remain safely in their homes and communities.

Many AD Waiver participants require round-the-clock supervision or hands-on assistance due to medical fragility, cognitive impairment, behavioral needs, mobility limitations, or a combination of these factors. For these individuals, reducing paid caregiver support to 40 hours per week creates an immediate and significant risk of neglect, injury, medical crises, and caregiver burnout.

The assumption that the remaining hours can be filled by “informal supports” is deeply concerning and does not reflect the lived reality of many Nebraska families.

In practice:
• Many individuals do not have extended family nearby
• Many families do not have relatives willing or able to provide unpaid care
• Some caregivers are elderly, disabled themselves, or working full-time
• Others are already providing significant unpaid care beyond what is sustainable

Informal supports cannot simply be created where they do not exist. Expecting families to replace up to 72 hours per week of paid care with unpaid labor places an unreasonable and inequitable burden on caregivers and ignores the realities of poverty, geography, workforce shortages, and caregiver health.

If these changes move forward, many families will be left with no viable option other than placement in nursing facilities or other institutional settings. This outcome directly contradicts the purpose of the AD Waiver, which is to support community-based care and prevent unnecessary institutionalization.

Institutional placement:
• Is often less safe and less appropriate for individuals with disabilities
• Results in loss of autonomy, stability, and quality of life
• Frequently leads to worsening health outcomes
• Costs the State of Nebraska significantly more than providing adequate home- and community-based services

Reducing caregiver hours may appear to be a cost-saving measure on paper, but in reality it is likely to increase long-term Medicaid expenditures through higher rates of institutionalization, emergency room use, and hospitalizations—while causing irreparable harm to individuals and families.

I strongly urge DHHS to:
• Reconsider any reduction in allowable caregiver hours
• Acknowledge that informal supports are not universally available

• Ensure that waiver participants with high and complex needs can continue to receive adequate paid support
• Evaluate the full fiscal and human cost of forcing individuals into institutional care

The AD Waiver should protect health, safety, and dignity—not place individuals at risk or force families into impossible decisions. I respectfully ask DHHS to revise the proposed changes to ensure that Nebraska's most vulnerable residents can continue to live safely in their homes and communities.

Thank you for the opportunity to provide public comment and for considering the very real consequences these changes may have for Nebraskans who depend on the AD Waiver.

Sincerely,
Sage Parra

To Whom It May Concern,

Recently I received a letter about DHHS proposing to cut hours for Caregivers in the home down to 40 hours a week. This deeply concerns me and my family as my adult child (age 32) is 100% disabled (Nursing Home Level of Care) and I am her primary caregiver. I take care of my daughter 24 hours a day — all day and periodically during the night to keep her safe and comfortable during episodes of seizures. My daughter has 50+ seizures daily ranging from small staring seizures all the way up to Grand Mal Seizures and I am here in the home with her seizure alert dogs to keep her from falling or collapsing and hurting herself which could require trips to the hospital. If you cut our hours I fear that she will be put into a nursing home and would not be able to get the care she needs. The nursing staff at the care centers are not able to stay with her during the day to watch her and see when she's going to go into a big seizure and use methods to help try to prevent injury without strapping her into a chair like a quadriplegic and making her feel less of a human and more like a prisoner in her own body then she already does. Sadly my daughters seizures are Non-Epileptic and many doctors have seen her with no clue as to how to help her. The medical advice given is to learn to live with them.

If you cut hours for home care this leaves me to having to go get another job and leaving her without the supervision or the care she desperately needs. How can DHHS justify the safety and care of disabled adults on this Waiver and the cutting of hours? Do they expect caregivers to work for no wages or do they want to overburden the system more by moving these patients into care institutions and removing all quality of life that the individuals still possess? This could pose a severe safety risk for not only my daughter but many other individuals who live in their homes and that deeply concerns me! My daughter requires 24/7 care and I am here to give her that care as long as I possibly can.

The cost of putting these individuals into institutional facilities would cost more to the state then by letting them live in their own homes and get the care they desperately need to stay safe and get what they need. My daughter alone needs one on one care and institutions won't be able to give her the care she would need to keep her safe and would put her life at serious risk. The real world is complicated and these changes are not considering the ones who need to be given in-home-care to give them the security they need to feel safe and cared for.

Please for the sake of my daughter Heather — and many, many others in this state like me who do home health positions — Please do not strip us of our hours needed to keep family safe and our loved ones in their home.

Sincerely,

Sheryl Wallerich

From: cindy jackson
To: DHHS HCBS Public Comments
Subject: hours
Date: Monday, January 5, 2026 9:00:33 PM

> You don't often get email from [redacted]. Learn why this is important

Hi my name is Cindy and im writing this letter to hope to help stop with the hours being cut for the disabled individuals rely on the program. I currently take care of my brother that is unable to speak, has behavior issues and is blind. He has been on this program for many years. I have had to cut back on my job to care for him and have one other caregiver. He is unable to communicate and unable to ambulate any without someone helping him. He CAN NOT be left alone at all. He requires 24 hour care. I feel like he is being punished by taking hours away to do his disabilities. Im asking to PLEASE PLEASE PLEASE do not take any hours away. Please stop and consider these individuals with disabilities

Cindy Jackson

From: DIANA LUNDQUIST
To: DHHS HCBS Public Comments
Subject: https://nebraska.tv/news/local/nebraska-medicaid-cuts-spark-concern-for-elderly-and-disabled-care?fbclid=IwRlRTSAPJbFJleHRuA2FlbQIxMQBzcnRjBmFwcF9pZAo2NjI4NTY4Mzc5AAEeb7HdyIIn4E8iBiXmIQPHo0AR2TelhPkQlGMQMivkwv7oS224-ULigjFDR-s_aem_1ZqRmmITXKEvByL5Bqqu6g
Date: Monday, January 5, 2026 10:18:42 PM

You don't often get email from [redacted] Learn why this is important

https://nebraska.tv/news/local/nebraska-medicaid-cuts-spark-concern-for-elderly-and-disabled-care?fbclid=IwRlRTSAPJbFJleHRuA2FlbQIxMQBzcnRjBmFwcF9pZAo2NjI4NTY4Mzc5AAEeb7HdyIIn4E8iBiXmIQPHo0AR2TelhPkQlGMQMivkwv7oS224-ULigjFDR-s_aem_1ZqRmmITXKEvByL5Bqqu6g

Sent from Yahoo Mail for iPhone

From: DIANA LUNDQUIST
To: DHHS HCBS Public Comments
Subject: https://nebraskaexaminer.com/2025/12/24/families-fear-devastating-changes-to-nebraska-program-serving-people-with-disabilities-elderly/?fbclid=IwZnRzaAPJbJpleHRuA2FlbQIxMQBzcnRjBmFwcF9pZAo2NjI4NTY4Mzc5AAEeOHBhxDRTBU-ePbG53qM7BNwTYDM2GwgPCzDETzL6iXddFGb...
Date: Monday, January 5, 2026 10:19:46 PM

You don't often get email from [redacted] Learn why this is important

https://nebraskaexaminer.com/2025/12/24/families-fear-devastating-changes-to-nebraska-program-serving-people-with-disabilities-elderly/?fbclid=IwZnRzaAPJbJpleHRuA2FlbQIxMQBzcnRjBmFwcF9pZAo2NjI4NTY4Mzc5AAEeOHBhxDRTBU-ePbG53qM7BNwTYDM2GwgPCzDETzL6iXddFGbpK5eXIEZ05gI_aem_yn7faNrFkBqzv7igI6l2NA

Sent from Yahoo Mail for iPhone

From: DIANA LUNDQUIST
To: DHHS HCBS Public Comments
Subject: https://www.1011now.com/2025/12/23/nebraska-families-face-caregiver-hour-cuts-under-proposed-dhhs-changes/?fbclid=IwZnRzaAPJbAZleHRuA2FlbQIxMQBzcnRjBmFwcF9pZAo2NjI4NTY4Mzc5AAEepS3o53sGAMVEYrLzQh32Tx_j1Vvei-6RIHt9i7Di6J0DuC-o-_PSi_JNHl8_aem_0AJf2zXHZG8w...
Date: Monday, January 5, 2026 10:17:24 PM

You don't often get email from [redacted]. Learn why this is important

https://www.1011now.com/2025/12/23/nebraska-families-face-caregiver-hour-cuts-under-proposed-dhhs-changes/?fbclid=IwZnRzaAPJbAZleHRuA2FlbQIxMQBzcnRjBmFwcF9pZAo2NjI4NTY4Mzc5AAEepS3o53sGAMVEYrLzQh32Tx_j1Vvei-6RIHt9i7Di6J0DuC-o-_PSi_JNHl8_aem_0AJf2zXHZG8wH5_kEHauYA

Sent from Yahoo Mail for iPhone

From: DIANA LUNDQUIST
To: DHHS HCBS Public Comments
Subject: https://www.facebook.com/share/p/1D7AV5otK8/?mibextid=wwXIfr
Date: Monday, January 5, 2026 10:15:49 PM

You don't often get email from [redacted]. Learn why this is important

https://www.facebook.com/share/p/1D7AV5otK8/?mibextid=wwXIfr

Sent from Yahoo Mail for iPhone

From: Trisha Reierson
To: DHHS HCBS Public Comments
Subject: Impact of funding cuts
Date: Friday, December 12, 2025 8:11:18 AM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

To whom It

I am writing to express my deep concern regarding the recent funding cuts affecting disability services and home- and community-based support programs in our state. These changes have had a direct and serious impact on my 21-year-old daughter, who requires around-the-clock care, as well as on my ability to provide for our family.

Due to the level of care my daughter needs, I am unable to work outside of the home. I am her primary caregiver every hour of the day, ensuring her safety, medical needs, and daily living supports are met. The services and supports provided through state funding are not supplemental for us—they are essential. They allow my daughter to maintain stability, dignity, and quality of life, and they allow me, as her caregiver, to continue meeting her needs without compromising her health or well-being.

The recent cuts have placed us in an extremely difficult and unsustainable situation. Reduced services mean gaps in care, increased caregiver strain, and a decline in my daughter's overall support system. Families like mine rely on these programs not by choice, but by necessity. Without adequate funding, we face impossible decisions that no parent or caregiver should ever have to make.

I am respectfully requesting that you review and reconsider these funding reductions. Continued investment in disability services not only protects vulnerable individuals like my daughter, but also ensures that families providing full-time care are not pushed to a breaking point.

Thank you for your time, your attention, and your service to our community. I would welcome the opportunity to discuss our situation further or provide additional details about how these cuts have affected us personally.

Sincerely,
Trisha Reierson

From: Donna - Sky Blue Aussies
To: DHHS HCBS Public Comments
Subject: In Home Caregiver cuts!
Date: Monday, December 22, 2025 9:29:36 AM

> You don't often get email from [redacted]. Learn why this is important

This petition is gaining and will be over 5000 by the time you make this horrible decision ! Shame on you. If this was your child, there is no way you would make this decision to leave gaps in their care because of your budget cut line, you are not listening to the people of Nebraska or to the disabled community at all. We protest this cut in caregiver hours! You have no alternative plan for care for these disabled people who require it. Leaving a gap of 100's of hours in one week. This should be a crime .

Sent from my iPhone

From: A Downs
To: DHHS HCBS Public Comments
Subject: InterRAI assessment appeals
Date: Thursday, December 18, 2025 3:42:13 PM

You don't often get email from [redacted]. Learn why this is important

The number of DHHS DD InterRAI assessment appeals is staggering. There is no public information on the results of these appeals.

We need information on:

- Total number of DD InterRAI appeals received/denied since it's inception.
- Outcomes of hearings (upheld, reversed, settled).
- Breakdown for appeals involving InterRAI assessments/decisions.

Thank you,

Concerned stakeholder

From: Jodi Tolman
To: DHHS HCBS Public Comments
Subject: Irrelevancy of who works hours that a participant qualifies for
Date: Saturday, December 27, 2025 10:23:06 AM

> You don't often get email from [redacted]. Learn why this is important

Dear DHHS,

I am an independent provider on the AD Waiver for my adult daughter with severe disabilities and complex medical needs, requiring 24 hour/day care. I have major concerns about the proposals presented in the renewal of the AD Waiver, specifically the 40 hour/week limit placed on live-in family caregivers.

IF A PARTICIPANT, BASED ON NEED, QUALIFIES FOR MORE THAN 40-70 HOURS/WEEK, IT IS IRRELEVANT WHO WORKS THOSE HOURS.

If a participant is evaluated based on need and is determined to qualify for more hours than the allowed 40-70/week, up to the 150% or 175% institutional cost limit, why does it matter who works those hours?! If you are willing to pay that money to agencies, why not save money by paying the live-in family caregivers at an even lower wage?! **It is inconsistent, contridictory, and discriminatory to determine that a participant requires a certain number of care hours per week, but restrict who is allowed to work those hours.**

Live-in family caregivers should receive AT LEAST the average cost of institutional care at a MINIMUM! That is the whole purpose of the waiver—to provide a COST-NEUTRAL alternative to institutional care. You are proposing that **live-in family caregivers receive just $31,200/year** ($15/hr x 40 hrs/wk x 52 weeks)—**only ONE-THIRD of the average cost of institutional care!** That is unreasonable and unacceptable.

Live-in family caregivers are a valuable resource for the state. Utilize us appropriately! Pay us what we are worth! Don't disrespect us or take advantage of us by assuming we will provide care for free! Continue to compensate us reasonably and equitably, or risk losing a large portion of these family caregivers. Losing live-in family caregivers will only cost the state more to pay for agency providers, or create even bigger financial and logistical problems with a surge of participants suddenly requiring institutional care.

I plead with you to exempt live-in caregivers from the propsed 40 hrs/week restriction in the AD Waiver renewal.

To Governor Pillen, Nebraska DHHS Leadership, and Nebraska Lawmakers,

My name is Kimberly Troia, my husband and I are parents of two adult children with Cerebral Palsy who rely on Nebraska's Aged and Disabled Waiver services to live safely and meaningfully in our community. I am writing in strong opposition to the State of Nebraska's proposal to reduce waiver services from 112 hours per week to 70 hours per week and to limit family-provided care to only 40 of those hours.

Although our children are adults, they still require consistent, hands-on support to live healthy, engaged, and productive lives. As their parents, my husband and I have been their primary caregiver for decades. We know their medical needs, communication styles, safety concerns, and daily routines better than anyone. The care we provide cannot simply be replaced by unfamiliar workers without serious consequences.

On a weekly basis, my husband and I support our adult children with essential activities that allow them to participate in everyday adult life, including:

- Taking them to and from work and supporting them in employment-related responsibilities
- Helping with projects, daily tasks, and skill development
- Accompanying them on walks with their service dogs
- Supporting them as they learn how to drive safely
- Driving them to community outings that enhance their physical and metal well being
- Grocery shopping and trips to the mall
- Visiting and caring for their horse
- Providing transportation in our accessible van when they go out to dinner
- Helping them get to and from church and bible studies multiple times each week
- Coordinating and attending medical, dental, and counseling appointments
- Transporting them to occupational, physical, and speech therapy
- Taking them to out-of-state appointments and surgeries when needed
- Providing backup transportation when the Metro Area Transit Moby system is unavailable because of time limitations
- Preparing healthy meals to ensure they maintain a healthy weight and long-term wellness

These are not optional services. They are the supports that allow our children to live as adults in their community rather than being isolated or placed in more restrictive settings.

The proposal to cap family caregiving at 40 hours per week and require the remaining hours to be filled by strangers is deeply concerning. Like many families, we already face ongoing workforce shortages, high turnover, and difficulty finding reliable direct support professionals. Forcing additional hours to be covered by unfamiliar caregivers is unrealistic and puts our children's safety, mental health, and stability at risk.

Our adult children depend on trust, consistency, and routine. Frequent caregiver changes can cause anxiety, setbacks in progress, and increased medical or behavioral needs. Family caregivers provide continuity of care that cannot be replicated by a rotating workforce.

Family caregiving also saves the State of Nebraska significant money. By supporting our children at home, my husband and I prevent emergency room visits, hospitalizations, and costly institutional placements.

Reducing hours does not reduce need—it simply shifts the burden onto families and increases long-term costs for the state.

I respectfully urge you to reconsider this proposal and to meaningfully include parents and individuals with disabilities in decisions that directly affect our lives. Please do not reduce waiver hours, and please do not limit the ability of parents to continue providing the care our adult children depend on to live with dignity, safety, and purpose.

Thank you for your time and consideration.

Sincerely,

Kimberly Troia
Mother of Sarah and Alex Troia

From: Renee Berumen
To: DHHS HCBS Public Comments
Subject: Live in caregivers
Date: Wednesday, December 31, 2025 4:08:41 PM

> You don't often get email from [redacted]. Learn why this is important

To whom it may concern, I was born and raised in Nebraska but live in Nevada now.
I take care of my step daughter who was formerly in Nebraska.

I disagree with reducing the hours a person cares for a loved one. It is the only way people get loving care workout a nursing home.

Cutting the hours to 40 is unheard of when the care is needed 24/7.

You need to really re-think this.

Thank you,

Renee Berumen

From: Julie Wondercheck
To: DHHS HCBS Public Comments
Subject: Live-in Caregivers hours!
Date: Monday, January 5, 2026 6:30:26 AM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Please do not cap the live-in caregiver hours for disabled on the AD waiver. This will destroy families. Facilities cannot provide the one on one care that these individuals need to live. Individuals with disabilities could lose their life or be taken advantage of when not provided one-on-one care in their home. Please do not cap the live-in caregiver hours. This should not be on the table to even consider, we need to support families, especially ones working so hard to love and care for their family members.
- Julie Wondercheck

From: Katie Novakoski
To: DHHS HCBS Public Comments
Subject: LRI concerns AD waiver proposal changes
Date: Saturday, January 3, 2026 1:12:43 PM

Hello,
I am concerned with the changes to provide LRI paid care to minors over the summer. You were well aware that the cuts were coming to the adult portion of the personal care hours when LRI for minors was implemented. Please explain to me why those changes were introduced if there was no money and the drastic cuts were coming to the adult side of personal care. I do not agree with paying parents to care for minors if it means that there will not be money to make sure that adults are safe in their homes and with their preferred caregviers. How does this make sense?

Katie Kuecker

From:	Nicole Mattson
To:	Pillen, Jim
Cc:	Kelly, Joe; DHHS HCBS Public Comments; Strimple, Laura; Powell, Jeff; Davis, Alycia; Spilinek, Collin
Subject:	Nebraska Must Protect Family Caregivers and Vulnerable Residents
Date:	Thursday, December 25, 2025 3:12:10 PM

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Governor Pillen,

My name is Nicole Mattson and I live in Elkhorn, Nebraska. I am writing to urge you to reconsider and oppose the proposed changes to the Aged and Disabled Medicaid Waiver that would reduce reimbursable caregiver hours and cap paid hours for family members who live with the individual.

These changes would place disabled Nebraskans and aging adults at real risk. Home care is not only more compassionate, but also cost-effective. When support hours are reduced, care needs do not decrease. Instead, families face burnout, financial strain, and difficult decisions that can lead to premature institutional placement or increased medical emergencies. That shift will increase overall costs to the state, not reduce them.

I have a disabled nephew who depends on consistent care from people he knows and trusts. I also had aging grandparents who benefited from waiver services prior to their passing, which allowed them to remain at home with dignity. I cannot imagine how families like ours would maintain safety and quality of life under these reductions.

Family caregiving is not simply being a grandma or being family. It is lifting, bathing, medication management, seizure monitoring, behavioral support, nutrition oversight, transportation, therapy coordination, and in many cases around-the-clock supervision. Reducing it to a casual family duty minimizes the time, labor, and medical complexity involved. Nebraska should support the families doing the hardest work, not diminish what they provide.

And financially, compensating caregivers is not paying someone “to be a grandma.” It is compensating labor that replaces the cost of professional staffed care and prevents far more expensive institutional placement. When families can no longer sustain this care due to hours being cut, Medicaid will bear the cost elsewhere. Reducing hours does not reduce need; it simply shifts cost and risk to another part of the system.

Nebraska families are already providing tremendous unpaid labor to keep loved ones safe. Limiting waiver hours does not make the program sustainable; it simply transfers burden to families least equipped to absorb it. Balancing budgets should not come at the expense of those most vulnerable.

I respectfully ask that you protect current waiver support levels, consider alternative funding solutions, and ensure that families and caregivers are heard as decisions are made.

Thank you for your time and consideration.

Nicole Mattson

[redacted]

AARP Nebraska

301 South 13th St., Suite 201 | Lincoln, NE 68508
866-389-5651 | Fax: 402-476-0087 |
aarp.org/ne | neaarp@aarp.org | twitter: @aarpne
facebook.com/aarpnebraska

December 30, 2025

Tony Green, Director
Nebraska DHHS Division of Developmental Disabilities
301 South Centennial Mall South
PO Box 95026
Lincoln, NE 68509-5026
DHHS.HCBSPublicComments@nebraska.gov

RE: 1915(c) Medicaid Home and Community Based Services (HCBS) Aged and Adult and Children with Disabilities (NE.0187) Waiver

Dear Director Green:

Thank you for the opportunity to comment on Nebraska's 2026 1915(c) Medicaid Home and Community Based Services (HCBS) Aged and Adult and Children with Disabilities waiver renewal (waiver). AARP is the largest nonprofit, nonpartisan organization representing the interests of Americans age 50 and older and their families. Key components of AARP's advocacy agenda include helping to ensure that Nebraskans and all Americans are financially secure and can age in their own homes and communities, among family and friends.

AARP believes that all individuals have the right to be self-reliant and live with dignity. The proposed 2026 waiver renewal supports this principle in two important ways: by increasing the current waiver cap from 8,900 to 13,000 waiver slots over the next five years and through improved access to high quality adult day services enabled by the proposed enhanced training requirements and the elimination of the 4-hour minimum service requirement. AARP Nebraska applauds these proposed changes that will serve Nebraskans well by increasing access to preferred HCBS while providing significant Medicaid savings through institutional diversions. Not only is home-based care more affordable than institutional care, 95% of Nebraskans age 45 and older say that it is important for them to stay in their home as they get older.

To capture the full benefits of these proposed waiver enhancements, it will be important to maintain the current level of waiver services and *access* to those services while expanding the numbers served. In our review of the proposed waiver renewal application, we believe that some of the proposed changes may inadvertently narrow access to needed supports. We offer the following observations

and priority recommendations to ensure that the proposed waiver expansion achieves its full potential for the Nebraskans who will be served by the waiver:

1) ***Individual Cost Limit*** *(Page* 25*):* The waiver renewal application proposes an individual cost cap for waiver participants of 175% of the average cost of institutional care. Imposing an individual cost cap may force some current and potential participants into nursing homes when costs may increase only for a short period of time. While we understand the budget pressures the state is facing, the overall program savings from institutional diversions should be more than enough to cover the minority of participants with short-term high-cost needs. AARP recommends including a specific provision in the waiver renewal allowing the Division to grant a waiver from the 175% cost cap at its sole discretion when the duration of the need is expected to be less than twelve months or if the move to a nursing home is expected to have significant negative health and quality-of-life consequences for the individual.

2) ***Quality Council*** *(Page 2):* The waiver renewal application proposes to eliminate the existing Quality Council and assign its work to the existing DDD QI Committee composed of state staff. It is important for consumers and their representatives to have meaningful opportunities to participate in state HCBS quality monitoring and improvement activities by serving on advisory committees and governing boards. Eliminating the current consumer focused Quality Council removes important consumer involvement and we strongly recommend retaining the Quality Council or adding a requirement to include a minimum of two HCBS consumers and two consumer advocacy organization members to the DDD QI Committee.

3) ***Respite*** *(Page 59):* The waiver renewal application proposes adding an annual 360-hour cap to the current waiver's respite benefit. The 360-hour annual service cap may limit respite access to less than what is needed to support some caregivers, causing avoidable institutional placements that diminish participants' quality of life and add unnecessary costs to the state's long-term services and supports (LTSS) budget. We recommend removing the proposed hourly cap or adding flexibility to allow state staff to determine when exceeding the cap benefits the participant and the state.

   The waiver renewal application also proposes adding a new "community respite provider" type to the currently authorized independent and agency respite providers. Community respite providers appear to have to meet the same staff training and certification requirements as licensed respite agencies but without the public oversight afforded by a licensing requirement. We strongly support adding qualified providers to expand access to respite services. However, AARP calls for licensing (or comparable certification requirements) for all LTSS providers to assure quality care, including any agency providing home health or personal care services. We recommend including a requirement in the waiver for community respite providers to be licensed or certified, including appropriate standards and oversight.

4) ***Assistive Technology*** *(Page 62)*
   The 2026 waiver renewal application proposes to allow participants to use waiver funds to lease as well as buy assistive technology and to pay for services associated with that assistive technology, including training, customization, maintenance, and repair. We strongly support the addition of leasing and the associated services to the assistive technology benefit and commend the Division for adding this flexibility for the increased support it offers for community living.

The waiver renewal also proposes:

- Additional eligibility requirements for the assistive technology benefit, including that the technology is limited to items that assist participants in their home and are of direct medical or physical benefit to the participant.
- A limit of $10,000 ($20,000 with a waiver) for assistive technology over a 5-year period.

These new restrictions may cause confusion what technology qualifies for funding and will likely limit access to current and evolving assistive technology supporting community access and integration, impacting a participant's maximum functional independence and associated Medicaid LTSS cost savings (for example, will GPS trackers and wayfinding devices be allowed to assist participants with dementia remain safely engaged in the community?). Limiting assisted technology is contrary to AARP's principles that LTSS should be provided in the least restrictive setting possible and that states should fund the LTSS needed to meet individuals' needs in the community. We recommend removing the new direct medical, physical, and home-based restrictions and adding flexibility to allow state staff to determine when exceeding the assistive technology cap benefits the participant and the state.

In addition to these priority recommendations, the proposed waiver renewal narrows program eligibility and the services that may be delivered in several other program areas, including personal care, assisted living, chore, companion, and home modification. Imposing new limits in these areas will impair important state flexibilities to address individual circumstances and for the state to achieve budget savings through institutional diversions. AARP Nebraska recommends removing or limiting new eligibility and service limits proposed throughout the waiver renewal application to ensure that the waiver expansion provides the maximum benefit to Nebraskans through enhanced access to HCBS.

Thank you again for the opportunity to comment on the proposed 2026 1915(c) Medicaid Home and Community Based Services Aged and Adult and Children with Disabilities waiver renewal. Please call or email me with any questions you may have regarding our comments and recommendations.

Sincerely,

Todd Stubbendieck
State Director
AARP Nebraska

Sincerely,

Todd Stubbendieck
State Director
AARP Nebraska

From: Shelley Snyder
To: DHHS HCBS Public Comments
Subject: New Proposed Changed to the AD Waiver
Date: Wednesday, December 10, 2025 8:10:16 AM

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To Whom it May Concern ~

I am writing to you today to voice my concerns about the Proposed changes for the AD Waiver. My son is an almost 30 year old adult male. I am his caregiver. Some of these proposals are ridiculous. First of all I thought the purpose of this waiver is to be able to keep them at home where they are most comfortable. It is way more cost effective in our situation even with overtime and the amount of hours we receive each week. I am able to monitor his needs closer and take care of them as they happen. He is comfortable here. He is tube fed, incontinent and nonambulatory. He relies on me to be his arms and legs. I have to set up and administer his feeds and meds. Using "informal supports" is something we use for short periods of time as like I said before he is an adult male. Most people are not comfortable changing him. He is also on a lot of medication as he has seizures. Some of his meds he takes orally but most of them have to be given through his feeding tube. Feeding tubes are scary and most people will not even touch them. We have a lift that we use several times a day to move him. He is comfortable with me being his provider. We currently get 86 hours a week. I am an independent provider. He should be getting much more than that but I will gladly take what we get as long as it's a reasonable amount of hours. He cannot be left alone. Proposing to drop hours for a live in provider to 40 hours a week is totally ridiculous. Please consider being smart about the changes you are proposing. Institutions are going to cost you way more than it is currently costing you to keep most of these individuals in their homes where they are comfortable. You need to look at each individual's situation and not at everyone as a whole. These individuals needs are all different. I invite you to come hang out with us for a day to see what really goes on caring for a loved one with a severe disability. Most of you have no clue and just because it looks good on paper doesn't mean it's a good change. Please reconsider these changes so we can continue to give these individuals the best life possible and keep them in their homes.

A concerned parent and caregiver,
Shelley Snyder
Sent from my iPhone

From: Pamela Marie
To: DHHS HCBS Public Comments
Subject: New proposed ruling thoughts
Date: Thursday, January 1, 2026 8:42:24 PM

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DHHS.HCBSPublicComments@nebraska.gov

To Whom it May Concern,

I am writing to explain that the new proposed ruling that my grandson would receive a max of 40 hours a week of care by me would be detrimental to him. Currently he has 88 hours of care per week, including supervision.

We live in rural Nebraska, and it is extremely hard to find a caregiver to come out and take care of him. A few years ago, an agency found someone to come to the house. She came over an hour to get to the house. It did not work because my grandson DID NOT want someone to take care of him. He doesn't understand his limitations. When that caregiver was there it put him into a very bad mental state and she quit after a week.

Since my daughter was unable to find anybody to help care for him due to their rural location, I decided to move from my home in Colorado and buy a home here in Nebraska so he could come live with me and I could be his full time caregiver with the consistent structure he needs to function throughout daily life. I was able to provide the care he needed that no other caregiver, school, or institution had been able to for years prior. He has made progress but is not ready to be without care.

Possibly losing the hours for supervision that he currently has would be so harmful. He is not able to make safe choices when unsupervised. Poor choices affect his health and safety. He suffers from significant gut issues which can result in internal bleeding. He has wound up on bedrest for weeks at a time, more than once, because he caused himself a very preventable bleeding episode when left without supervision. He has poor impulse control and needs supervision. He also wanders when not supervised.

Outside caregivers do not understand my grandson. He sounds so believable that he can do something, convinces them to allow him the freedom to do things he is not capable of, then does it and then he gets a bleed. He has tried public school (unsupervised he was constantly stealing from unoccupied rooms, Job Corps and a small private Christian college didn't work either. He was not able to make choices that were safe for him or that allowed him to function with daily tasks. They were very harmful.

My daughter one backup family who providers care to help share in his care, occasionally. If they would go on vacation or have a health issue arise, the full 88 hours each week falls back on me. Or vice versa, if I want to go on vacation, they have to do all 88 hours. There are NO caregivers willing or able to come to his location to care for him and he is NOT safe or capable of caring for himself.

My grandson requires intravenous medication given on a regular basis, as well as extra doses given as he has breakthrough bleeding. He REQUIRES help with this and cannot handle this on his own. This medication costs thousands of dollars and is extremely fragile with handling. If he needed a caregiver ,outside of me, since I have spent years training/learning how to do this –he would now also need nursing services to come and that is extremely difficult to find in our rural areas. That means we would now be making ER visits, for non-emergency issues, that could have been handled in the comfort and privacy of his own home. This would also be costly to the state and right now I am doing it as part of his care at no added costs. It seems that the nursing/hospital costs would be more than some overtime hours paid to me past the 40 hours.

My grandson struggles with significant depression and anxiety. If he had to have a non-family member taking care of him (if they could find someone) the results would be beyond bad. I feel he would give up on living for sure.

He has shown us repeatedly that supervision is vital to his safety and wellbeing.

The disabled population struggles so much with life as it is. IF, you could find a caregiver that would be willing to come to our rural area, IF that person will stay long enough to learn how to best care for my grandson, then you are still left dealing with his mental health. It makes me terribly sad that the way we have been doing his daily life is FINALLY working and he will absolutely go backwards in all areas of his mental and physical health. I am a 30-year retired special education teacher and I know what will result if he loses his supervision, care, and structure. More importantly, I have spent the last 25 months with him and have seen firsthand how much he needs supervision and consistency.

Please look carefully at the option of allowing family-in-home caregivers to only work 40 hours when some people need fulltime supervision. No one will love and consider this person like a family member can. These are real people with real needs and deserve quality care. Please stand up for our loved ones.

Pamela Mako

[redacted]

[redacted]

[redacted]

From: Tammy Nielsen
To: DHHS HCBS Public Comments
Subject: New Provider Rules
Date: Thursday, January 1, 2026 8:25:40 PM

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To Whom It May Concern:

I recently moved to the area to be near my family. My sister has two disabled adult children she adopted when they were minors. We are in a very rural area and she has struggled for years to find care. Since they were young, I have made usually a couple trips a year from California to Nebraska to come help when they were needing care because they have never successfully found outside caregivers who were capable of helping due to their needs and their location. They are extremely rural and both boys have very high needs. I have witnessed the struggle they have trying to find ANYBODY who is willing to help. I helped them out prior to moving here and becoming a provider on the AD waiver as I have been able, but I can say that the needs these boys have far exceed what almost anybody would be willing to do for $15 an hour. Add to the fact that they would have to make a 1.5 hour drive (one way) on their own dime each dime they need to come out and it won't happen. The fact that these two boys have only a few caregivers and extremely high needs, means that they WILL lose out on care if the 40-hour max rule is put into play. I can guarantee that they absolutely will not find somebody to come out as they have tried for years. If you remove all hours past 40 you will be putting these very disabled adults in a bad position and even more so for the people who have given up their lives to adopt and care for them. You will put more on the Medicaid system when people are no longer able to help disabled adults because of the limitations to help them care or you will overwhelm nursing homes with people who could be living in their own family homes receiving better care at a lower cost to the state.

Sent from my iPhone

nebraska
health care association

advocate. educate. support.

January 5, 2026

Aged and Disabled Medicaid Waiver Program
Division of Developmental Disabilities
Nebraska Department of Health and Human Services
P.O. Box 95026
Lincoln, Nebraska 68509-5026

RE: NHCA Comments on Proposed Changes to the Aged and Disabled Waiver Program

On behalf of our 217 assisted living members and the Nebraskans served by the Aged and Disabled Medicaid Waiver (AD Waiver) program providers, the Nebraska Health Care Association (NHCA) respectfully offers the following comments on the Nebraska Department of Health and Human Services' (DHHS) proposed changes to the AD Waiver program, as identified in its renewal application.

Excerpts from the Waiver Renewal Application are in **red font** below and organized by specific recommendations in black.

#1 Recommend Elimination of Duplication

Excerpts From Application:

- **(Page 5) DHHS, the Single State Medicaid agency, contracts with community partners to provide service coordination (case management). These activities include, but are not limited to, developing the person-centered plan, completing service authorization, monitoring service delivery, and participating in quality assurance reviews.**

- **DHHS contracts for the provision of service coordination with 1) Area Agencies on Aging for the aged population; 2) Independent Living Centers for adults with disabilities; and 3) Early Development Network agencies for infants and toddlers. State requirements are developed for every waiver service.**

- **(Page 15) Area Agencies on Aging, Independent Living Centers, and Early Development Network agencies perform all of the following operational and administrative functions for the participants they serve, except where noted:**
  - **Disseminate information concerning the waiver to potential enrollees**
  - **Assist individuals in waiver enrollment**
  - **Develop Person-Centered Plans**
  - **Review participant service plans to ensure that waiver requirements are met**
  - **Perform prior authorization of waiver services**
  - **Conduct utilization management functions**
  - **Recruit providers**

- **Execute the Medicaid Provider Agreement, including negotiating rates for applicable services.**
  - **Early Development Network does not complete this function.**
  - **Area Agencies on Aging and Independent Living Centers complete provider service referrals in the provider enrollment brokerage system for tasks related to completing background checks.**
- **Conduct training and technical assistance concerning waiver requirements**
- **Perform supervisory oversight and training of Service Coordination and Resource Development staff**
- **Monitor claims that are not subject to Electronic Visit Verification (EVV).**
  - **Claims subject to EVV can be monitored post-payment in the DHHS system.**
- **Monitor service provision**
- **Conduct ongoing case management**
- **Assess and re-assess participant needs, strengths, and priorities**
- **Complete quality assurance reviews**
- **Investigate, resolve, and report incidents and complaints**

The DHHS Developmental Disability (DD) Division contracts with an outside entity, Liberty Healthcare, to conduct remote quality assurance reviews that often duplicate the timelier and more effective, in person, quality assurance reviews conducted by the Area Agencies on Aging (AAAs), whose responsibilities are outlined in the above excerpt from pages 5 and 15 of the renewal application.

Duplicating processes is not only administratively burdensome for providers but adds unnecessary costs for DHHS and taxpayers.

RECOMMEND: The Liberty Healthcare contract is reviewed and any duplicative tasks that already performed by other DHHS-connected entities are eliminated.

#2 Recommend a Timelier Deadline for Conducting LOC Assessments

Excerpt From Application:

- **(Page 39) The process for NF LOC evaluation and reevaluation includes a person-to-person assessment and observation with the participant, guardian, or an individual with knowledge of the individual's functioning when needed. The LOC assessor must contact the participant within 14 days of the date of application to schedule the initial LOC assessment. The level of care assessor meets with the participant to evaluate NF LOC. The assessment must be conducted, if possible, at the participant's residence to allow observations of the home situation. The assessment must be held at a date and time convenient to the participant/guardian. Assessments for ages 4 and up are completed by the Eligibility and Enrollment (E&E) Unit.**

We have received concerns from multiple assisted living (AL) providers that It can take months for an individual requesting Waiver services to have their initial level of care (LOC) assessment completed. In some cases, the individual has passed away or been admitted to a nursing home before the LOC assessment is done.

According to the above excerpt from page 39 of the renewal application, the LOC assessor has 14 days to make an initial contact with the individual to schedule the assessment, which means the actual assessment may not take place for several more days or weeks.

Following the assessment meeting, the assessor has to complete the assessment, enter the information into the system, notify the services coordinator who then needs to schedule a time to meet with the individual to identify their specific service needs, develop an individualized person-centered plan of care, review it with the individual and get it signed.

This creates significant delays in the individual actually being approved and able to receive Waiver services.

Prior to the transition of the LOC assessment responsibility to the DD Division, the LOC assessment was performed by a service coordinator at one of the contracted entities, such as the Area Agency on Aging. The service coordinator met with the individual and completed the plan of care within 48 hours of receiving the referral. Now it can take months for individuals to be approved and access Waiver services.

RECOMMEND: If the DD Division is unable to conduct the initial LOC assessment within a reasonable amount of time (e.g., 5 working days), recommend consideration of other approaches, including contracting with the Area Agencies on Aging (AAAs) for this task. If this is considered a 'conflict of interest' with the AAAs' service coordination responsibilities, recommend the DD Division consider approaches for separation of responsibilities within the same agency to address/remove the conflict.

#3 Recommend Eliminating Barriers to Payment for Waiver Services

On a related note to the issue described in #3 above, Nebraska Medicaid will only pay an AL Waiver provider from the date the individual's Waiver plan of services and supports is signed. If an AL provider admits an individual prior to the plan of services and supports being signed, it means any care provided will not be reimbursed by Medicaid. This payment limitation creates an unnecessary barrier that can delay the individual's access to needed services.

RECOMMEND: We have shared information with the DD and Medicaid Divisions about other states that have found workable approaches to resolve the Waiver payment limitation, including the development of 'preliminary' plans of services and supports, which individuals sign but do not go into effect unless or until they are approved for the Waiver program. This allows the Medicaid payment to be retroactive to the individual's signature on the 'preliminary' plan once the individual be approved.

#4 Recommend AL Providers be Categorized as "Facility" Providers

Excerpts From Application:

- **(Page 2) Updated "assisted living" term to "supported residential living" (Appendix B-5-b-i and d-i); and Updated the name of the Assisted Living Service to Supported Residential Living (Appendix C-1/C-3);**

- **(Page 99) Service Type: Other Service, Service Title: Supported Residential Living.**
- **(Page 101) Provider Category: Agency, Provider Type: Assisted Living Facility.**

We understand the DD Division is proposing to change the service title for AL providers to "supported residential living," to be compliant with CMS direction.

However, our AL members are concerned about the change of AL from a "facility provider" to "agency provider," as identified in the above excerpt from page 101 of the renewal application.

The DD Division often issues provider bulletins regarding certain HCBS requirements. In the past, AL providers have been told they are categorized as "facility providers," not "agency providers," which has been very helpful because many of the requirements for agency providers, such as home care providers, do not apply to AL providers (e.g., electronic visit verification – EVV).

Enhanced oversight, such as electronic visit verification (EVV), when a home care agency is sending a lone caregiver into an individual's home makes sense, especially if the individual is living alone.

AL is a different care environment. There are multiple staff interacting with the individuals receiving care and the individuals are constantly out in the assisted living community participating in activities and sharing meals. In this environment there are multiple people who would be aware if the individual had a concern or needed assistance.

RECOMMEND: As the Waiver provider categorization type has led to significant confusion in the past, recommend assisted living providers be categorized as "facility providers," rather than "agency providers," so the Waiver requirements that apply to each category are clear. If this approach isn't possible, recommend Waiver communication specifically addresses whether a particular requirement applies to AL providers or not. Also, please see Recommendation #5 below for additional examples that have resulted in confusion.

#5 Recommend Clarification that the Following Agency Provider Requirements do not Apply to AL providers

Excerpts From Application:

- **(Page 102) Agency provider employees and back-up staffing delivering direct services and supports must:**
  - **Meet and adhere to all applicable employment standards established by the hiring agency;**
  - **Have training in the following areas, and provide evidence of current certificate of completion from an accredited source, when applicable or upon request:**
    - **Abuse, neglect, and exploitation and state law reporting requirements and prevention;**
    - **Cardiopulmonary resuscitation; and**
    - **Basic first aid;**
  - **Be authorized to work in the United States;**

- **Be 19 years of age or older;**
- **Not be a person legally responsible for the participant; and**
- **Not be an employee of DHHS, unless approved by DHHS as compliant with DHHS policy and applicable law and regulation.**

- **(Page 106)**
  - **Regulations found in Nebraska Administrative Code (NAC) Titles 471 and 480 outline the process to ensure criminal history compliance. Individual providers, employees of agency providers, and employees of assisted living facility providers must sign a statement approved by DHHS, identifying any record of any felony or misdemeanor convictions and/or pending criminal charges. This must include details, dates, and disposition (e.g., parole, probation, incarceration, fine, community service, etc.). Minor traffic violations must be included only if transportation services are to be provided. If the individual provider will be providing waiver services in his/her home, the provider must also provide this information for all household members age 13 or older. Assisted Living facility providers must obtain this statement at the time of hire and at least annually. All agency providers must have a policy that fully states the agency's practice in assuring safeguards are in place to protect the well-being of waiver participants.**

  - **For agency providers, the assigned Resource Development staff review the policy of the agency upon provider enrollment and annually to determine that safeguards are in place to protect the well-being of waiver participants. For Assisted Living facility providers, this includes review of staff statements of criminal history. Other Assisted Living facility assurances in this area are provided through Regulation and Licensure, Nebraska Administrative Code (NAC) Title 175.**

The above excerpts from pages 102 and 106 of the renewal application include examples of the differences between current requirements for "agency providers" and "facility providers," such as assisted living.

For example, Nebraska's AL licensure requires that staff have the knowledge and skills to respond to an emergency resident situation. There is not a requirement for AL staff to be certified in CPR or first aid.

AL residents are made aware of the facility's emergency response procedures upon admission, including whether this means staff will begin CPR or contact local emergency medical services, if requested by the resident's advance directive.

Adding this requirement for Waiver residents would add significant administrative cost for AL as often the number of Medicaid Waiver participants are a small percentage of the AL's overall occupancy.

Additionally, AL providers often hire nurse aides to provide care for residents. Federal and state regulations allow trained and competent nurse aides to be placed on the State Registry and provide care if they are 16 years of age or older. With Nebraska's current workforce challenges, it would be virtually impossible to ensure AL staff providing care to Waiver residents are 19 years of age or older.

RECOMMEND:

- ***Again, as the Waiver provider categorization type has led to significant confusion in the past, recommend assisted living providers be categorized as "facility providers," rather than "agency providers," so the Waiver requirements that apply to each category are clear. If this approach isn't possible, recommend Waiver provider communication specifically addresses whether a particular requirement applies to AL providers or not.***
- ***Also recommend that the CPR and first aid certification requirements and minimum staff age of 19 not be applied to employees of "facility providers" AL providers.***

#6 Recommend Waiver Death Review Process be Modified to be More Person-Centered

Excerpts From Application:

- **(Page 138) The Medicaid agency reviews 100% of all PCPs for participants who have died during their waiver eligibility. Service coordination agencies are responsible for remediating all PCP-related problems identified through the discovery process in an appropriate and timely manner (45 days). PCP reviews, as assigned by DDD, are completed in an electronic system by service coordination supervisors for each agency providing service coordination. These file reviews ensure that PCPs are completed accurately, are consistent with assessed needs, and that services are delivered in accordance with the participant's PCP. If a PCP needs to be revised, the service coordination supervisor provides the SC with information concerning corrections needed. Required corrections are documented by the SC on the PCP form.**

It's our understanding Liberty Healthcare reviews the records for all participants who die while they are receiving Waiver services, although the above excerpt from page 138 of the renewal application appears to limit the review to the individual's person-centered plan (PCP).

If this is correct and the death reviews are a review of the individual's PCP, then our members would support this change.

Liberty Healthcare's current death review process is extremely burdensome as they require providers to send them copies of all the individual's records.

Although we understand it is important to thoroughly investigate the sudden and unexpected death of a young, physically healthy, Waiver individual, applying exactly the same investigative process to the expected death of an elderly Waiver client residing in assisted living and receiving end-of-life hospice services seems unjustified and inefficient.

This death investigative process also seems disrespectful to Waiver individuals and their families who have chosen to have a peaceful death and to the physician, assisted living staff, service coordinator, and hospice team who cared for the individual during their journey.

RECOMMEND: If it is a requirement that all individuals' deaths while receiving Waiver services must be reviewed, recommend a modified and more person-centered review process when the individual's death is expected.

#7 Recommend Redacting Waiver Participant's and Provider's Names for Committee Reviews

It's our understanding that the Waiver Death and Incident Review Committees, which are comprised of representatives from Liberty Healthcare, DHHS, service coordinators, and consumers, review the information on the death or incident with the individual's and provider's name included because Liberty Healthcare's system does not allow the names to be redacted.

We believe it could be a HIPAA violation to have non-DHHS individuals reviewing individuals' protected health information and may create unwarranted legal issues.

RECOMMEND: Recommend the Waiver individual's and the provider's names be redacted when sharing death or incident information with the Review Committees.

#8 Recommend an Improved Solution to Claim Denials for Incorrect Share of Cost

Excerpts From Application:

- **(Page 140) The SC monitors Medicaid eligibility and participant share of cost obligations using the DHHS systems containing this information. The SC also monitors the share of cost obligation being obligated to Medicaid waiver services in order for the participant to maintain Medicaid eligibility.**

The DD Division requires AL providers to bill through its Therap database system. Currently, claims submitted correctly can be denied because the individual's share of cost amount on the claim does not match the share of cost amount in the Medicaid payment system (MMIS).

However, the share of cost amount information on the claim is automatically generated within the Therap system and the provider is not authorized to enter or change this amount.

The DD Division's current guidance is for AL providers to avoid claim denials by first running a report and then verifying the client's share of cost amount is correct for each month. If the amount is incorrect, the AL provider is directed to contact the individual's service coordinator to request they manually update it to the correct amount.

RECOMMEND: It seems unfair to put the burden for correcting errors they do not control on the AL provider. As the Medicaid payment system already has the current, correct share of cost information, recommend this process be changed to eliminate the providers' responsibility for correcting errors. For example, Medicaid could remove the MMIS edit for the share of cost amount that denies claims and authorize the claim to pay the correct amount or build an interface between MMIS and Therap to update the share of cost amount automatically.

#9 Recommend Elimination of Duplicate Provider Reporting Requirements

Excerpts From Application:

- **(Page 165) Situations or environmental events (e.g. fire, weather, flooding) that cause risk to participants and imminent (life threatening) danger will also be tracked through**

this process. These situations will be reported to DDD staff and also to other authorities as appropriate.

- **Providers must report the following types of critical incidents to DDD:**
  - **Allegation, suspicion, or actual events of verbal, physical, sexual, psychological, emotional abuse, neglect, or exploitation of a child or vulnerable adult.**
  - **Allegation or suspicion of financial exploitation.**
  - **Misuse or unauthorized use of restrictive interventions or seclusion.**
  - **A medication error resulting in a telephone call to, or a consultation with, a poison control center, an emergency department visit, an urgent care visit, a hospitalization, or death.**
  - **Unexplained or unanticipated death, including but not limited to a death caused by abuse or neglect.**

AL providers, per Nebraska statute, are required to self-report the incidents described in the above excerpt from page 165 of the renewal application to DHHS via its Children and Family Services (CFS) Division's adult protective services (APS) hotline. As the incident is being self-reported by a licensed facility, this information is also shared internally with the facility licensure unit in the Public Health Division. Both DHHS entities have the authority to investigate the incident.

As the DD Division is also located within DHHS, it would seem to make sense that APS could just share the facility's self-reported information with them, rather than requiring duplicate reports to the same state agency.

Although it's our understanding it makes it easier for Liberty Healthcare to review the information if it is entered directly into their system, this seems like an unnecessary administrative burden.

RECOMMEND: Recommend that the initial self-report made by the AL provider to DHHS' CFS Division be shared with the DD Division in the same way it is currently shared with the Public Health Division and other DHHS entities.

#10 Recommend This Explanation be Modified

Excerpt From Application:

- **(Page 209) Initial rates for the Supported Residential Living Services were determined through a public stakeholder process. Numerous meetings were held with provider association groups to determine the current formula, which recognizes urban and rural variances.**

According to the Medicaid Director at the time the AD Waiver was implemented and AL services were included, he developed what he considered fair rates at the time and the provider association agreed. There was not a public process or numerous meetings. At that time – more than 25 years ago – the rates did seem fair. Since that time, the AL rates have either remained the same or increased slightly based on legislative direction, which has resulted in an increasing gap between the Waiver AL rate and the cost of care.

Overall Comments
Our goal remains to encourage our AL members to participate in the Medicaid Waiver program so all Nebraskans who need and choose AL level of care have access. However, the additional Waiver requirements, delays in eligibility, and Medicaid underpayment make this a challenge.

Just an additional note that we have previously shared the concerns and recommendations described in this letter with DHHS and appreciate their attempts to try to find solutions. We are grateful for the DD Division being open to discussion of provider concerns, transparency on upcoming changes, and willingness to work together.

Thank you for the opportunity to provide comments. We feel advocating for our AL members is important in keeping their concerns at the forefront. Please let us know if you have questions.

Sincerely,

Jalene Carpenter

Jalene Carpenter, President and CEO
Nebraska Health Care Association

From: Amanda G
To: DHHS HCBS Public Comments
Subject: No cap!!!
Date: Sunday, December 28, 2025 6:31:49 AM

You don't often get email from [redacted] Learn why this is important

No cap!!!! Disabled deserve dignity. Caregivers deserve dignity

As Co-Chairs of the Olmstead Advisory Committee we are writing to clarify the direction DHHS is going regarding disability and the Olmstead decision.

> The Supreme Court ruled people with disabilities have a right to lives of inclusion and integration. Disability is a normal part of life and we all benefit from communities made up of diverse people, life experiences, and abilities.
>
> The Olmstead Case centered on two women, Lois Curtis and Elaine Wilson. Both had disabilities and experienced going in and out of state run hospitals. Their doctors believed they could safely live in the community. Every time they left the hospital, they would go home without support and end up back in a hospital. They asked the State of Georgia to give them the help they needed to integrate into their communities and stop going into hospitals. (http://dhhs.ne.gov/pages/Olmstead.aspx)

Recently we became aware of the Aged & Disabled Waiver Renewal and we are very concerned about the following :

> *All current waiver participants will continue to receive the services as outlined on their person-centered plan (PCP). Prior to the participant's next eligibility year, the Service Coordinator (SC) will meet with the participant to complete the high-utilization review. When the combined costs of waiver and state plan services exceed the applicable cost limit, the SC will work with the participant to reduce services below the 175% limit, while still ensuring health and safety are met. When the participant's needs cannot be met, referrals to other community services, including institutional services, are provided to the participant. The participant is provided with alternative options to meet their needs, including but not limited to nursing facility placement."* (AD Waiver Renewal Application, Page 12)

Considering placement in a Nursing Home or other institution seems counter to the Nebraska Olmstead efforts.

Therefore we are requesting an emergency Olmstead Advisory Committee Meeting, preferably a hybrid meeting prior to January 5, 2026. The Olmstead Advisory Committee needs to know the following at a minimum:

- Why are these changes being made?
- How many people will be removed from the waiver when they are reviewed by cost?
- What are the ages? Differences between over 65 versus under 65.
- How does actions regarding EVV (Electronic Visit Verification) and changes to AD Waiver work together to impact Olmstead Advisory Committee?
- What type of Nursing Home or Institution will be used to make determination of cost?

These are only a few of the questions that we will need addressed at the meeting. So please come to the meeting prepared to discuss this topic in detail. Initially, we are considering that DHHS is attempting to sabotage any efforts to move the Olmstead decision forward in Nebraska.

Because this time frame is determined by the public comment period established by the AD Waiver Renewal Application. We would appreciate a response by Tuesday December 16, 2025.

Thank you,

Kathy Hoell

Mark Smith

From: Laura Vajgrt
To: DHHS HCBS Public Comments
Subject: Open comment response
Date: Monday, December 29, 2025 11:51:09 AM

You don't often get email from [redacted] Learn why this is important

To whom it concern,

I am submitting this public comment in strong opposition to the proposed 40-hour cap on caregiving services, particularly as it applies to medically complex and ventilator-dependent individuals. This proposal raises serious public safety concerns. There has been no clear plan presented for what happens when a complex individual has no outside help available and no skilled care beds to transfer into. The options being offered do not work for this population, and the absence of a realistic contingency plan places both individuals and the broader healthcare system at risk.

A 40-hour cap is not feasible for this population. Most families caring for medically complex individuals are effectively running an intensive care unit out of their home. These parents and caregivers are providing continuous, high-risk medical care, often 24 hours a day. Ventilator management, oxygen support, suctioning, medication administration, and emergency response do not stop after 40 hours per week. Capping care at this level is unrealistic and places lives at risk.

The proposal relies on the assumption that families and community members can provide the remaining care. In reality, families are already providing far more than 40 hours of "implied care." These parents are highly trained, and carrying responsibilities comparable to skilled nursing staff—without adequate compensation or relief. By doing so, they are saving the state a substantial amount of money by preventing hospitalizations, ICU stays, and institutional placements that cost thousands of dollars per day.

Medically complex and ventilator-dependent individuals should not be umbrellaed into a low-level skilled care community or budget model designed for populations with significantly lower acuity, such as many older adults who require limited skilled services. These are fundamentally different populations. Medically complex individuals have continuous, high-intensity medical needs that require significantly more care, oversight, and specialized skill. Placing them under the same budgetary umbrella ignores medical reality and results in policies that are unsafe and inequitable.

There are also no realistic alternatives available if hours are reduced. In the Omaha area, there are extremely limited skilled facility beds willing and able to accept ventilator-dependent children and complex individuals. Only a few beds exist, and they are often full. Institutional placement is not a realistic option.

If families can no longer safely care for their loved ones at home due to hour reductions, the likely outcome will be increased hospital admissions. This will place additional strain on hospitals, emergency departments, and healthcare workers, potentially leading to delayed treatment for other patients and worsening outcomes system-wide. This

proposal does not reduce costs; it shifts them to more expensive and less appropriate settings.

The proposed "companion care" option is not viable for medically complex individuals. Companions are not permitted to manage ventilators, perform skilled medical tasks, or intervene in emergencies. Companion care cannot replace skilled nursing hours and does not meet the needs of this population.

In effect, this proposal provides no workable plan for medically complex individuals. Families are being asked to absorb even more care, rely on untrained or inappropriate supports, or pursue placements that do not exist. This creates unsafe conditions for individuals who depend on continuous skilled care to survive.

Medically complex individuals represent a very small percentage of the waiver population, yet their needs are significantly higher and cannot be addressed through a one-size-fits-all cap or a generalized budget model. A separate tier, carve-out, or exception process is necessary to reflect the true level of care required.

I urge the Department to reconsider this proposal, recognize that medically complex individuals cannot be treated the same as low-acuity populations, and develop a policy that prioritizes public safety, medical necessity, and fiscal responsibility. Do you have a plan that actually is viable considering what I have mentioned that doesn't apply to complex needs individuals.

Thank you for the opportunity to provide public comment.

Sincerely,
Laura Vajgrt
Family Member and Caregiver of a Medically Complex Individual

From: Sandra Miller
To: DHHS HCBS Public Comments
Subject: open forums
Date: Thursday, December 18, 2025 1:50:06 PM
Attachments: image001.png

> You don't often get email from [redacted] Learn why this is important

I know it may be a logistical nightmare, but it seems like it would be beneficial to have two different calls. One for independent caregivers and one for companies because we do have different issues.

Warm Regards,

Sandra Miller, BSW MBA
712.310.3496
https://trustedlifechoicesllc.com/personal-care/

woman owned

TRUSTED LIFE CHOICES LLC | key home care
Where Compassion is Key

From: Desa
To: DHHS HCBS Public Comments
Subject: Opinion
Date: Sunday, January 4, 2026 8:37:40 PM

You don't often get email from [redacted]. Learn why this is important

I have been a mom of 2 adult disabled children . I feel that the state has a lot of questions about their funding towards different programs. I feel that taking hours n payment away from caregivers is not the answer. The facilities like nursing homes and hospitals, are understaffed, or not qualified for the quality care of a person who is disabled or a person that has special needs. and wouldn't be able to give the quality of care needed.

Past incidences with nursing homes and other facilities have proven to fail. And cause nothing but damage and neglect to the client. And I feel that the client is more likely to flourish and live a more healthier happier life. If taken care by a family member or taken care of at their own home. And keep them happier at home for both families n clients. I feel that taking

The responsibilities from the caretakers away from them or reducing their hours, will only hurt the client in the long run n and cause the caregiver to have to find another means of making a Living. And it is hard work taking care of a disabled person, not that it is a burden but it is hard on a person. Financially, mentally and physically. The state should continue relying on the social worker that does the evaluations of these families. To determine how many hours they should receive, and the care the client gets. I feel that there's also the people that take advantage of the system should be the ones that be punished. And not the people that follow the rules and take quality care of their clients shouldn't be punished by these people who take advantage of the system.

I believe that the state needs to monitor better and to follow-up on these people that take advantage of the system. And also let the social workers do their jobs and evaluate and keep track of the quality of care and the hours.

If I can explain this properly, I feel the companies that run the different programs like care tech , home instead, home alone or those kind of facilities where the client is authorized $45 an hour n where actually the actual caregiver only gets $13 dollars an hour.And the rest goes towards caretec, home instead etc. For their half of taking care of the paperwork and fees, they should not be able to take as much from the caregiver. Not that the facilities shouldn't have a percentage of it but not as much as should be paid out to the facilities. I just feel we were pushed into having to rely on these facilities like care tech and home instead. And instead of being able to do our own because the state didn't want to have that burden of the paperwork and the fees. And now we're being questioned on how much we are paid. And the hours we are given . The facilities do deserve to have their part of the pie. You might say, but I feel that they get alot an hour for what out of that $45. But anyway, that's my example, and I feel that this should be looked into more than taking away hours from people like us who are doing the actual work in the field. And actually taking care of the clients, but I don't think that we should rely on retirement homes or hospital facilities. Because the quality of care will only suffer for the client.And they'll be badly and sadly neglected.And the family members deserve to be able to have quality care for their loved ones.And I think they should be able to keep them at home and take care of them and be reimbursed for their efforts n time. Why

would you want to cause a person who has struggled their whole life with their disabilities to have their world turned upside down? And cause chaos, when their content and happy, being home with their family members that have taken care of them or care from people who are like family members.. Most of their lives just so that the state or facilities like care tech, Home instead, or other facilities like that to take quality care n money from them. I'm not saying that these facilities are bad. It's just I feel that there could be better ways of paying these facilities and caregivers and without taking away hours or pay from the caregiver

I truly believe that the social workers that are in place should be able to do their jobs and keep on monitoring the clients and the caregivers. The misuse of the program, it is definitely out there. And there is people that rack up the hours that don't actually do the hours. And misuse or misplace of funds are there but I don't feel that every caregiver is dishonest at all, they have their clients best interests in mind and a lot of family members should not be questioned or placed in the same category as of someone who does misuse the program hours or questioned of pay. That's what the social workers evaluate every month that they visit their clients, And the caregivers and also the yearly evaluations of everything that they see that is needed for the client or the caregiver. Shouldn't be questioned. That is the reason why they do home visits monthly and their yearly evaluations.Let the social workers do their job . I don't feel that a person should have more than 2 or 3 clients at the same time. But it also depends on how many hours that the

caregiver is given.

I appreciate your time and also. I'm sorry if this is confusing. My wording, if any questions I would greatly appreciate you contacting me. I have so much on my mind and opinion. But I understand that there is so much at stake in that there is a lot of people's opinions, but I appreciate your time and please take careful consideration.People with disabilities are very precious and need to have quality care.Thank you again.

Have a good day.

From: Anthony VanNoordwyk
To: DHHS HCBS Public Comments
Subject: Oppose Cuts to Aged & Disabled Waiver Caregiver Hours
Date: Saturday, January 3, 2026 7:03:37 PM

You don't often get email from [redacted]. Learn why this is important

To Whom It May Concern:

I am writing to voice strong opposition to the proposal to reduce paid caregiver hours under Nebraska's Aged & Disabled waiver from 112 hours per week to just 40 hours per week. Such a drastic cut would place disabled and elderly Nebraskans, as well as individuals living with traumatic brain injuries, at serious risk.

From both a financial and human perspective, this reduction is short-sighted. Caregiver hours are what allow many people to remain at home with family support instead of entering institutional care, which is typically more expensive for the state and associated with worse health outcomes and quality of life. (https://pmc.ncbi.nlm.nih.gov/articles/PMC4192933/)

In my own family, my sister-in-law has multiple disabilities and currently qualifies for caregiver hours. She is thriving in a home environment where relatives who know her well provide consistent care, follow her routines, and understand how she communicates. Forcing her into a facility because her caregiver hours were slashed would be traumatic and would likely harm both her physical health and emotional well-being.

The ripple effects on our family would also be immense. My brother has built his life around ensuring that she is safe, supported, and cared for every day, and the prospect of her being moved away from their home is devastating. Reducing caregiver hours to 40 per week would make it nearly impossible for them to preserve the stable, loving arrangement they have now.

I strongly urge DHHS to reject this proposal and instead prioritize investment in home- and community-based services that keep disabled Nebraskans, older adults, and people with traumatic brain injuries in their homes, where they can live with dignity and connection to their families.

Thank you for taking my concerns into account.

Sincerely,
Anthony VanNoordwyk
[redacted]

From: Cheryl Fuhrmann
To: DHHS HCBS Public Comments
Subject: OPPOSE PROPOSED CAPS ON HCBS IN-HOME CARE SERVICES
Date: Monday, December 29, 2025 9:53:18 AM

You don't often get email from [redacted]. Learn why this is important

Dear Nebraska Department of Health and Human Services Leadership,
My name is Cheryl Fuhrmann, and I am a Nebraska resident from Fremont, NE.
I am writing to submit a public comment in opposition to the proposed caps on Home and Community-Based Services (HCBS) hours and related policy changes that would reduce access to in-home caregiving for adults with disabilities. These proposed changes will harm Nebraska families and will ultimately cost the state more, not less.

More than one in eight Nebraskans live with a disability, and many adults with severe disabilities rely entirely on in-home care to live safely in their homes. For these individuals, home care in not optional - it is essential. Reducing or capping care hours does not eliminate the need for care; it only shifts the cost to more expensive systems.

When families lose necessary in-home care hours, they are pushed into crisis. Caregivers are often forced to leave the workforce or reduce work hours, increasing reliance on public assistance programs. Health and safety risks increase, emergency room visits become more common, and many families are eventually forced to place their loved ones into institutional care. Institutional care is the most expensive outcome possible. Nursing facilities can cost the state well over $150,000 per person each year, while family-provided in-home care costs a fraction of that amount. Keeping people in their homes is both more humane and more fiscally responsible.

I respectfully urge Nebraska DHHS to reject arbitrary caps on HCBS hours, preserve needs-based services, and avoid policies that force people out of their homes and into higher-cost institutional care.

Thank you for the opportunity to provide public comment.

Sincerely,
Cheryl Fuhrmann
[redacted]

From: Katie Novakoski
To: DHHS HCBS Public Comments
Subject: Opposing AD wavier proposal cuts
Date: Thursday, January 1, 2026 3:10:30 PM

You don't often get email from [redacted] Learn why this is important

Dear DHHS,

I am writing to express serious concerns regarding the proposed cost caps and service reductions to Nebraska's Aged and Disabled (AD) Waiver. I strongly oppose these changes proposed in to the AD wavier. The Nebraska Department of Health and Human Services' (DHHS) own Medicaid Annual Report directly contradicts the justification for these changes and shows they will increase costs, harm medically complex individuals, and undermine state and federal policy goals.

DHHS explicitly acknowledges that home and community-based care is generally less expensive and offers greater independence than facility-based care. Despite this, the proposal imposes rigid cost limits on AD Waiver services while nursing facility care remains uncapped and reimbursed on a daily basis. This creates a structural incentive toward institutional placement, even though DHHS's own data confirms community-based care is the more cost-effective option.

Rising AD Waiver expenditures do not reflect waste or inefficiency. DHHS reports a 24.49% increase in AD Waiver spending in one year, totaling $409,551,107 in SFY25. This increase reflects a growing population of medically complex individuals who require intensive, individualized supports to remain safely in their homes. Using this increase to justify flat cost caps ignores the true drivers of spending and disproportionately harms those with the highest medical needs.

DHHS data also shows that individuals who are aged, blind, or disabled make up only 16.46% of Medicaid beneficiaries but account for 41.38% of total Medicaid expenditures. This demonstrates why average-based cost models are inappropriate for waiver participants. A small subset of medically fragile individuals will always fall far outside standard cost curves, making uniform caps inherently incompatible with medical reality.

At the same time, long-term care expenditures rose by 10.49% in SFY25 while Medicaid provider rates remained frozen in both SFY25 and SFY26. This contradiction directly contributes to the workforce shortages DHHS now cites as justification for service reductions. The state cannot freeze rates, allow acuity and costs to rise, and then fault families and providers when the system becomes unsustainable.

The proposal also treats waiver participants and nursing facility residents unequally. Nursing facilities are reimbursed daily based on level of care and are not subject to annual hard caps.

In contrast, AD Waiver participants face strict annual cost ceilings that trigger institutional referrals once exceeded. This incentivizes institutional placement and directly conflicts with federal Medicaid policy and DHHS's stated commitment to community-based care.

Finally, DHHS acknowledges that long-term services and supports remain fee-for-service, meaning the state controls reimbursement, staffing rates, and waiver design. Any resulting service instability or workforce collapse is therefore the result of state policy choices, not market forces. This is especially concerning given DHHS's stated support for community integration and federal initiatives favoring care in the community over institutional settings.

In conclusion, DHHS's own data shows that the proposed AD Waiver caps contradict documented cost-efficiency findings, disproportionately harm medically complex individuals, worsen workforce shortages, favor institutional care, and conflict with federal integration mandates under the ADA and *Olmstead v. L.C.* The Department cannot claim to support community-based care while advancing policies that make it inaccessible to those who need it most.

Sincerely,
Katie Kuecker

From: Whitney Hansen
To: DHHS HCBS Public Comments
Subject: Opposition for Hours Cuts
Date: Tuesday, December 23, 2025 3:12:31 PM

> You don't often get email from [redacted] Learn why this is important

Good afternoon,

I am writing to you today in extreme opposition to the proposed hours cut from 112 to 40 hours a week.

Caring for many of these individuals is beyond a full time job — it is 24/7. By cutting these paid hours, you would be drastically harming Nebraska families in a multitude of ways. Individuals with disabilities deserve the dignity of at-home care and should not have to be forced into facilities due to these cuts.

Sincerely,

Whitney Hansen

From: Nelson, Lizzy E
To: Sen. Kathleen Kauth; DHHS HCBS Public Comments
Subject: Opposition regarding the proposed changes to the AD waiver personal care program
Date: Sunday, January 4, 2026 3:45:45 PM

You don't often get email from [redacted] Learn why this is important

Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers. These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.

If cost containment is necessary, there are better alternatives:

- Maintain current hour limits for existing participants (grandfathering).
- Remove or revise the 40-hour cap for live-in caregivers.
- Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment.

Lizzy Nelson
[redacted]

From: Nelson, Kelly S
To: Sen. Kathleen Kauth; DHHS HCBS Public Comments
Subject: Opposition regarding the proposed changes to the AD waiver personal care program
Date: Sunday, January 4, 2026 11:39:32 AM

You don't often get email from [redacted] Learn why this is important

Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers.

These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

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The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment.

Kelly Nelson, PT, DPT
Board Certified Pediatric and Wound Management Physical Therapist
Assistant Professor|Department of Physical Therapy
Creighton University

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Omaha, NE 68130
402-280-2200
Providing care on Tuesdays (west clinic), Wednesday afternoons (campus clinic), Thursdays (campus clinic and pool), and Fridays (west clinic and pool)

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From: Alberts, Elizabeth C
To: Sen. Kathleen Kauth; DHHS HCBS Public Comments
Subject: Opposition regarding the proposed changes to the AD waiver personal care program
Date: Sunday, January 4, 2026 3:48:45 PM

You don't often get email from [redacted] Learn why this is important

Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers.

These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.

If cost containment is necessary, there are better alternatives:

- Maintain current hour limits for existing participants (grandfathering).
- Remove or revise the 40-hour cap for live-in caregivers.
- Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment.

Ellie Alberts

From: Stanley Thomas
To: DHHS HCBS Public Comments
Subject: Opposition to AD Waiver changes
Date: Sunday, December 28, 2025 5:09:54 PM

You don't often get email from [redacted] Learn why this is important

Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers.

These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

If the proposed changes pass, I personally know caregivers that will need to take a second job in addition to caring for their severely disabled child/client which is more than a 40 hour per week job. What would more likely happen is families with severely disabled children, will have to put their children in institutional care/SNFs which will actually cost more to the taxpayer.

Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.

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The AD Waiver was created to protect vulnerable individuals, support caregivers, and use

public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment.

Stanley Thomas, D.O., FCCP
Assistant Professor
Division of Pulmonary, Critical Care and Sleep Medicine
Creighton University School of Medicine
CHI Health

From:	Doug Lynn
To:	DHHS HCBS Public Comments
Cc:	philip gray
Subject:	opposition to cuts to at-home services provided under the Social Security Aged and Disabled (AD) Medicaid waiver
Date:	Monday, January 5, 2026 2:48:35 PM

You don't often get email from [redacted] Learn why this is important

From: Warren Lynn, 1200 Garfield St, Lexington, NE, 68850, cell: 308-325-7136

Several points, as the father of a developmentally disabled, 49-year old daughter who since birth in a U.S. Navy hospital in the Philippines, is totally dependent upon the care of others and who receives residential and day program services through AD waiver funding from Nebraska DHHS:

1. The purpose of one of the programs under the AD Waiver is to provide services that help aged and/or disabled individuals to live in their own homes safely instead of in a nursing home, the valid assumptions being that a person's family members provide far better care than paid strangers and that the individual should live in the least restrictive setting possible. The proposed cuts to AD waiver funding involve another assumption but one that is not valid: the cost of paying family members to care for an AD family member is comparable to the cost of a nursing home in Nebraska, which as stated by the NE DHHS was $92,438 for the fiscal year ending 30 June 2025.
Comment: According to the 24 Dec 2025 Nebraska Examiner article "Families fear 'devastating' changes to Nebraska program serving people with disabilities, elderly", Kierstin Reed, president and CEO of LeadingAge Nebraska, which represents nursing homes and assisted living facilities, stated that the $92,000 figure represents the cost only of "custodial-level care" whereas AD waiver individuals require various additional supports (some examples: assistive technology, non-medical transportation, independence skills building, home and vehicle modifications). With such supports as these (and others), Reed "guarantees" that most AD individuals living expenses would exceed $162,000, and in some cases reach $1,000 a day.

2. AD individuals have their disabilities and limitations of advanced age 168 hours per week (7 days x 24 hours); no time off for them, their family member caregivers, or paid staff if if the AD individual is placed in a state institution. No reimbursements for at-home care under current regulations cover all of those hours, and the proposed limit of 70 total hours (40 for family member providers and 30 for non-family member providers) would cover only 42% of the week.
Comment Family members are on-call 24 hours day, regardless of what care expenses are reimbursed (example: AD individual on a ventilator 24 hours a day), and reimbursing family members is a more efficient method of providing effective care, compared to placement in a state institution.

3. According to the same Nebraska Examiner article mentioned in paragraph 1. above, Governor Pillen has made several statements that I find troubling regarding Nebraska state-sponsored payments to family members for the at-home care of AD individuals. One statement was "But, I mean, the hardcore reality, we the people in Nebraska, in instances, are paying grandmas to be grandmas."

Comment: If Pillen understood the reasons for keeping as many AD individuals at-home as possible, he would have said instead: “the hardcore reality, we are paying the grandmas of AD individuals for doing all the things that grandmas of AD individuals do to keep their grandchildren safely at-home instead of in a nursing home."
Another troubling statement: Nebraska DHHS had written $300,000 checks so Nebraskans aged 98 to 100 could stay at home, which Pillen said “sure as hell” ought to be the exception, not the norm.
Comment: What documentation is there to support such a statement? How long a period did the $300,000 checks cover? What was the extent of disabilities of the AD individuals covered? How do we know that $300,000 checks are not the exceptions? Could there have been just two such checks and could both of them been the result of paying for approved services to severely disabled or aged individuals? According to DHHS more than 10,000 Nebraskans are using this specific Medicaid waiver. when in the following paragraph of the article a Nebraska DHHS representative stated that 95% of AD waiver recipients already receive services “at or below the proposed budget limit” that is based on the nursing home rate (of $92,438).

4. Nowhere on the internet can be found an estimate of what the “savings” to the Nebraska state government will be under this services reduction proposal.
Comment: could the reason be that such an estimate would have to address what the real cost would be to the state of taking AD individuals out of their homes and into state institutions? Paying families to care of their AD family members is far less expensive and far less effective than placing AD individuals in state institutions.

5. More comments and personal examples can be found at MTV 3 News Now entry "posted on 30 Dec 2025 (www.3newsnow.com/„„/nebraska-families-fear-state…)

From: Welch, Marisa R.
To: DHHS HCBS Public Comments
Subject: Opposition to proposed AD Wavier changes
Date: Friday, January 2, 2026 11:22:04 AM
Attachments: image001.png

You don't often get email from [redacted] Learn why this is important

Greetings,
I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers. These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable. Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.

If cost containment is necessary, there are better alternatives:

- Maintain current hour limits for existing participants (grandfathering).
- Remove or revise the 40-hour cap for live-in caregivers.
- Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.
Thank you for considering my comment.

MARISA WELCH, OTD, OTR/L, BCP
Assistant Professor | Department of Occupational Therapy
Pediatric Occupational Therapist | Creighton Pediatric Therapy
AOTA Board Certification in Pediatrics
School of Pharmacy and Health Professions
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My Office is a Safe Space

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Creighton UNIVERSITY

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From: Steven Mahlendorf
To: DHHS HCBS Public Comments
Subject: Over lapping hours
Date: Friday, December 19, 2025 7:39:29 AM

> You don't often get email from [redacted] Learn why this is important

During school year if the child is unable to attend school due to illness, are we allowed to bill for that time and do we need pre approval or documentation for those days or hours?
Ann

Sent from Yahoo Mail for iPhone

From: April Summers
To: DHHS HCBS Public Comments
Subject: Parent full time caregiver for adult son
Date: Thursday, December 25, 2025 4:05:37 PM

[You don't often get email from a[redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

I was not informed of the meetings by my service coordinator until afterwards. I want to understand why you feel it's fair to cut my hours down to only 40 a week. This is no ordinary job where you go home at the end of the day, have weekends off, holidays or vacations it's my life 24/7. My son has more than just severe medical disabilities but also severe intellectual and developmental disabilities including seizures. He can't do anything for himself (read write bathe tell time know what food he can have change out both Urostomy and ileostomy change his diaper or take his meds. He is basically bedridden and housebound except for Dr appointments then basically wheelchair bound and completely dependent on someone (me) I am at home with him 24/7. My husband works full time and I have no extended family or friends that can help. He can't be left alone ever. His medical needs are so complicated someone off the street can't come in and watch him. I think there are plenty of other ways to save money than hurt the caregivers/parents who most have given up any form of a regular life to care for their adult children. Especially one like mine where even if I wanted to put him in a facility (which I don't) there is not one that can meet all his needs. We need every penny we get from the state just to survive. We had to relocate to the east side of the state for him to be close to his specialists instead of doing a 4-5hr drive (one way). It was so hard on him to do that. It is so much more expensive to live here and that it takes both of our salaries. If you want to save money go after the healthy adults in this state that abuses the medicaid snap government housing systems instead. I could say a lot more but I think I have expressed my concerns and explained why it is so important not to make cuts to this program.

April Summers
Sent from my iPhone

From: Kelly Wagner
To: DHHS HCBS Public Comments
Subject: Parent Testimony – Public Comment on Proposed AD Waiver Changes
Date: Friday, January 2, 2026 2:59:40 PM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

To Whom It May Concern,

I am writing as a mother and full-time caregiver to my adopted daughter, Allyson, who is 25 years old and lives with profound, lifelong disabilities. I am asking you to read this not as a policy document, but as a window into what these proposed changes mean inside a real home.

Allyson has the cognitive ability of a young child, approximately ages four to seven, depending on the topic. She is a paraplegic with spina bifida and cerebral palsy. She has osteoporosis, epilepsy, hydrocephalus with a shunt, kidney reflux, GERD, and a neurogenic bowel and bladder. She has a Chait tube, a colostomy, and a vesicostomy. She has undergone 54 surgical procedures in her life.

Allyson requires 24-hour supervision. This is not optional. It is not flexible. It is not something that can be "made up" later if hours are cut.

She cannot perform basic self-care. She needs assistance with dressing and undressing, bathing, brushing her teeth, food preparation, mobility, transfers in and out of vehicles, and every aspect of her medication routine. She cannot manage her bowel or bladder independently. Every single day, she requires a bowel washout through her colostomy. She must be catheterized every two to three hours because she cannot urinate on her own. If this care is delayed or missed, she is at risk for kidney damage. She already has kidney reflux.

Allyson also has epilepsy. If she were left unsupervised and experienced a seizure, it could be life-threatening. A shunt blockage could be life-threatening. These are not hypotheticals. These are real medical emergencies that require immediate recognition and response.

Allyson is 100% reliant on her caregivers—during the day and throughout the night. Even while sleeping, she must be checked on. There is no true "off duty" time.

Because Allyson's cognitive and communication abilities are limited, she cannot always articulate when something is wrong. Those who know her best—her parents and her sister, who is a CNA—recognize changes in her behavior, her words, her facial expressions, and her routines that signal pain, illness, or danger. This knowledge is built over years, not hours.

Allyson has also experienced abuse in the past. Because of that trauma, feeling safe and protected is not simply emotional comfort—it is essential to her well-being. Familiar, trusted caregivers are not a preference for her; they are a safeguard.

When policies impose blanket hour caps or reduce caregiving support based on relationship rather than need, they ignore the reality of lives like Allyson's. Her medical needs do not pause at 40 hours. Her seizures do not wait for staffing availability. Her kidneys do not know whether a caregiver is being paid or is exhausted and unpaid.

Cuts to caregiving hours do not eliminate the need for care—they simply shift it onto families in ways that are unsustainable and unsafe. They force parents into impossible choices: between exhaustion and risk, between financial survival and medical vigilance, between keeping a child at home or facing institutional placement not because it is best, but because it is the only remaining option.

I am not asking for special treatment. I am asking for policies that recognize medical reality, honor person-centered planning, and allow adults with disabilities like Allyson to remain safely in their homes, surrounded by those who

know her, love her, and can keep her alive.

Please understand that when you reduce hours on paper, the consequences are lived out in bodies, in emergencies, and in families who are already giving everything they have.

Thank you for taking the time to hear a mother's voice.

Respectfully,

Kelly Wagner
Parent and Full-Time Caregiver
[City, Nebraska]

Sent from my iPhone

VIA EMAIL: DHHS.HCBSPublicComments@nebraska.gov

January 5, 2026

RE: Public Comment on Proposed Amendments to Nebraska's HCBS Aged and Disabled Waiver

To Governor Pillen, Nebraska DHHS Leadership, and Nebraska Lawmakers,

I. Introduction and Standing

I submit this comment as both a parent of two adult children with disabilities who rely on Medicaid Home and Community-Based Services (HCBS) and the owner of an agency that provides Personal Care, Companion, and related services under Nebraska's HCBS waivers.

I therefore experience the impact of these proposed amendments from both sides of the system:

As a family member responsible for ensuring my adult children's health and safety in the community, and as a provider responsible for delivering services in compliance with state and federal requirements while maintaining a stable workforce and sustainable operations.

From both perspectives, I am deeply concerned that the proposed amendments, if approved, will increase the risk of unnecessary institutionalization, undermine person-centered planning, and place Nebraska out of compliance with the Americans with Disabilities Act (ADA), Olmstead v. L.C., the HCBS Final Settings Rule, and EPSDT requirements.

II. Cost Caps That Function as Institutional Triggers

The proposed amendments require service reductions when combined waiver and State Plan costs exceed 175% of the institutional cost limit, and direct Service Coordinators to refer participants to nursing facilities when needs cannot be met within that cap.

As a parent, this language is alarming. It tells families that if their loved one's needs are too complex or too expensive to serve at home—regardless of appropriateness or safety—the solution is institutional placement. That is not a choice; it is a forced outcome driven by budget policy rather than individual need.

As a provider, I know this structure will inevitably result in:

- Unsafe reductions in authorized hours,
- Increased hospitalizations,
- Workforce instability when care plans are repeatedly cut, and
- Eventual institutional placement for individuals who could otherwise remain safely in the community.

Federal law is clear that states may not design HCBS programs that steer individuals into institutions when community placement remains appropriate. These amendments do exactly that.

III. Rebalancing Costs Cannot Override Civil Rights Obligations

The waiver identifies “rebalancing the long-term care system Medicaid costs” as a primary goal. While fiscal stewardship is important, cost rebalancing cannot be achieved by limiting community services to the point that institutional care becomes the only viable option.

As both a parent and a provider, I can state unequivocally that:

- Institutional care is often more costly over time.
- It removes individuals from their families, communities, and natural supports.
- It contradicts the very purpose of HCBS waivers.

Federal courts and the Department of Justice have consistently held that budget considerations do not excuse violations of the ADA’s integration mandate. The proposed amendments elevate cost ceilings above person-centered planning in a manner that federal law does not permit.

IV. Service Design That Replicates Institutional Conditions in the Home

The Personal Care service definition requires providers to fragment care based on task type, repeatedly clock in and out of services, and cease billing during sleep hours even when overnight presence is necessary for health and safety.

As a parent, this approach ignores the reality of disability support. Care needs do not occur in neat billing increments, and safety does not stop at bedtime.

As a provider, these requirements:

- Force agencies to deliver care in a way that mirrors institutional task-based models,
- Discourage continuity of care,
- Increase administrative burden without improving outcomes, and
- Make it harder to recruit and retain qualified caregivers.

The HCBS Final Settings Rule requires services that support autonomy, dignity, and integration, not models that turn private homes into de facto regulated facilities.

V. Rigid Hour Caps Undermine Person-Centered Planning

The proposed caps on Personal Care—40 or 70 hours per week depending on living arrangement—override individualized assessments and person-centered planning.

As a parent, rigid caps mean living with constant fear that support will be reduced even when needs remain unchanged.

As a provider, rigid caps create:

- Unfillable staffing gaps,
- Unsafe handoffs,

- Moral distress for caregivers, and
- Pressure to recommend institutional placement when home care becomes unworkable.

True person-centered planning cannot exist when predetermined limits control outcomes.

VI. Disproportionate Harm to Families and Children

The proposed restrictions Personal Care—including narrow definitions of "extraordinary care," strict hour caps, and limitations on service delivery—place an unfair burden on families.

As a parent, I know firsthand that families already provide extraordinary levels of unpaid care. These amendments presume that family labor should replace medically necessary services unless the State narrowly defines otherwise.

As a provider, I see families forced to choose between:

- Leaving the workforce,
- Providing unsafe levels of care without support, or
- Pursuing institutional placement they never wanted.

For children and youth, these restrictions conflict with EPSDT, which requires Medicaid to cover all medically necessary services to correct or ameliorate conditions. Limiting services based on age, school hours, or arbitrary caps violates that obligation.

VII. Cumulative Impact and Legal Risk

Taken together, these amendments:

- Normalize institutional referral,
- Penalize high-need individuals,
- Shift responsibility from the State to families and providers, and
- Replicate institutional logic in community settings.

As both a parent and a provider, I believe these changes place Nebraska at substantial risk of federal noncompliance, CMS disapproval, and DOJ enforcement under Olmstead.

VIII. Requested Action

I respectfully urge the State to:

1. Withdraw or substantially revise the proposed amendments.
2. Remove cost-based triggers that lead to institutional referral.
3. Eliminate rigid service caps that override assessed need.
4. Redesign Personal Care and LRI services to support continuous, integrated care.
5. Ensure full compliance with Olmstead, the HCBS Final Settings Rule, and EPSDT.

Nebraska's HCBS system should support families and providers in keeping people safely at home—not push them toward institutions through policy design.

IX. Conclusion

I submit this comment not only as a stakeholder, but as someone whose family and business will be directly affected by these changes. Community-based services work when they are adequately funded, flexibly designed, and grounded in person-centered principles. The proposed amendments move Nebraska away from those principles and should not be approved in their current form.

Thank you for the opportunity to comment.

Richard Troia
Father of Sarah and Alex Troia

President and Owner
Special Sitters LLC
rtroia@specialsitters.com

From: TheVolumesofTruth
To: DHHS HCBS Public Comments
Subject: Plans to cut caregiver hours for medically needy
Date: Monday, December 22, 2025 7:08:58 PM

You don't often get email from [redacted]. Learn why this is important

"Thus says The Lord: Blessed is that servant of Mine who seeks out the poor, whose heart is eager to help the needy, for they know My ways and seek to please Me. Blessed also is My servant who gives out of the abundance they have received, for they walk in My ways. Yet most blessed is My servant who gives from their lack, for they do justly, love mercy, and walk humbly with their God; indeed, they have understood.

Yet woe to those who ignore the poor and draw back their hand from the needy, while they sit at ease in their abundance. For destitution is coming, and shall be born out of great desolation, in the day I take away their abundance and leave their houses desolate. Woe also to those who say they are My servants, yet refuse to help those in need, for only tears and sorrow await them. And woe to those who fail to give even the smallest amount, claiming they are in lack, for they have no trust, having learned nothing from the poor widow.[1]

Little flock, have you learned nothing from My Word? Have you so quickly forgotten My Letters, in where I have taught you the way in which you should walk? Indeed, who you choose defines what you do, as I have already told you.[2] And who are the poor and the needy? How have you treated them, while entreating Me? Do not lie to yourselves, beloved ones. Every one of you who sit at this table want for nothing. Shall you mince words over a dollar, while others sit upon the ground seeking to draw water from a pit? Shall you covet five dollars or even ten as you drive about in your automobiles, while your brothers and sisters abroad willingly walk miles to preach My Word, with joy, even to their dying breath?

And still some of you sit at ease in your padded chairs, punching the keys, saying within yourselves, ***"I am delivered."*** You are not delivered! From the power of sin, yes, My children, I have delivered you, yet some of you remain married to this world. And those who remain married to another, even to themselves, can by no means be joined unto Me, lest adultery be brought into the house of The Lord.

Beloved ones, you are My treasure. Yet some of you count yourselves as first, having loved another more than Me; therefore you must be last. For I search the hearts and minds. And that discipline reserved for the churches of men, is it not also for you, even to a greater degree? Or have you forgotten this Scripture: ***For everyone to whom much is given, from him much will be required; and to whom much has been committed, of him they will ask the more?***

Therefore choose, make your decision...

It is time...

Says The Lord."

(From The Volumes of Truth, Volume Six, an excerpt from "Reasonable Service:)

TheVolumesofTruth.com

Hear the Word of The Lord Spoken to THIS Generation

From: Jennifer Melvin
To: DHHS HCBS Public Comments
Subject: PLEASE don"t cut AD hours
Date: Monday, January 5, 2026 5:13:17 PM

> You don't often get email from [redacted]. Learn why this is important

To whome it may concern,

I know by now you've heard many stories and many points regarding the changes to the AD Waiver program. Our family has a couple more to add.

1. You already cut hours in July, stating a mandatory 8 hours off rule. Which us families did, adjusted our lives and made it work. We are not money grabbing families. We are caring for a person that, if they were normal, would be on their own. On page 108 you talk about extraordinary care. These children grow up to be adults with the same, often times worse issues/conditions. Making that extraordinary care continue to adulthood. At this time our 'informal supports' disappear. They age out of schooling and often times age out of the 1 on 1 services, as many places will not take them. So we step into a job that no one else wants, without complaint, and jump through every hoop and face every challenge to keep them healthy, happy, SAFE and ALIVE.

2. We complete background checks, and yearly renewals. Attend training for new programs like Therup, Netsmart and the mobile caregiver app, but you consider us 'informal support'. Which, as stated before, we are doing a job NO ONE ELSE WANTS.

3. There are 25 levels of nursing home care, so using a blanket number is unrealistic. A cap goes against the Olmstead act and your own words of 'person centered practice' as well as 'Home and Community-Based Settings' and keeping these individuals in the least Restrictive Environment. There is also, at present, a many year waiting list for places that would take some of our loved ones, up to 5,7,9 years. At a cost of upwards of $1000 a day, or at Beatrice which is quoted around $358,000 a year.
We are in a nursing shortage, there are NO ROOMS for these individuals in nursing homes. Day programs do not care for high needs medically coplex/fragile people. Also, the fed is changing RN mandates Feb 2nd so there will be less nurses on the floors of these homes with less eyes on these individuals, increasing the risk of neglect, injury, abuse and death.

4. What is Acentra Healths role in all of this? And why is there is a sudden push for institutionalization care comparison. Does Acentra or any other organization have a contract for day programs, institutional care etc.
 How much does Acentra, Therup, Net Smart Mobile Caregiver App cost the state? Seems like Therup and Netsmart are a duplicate service.

5. A out of home service provider can charge $48-$68 an hour. How is paying them double/triple for less time economically sound.
30@$48=$1440
30@$58=$1740

30@$62=$1860
30@$68=$2400
*A family caregiver ~ 112@$15=$1680
Not to mention forcing people to have people they DO NOT want in their home.

6. Are any other programs being hit with these types of cuts? You can't end a waitlist, add people to another, increase the numbers and then state we have to 'decrease' spending in those categories.

7. Poor lack of planning should not trickle down to the most vulnerable. Costs rise, that's a part of life, how was this not included into the planning of all this.

8. Last point. If you have been working on this for 6 months, why wait till the last minute to share? Why weren't commities informed like the Nursing Home Association Or the Olmstead group?

You ruined the holidays for so many, people who are already at their limits trying to keep everything together and keep people safe, happy and alive.

We all have unique stories with similar roads and concerns.
Us family caregivers have given up our own lives, jobs, dreams, retirement and quite frankly our hearts to care for our loved one.
We should not be discriminated against for doing a job, that quite frankly no one else wants, or can do. I personally wake up every morning praying my daughter is still alive and I go to bed every night praying for 'just one more minute'. That I live one more minute more than her, because the thought of anything happening to her if I'm gone is more than my heart can handle. Our family is going to have to move, and restructure our already modified house to accommodate this decrease. Our daughter currently has her own room, a play room and a bathroom. Freedom to use the toys, crafts, items in her home. She gets her trips to get 'cheeseburger' Happy meals and 'cards' at the dollar stores.(Things she would not have in a nursing facility/institution).

Thank you for your time,
Jen

From: Becca Volz
Subject: Please Reconsider: 40-Hour Cap Threatens Families Under A&D Waiver
Date: Monday, January 5, 2026 7:55:07 AM

You don't often get email from [redacted] Learn why this is important

To Whom It May Concern,

I am writing as a Nebraska constituent, a voter, and a family member of a person with disabilities to express deep concern and heartbreak over the Nebraska DHHS proposal to impose a **40-hour cap on live-in caregivers under the Aged & Disabled Waiver**.

This proposal would directly affect my brother (Peter Hegg) and our family. My brother depends on consistent, live-in care to safely remain in his home. This is not a preference—it is a necessity. A rigid hour cap would disrupt his care, increase risk in countless ways, undo years of hard-fought stability and progress, and force devastating, life-altering decisions on our family—exactly what this waiver program was created to protect families from.

I have spent most of my life watching my parents sacrifice—physically, emotionally, and financially—to care for my brother for nearly 30 years. They have carried this responsibility with love and resilience, and policies like this risk breaking families who have already given more than most will ever be asked to give.

They have done everything asked of them. They have built a stable, safe, home-based care plan that keeps my brother out of institutional care and allows him dignity, consistency, and security. A 40-hour cap ignores the reality of disability and the lived experience of families like mine. Disability does not pause after a standard workweek ends.

As members of the Health and Human Services department, you are entrusted with protecting vulnerable Nebraskans and ensuring that policies are grounded in sound judgment, compassion, and fiscal responsibility. This proposal falls short on all three. It places impossible burdens on families, increases safety risks for medically fragile individuals, and is likely to raise long-term costs by driving people toward institutional care and emergency services.

This decision impacts real people and real families. It impacts my brother. It impacts my parents. It impacts us. And it threatens to unravel years of stability in the name of an arbitrary cap that does not reflect real care needs.

I urge you to oppose this proposal and to stand up for Nebraska families who rely on the Aged & Disabled Waiver to survive—not just to get by, but to live safely and with dignity. Please listen to the families affected and use your position to ensure that policies meant to protect do not instead cause harm.

I would appreciate a response outlining your position on this proposal and how the committee plans to address the concerns raised by affected families. Sincerely,

Rebecca Volz [redacted]

From: jeanette brezina
To: DHHS HCBS Public Comments; Pillen, Jim
Cc: Amy Davis
Subject: Potential Cuts to Caregiving Hours
Date: Thursday, December 18, 2025 10:49:24 PM

You don't often get email from [redacted]. Learn why this is important

I can't believe that you are doing a blanket cut back on caregivers hours.

Justin Davis is an extreme case that requires 24/7 care. His mother is providing the majority of his care at her home, with outside caregivers coming in approximately 62 hours a week (while Amy if providing 112 hours of week of the care). Her goal is and will always be trying to work with Justin so we don't need this level of care--but know they need it---JUSTIN NEEDS IT!!

On September 24, 2024, Justin experienced an undiagnosed AVM (arteriovenous malformation) in his brain that suddenly ruptured, causing a massive brain bleed. To this date, he is nonverbal, totally handicapped and has extreme needs. Cutting down his caregiver hours will be a huge detriment to Justin. His mother has been a big supporter of his care and has had to read charts when he has been hospitalized several times since then (where they were going to give him meds with lactose (which is is allergic), etc. 2-hour check in (rounds) is just not acceptable or safe for Justin. How can this be acceptable or safe for him.

Is it that Nebraska wants him to "rot" and then eventually die so they don't have to deal with him? I'm wondering.

It's a shame this young man has had to go through the tragic brain bleed and now he can't get the help that he desperately needs. His adult life was just beginning and is now on hold for the time being.

I'm sure you can look up his records to see all the help that he requires.

I pray that you do not take his hours down so that he doesn't have any hope whatsoever.

Jeanette Brezina

[redacted]

From: [redacted]
To: DHHS HCBS Public Comments
Subject: Proposal for A/D Waiver Changes
Date: Friday, January 2, 2026 3:33:16 PM

You don't often get email from [redacted] Learn why this is important

To whom it may concern,

I am writing in response to the proposed changes to the A/D Medicaid waiver.

Our son is 28 years old and needs 24/7 care. He has multiple cognitive and physical disabilities, uses a wheelchair, and is blind. He also has unique medical issues that need constant monitoring for extra lifesaving medication given through a g-tube or injection.

The deep cuts being proposed would greatly reduce his quality of life by reducing or eliminating the care he receives from his live-in sister. We are currently getting 112 hours per week of paid caregiver time split between Peter's sister and me. The cuts would reduce this to 40 hours per week. Our family has worked hard and sacrificed much to care for Peter and are very thankful for what the waiver has provided. But the cap on hours for live-in caregivers is unrealistic and strongly limits who can provide quality care. Our loved ones should be able to choose their caregivers! We have no "informal supports" and live a very isolated life due to Peters fragile health. We do not have friends or family that are available or qualified to care for him the way he needs or would be comfortable with. Comfort and consistency are extremely important for Peter's health and well-being. Our primary goal has always been to keep him healthy, safe and happy. Reducing hours would cause a complete strain on our lives, affecting those we care for and the life we have taken years to build for Pete. We want to continue to give him the quality of life and purpose that he deserves.

Thank you for considering this,

Lissa K. Hegg- Peter's mother and loving caregiver

From:	Mitch Hegg
To:	DHHS HCBS Public Comments
Subject:	Proposed Amendment cuts to the Nebraska Medicaid Home and Community-Based Services (HCBS) Aged and Disabled (AD) Waiver
Date:	Thursday, January 1, 2026 3:55:48 PM
Importance:	High

You don't often get email from [redacted] Learn why this is important

To whom it may concern,

I felt it imperative that I voice my strong concern and opposition for the proposed cuts to the Nebraska Medicaid Home and Community-Based Services (HCBS) Aged and Disabled (AD) Waiver service hours for the care of our most vulnerable people. These proposed draconian cuts reducing service hours to just 40 hours per week for live-in family members will be devastating and possibly life-threatening to the disabled persons and a significant financial burden on the family caregivers that care for these family members. These are our Sons, Daughters, Parents, Brothers, Sisters, Aunts and Uncles. How have we come to this, that we would introduce and move forward on budget cuts that adversely affect the already difficult lives that aged and disabled loved ones live? It's downright shameful.

I understand that budgets need to make sense, but to cut care hours for people that can't care for themselves. How can you convince yourself that is the right way to balance your budget. I'm sure their other areas that can be cut that don't affect the lives of people that can't take care of themselves.
I sincerely ask you to re-look at what is being proposed, close your eyes and imagine you are doing this to one of your loved ones to save a few dollars in the grand scheme of an entire budget where cuts can be made to things that don't affect the care of our most vulnerable people.

Every aged or disabled persons care is different; some require a lot of hours spent caring for and helping them to enjoy life and others require less hours. Lumping them all together and setting a maximum number of hours (the propose 40 hours) for all, is just not very caring or loving and frankly it's an easy way to make a cut without providing diligence to truly support and care for all involved, the aged, disabled and caregiver alike.

Our son is 28 years old and has many disabilities that would prevent him from surviving in a nursing home or a group home. He is blind, does not take anything by mouth (he is tube fed), he is incontinent, has cerebral palsy and is on life-saving medications. He requires 24/7 monitoring and care just to survive. Because of our diligent care we have kept him safe and out of the hospital. Bringing "outsiders" in to care for him would be devastating to his emotional state and his physical health and would be drastically more expensive then to just continue to provide the current 112 hours of in-home family care he receives now.

One DHHS employee is stated as saying "You'll be paid for a 40-hour work week, just like other working people" Our son and other aged and disabled people receiving

care, don’t just stop being disabled or needing care at the close of a 40-hour work week!
If this is all about the budget – what are you doing? How are you convincing yourself that this is somehow the right and prudent course of action?

Due to his emotional anxiety, routine and his life-saving medications he would never survive outside our care, we know him best and understand his unique medical condition that if not monitored throughout the day constantly, he would slip into a medical crisis and not survive. Because we are diligent and know him and his medical crisis signs, we have avoided many hospital stays and emergency room visits over the last 28 years.

Please reconsider the proposed cuts to the A&D care hours! As you can see, we spend way more than 40 hours a week caring for our son. The loss of hours would be a financial burden to all his care givers and a strain on the health of those caring for him by requiring employment outside of caring for our son.

Being leaders requires you to not only evaluate and make decisions but to do it with compassion, care and what is right and not just easy and budget line cuts.

Thank you for taking the time to read and understand our concerns.

Sincerely,
Mitchell Hegg
Father and caregiver for Peter Hegg

From: Deb Lairmore
To: DHHS HCBS Public Comments
Subject: Proposed changes for AD Waiver
Date: Tuesday, December 23, 2025 6:02:45 PM

You don't often get email from [redacted]. Learn why this is important

I am the caretaker for my son who is on the AD waiver program.
Devon is 26 years old and is completely reliant on me for his daily care. He is tube fed, in diapers, in a wheelchair and is not able to do anything for himself. He has severe Quadraplegic Cerebral Palsy with cognitive issues. I am presently allowed 98 hours a week, 14 hours a day for his care.
I also feel that if these changes are made that the State is apparently wanting to force parents to put their family members in an institution. Which, I also believe the institutions are mostly overloaded with the vast amount of patients now. I feel that the cost of a care facility would definitely far exceed what I receive for his care.
With the proposed changes to 40 hours a week pay that would leave 6 hours a day and weekends that he is awake and needing care that I would not be compensated for his care. He is receiving alot better care with a one on one situation in our home than any other place in my opinion.
I would request that the State not adopt these changes to the AD Waiver Program.

Debra Lairmore
[redacted]

From: Jennifer Alonso
To: DHHS HCBS Public Comments
Subject: Proposed changes for Caregivers 2026
Date: Friday, December 26, 2025 1:47:55 PM

You don't often get email from [redacted]. Learn why this is important

I find this appalling. Many caregivers receive next to nothing for a full day of care for a family member who cannot do things on their own. I am one of those caregivers. I receive a measley $400 per month when I should be receiving minimum wage per hour for the hours I render services to care for my ailing father. That amounts to $5 per hour for 20 hours a week for what I receive now. How many others are underpaid like I am? Now this proposal to downgrade even more? Changes need to be made, but not this.

Jennifer Alonso

From: Tiffany Messman
To: DHHS HCBS Public Comments
Subject: Proposed Changes to A&D Waiver
Date: Monday, January 5, 2026 8:47:01 AM

You don't often get email from [redacted]. Learn why this is important

Comments on Proposed Changes to the Nebraska Aged & Disabled (A&D) Waiver

The participants who will be affected by these proposed changes represent the most vulnerable individuals in Nebraska—older adults and people with disabilities who rely on the A&D Waiver for their health, safety, and ability to live with dignity in the community.

Under federal Medicaid law and the Olmstead v. L.C. decision, the State of Nebraska has an affirmative obligation to provide services in the most integrated, least restrictive setting appropriate to the individual's needs. This responsibility rests with the state—not with unpaid or underpaid family members placed in financially unsustainable caregiving roles.

The proposed changes appear to rely on unreasonable and unsupported assumptions, including:

• That families are obligated to provide extensive, often medically complex, care at extremely low reimbursement rates

• That families can absorb the financial and emotional burden of 24/7 caregiving without placing the entire household at risk

• That participants who cannot rely on family caregivers can readily transition to institutional settings, despite:

o Severe workforce shortages

o Limited nursing home capacity for waiver participants

o Few facilities willing or able to accept individuals with high-acuity needs

o Reduced nursing requirements in nursing facilities, including the lack of guaranteed 24/7 nursing coverage

Given these realities, the proposed changes raise serious concerns about participant safety, access to care, financial coercion into institutionalization, and compliance with federal disability rights law.

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1. Waiver Funding and Fiscal Justification

Please respond to the following:

1. Is there currently a funding shortfall in the A&D Waiver?

o a. If not, is DHHS projecting a future shortfall? If so, based on what data and timeline?

o b. What specific budgeting, actuarial, and forecasting methodologies are being used to determine the existence or likelihood of a shortfall?

o c. Why did the state contract with a company whose primary function is to reduce Medicaid expenditures and allow that entity to make recommendations affecting HCBS waiver services, which serve the most vulnerable population in Nebraska?

This company has no accountability to waiver participants or the disability community.

DHHS does have legal and ethical accountability to Nebraska residents.

Allowing cost-containment recommendations without participant-centered safeguards appears negligent and inconsistent with the intent of HCBS waivers.

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2. Limitation of Personal Care and LRI Personal Care to 40 Hours per Week for Live-In Caregivers

The A&D Waiver exists specifically to prevent unnecessary institutionalization and to promote dignity, stability, and independence in the community.

It is a demonstrable fact that participants requiring high levels of care cannot obtain sufficient

services at a limit of 40 hours per week at $15.00 per hour, whether through agencies or individual providers.
2. Please explain:
o a. How does the state justify expecting family members to provide extensive, often round-the-clock care at such a low wage and with such limited authorized hours?
o b. Why was an arbitrary 40-hour limit selected when many participants have documented 24/7 care needs?
o c. The proposed reimbursement rate is far below what medical professionals receive for similar levels of care and places families in severe financial jeopardy.
This will inevitably force families to choose institutional care, removing the participant's right to choose community-based services.
How does the state plan to prevent this outcome and ensure participant needs are actually met?

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3. Combined 70-Hour Weekly Limit for Personal Care, LRI Personal Care, and Companion Services
The proposal allows agencies to provide up to 30 hours per week, while family caregivers are paid significantly less.
3. Please address:
o a. How does the state justify the wage disparity between agency providers and family caregivers providing the same—or higher—levels of care?
o b. If the goal is to reduce Medicaid expenditures, why does the state pay substantially more for agency staff than for family caregivers who already provide consistent, trusted care?
o c. Many participants are not comfortable receiving intimate or complex care from strangers.
These limits effectively remove participant choice, in direct conflict with HCBS principles and disability rights protections.

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4. Institutional Cost Limit of 175% for Waiver Nursing Home Services
As noted above, the proposed changes will financially coerce families into institutional placement, despite clear evidence that:
• High-acuity participants often exceed the care capabilities of standard nursing facilities
• There is an ongoing shortage of qualified staff
• Nursing homes are no longer required to have a nurse on staff 24/7
4. Please explain:
o How does the state justify pushing participants toward institutional settings that may be less safe and less appropriate than their current community-based care?
o Is the state assuming families will simply "figure it out" and continue providing unpaid or underpaid care, regardless of financial hardship or caregiver burnout?
Additionally:
• a. Will DHHS open or expand institutions capable of providing high-level medical and personal care for these individuals?
• b. If so, will these facilities be operational by July 2026, when the proposed changes take effect?
• c. If not, where and how will the state ensure participants receive necessary care and services?
• d. What is the state's plan to provide appropriate institutional care in the least restrictive environment, given workforce shortages, limited bed availability, and reduced nursing requirements?
• e. What specific criteria will DHHS use to determine whether an exception to these limits is warranted?

Closing Statement

These proposed changes appear to prioritize cost reduction over participant safety, federal compliance, and human dignity. Without meaningful revision, they risk violating the Olmstead mandate, undermining HCBS goals, and placing Nebraska's most vulnerable residents in harm's way.

The state must provide clear justification, transparency, and safeguards before proceeding with any changes that so profoundly affect the lives of A&D Waiver participants and their families.

From: Joan Gilbreth
To: DHHS HCBS Public Comments
Subject: Proposed changes to Medicaid Waivers for family caregivers.
Date: Saturday, December 27, 2025 12:07:46 PM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

As a Nebraska citizen, voter, and family member of someone who worked for decades in serving adults with disabilities, I strongly oppose the proposed cuts that will diminish the number of paid hours of care that family members can earn while caring for their loved one.

How can this even be a fiscally responsible plan? It doesn't make sense to think that the State will save money by reducing these paid hours. If families can no longer afford to care for their loved one and that individual needs to go in to institutional care, the increased costs will be astronomically higher.

Please do not add another financial mistake to the previous ones of lowering taxes on those who can well afford to pay income taxes. We're in this financial fix because of those 2023 tax reductions. Now the governor wants the most fragile individuals in this state to suffer the consequences of that bad plan.

Let me add one more thing. The governor owes an apology to the family caregivers for his insensitive and out-of-touch comment that the State is "paying grandmas to be grandmas." He's implying that this is women's work and that women, even older women, are shirking their family duties or wanting to get paid for them.

That is such a clueless comment. Is he really that out-of-touch with the life of average families that he doesn't realize that our current economy now requires at least two incomes, or more, to keep many households afloat? Many of those grandmas he denigrates for not doing their familial duty are working paying jobs to keep their own immediate households afloat.

I'm stunned that the governor is so uninformed that he thought that comment was a good idea. He needs to apologize to those "grandmas" and to all the family members cobbling together caregiving for their loved ones.

He can give a sincere apology for his cluelessness and then have DHHS withdraw this heartless and fiscally irresponsible proposal. That is what I request of my State government leaders.

Joan Gilbreth
Nebraska citizen and voter

From: Shelley Snyder
To: DHHS HCBS Public Comments
Subject: Proposed Changes to the A&D Waiver
Date: Tuesday, December 30, 2025 8:02:33 PM

You don't often get email from s[redacted]. Learn why this is important

To Whom it May Concern ~

I have already submitted a comment for the changes being made to the A&D Waiver but after listening in on the Zoom on December 10 I have more concerns. These proposed changes are sickening. I don't know how you guys can do this to the most vulnerable. I hope you never have someone close to you in the situation we are in. I am my son's provider. He is an almost 30 year old adult male with Cerebral Palsy and a Seizure Disorder who is 24/7 cares. He has no functional use of his arms or legs so he cannot feed, dress or administer his meds himself. We currently get 86 hours a week. I do not know how you guys can justify 40 hours a week but if other providers (who most are not reliable) come in to my home you will justify 70 hours a week. That makes absolutely NO sense. NONE!!! I would be happy with 70 hours a week. We have very minimum informal supports. Like barely any help. Maybe an hour or 2 max a week. He is incontinent and most people are not comfortable changing him. Like I said earlier he's an almost 30 year old adult male. He is tube fed and takes most of his meds via feeding tube. Again most people are not comfortable handling his feeding tube. What he does take orally he is a huge choking risk. He also has seizures and needs to be closely monitored. Most people don't even know when he's having a seizure. Let alone know what to do when he's having one. He is in a wheelchair and requires a lift to move him. As far as nursing goes we've went that route and had a nurse steal from us so I'm not going that route again. Besides nurses are hard to come by as are caregivers. The good reliable ones are already taken. The amount of times I had a caregiver not show up was ridiculous. Therefore I quit my job to be able to take care of my son and provide for him. Actually you guys made me quit doing daycare if I wanted to be his provider. Please reconsider cutting our hours so drastically. I get you have to make some cuts but at least give us providers that live with our people the same amount of hours as you are willing to give someone who doesn't live with their person. If you look at the bigger picture a care facility is going to cost the state a lot more than paying a parent to take care of their adult child. I cannot fathom the fact that you would be ok with paying a nursing home the rates they charge and not pay me way less than that to take care of my son at home where he is comfortable and happy. Please

STOP this discrimination! It is sickening and hopefully you guys can look at other ways to cut the budget without putting these vulnerable adults in harms way. We are not even close to going over the supposed 175%. I'm not even sure where you guys are getting your numbers. If you want to save a buck continue to let me be my son's caregiver. But in doing that you NEED to give me more than 40 hours a week. Like I said in my other comment just because it looks good on paper doesn't mean it is the way to go. Please reconsider the changes. Our kids/adults deserve to live a good happy life in their homes where they are most comfortable just like everyone else.

A Mother/Caregiver that will NOT stop fighting for her son,

Shelley Snyder

Sent from Yahoo Mail for iPhone

From: Shelley Snyder
To: DHHS HCBS Public Comments
Subject: Proposed Changes to the A&D Waiver
Date: Sunday, January 4, 2026 6:30:45 PM

You don't often get email from [redacted] Learn why this is important

To Whom it May Concern ~

I am not understanding why you cannot look at each of these individuals as individuals. If only 3% of the individuals are over their budgets then why aren't you focusing on trying to problem solve those individuals instead of looking at all of us. We aren't even close to going over budget. We currently get 86 hours a week. We don't even get the 16 hours a day. Why punish all of us that are under budget.

Years ago when my son was first on the waivers program they had an hourly rate for providers up to a certain amount of hours and if it was over say like 8 hours a day then they gave a day rate. Why can't we do that to live-in providers? Especially those that are 24/7 cares. Do the day rate at say between $250-$300 a day depending on the severity of the individual. You would still be under most peoples budget. It's just food for thought.

Forcing these individuals into a facility does NOT give them a choice. It is taking away from their comfortable environment. There are not enough facilities or nurses around to accommodate all these needs. Why not let parents who are reliable continue to care for their adult children and pay them to do so. It would be a reasonable compromise. My son is most comfortable with me. I know how to read his expressions and whimpers. He is not comfortable around people who are not comfortable with his cares.

If more people were Independent Providers instead of going through an Agency that would save the state a bunch of money. I am an independent provider. Agencies are charging almost double what you are paying me per hour. I get it some people cannot handle their own scheduling and claims. Given the proper training it really isn't that hard. Maybe train your service coordinators better how to help us when problems do arise.

I am inviting all of you including Governor Pillan to come visit our home. See what it all entails. My son is happy here. Please reconsider these cuts to these waivers. I promise you that you won't regret letting us parents continue to care

for our adult children and giving us more than 40 hours a week to do so.

Thank you for your time,

Shelley Snyder

Sent from Yahoo Mail for iPhone

From: Staci G
To: DHHS HCBS Public Comments
Subject: Proposed changes to the AD waiver
Date: Friday, December 19, 2025 11:25:58 AM

> You don't often get email from [redacted]. Learn why this is important

I am a current respite worker for a 25 year old on the AD waiver. I cannot work there full time, as my full time job offers benefits and more money. His mother is always on the lookout for help, so she can take care of her other children and aging mother, as well as catch some sleep. With his medical complexities, leaving him alone is not an option, as his TBI often keeps him up for days, with tremors, cramps, pain, anger issues, body temperature control issues, and more. This family and others like her need more help, not cuts. Caring for their loved ones at home is cheaper than a nursing home, and more loving for quality of life. If examples of this are needed, they have been shared extensively, but I can find more to share them with you. The things being proposed will hurt Nebraskans, the most vulnerable among us, and those families who love them. We can't let that happen.

Staci Greunke
56472 854th Rd
Winside, NE 68790

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From: Lydia S
To: DHHS HCBS Public Comments
Subject: Proposed changes to the AD waiver
Date: Thursday, January 1, 2026 4:22:09 PM

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To whom it may concern:

On December 5th DHHS released proposed changes to the AD waiver. Part of these changes was to LIMIT live in care giver hours to 40 hours per week. For some of these live-in providers and their clients, this change would be very detrimental. Some of the MOST disabled folks in our state receive the maximum amount of 112 hours per week for their paid care (payment for 16 hours per day of care). Of that group, live-in caregivers provide the majority of those hours. Many of these live-in caregivers are parents or spouses of these disabled people, and many of them have left careers to take care of their loved ones. Some have been caring for their loved ones for 30 years or more. To suddenly cut their hours and income by 72 hours per week is DANGEROUS and very destabilizing for these disabled clients. This could lead to the loss of homes, mental health crises, hospital stays, and possibly death for some of the most medically needy clients.

Families affected by these changes will face severe financial issues. A loss of 72 hours per week at $15.00/hour is a cut of $4320 per month for these households. How will they be able to find jobs that pay that much, as people who have been out of the work force for so long? These families must also balance doctor appointments, hospital stays and the stress of caring for their loved ones, which would make working outside of the home very difficult for them at times. This plan assumes that suddenly, after YEARS of searching, hiring, training and losing paid care givers, that they can find someone to do their jobs. This is further complicated by the fact that these paid caregivers aren't able to administer medications or provide the medical decision-making necessary to ensure proper care for clients at all times, which means our most disabled will be in danger.

This plan will NOT work for the most medically fragile and high needs disabled adults on this waiver. If you are to go forward with limiting live-in care givers to 40 hours per week, you will be forcing people to sell their homes and put their loved ones into nursing home facilities. The waiver program was created in order to stop this exact situation from happening. Also, moving disabled clients into nursing homes will be further complicated by a current shortage of Medicaid funded beds available.

Instead, we propose that since this waiver has enough funds to make it through this year, that you spend this year meeting with the families of these individuals and create a plan that will actually work. I believe there are solutions available in this situation! The current system that's in place was created for individualized care, and there are already evaluations that were created to determine services and hours. If you want to create caps, please do it moving forward--not retroactively and NOT so suddenly and NOT so drastically. Consider contracting with each family individually (perhaps less agency contracting and more live-in caregiver contracting?), consider a tiered system like DD services use to determine pay rates.

Also please consider seeking out the funds you need:

a. Find an agency or non-profit, or create one, and begin to hold an annual fundraiser that gives average Nebraskans and wealthy Nebraskans a chance to care for the disabled of our state.

b. Perhaps the Huskers could run a fundraiser at one home game a year where they advertise the needs of those who are disabled in our state and give a matching percentage of ticket sales that day.

c. Would the Volleyball team and their fans want to help protect the disabled of our state?
d. Ask the Nebraska legislature to allocate more money for this program, due to the rising number of individuals in this program. I believe this sort of thing happens (for example, asking for raises for state employees, you look at the cost of living and then approve a 3-6% raise for your employees). A request for additional funding seems appropriate in this situation.
i. Or perhaps it would be a GREAT time for the legislators to PAUSE or freeze the corporate tax cuts that are creating some of these budget shortfalls?
e. Would Larry the cable guy be willing to help in some way as a Nebraskan with a HUGE platform? Would Warren Buffett want to help? We could ask some of the wealthiest Nebraskans to step up for those who are disabled in our state.

Please consider solutions that are PEOPLE focused, individualized and caring, not just focused on the dollar signs. Thoughtful policy making will ensure that those who are disabled, as well as their families, can continue receiving the care they need and avoid damaging and life-altering circumstances. This waiver program has blessed a whole lot of Nebraskans and allowed them to flourish. It has helped provide dignity and care for so many people! Please consider that as you move forward and make necessary changes.

Signed:
Lydia Shearer
[redacted]

From: DARIN CASTER
To: DHHS HCBS Public Comments
Subject: Proposed changes to waivers in 2026
Date: Wednesday, December 31, 2025 9:36:54 AM

You don't often get email from [redacted]. Learn why this is important

To Whom it May concern,

The proposed changes to the waivers in 2026 will effect my family tremendously. My son had Duchene Muscular Dystrophy and is on a ventilator and can't do anything for himself. Both my wife and I are registered care givers with the State and have been taking care of him since he was first diagnosed in 2001. As of 2020 when he was put on the vent after a scare where he coded, he has needed 24 hour care, 7 days a week.

Reading these changes I'm having a hard time comprehending why they are being suggested. Cutting us down to 40 hours a week is ridiculous and then saying we can get a nurse to come in for another 30 hours, where the nurse would be charging over double what we're getting paid is unbelievable. My wife and I will be the only ones taking care of my son as I've seen and heard way too many stories of abuse from caregivers and on some occasions theft and even stealing of handicap vehicles from the caregivers. If we're forced to have an outside person come into our house and something like that happens, you can bet there will a lawsuit filed against DHHS.

There should be instances where each case is reviewed and those that need care 24/7 should not be effected. I understand DHHS trying to control unneeded spending after what was exposed in Minnesota but don't hurt those of us who actually are legit and truthful about the care we are giving to our son. These changes need to be reviewed and modified so they don't hurt families like mine. If you would like to come see what my wife and I do and deal with on a daily basis, we'd be more then happy to show you.

Please do not allow these changes to occur as they are planned, this will devastate families that have someone who needs care 24/7.

Thank you.
Darin and Tammy Caster on behalf of my son Derek.

[redacted]

Sent from Yahoo Mail for iPhone

From: Josh and Sarah Henderson
To: DHHS HCBS Public Comments
Subject: Proposed Changes
Date: Thursday, January 1, 2026 8:55:32 PM

You don't often get email from [redacted] Learn why this is important

To Whom It May Concern:

I am writing regarding the proposed changes to the AD waiver. A couple of these changes would be extremely detrimental to my two disabled adult sons (one who lives with us full time and one who lives with his grandmother full time) who utilize the AD waiver.

Requiring only 1 in-home caregiver to have a max of 40 hours before requiring outside caregivers to enter the home:
In our rural area it would be impossible to get caregivers to come to our home, and especially when have to travel this far (time/expenses) to get here and only be paid $15 hour - nobody wants to do that. Especially with no benefits or travel expenses paid. We have tried for years to get caregivers, we have not even been able to find respite care for them, let alone full time at a low rate. Their only options is us as family caregivers - if you limit that to 40 hours, where do you expect their care to come from? We feel like we are saving the state a tremendous amount of money and resources by caring for him ourselves. We have extensive modifications to our home, at our own expense, to keep him safe and to be able to provide the best care for him. The son who lives with us would be cared for in a nursing home at the states expense if he wasn't her. He requires 24 hour care that we provide, even though we are not paid for all of it. He gets up throughout the night, he is a fall risk, has epilepsy and functions around the 10 month level. In a nursing home he would need a caregiver by his side 24/7 as well. The costs of this would be astronomical. We require nothing extra to provide care for him- we pay and set everything up he needs on our own, we ask for nothing extra - services/money/modifications. Just the hours allowed for his care. We use the money we make to provide all the things he needs. If that funding goes away - now we are paying out of pocket for all his care, while not able to work because we provide all his care and nobody will come here to help. We cannot have no income and all the expense of his care! How do you suggest he be cared for? No caregivers will come out this far, and if they do it is definitely not going to be for $15 per hour. Eliminate overtime if you need to cut costs, but don't take the only caregivers away from some of these adults who have nobody else!

Joshua Henderson

From: Deanna Henke
To: DHHS HCBS Public Comments
Subject: Proposed changes
Date: Sunday, January 4, 2026 10:02:40 PM

You don't often get email from [redacted]. Learn why this is important

I'm writing to express my concerns about the proposed changes to Caregiver's in Nebraska. There has been a proposal to cut the hours of caregivers that allow the elderly and people with disabilities to receive in-home services.
I'm a person with a disability and let me tell you what it means to me. I currently have Caregivers seven days a week, three hours a day. The symptoms of my disease include extreme fatigue as well as loss of muscle and dexterity. I also use a wheelchair as I have a loss of mobility. Without the help of caregivers each day I would not be able to accomplish all of my activities of daily living. They help me with light house work so I have energy left to shower, eat and brush my teeth. They also help me with running errands like picking up my medicine at the pharmacy or picking up my groceries. They make food for me so I'm able to have at least one healthy meal a day. We often run out of time before we run out of things that need to be done, but I'm grateful for getting at least some time. If these hours are cut further, I would not be able to stay in my home where I feel safe and have my things and my dignity. I didn't ask for this disease and I do what I can to remain as independent as possible. It is already hard to qualify for in-home services and equally hard to admit you need help and ask for it. Reducing caregiver hours would force me into an institution where I would be just another number not an independent person in her own home. As my disease progresses, I'm going to need more help, not less. Not having those hours available for my care would be devastating.
If the driving force behind this change is money, let me remind you that Medicare or Medicaid funds used to house people in institutions cost a lot more than what a caregiver is paid for the person to stay at home. Also, the age of death of people in institutions is far lower than if they remain at home. The cases of depression, feelings of abandonment and total loss of making even minimal decisions, like what to wear or what time to go to bed or what to eat, cause worsening symptoms and a life of hopelessness.
This is the reality of so many citizens, like me, who just ask for the assistance they need to live safely at home. Finding quality, compassionate, and capable
caregivers is already difficult, don't make it harder by driving people away from this profession.

Deanna Henke

From: Tricia Gushard
To: DHHS HCBS Public Comments
Subject: Proposed cuts to A&D Waiver
Date: Sunday, January 4, 2026 1:00:51 PM

You don't often get email from [redacted]. Learn why this is important

Good Afternoon,
Dear leaders in Nebraska and Nebraska Lawmakers,
I am a caregiver for a person on the A & D waiver. I provide 24/7 care with all aspects of daily living. My client uses a wheelchair and has 50% nutrition through G- Button feeds. In order to eat by mouth he needs help with getting that food into his mouth and swallowing without choking. He cannot go to the bathroom by himself and needs me to catheterize him every 3 hours. He needs what is called "bladder irrigation" done every day due to having a bladder made out of his intestines. He also has a colostomy and has to have me change the bags and wafers. Due to all the missing intestines, it is very hard for him to digest even liquid nutrition. Since he has had a fundoplication surgery, I have to burp his G-Button after every meal or snack. He is on oxygen about half the day and requires my help to use a cough assist machine. He needs physical help in all aspects of daily life and he needs emotional support due to the tremendous amount of pain he is in every day. He cannot be left alone for any amount of time as he is also prone to having seizures or just choking on his own saliva. I sleep off and on in a bed next to his as he needs help throughout the night with colostomy care (explosions can happen when you have a colostomy and use a Bipap) and position changes to avoid pressure sores as well as those G-button burps. He sees a doctor once a week due to seeing so many specialists. It is impossible to be employed in a capacity to afford his care with all the time he requires from us. He takes 27 medications, some go through the G-Button, some are inhaled, others go up his nose and some have to be injected with a syringe. The compensation I received is only for some(2/3) of the 24 hours that I take care of him and the rate is $21 per hour. If I need to leave him, I must secure a Registered Nurse due to his medical needs and that person is paid by me at a rate of $40per hour.
How can this be so?
I am his mother and I have been caring for him for over 25 years. My other children have gone away to college and gotten married and had their own families. But that will never be the case for Elijah. He will always need my care as long as he is alive.
I had Merv Riepe over to my house last week and showed him what a day in our shoes looks like. My challenge to all of you is to come care for Elijah for a 24 hour stint and determine what the pay should really be for that much work. Imagine what it feels like to not have a full night of sleep in 26 years. I also would like you to go to Emerald by Bergan Mercy Hospital. Make sure you show up unannounced and look at the facility. Imagine if your child was disabled and would you be able to sleep at night knowing they were living in that type of neglect? Even the best nursing homes are no replacement for the care I provide my son. Especially when he is not able to communicate with others about his needs. To send my son to an institution would be a death sentence.
So many of the people you are considering cutting funding for are not able to speak for themselves. It is a deplorable thing that you are considering doing to the most vulnerable population of our State.
I could leave you with all the facts about violating the Olmstead etc. but you already know you are doing that. What you seem to lack is any real first hand knowledge of what it is like to be a person who needs to A & D waiver.
--I am expecting a reply to my email and I can also be reached tomorrow Monday Jan 5 at [redacted]

From: DOMINIC GILLEN
To: DHHS HCBS Public Comments
Subject: Proposed Cuts to the A&D Waiver and TBI Waiver
Date: Wednesday, December 31, 2025 10:52:33 AM

You don't often get email from [redacted] Learn why this is important

I am writing as a very concerned parent of an adult son who is severly disabled, and as a family will be deeply and negatively impacted by the proposed cuts to the A&D and TBI Waivers. These waivers are essential lifelines for individuals with severe disabilities, and for the families who provide their daily care. These services make it possible for individuals to remain safely in their homes and communities rather than being forced into institutional settings, which would also be more costly for the state. Reducing or eliminating these waivers would place an overwhelming burden on families who are already stretched emotionally, physically, and financially. Caregivers depend on these waiver services to be able to provide high quality and individualized personal care for their loved one. It allows them to continue making some kind of income since it is impossible to work outside the home when being a 24/7 caregiver. Cuts to these waivers would not only harm Nebraska's most vulnerable citizens, but would also inevitably and ultimately increase state costs through higher rates of hospitalization and/or institutional care. We ourselves are paid a very conservative wage of $17/hour compared to what would easily be $1,000 a day in a facility. I am begging, imploring, and strongly urging you to fully fund the A&D and TBI waivers, and to prioritize policies that honor dignity, independence, and home-based services for individuals with disabilities who are unable to speak for themselves.

Sincerely,
Shelley Gillen
Mom to Will

From: Cindy Guthmiller
To: DHHS HCBS Public Comments
Subject: Proposed Medicaid Waiver changes
Date: Monday, January 5, 2026 4:07:24 PM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

To whom it may concern:

My 45-year-old daughter was born in a small Nebraska hospital where surgical intervention was not available. The only doctor there reassured me that he could intubate and that it was safe to deliver my twins there even though they were both born breach in a vaginal delivery. This was clearly malpractice but I had previously worked at the hospital, so I chose not to file suit which was a poor decision on my part because now my daughter is dependent on the government in order to live with some sense of dignity. Her happiness and dignity was possible due to the waiver, which is now set to be eliminated for our weakest and most vulnerable citizens. My daughter had almost constant tremors for most of her life. She is unable to feed herself, go to the toilet without assistance or complete any activities of daily living by herself. She has tube feedings twice a day and her medications are all given via G.I. tube. My daughter is currently living on her own in an apartment which she pays for with her Social Security disability which was available to her after I retired a few years ago. She requires 24 hour/7 day a week care and she has qualified for this level of assistance for several years. I was told in November that she continues to qualify for the same level of care as last year and because of this decision, I renewed her apartment lease for the next year. Now I'm being told that she may lose all, but 40 to 70 hours of care a week. This would mean that she would have to go without eating at least one meal a day, her meds would be delayed and her condition would suffer. She would try to make it to the bathroom alone, which most likely would result in a fall and hospitalization. In the case of a fire, she would be unable to get out of her apartment by herself. My daughter has near normal cognition and she is a social butterfly even though she is nonverbal without technology. Can you imagine the devastating effect she will suffer if she has to be placed in a nursing home where the majority of clients will be the age of her grandmother. Nursing homes do not have enough staff to care for clients who require one-to-one care like my daughter and many other adult disabled children. I am a retired nurse practitioner. I listened to the parents' talk forum, that you provided for those affected to express their concerns for their adult children, many who had a tracheotomy. I can tell you that the majority of nurses are not trained to care for patients with tracheotomies or ventilators. This will require skilled nursing with a one-to-one nurse which will increase healthcare costs by a significant amount. Most nursing homes do not even have enough nurses to give patients their medications and a nursing aide is needed to give all residents their medications. There are not enough skilled nursing homes in the Midwest for the amount of patients that you are projecting that they will need to accept. Years ago, my
daughter went to work in a work center for disabled adults, which had to close because some human rights group decided that the workers could not be paid $.50 an hour even though most of the workers were unable to accomplish anything without much assistance. My daughter didn't care how much money she made. She was so proud that she could work just like her brothers did. After the decision was made to close all these workforce centers, my daughter suffered severe depression. Many parents had to quit their jobs and stay home with their adult children who were no longer allowed to attend the day workforce center. It was a disastrous policy decision. I truly believe that this is another disastrous policy decision, and I hope that you will reconsider this.
Sent from my iPhone

From: ROBERT and CINDY GETTY
To: DHHS HCBS Public Comments
Subject: Proposed Nebraska Medicaid Waiver Changes
Date: Monday, January 5, 2026 7:06:18 AM

You don't often get email from [redacted] Learn why this is important

HCBS Public Comments,

About the Nebraska Medicaid Waiver, I encourage the Nebraska Department of Health and Human Services to keep the current largest reimbursable caregiver hours. This would add problematic restrictions for Nebraskans who medically require round-the-clock care. Nebraska needs to support caregivers providing care to its citizens and taxpayers who are less able to care for themselves.

The proposed changes to the Nebraska Medicaid Waiver undercalculate the actual nursing facility rate and are not accurate, as most nursing facility rates would exceed $162,000. In addition, Nebraska nursing facilities are experiencing a severe shortage of skilled workforce.

Instead of restricting reimbursement for family caregivers, I recommend that the Nebraska Department of Health and Human Services request added state dollars for the increases in the needs that vulnerable Nebraskans are experiencing. I will follow up with my state senator to back up this request for additional state dollars for the Nebraska Medicaid Waiver.

Sincerely,

Robert J Getty

[redacted]

[redacted]

[redacted]

From: Scott Reierson
To: DHHS HCBS Public Comments
Subject: Proposed Waiver Changes
Date: Tuesday, December 16, 2025 9:30:38 PM

[You don't often get email from s[redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

To whom it may concern:

As a stepparent to an adult daughter with severe special needs I am very concerned about the proposed changes to the A and D waiver program which she currently receives services through. She requires round the clock care as she needs assistance with all basic needs. I have become aware that the current proposal will cap the number of hours for in home care at 70 and further break that down to 40 hours to a family member and the other 30 must be from an unrelated caregiver.

While I can understand reasoning behind capping the total hours to an amount comparable to the cost of nursing facility care, since in a situation like ours care in home or a nursing facility are the only realistic options. However I do not understand the reasoning behind requiring the available hours to be divided between a family member and an unrelated individual as this has no bearing on costs to the state.

As a family we have been down the road of trying to find a reliable caregiver whether that be through an agency or directly through an individual. My wife has hired outside caregivers many times so that she can return to work. The reality is there is a lack of qualified caregivers in this state, especially for kids and young adults with special needs. This makes it nearly impossible to maintain employment as your ability to work is directly tied to the reliability and schedule of the caregivers.

This is why in my family's experience there is no one that is more reliable than a family member. As a family we are the ones that there around the clock no matter what. We do not call in sick we still care for her even if we are, when we go on vacation she goes with us. The state will see no reduction in costs by splitting how the total hours are allocated. This is why I hope you will reconsider at least splitting the available hours between family and an unrelated caregiver.

Thank you for your consideration

Scott Reierson

From: Marissa Sims
To: DHHS HCBS Public Comments
Subject: Proposed waiver changes-Rate methodology
Date: Monday, January 5, 2026 8:56:08 PM

You don't often get email from [redacted] Learn why this is important

I am writing to submit a public comment and request clarification regarding the reimbursement rate methodology for Aged and Disabled (AD) Waiver agency providers.

As an AD Waiver agency provider, it was my understanding that DHHS was considering a move toward a flat, standardized reimbursement rate for agencies statewide—potentially calculated by averaging existing agency rates and applying that rate uniformly across Nebraska. This change was anticipated to occur within this year, and many agencies have been planning with that possibility in mind, particularly in light of other proposed changes impacting waiver services.

DHHS currently publishes Medicaid provider fee schedules for AD Waiver services that reflect varying agency rates by service type and provider category. While helpful, agencies would benefit from clarification on whether a standardized, flat agency rate for AD Waiver services remains under consideration.

The variability in agency reimbursement rates presents challenges for providers offering identical waiver-covered services. For example, one agency is reimbursed at $39.56 per hour, while many others receive rates closer to an average of approximately $32 per hour—or less—for comparable services. All AD Waiver agencies provide the same core services, such as personal care and companionship, under the same waiver framework. Greater consistency in reimbursement methodology could help support fairness, stability, and continuity of care.

As DHHS evaluates proposed changes to waiver services and reimbursement structures, agencies must operate within each participant's annual budget, which is tied to nursing facility cost neutrality requirements. When agency rates vary widely statewide, these differences can directly impact the number of service hours a

participant is able to receive within their budget. In some cases, higher rates may result in fewer authorized hours for participants with identical care needs, unintentionally affecting access and choice of providers.

As a newer agency, we are currently contracted at a rate of $28 per hour while continuing to offer competitive wages to recruit and retain caregivers in a challenging labor market. Clear guidance on future rate methodology would assist agencies in planning responsibly and ensuring continuity of care for participants.

To assist AD Waiver agencies with budgeting, staffing, and long-term sustainability, I respectfully request clarification on the following:

1. Is DHHS considering implementing a flat, standardized reimbursement rate for AD Waiver agency providers statewide?
2. If so, what is the anticipated timeline for implementation and public guidance?
3. Would a flat rate replace the current AD Waiver agency fee schedule, or exist alongside the currently published rates?
4. Are there draft proposals, public notices, or stakeholder discussions available that outline this potential rate methodology?

Clear communication on this topic is critical for AD Waiver agencies to continue providing consistent, high-quality services to older adults and individuals with disabilities across Nebraska.

Thank you for the opportunity to submit public comment and for your consideration.

Marissa Sims

[redacted]

From: Adjinata, Armelle
To: DHHS HCBS Public Comments
Subject: Public Comment – A&D Regulations, 70-Hour Weekly Cap, and Live-In Caregiver Reductions
Date: Friday, January 2, 2026 11:15:40 AM
Attachments: Outlook-5x5u0sgm.png

You don't often get email from [redacted] Learn why this is important

To whom it may concern,

Please accept this email as formal public comment regarding the proposed changes to the Nebraska Aged and Disabled (A&D) regulations, including reductions to live-in caregiver hours and the proposed cap limiting total participant services to 70 hours per week. I submit this comment from a provider perspective and strongly object to these changes due to their impact on service delivery, workforce sustainability, and compliance with CMS Home and Community-Based Services (HCBS) requirements under 42 CFR §441.301.

HCBS regulations require that waiver services be authorized based on individualized, person-centered assessments rather than fixed caps or generalized limits (42 CFR §441.301(c)(1)). From a provider standpoint, a universal 70-hour weekly cap is incompatible with the needs of many A&D participants currently served and creates service plans that are not operationally feasible or clinically appropriate.

Providers are responsible for ensuring participant health and welfare and for delivering services consistent with authorized plans. Under 42 CFR §441.301(b)(1) and (c)(2), the state must provide assurances that services are sufficient to meet assessed needs. A 70-hour cap results in predictable gaps in coverage—particularly overnight, during high-risk periods, or when participants require hands-on assistance or supervision. These gaps place participants at risk and expose providers to increased liability, incident reporting, and service failures that are outside of provider control.

CMS HCBS regulations also emphasize the obligation to prevent unnecessary institutionalization and to support individuals in the most integrated setting appropriate (42 CFR §441.301(c)(4)). From a provider perspective, authorizing services at levels that do not meet actual participant needs increases the likelihood of crisis events, hospitalizations, and eventual placement in nursing facilities or other institutional settings. These outcomes undermine the purpose of the A&D waiver and increase long-term system costs.

The proposed reductions also raise serious concerns regarding provider capacity and workforce stability. Live-in caregivers and high-hour service models are already difficult to staff. Reducing authorized hours and imposing a 70-hour weekly cap makes many service models financially and operationally unsustainable, leading to increased turnover, inability to

staff cases, and potential provider withdrawal from the A&D program altogether. This directly conflicts with CMS expectations that states maintain a sufficient and qualified HCBS workforce.

From an operational standpoint, these proposed changes shift risk from the state to providers while limiting providers' ability to safely meet participant needs. Providers cannot ethically or effectively deliver services when authorizations do not align with assessed needs, and doing so places both participants and providers in untenable positions.

I strongly urge the State of Nebraska to withdraw the proposed 70-hour weekly cap and reductions to live-in caregiver hours and to reevaluate these changes through a provider-informed, CMS-compliant lens. Any revisions to A&D regulations should support realistic service delivery, workforce sustainability, participant health and safety, and continued compliance with 42 CFR §441.301.

Thank you for the opportunity to provide public comment and for consideration of the operational and compliance impacts these proposed changes would have on providers, participants, and the A&D system as a whole.

Armelle T. Adjinata
Residential Coordinator
Holistic Group Inc

Cell -786-354-6084
Office-402-718-6900
Fax-402-763-912

Address:
9001 Arbor St
STE 206
Omaha NE 68124

HGI
Holistic Group, Inc.

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From: Viles, Jennifer
To: DHHS HCBS Public Comments
Subject: Public Comment – A&D Regulations, 70-Hour Weekly Cap, and Live-In Caregiver Reductions
Date: Friday, January 2, 2026 10:53:48 AM
Attachments: Outlook-dkjf4gpm.png

You don't often get email from [redacted] Learn why this is important

To whom it may concern,

Please accept this email as formal public comment regarding the proposed changes to the Nebraska Aged and Disabled (A&D) regulations, including reductions to live-in caregiver hours and the proposed cap limiting total participant services to 70 hours per week. I submit this comment from a provider perspective and strongly object to these changes due to their impact on service delivery, workforce sustainability, and compliance with CMS Home and Community-Based Services (HCBS) requirements under 42 CFR §441.301.

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CMS HCBS regulations also emphasize the obligation to prevent unnecessary institutionalization and to support individuals in the most integrated setting appropriate (42 CFR §441.301(c)(4)). From a provider perspective, authorizing services at levels that do not meet actual participant needs increases the likelihood of crisis events, hospitalizations, and eventual placement in nursing facilities or other institutional settings. These outcomes undermine the purpose of the A&D waiver and increase long-term system costs.

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workforce.

From an operational standpoint, these proposed changes shift risk from the state to providers while limiting providers' ability to safely meet participant needs. Providers cannot ethically or effectively deliver services when authorizations do not align with assessed needs, and doing so places both participants and providers in untenable positions.

I strongly urge the State of Nebraska to withdraw the proposed 70-hour weekly cap and reductions to live-in caregiver hours and to reevaluate these changes through a provider-informed, CMS-compliant lens. Any revisions to A&D regulations should support realistic service delivery, workforce sustainability, participant health and safety, and continued compliance with 42 CFR §441.301.

Thank you for the opportunity to provide public comment and for consideration of the operational and compliance impacts these proposed changes would have on providers, participants, and the A&D system as a whole.

Jennifer Viles
Director
Holistic Group Inc.

Phone Number: 402-718-6900
Fax Number: 402-763-9126

Address:
9001 Arbor St Ste 206
Omaha, NE 68124

HGI
Holistic Group, Inc.

Supporting People in Living Their Best Lives

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From: Bellevie Home Health Care
To: DHHS HCBS Public Comments
Subject: Public Comment – AD Waiver Amendment (Provider Access & Workforce)
Date: Monday, December 22, 2025 10:24:04 AM

You don't often get email from [redacted]. Learn why this is important

Good morning,

To the Nebraska Department of Health and Human Services,

I am submitting this public comment on behalf of [Agency Name], a small and newer Medicaid provider serving individuals through the Aged and Disabled (AD) Waiver in Nebraska.

While we appreciate DHHS's goal of maintaining high-quality, fiscally responsible community-based services, we are concerned that the proposed AD Waiver updates may unintentionally worsen existing challenges related to provider sustainability, workforce shortages, and participant access, particularly for small and newer agencies.

Workforce & Reimbursement Challenges

Newer agencies operate at a disadvantage due to lower effective reimbursement and limited flexibility compared to older or legacy providers. At the same time, agencies struggle to compete with arrangements where family members are paid higher rates to provide care. This imbalance makes it difficult to recruit and retain caregivers.

As a result:

- Agencies cannot offer competitive wages
- Caregivers leave for higher-paying arrangements
- Authorized services go unfilled

Impact on Access & Choice

When agencies cannot hire staff:

- Service start dates are delayed
- Hours are reduced or unmet
- Individuals have fewer choices and may feel forced to rely on family caregivers

These outcomes undermine the intent of the AD Waiver to promote choice, independence, and community integration.

Administrative Burden

Waiver changes often increase documentation, monitoring, and compliance expectations without corresponding reimbursement. These unfunded administrative costs disproportionately impact small agencies and increase audit and recoupment risk.

Request

We respectfully ask DHHS to:

- Review reimbursement structures to ensure equitable treatment of providers, regardless of agency age or size
- Consider the workforce impact of paying family caregivers at higher rates than agency-employed caregivers
- Balance oversight requirements with realistic administrative expectations
- Ensure waiver language supports a stable provider network and meaningful participant choice

Thank you for considering provider input and the real-world impacts on agencies, caregivers, and the individuals we serve.

Administrator
Phone: 402-260-7426
Fax: 402-260-7401
Please visit us at www.bellevieinhomecare.com

Image

From: rosi jchavez
To: DHHS HCBS Public Comments
Subject: Public Comment - Aged and Disabled Waiver, Opposition to Proposed Changes
Date: Sunday, January 4, 2026 8:51:46 PM

You don't often get email from [redacted]. Learn why this is important

Hello,

My name is Rosalba and I am the caregiver of my 30-year-old daughter that suffered a stroke three years ago and now requires 24/7 care. I am reaching out with deep concern and opposition about the proposed changes by DHHS to the Aged and Disabled waiver program, which proposes cuts to family caregiver compensation reducing reimbursed care hours to no more than 40 hours per week.

As the mother and caregiver of a Nebraskan with a disability that relies on Medicaid and this waiver for continued care, I am strongly opposed to these changes. Three years ago, my now 30-year-old daughter suffered a stroke following several surgeries related to a brain aneurysm rupture. Prior to her hospitalization she had spent the years following her university graduation working at a local nonprofit, later at the Nebraska legislature, and on statewide campaigns. Our family had never needed to rely on Medicaid until the unexpected happened.

After spending several months at inpatient rehabilitation facilities, our daughter came home with us. We noticed great improvements in her mood and a stronger level of engagement once she was in a familiar environment surrounded by loved ones who know her best. The nights that she would wake up screaming not recognizing the environment around her also disappeared once she was back home with us. Having her at home with us has also significantly supported her adjustment to life with limited speech and mobility. While she cannot verbally communicate, we have learned how to engage with her in various ways and know when she needs something. We use her likes/dislikes to make her everyday enjoyable despite her limited abilities. My daughter is young, and bright which is why we will always choose home over institutionalization.

When my daughter first came home with us, we tried having caregivers come home to support her everyday needs. However, we soon realized that it was often different caregivers showing up to our house and that few of them were trained on the equipment she required for daily care. This meant we often had to train the caregivers ourselves, only for it to be someone new the next day. This became unsustainable so we chose to be the family caregivers. My husband had to quit his job to stay home to care for our daughter, and to have some flexibility for various doctors appointments my daughter has throughout the year, I have had cut down my total hours worked at my job and hover just at the minimum hours required to be considered full time in order to retain health insurance for myself and my younger daughter. This has kept us from having to rely on Medicaid ourselves for health insurance. Reimbursement for my hours worked as a caregiver to support my disabled daughter in the afternoon and evenings helps compensate for the hours I have had to cut down at my other job.

Our daughters also serve as her caregivers to allow my husband and I a break to run errands and get work done around the house. It is important to note that my disabled daughter requires 24/7 care as she needs to be transferred with a hoyer for restroom breaks, requires others to

cook her meals and do house chores, needs supervision while she eats, and has to be turned at least two times throughout the night to avoid pressure sores. The reality is that the total hours of reimbursed caregiving we receive are 76 hours a week, which is only a fraction of the care we provide, 24/7. I want to be clear that we are not getting rich through this compensation as much of it goes towards groceries for our family, my disabled daughter, and other medical expenses not covered by her Medicaid as well as other home expenses.

The reality is that we are constant caregivers, whether we are paid or not. Every morning my husband gets my daughter out of bed, does her morning routine (brushing hair, teeth, changing), makes her breakfast, feeds her, and transfers her to the toilet three times during the day for her restroom breaks. On a typical afternoon, I get home from work, put my daughter down for a nap, cook her dinner, get her up from her nap, feed her, let her watch tv for an hour after dinner, and later do her night routine and get her to bed, and turn her twice over night. Throughout the week our daughters help as they can. This is all on top of other responsibilities. Families like ours aren't making thousands with this reimbursed care. Whatever we do make often goes back to expenses for our daughter like groceries and other necessities. We are being compensated for work and labor and often that compensation only covers a fraction of care that is being provided. Our daughter has been a fighter since day one and she deserves to be in a place where she can best be cared for and continue to thrive in spite of the challenges she has to face on the daily. This is why my family and I strongly oppose these changes.

Thank you,

From: Vanessa CJ
To: DHHS HCBS Public Comments
Subject: Public Comment - Aged and Disabled Waiver, Opposition to Proposed Changes
Date: Monday, January 5, 2026 5:01:02 PM

You don't often get email from [redacted]. Learn why this is important

Hello,

I am emailing to express my opposition to the proposed changes to the Aged and Disabled waiver that would limit pay for family caregiving to no more than 40 hours.

Since my sister's stroke that has severely limited her speech and mobility, my parents have become her primary care givers. My dad quit working to become my sister's caregiver while my mom is at work. Following my sister's hospitalization my mom also had to balance my sister's doctors appointments as well as responsibilities as her legal guardian and cut back on her work hours, but she has remained at the minimum hours required to be considered full time in order to retain health insurance for herself and my younger sister (this has helped them avoid needing of Medicaid themselves for health insurance). However, while my mom takes over my sister's care in the afternoon and evenings so my dad can run errands and have some respite, my mom and dad still work overnight as they have to turn my sister every few hours to prevent bed sores. Both my mom and dad cook for my disabled sister, follow her bathroom break schedule, transfer using hoyer lifts, do her morning and night time routines, and never quit caring for her. My younger sister and I support her caregiving in order to give our parents occasional breaks.
We had given caregivers from a home health agency a chance when my sister first came home from inpatient rehabilitation, but soon found that they would send someone new every day, and that often the caregivers were not trained in the equipment my sister relied on. This meant we had to train someone new everyday on my sister's needs. We avoid institutionalization because we love her and we know she is happier living at home in a familiar setting with loved ones who understand her needs and likes/dislikes. Being in a familiar setting has helped her adjust to a life with limited speech and mobility because we know how to engage with her so she can still enjoy the things she has always loved. Receiving this reimbursement does not make our family wealthy, it is something that helps offset costs like hours my dad no longer works at a formal job and the hours my mom cuts back on to support my sister's care. That income goes back to home expenses for my sister and family. For these reasons I strongly oppose these changes.

Thank you,

From: Laura Vajgrt
To: DHHS HCBS Public Comments
Subject: Public Comment – Notice of Civil Rights Concerns and Risk of Enforcement Action
Date: Friday, January 2, 2026 10:55:06 AM

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To whom it may concern,

I submit this public comment to formally state that the proposed waiver changes of decreased personal care hours down to 40- and a yearly 175% cap raises serious and actionable civil rights concerns under Title II of the Americans with Disabilities Act (ADA), Olmstead v. L.C., and the Home and Community-Based Services (HCBS) Final Settings Rule.

As proposed, these changes eliminate any meaningful choice for my daughter and similarly situated individuals, leaving institutionalization as the only viable option. There are no available skilled nursing placements for her complexity, no sufficient community providers- nursing shortages, inadequate respite hours which you only get few of, and no alternative family or community supports that could run a ventilator or provide the high care she needs. By reducing authorized service hours, the state is removing the funding necessary to maintain a safe home environment and implicitly requiring unpaid family labor to fill the gap.

This structure creates a foreseeable and unnecessary risk of institutionalization, in direct conflict with Olmstead. Conditioning access to community-based services on a family's ability to provide uncompensated care is discriminatory and disproportionately harms individuals with higher medical and support needs, as well as those without available family caregivers. "Choice" under federal law must be real and functional, not theoretical.

These issues are not hypothetical. The ACLU is actively monitoring this proposal, and families are prepared to pursue civil rights enforcement and legal action should these changes be implemented in a manner that results in discrimination, segregation, or the loss of community-based living. Budgetary considerations do not excuse policies that violate federal civil rights law or shift costs onto families through coerced unpaid labor.

The HCBS Final Settings Rule requires that individuals be able to receive services in the most integrated setting appropriate. A system that reliably funds institutional care while underfunding community-based alternatives fails this standard and exposes the state to significant legal risk, including federal enforcement action.

I urge DHHS to halt or revise these proposed changes and to ensure that any approved waiver:

- **Provides services that are accessible in practice, not only on paper;**
- **Does not presume unpaid family caregiving as a substitute for Medicaid services;**

• Includes sufficient staffing and respite to maintain safe community placement; and
• Fully complies with the ADA, Olmstead, and federal HCBS requirements.

Absent these corrections, the proposed changes represent systemic discrimination rather than permissible program reform.

Respectfully submitted,
Laura Vajgrt

From: [redacted]
To: DHHS HCBS Public Comments
Subject: Public Comment A & D Waiver
Date: Friday, January 2, 2026 3:55:46 PM

You don't often get email from [redacted]. Learn why this is important

I am writing to comment on the Department's consideration to reduce caregiver hours. My daughter, Kaley Jones, receives services under the Aged and Disabled (A&D) Medicaid Waiver.

The A&D Waiver is a Home and Community-Based Services (HCBS) program that enables individuals who meet **nursing facility level of care** to remain safely in the community rather than in an institution. Services authorized under the waiver are based on an **individualized, person-centered plan** reflecting assessed need and the assistance required for health, safety, and daily living at home.

Kaley meets nursing-facility level of care and qualifies for waiver services because:

- She requires supervision and medically necessary care at all times due to her complex medical conditions.
- She cannot reliably communicate her needs.
- Without constant monitoring and intervention, she is at high risk of aspiration, respiratory distress, and emergency hospitalization.

Medical Necessity & Safety Risks
Kaley is wheelchair-bound, requires continuous feeding via a J-tube, and has a tracheostomy that needs frequent suctioning. She also has a seizure disorder and unpredictable vomiting episodes that require immediate suction and oxygen support to prevent aspiration and ER visits. These are not routine daily cares but **critical medical-necessity tasks** that require trained supervision and immediate response.
The waiver's purpose is to ensure that people who would otherwise need nursing facility services can remain in their homes with adequate supports. If someone is not present to monitor Kaley **24/7**, she will suffer preventable medical emergencies — exactly the type of adverse outcome the HCBS waiver exists to avoid.

No Available Alternative Resources
There are no respite agencies in our area willing to accept Kaley as a client due to her tracheostomy and medical complexity. The only potential respite provider we have secured is a nursing student who can offer a few hours of help monthly. Once she completes her schooling next year, that resource will disappear.

Cost Consequences to the State
Reducing caregiver hours shifts Kaley into a high risk of recurrent hospital stays, which are vastly more expensive than appropriate in-home care. The waiver exists to balance cost with **quality of life and safety**, yet the reduction of hours threatens both.

Waiver Standards & Person-Centered Plan Requirements
Nebraska's A&D Waiver requires that services be provided based on assessed need and an individualized service plan designed to support the participant's health, safety, and ability to remain at home. The waiver's service array — including personal care, supervision, respite care, and other supports — must be individualized to help participants

avoid institutional care.
Kaley's assessed medical and supervision needs clearly exceed a 40-hour week. Her condition demands a level of oversight and care that cannot safely be provided in that limited amount of time or by an unavailable respite workforce.

I respectfully urge DHHS to maintain caregiver hours as ordered in Kaley's current person-centered service plan. Reducing the hours jeopardizes her safety, contradicts the waiver's standards for service based on assessed need, and increases the risk of avoidable and costly hospitalizations.

I am willing to provide additional medical documentation, assessments, and letters from Kaley's physicians to support this appeal.

Thank you for your time and careful consideration.

Sincerely,
Amber Jones
[redacted]

From: amanda Vick
To: DHHS HCBS Public Comments
Subject: Public Comment about Respite Hours in budget
Date: Monday, January 5, 2026 8:12:45 PM

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I have serious concerns about the inclusion of respite hours within my son's overall budget, as well as overall capping individuals on a broad spectrum. Hours and budget need to be specific to the person for the best safety and well being to person on waiver. I agree the budget should be less than what they would recieve at a nursing home. I do believe my son would be more than the $161,000 (175%) and that isn't factoring in additional costs if he was at a nursing home that wasn't skilled.

At this time, I am unable to find appropriate or realistic respite options. Outside respite providers who are adequately trained to meet my son's complex medical needs are extremely difficult—if not impossible—to find. In-home respite, when available, can only be very short-term and limited caregivers.

Currently, I have only four caregivers in addition to myself for my son, who requires 24/7 high-needs care. Three of these caregivers have higher-paid full-time jobs elsewhere and can only work part-time hours for us. My son's current agency technically offers respite, but they do not have additional staff available to cover it. Even in the highly unrealistic scenario that my part-time caregivers used vacation time from their full-time jobs (time they need for their own personal lives), this would amount to approximately six days total and would require extensive planning. When I return, I am immediately overwhelmed with catching up and addressing issues that occurred in my absence, which is often more exhausting than restorative. Realistically, I could only leave for about three days, with the remaining time spent simply recovering and managing the fallout.

Despite these limitations, respite hours would still be deducted from my son's annual budget, directly reducing the daily care hours he critically depends on.

My son requires constant supervision. As just one example, today his staff stepped away briefly to use the bathroom, and during that time my son pulled out his suprapubic catheter. If this had gone unnoticed for more than a few minutes, it could have resulted in serious health and safety consequences, including infection, skin breakdown, or the need for emergency surgery if the catheter could not be reinserted in time. There is also the risk of introducing unsterile bacteria into the bladder or bloodstream.

If my son were in a nursing facility, this incident alone would likely have resulted in an emergency room visit and possibly emergency surgery—services that are not available in my town. This would require a transfer to a larger hospital over an hour and a half away, followed by the very real risk of the facility or insurance denying his return, something that has already happened in the past. This is one of the many reasons he is currently cared for at home.

Finding respite providers trained to handle even one of his medical needs is extremely difficult, let alone all of his complex needs.

Any reduction in hours will result in caregivers losing work hours, which increases the likelihood that they will leave. This would further destabilize his care and leave him with even

fewer trained staff. There are no “natural supports” available. My son is 25 years old, does not sleep regularly, and requires constant monitoring. I only sleep when staff are present. I am able to sleep in my own bed one night per week, and I rely on naps during the day when staff are here.

I am deeply concerned that these changes will force me to pursue nursing home placement for my son. However, this may not even be possible. He has been on a waitlist for years at a facility that would accept him, and multiple facilities have already rejected him due to the complexity of his care and saif they were not equipped or his cares are not appropriate to whatvthey offer. This was before many nursing homes in my area closed, and not factoring in how they are shirt staffed.

I respectfully ask that these realities be fully considered, as the current approach does not account for the medical, staffing, and safety risks involved and places my son’s health and well-being in jeopardy.

Sincerely,

Amanda Vick

From: Kellie Quinlin
To: DHHS HCBS Public Comments
Subject: Public comment ad waiver
Date: Wednesday, December 17, 2025 11:55:35 AM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

I understand that Medicaid budgets are strained and that limits are being considered. However, we must remember that the individuals affected by these proposed limits are those with the highest and most complex care needs. These are also the individuals whose families are often the only people willing and able to provide that level of care safely and consistently.

Families like ours routinely provide care at significantly reduced rates compared to nursing facilities or private agencies—often well below what the state would otherwise pay. We do this not because it is easy or expected, but because we know we are the only ones who truly can. Agencies are frequently understaffed, inadequately trained for extreme medical and behavioral needs, and experience high turnover. Nursing facilities, even at enormous cost, do not offer an acceptable quality of life for individuals like my son.

Allowing families to provide paid care at fair—but still lower—rates, for the hours that reflect actual need, is not only humane, it is fiscally responsible.

When a child becomes an adult, it is not a normal or expected part of family life for parents or siblings to bathe, change, feed, lift, reposition, and supervise an adult 24 hours a day. This is not "ordinary family responsibility." No one considers it normal to stop on the side of the road to change a 25-year-old's diaper, redirect severe behavioral episodes, prevent self-injury, or manage complex medical equipment. These tasks far exceed typical family caregiving and clearly meet the definition of paid attendant care.

Asking families to provide 168 hours of care per week while being compensated for only 40 hours is not reasonable, sustainable, or equitable. Yet the system readily acknowledges that no single worker should work 112 hours per week—while expecting families to do exactly that without pay.

The inconsistency is alarming.

Under current policy, Nebraska is willing to pay up to $161,766.50 prior to nursing facility placement. The state will approve 70 hours or more of care through agencies at $40–$60 per hour, but will cap family providers at 40 hours even when they are willing to provide care at $15.35 per hour, well below both agency and institutional costs.

My son requires 24/7 care. He is non-ambulatory, uses a wheelchair, weighs approximately 275 pounds, has severe contractures, a feeding tube, a baclofen pump, significant behavioral challenges, and cognitive functioning comparable to a young child. He has minimal verbal communication and does not tolerate unfamiliar caregivers. Forcing outside providers into his care places both him and others at risk.

If my son is injured—or injures someone—because the state leaves us no option but to use caregivers he cannot safely tolerate, who is accountable? Families are trying to prevent harm, not create risk.

This policy appears to conflict with the Olmstead decision and the HCBS Final Settings Rule, both of which prioritize integrated, community-based care and protection from unnecessary institutionalization. Capping family caregiving hours while approving higher-cost, less appropriate alternatives does not align with those principles.

Families are not asking for special treatment. We are asking for equitable, lawful, and practical solutions that recognize real-world care needs. Nebraska frequently highlights the value of family caregivers in public messaging, yet policies like this suggest that our labor—and our loved ones' safety—are undervalued.

The state must do better for individuals with the highest support needs. These are not abstract policy decisions.

These are real people, real families, and real risks.

I urge Nebraska DHHS to reconsider limits on family-provided care hours and to align waiver policy with both federal law and the lived realities of those it is meant to serve.

Public Comment Regarding Proposed Changes to Aged/Disabled Waiver Program by DHHS

The Nebraska Department of Health and Human Services has proposed changes to reduce the cost of the Aged/Disabled Waiver program by reducing the number of hours of paid care received by participants in general and in particular by reducing the amount of care provided by independent and/or residential caregivers in particular. **While that may initially reduce program costs, I believe the long term impact will not only increase program costs but will also negatively impact those who benefit from the services provided. I assert that this is a myopic attempt to reduce costs that does not consider the long term conditions it will create.**

Before starting, I'll note that I am aware of recent discoveries by the State Auditor of fraud and abuse in some of the programs administered by DHHS. I believe the perpetrators of said fraud should be held accountable to the fullest extent of the law. I hope however, that the many honest and dedicated providers of service to the disabled community are not punished for the actions of those who abused the program as retaliation for the actions of those who abused it.

To provide some background for my comments, individuals who qualify for service under the AD waiver program are awarded a maximum number of hours of service per week. The level of care needed is determined by a "Service Coordinator" who works in conjunction with DHHS to monitor those individuals on his/her caseload. The absolute maximum number of hours awarded would be 168 per week, which is 7 days at 24 hours/day. I know of one case where an individual who needs total care for all basic life needs has her own apartment and qualifies for 168 hours per week of attendant care to meet her life needs. Following years of working with different service coordinators, I also understand that individuals who reside in a home with a guardian but who need total care are often awarded 112 hours per week. The guardian is expected to provide care on an unpaid basis for 8 hours per day which is regarded as sleeping time. The total hours allotted may be less for those individuals who may not need total care for all basic life needs.

In the past, the care may have been provided by the live in caregiver (guardian/family member/etc.) or may have been provided by an agency licensed caregiver or by a combination of both. The rates for the live in caregiver versus the agency caregiver are quite different. Prior to 2024, the rate for a caregiver who lived in the home with the recipient was in the $10 per hour range. In January 2024 that rate increased to $12/hour and in January 2025 it increased to $15/hour. This increase was authorized by the Legislature. Conversely, the rate for an agency provided caregiver in the past was in the $24/hour range and is currently at or around $31/hour. It is easy to see that the most economical care provided to the individuals who qualify for the AD Waiver program is that which is provided by a member who lives in the home or who is independent of an agency and is willing to work for the rate provided by DHHS which is about half the cost of the agency provided caregivers.

It is my belief stemming from conversations with representatives of DHHS that "the elephant in the room" appears to be that the DHHS expenditures for Medicaid Waiver programs have skyrocketed and are currently being viewed as out of control. I am not surprised by this and believe it is due in part to the following factors:

- Over the last three years, the rate of pay for independent caregivers has increased from the $10/hour range to $15/hour range. If the rates for agencies has increased by the same percentage, DHHS is looking at cost increases of between 40 and 50 percent in the last three years.
- For many years, entry into some of the waiver programs was on a very limited basis. In the past year, removal of any waiting lists was authorized by the state (through the Governor's office I believe). It is logical to assume that a number of individuals needing substantial care have entered the system under this new opportunity.
- Two years ago DHHS rolled out changes that required all independent caregivers submit their hours through an electronic portal. The initial months were problematic as the system would occasionally 'crash' and make it difficult to submit hours. Last year, DHHS implemented additional requirements that made it extremely difficult to report hours worked. While done under the auspices of accountability, it was obvious to me as a frequent user of the software that the DHHS presenters were not familiar with how it worked and were continually creating roadblocks to its effective use. In conversations with other independent caregivers, I understand that a number of them chose to link with an agency rather than fight the electronic system. By doing so, the agency was responsible for submitting their hours and issuing their pay. The problem as I saw it was that this doubled the cost for the state as the agency rate is about double what is paid to independents.

It is my opinion that all of these factors have contributed to the increased program costs experienced by DHHS. I only ask that the persons responsible for these proposed changes understand that all of these costs were approved by either the Governor, the Legislature or implemented by DHHS to comply with Medicaid requirements and carefully consider the whether the impact of these decisions should be taken on the backs of the individuals who provide care to the disabled individuals in the program.

This then brings me to the point of these comments. Recently DHHS announced they were in the process of renewing the AD Waiver program which is due to expire in July 2026. They opened the proposed changes to questions and comments registered in four ZOOM meetings. I participated in the first meeting and was very surprised at the proposed changes**. DHHS has indicated that effective July 1, 2026, the maximum number of hours that may be awarded to an individual in the AD Waiver program will be reduced to 70 per week. Additionally, of that 70, only 40 of those hours may be provided by a live in caregiver.**

From an extreme case maximum of 24/7 care that requires 168 hours, come July, those individuals will only be permitted 70 hours of care. In many cases where the AD Waiver participant lives in a home with a guardian and is provided service by that guardian, the previous allotment of 112 hours per week (16/day with 8/day volunteered by guardian) the guardian will now be limited to no more than 40 hours per week. An additional 30 may be covered at double the cost by an agency caregiver.

The emotional response from many of the attendees at the ZOOM meeting was immediate. Since the wage they receive as a caregiver may be their only source of income, some individuals shared that they may be forced to institutionalize their loved one. One attendee indicated she provided total care for her son who is on a ventilator. While she currently receives payment for 112 hours per week at about $15 per hour, she indicated a skilled nursing facility able to treat a ventilated patient would cost over $1300/day. (An online "Google" search revealed that the current cost in Nebraska for such service would be

$1332/day). Just doing the math, caring for this individual in his home by his guardian would cost DHHS just under $88,000 per year. Should she place her child in an institution the cost would be nearly $475,000 per year.

While the above represents an extreme case, just a cursory glance at the numbers reveals that the cheapest care for individuals in the disabled community is that provided by guardians who live in the home with the disabled individual. In a number of cases, the guardian provides most if not all of the care for these individuals. By reducing their time from 112 hours per week in case of severe needs to 40 hours per week there is a reduction in hours of over 65 percent. When this is the only source of income, it is not hard to understand why these people are panicking at the proposed change in the program.

I am concerned that if DHHS implements the changes as proposed, not only will the members of the disabled community see a substantial reduction in the quality and quantity of their care but that the long term impact to the State of Nebraska will increase as more families are forced to institutionalize their loved one since they cannot live on a 40 hour per week maximum at the rate provided by DHHS.

That then brings up the secondary concern that given the past position of the state to 'deinstitutionalize' the disabled population, I think it is doubtful that the State of Nebraska even has enough institutions to care for this population if it becomes impossible for families to do so due to the proposed cut in hours.

I respectfully request that the decision makers who will determine the 2026 program limitations will consider the long term impact of their decision.

Sincerely,

Dale Rawson
[redacted]

From: M F
To: DHHS HCBS Public Comments
Subject: Public Comment AD Waiver changes
Date: Monday, December 22, 2025 9:48:23 AM

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As an AD Wavier Provider, I would like the concerning, long-standing, unaddressed issue of severely delayed overtime payments to providers.

One would reasonably think when switching to the EVV system, this issue would have been resolved but it did not.

The current process is redundant, convoluted, ineffective, inefficient and is completely unacceptable. AD Waiver Providers with clear, properly billed claims wait as long as 6 months or more to receive their overtime payments.

This issue must be addressed during this process.

M. Farris

From: Prairie Hill Home Care
To: DHHS HCBS Public Comments
Subject: public comment AD
Date: Saturday, January 3, 2026 7:49:30 PM

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To whom it may concern,
Please accept this email as formal public comment regarding the proposed changes to the Nebraska Aged and Disabled (A&D) regulations, including reductions to live-in caregiver hours
and the proposed cap limiting total participant services to 70 hours per week. I submit this comment from a provider perspective and strongly object to these changes due to their impact on
service delivery, workforce sustainability, and compliance with CMS Home and Community-Based Services (HCBS) requirements under 42 CFR §441.301.
HCBS regulations require that waiver services be authorized based on individualized, person-centered assessments rather than fixed caps or generalized limits (42 CFR §441.301(c)(1)). From
a provider standpoint, a universal 70-hour weekly cap is incompatible with the needs of many A&D participants currently served and creates service plans that are not operationally feasible or
clinically appropriate.
Providers are responsible for ensuring participant health and welfare and for delivering services
consistent with authorized plans. Under 42 CFR §441.301(b)(1) and (c)(2), the state must provide assurances that services are sufficient to meet assessed needs. A 70-hour cap results in predictable gaps in coverage—particularly overnight, during high-risk periods, or when participants require hands-on assistance or supervision. These gaps place participants at risk and
expose providers to increased liability, incident reporting, and service failures that are outside of
provider control.
CMS HCBS regulations also emphasize the obligation to prevent unnecessary institutionalization
and to support individuals in the most integrated setting appropriate (42 CFR §441.301(c)(4)). From a provider perspective, authorizing services at levels that do not meet actual participant needs increases the likelihood of crisis events, hospitalizations, and eventual placement in nursing facilities or other institutional settings. These outcomes undermine the purpose of the A&D waiver and increase long-term system costs.
The proposed reductions also raise serious concerns regarding provider capacity and workforce
stability. Live-in caregivers and high-hour service models are already difficult to staff. Reducing
authorized hours and imposing a 70-hour weekly cap makes many service models financially and
operationally unsustainable, leading to increased turnover, inability to staff cases, and potential
provider withdrawal from the A&D program altogether. This directly conflicts with CMS expectations that states maintain a sufficient and qualified HCBS workforce.
From an operational standpoint, these proposed changes shift risk from the state to providers

while limiting providers' ability to safely meet participant needs. Providers cannot ethically or effectively deliver services when authorizations do not align with assessed needs, and doing so places both participants and providers in untenable positions.
I strongly urge the State of Nebraska to withdraw the proposed 70-hour weekly cap and reductions to live-in caregiver hours and to reevaluate these changes through a provider-informed, CMS-compliant lens. Any revisions to A&D regulations should support realistic

service delivery, workforce sustainability, participant health and safety, and continued compliance with 42 CFR §441.301.
Thank you for the opportunity to provide public comment and for consideration of the operational and compliance impacts these proposed changes would have on providers, participants, and the A&D system as a whole.
Sincerely,
Caroline Anuh-Ndumu
PRAIRIE HILL HOME CARE
7200 S 84TH ST #6, LA VISTA
NE, 68128.
PHONE : 531 999 2503
FAX: 5319992504
EMAIL: INFO@PRAIRIEHILLHOMECARE.COM

From: Laura Vajgrt
To: DHHS HCBS Public Comments
Subject: Public comment cap
Date: Friday, January 2, 2026 4:58:13 PM

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—-Method of Implementation and Cost Limit – Page 26-B

I oppose the proposed 175% institutional cost limit and the associated referrals to institutional services once that threshold is reached. The resulting annual cap of $166,766.50 fails to adequately account for individuals with extreme medical and support needs on the waiver.

This proposed cap is fundamentally flawed because it relies on an *average*nursing facility cost to determine an individualized limit for Home and Community-Based Services. Averages may work for the majority of waiver participants, but they fail entirely for individuals with complex medical needs, higher physical care demands, or significant support requirements—including my daughter.

My daughter is a high-need individual. Her care costs are not inflated due to inefficiency or overutilization, but because her size, medical complexity, and daily care needs require more staff time, more physical assistance, and more intensive support. Applying a uniform 175% cap based on an average nursing facility rate ignores these realities and results in a cap that is mathematically disconnected from actual need.

This proposal effectively uses bell-curve budgeting to govern individualized medical care. While the majority of waiver participants may fall near the average, a small but critical population falls far outside of it. These individuals should not be penalized and discriminated for having needs that exceed an artificial benchmark derived from averages rather than medical necessity.

Further, the proposed cap creates a dangerous incentive toward institutionalization. Nursing facilities are reimbursed differently, operate under different staffing models, and often bill at rates that exceed what the waiver would cover for the same individual in the community. A hard cost cap that triggers service reductions or institutional referral conflicts with the purpose of the AD Waiver, the Americans with Disabilities Act, and the Olmstead decision, which require services to be provided in the most integrated setting appropriate.

DHHS has access to its own data showing that high-cost waiver participants represent a small percentage of the overall population. (Division of Medicaid and long term care Nebraska Medicaid annual report 2025) Instead of addressing outliers through individualized review and exceptions, this proposal imposes a blunt cap that will disproportionately harm those with the highest needs while producing minimal overall savings.

I urge DHHS to withdraw the 175% institutional cost cap and replace it with a policy

that:

- **Accounts for individual medical and physical needs,**
- **Allows for exceptions past the 175% when services are medically necessary,**
- **Avoids automatic or coercive pathways toward institutional care, and**
- **Aligns with federal disability rights law and the intent of HCBS waivers.**

The math must reflect reality. Averages cannot be used to justify limits that ignore complexity, size, and medical necessity. Families like mine should not be forced to choose between unsafe reductions in care hours, a cap that their care exceeds or institutional placement due to a formula that was never designed to fit our complex loved ones.

Thank you for the opportunity to submit this comment.

Sincerely,
Laura Vajgrt

From: kelli Colvard
To: DHHS HCBS Public Comments
Subject: Public Comment
Date: Wednesday, December 17, 2025 12:28:21 PM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Don’t you dare pull ANY support from families caring for disabled family members in their homes. They’re saving the State a FORTUNE by doing so in addition to giving the disabled person a quality of life they could never have in a nursing facility. Those caregivers deserve MORE financial support from the State, certainly not less.
Sent from my iPhone

From: Sarah Hegg
To: DHHS HCBS Public Comments
Subject: Public comment concerning AD Waiver changes
Date: Wednesday, December 31, 2025 2:09:14 PM

You don't often get email from [redacted]. Learn why this is important

To whom it may concern:

I am writing in response to a proposed amendment to the AD Waiver, specifically Appendix C, Section C-1/C-3: Service Specifications. I ask that you reconsider imposing a 40 hour-a-week limit for live-in caregivers providing Personal Care services. This could be devastating to both the caregivers and the vulnerable people they care for.

I live with and care for my severely disabled 28-year-old brother, Peter. My mom and I split our allotted hours to continually supervise, give medications, provide personal hygiene care, plan activities, etc. His needs do not end after 40 hours a week. He doesn't just take the evenings or weekends off from living. This is not a normal job! I quit my full-time job several years ago to help my mom with his constant care. We both need to earn money to contribute to the household and limiting us to 40 combined hours a week just won't cut it. This is true for many other families as well. If I have to get another job, that greatly decreases the time I have to help care for Peter. He will have to give up the activities we do every day that have helped him to expand his skills and his life. Without these extra hours, many families may not be able to afford to keep their disabled loved one at home anymore. And putting them in a nursing home or assisted living facility will only end up with them receiving a lower level of care and costing the government even more money.

A recent news release from DHHS (November 24, 2025) stated "Family Caregivers Strengthen Nebraska Homes and Communities." This is so true! Who could give better care for an aging or disabled person than someone who already loves them and is invested in their well-being? The news release goes on to state that many caregivers feel "overwhelmed" because they have to work another job while also caring for a loved one. DHHS claims to want to alleviate this problem, but it will only be exacerbated if hours are limited as more caregivers will be forced to get second jobs to be able to pay their bills. The news release also acknowledges that "Easing the burden for caregivers will improve the overall quality of care." Limiting hours for live-in caregivers will only *increase* the burden and *decrease* the quality of care. DHHS claims to support these family caregivers, but a cap on hours seems instead like a targeted punishment.

DHHS also claims to encourage "Person-centered planning" where waiver participants can choose their type of care and be involved in making a plan for their lives. According to the DHHS website, Nebraska's Olmstead Plan is committed to providing care and services according to each participant's "needs and preferences." I can assure you that the majority of these participants prefer that their families, not strangers, care for them when possible. I know that's what my brother wants. A stranger coming into our home to provide a lesser level of care would be extremely disruptive. And having to move to a nursing home or assisted living facility would cause extreme anxiety and stress, which could lead to medical complications and even death. This is the reality for many other families as well.

Families know their elderly/disabled loved ones and know the kind of care they need. These live-in caregivers should be properly compensated for their important work, work that is actually saving the government money by preventing the mass institutionalization of vulnerable people. The proposed 40-hour cap on paid hours is an insult to these hard-working

Nebraskans.

Here are my questions:

-Why are live-in caregivers (families) being specifically targeted by the 40-hour cap? What is it about being “live-in” that requires this limit as opposed to a caregiver who lives outside of the home?

-If this proposed hour limit is unfortunately approved, what does the appeal process look like? What criteria will be examined to determine a possible increase in paid hours? How many hours could live-in caregivers potentially receive?

Sincerely,

Sarah Hegg

From: J S
To: DHHS HCBS Public Comments
Subject: Public Comment for AD and TBI wavier changes
Date: Friday, January 2, 2026 10:55:46 AM

> You don't often get email from a [redacted]. Learn why this is important

I am reaching out to express my profound concern about the proposed DHHS cuts to Nebraska's Aged and Disabled (AD) and Traumatic Brain Injury (TBI) waivers. These programs are a lifeline for families caring for loved ones with complex needs, allowing them to remain at home, maintain routines, and live with dignity. When these supports are reduced, families are left to fill impossible gaps on their own, often at great personal cost. For many, this is not a budget line item — it is the support that keeps their households functioning and their loved ones safe.

The ripple effects of these cuts will be felt immediately and painfully across our communities. Caregivers may be forced to leave their jobs, families may face emotional and financial collapse, and individuals may be pushed into institutional settings that no one wants and that ultimately cost the state more. I urge you to consider the real people behind these programs and to oppose any reduction in funding to the AD and TBI waivers. Nebraska families need leadership that values compassion, stability, and long-term solutions. The forty hour cap is not in any way sustainable and will horribly affect countless families.

-Jessica Schaben, RN

To whom it may concern,

Please accept this email as formal public comment regarding the proposed changes to the Nebraska Aged and Disabled (A&D) regulations, including reductions to live-in caregiver hours and the proposed cap limiting total participant services to 70 hours per week. I submit this comment from a provider perspective and strongly object to these changes due to their impact on service delivery, workforce sustainability, and compliance with CMS Home and Community-Based Services (HCBS) requirements under 42 CFR §441.301.

HCBS regulations require that waiver services be authorized based on individualized, person-centered assessments rather than fixed caps or generalized limits (42 CFR §441.301(c)(1)). From a provider standpoint, a universal 70-hour weekly cap is incompatible with the needs of many A&D participants currently served and creates service plans that are not operationally feasible or clinically appropriate.

Providers are responsible for ensuring participant health and welfare and for delivering services consistent with authorized plans. Under 42 CFR §441.301(b)(1) and (c)(2), the state must provide assurances that services are sufficient to meet assessed needs. A 70-hour cap results in predictable gaps in coverage—particularly overnight, during high-risk periods, or when participants require hands-on assistance or supervision. These gaps place participants at risk and expose providers to increased liability, incident reporting, and service failures that are outside of provider control.

CMS HCBS regulations also emphasize the obligation to prevent unnecessary institutionalization and to support individuals in the most integrated setting appropriate (42 CFR §441.301(c)(4)). From a provider perspective, authorizing services at levels that do not meet actual participant needs increases the likelihood of crisis events, hospitalizations, and eventual placement in nursing facilities or other institutional settings. These outcomes undermine the purpose of the A&D waiver and increase long-term system costs.

The proposed reductions also raise serious concerns regarding provider capacity and workforce stability. Live-in caregivers and high-hour service models are already difficult to staff. Reducing authorized hours and imposing a 70-hour weekly cap makes many service models financially and operationally unsustainable, leading to increased turnover, inability to staff cases, and potential provider withdrawal from the A&D program altogether. This directly conflicts with CMS expectations that states maintain a sufficient and qualified HCBS workforce.

From an operational standpoint, these proposed changes shift risk from the state to providers while limiting providers' ability to safely meet participant needs. Providers cannot ethically or effectively deliver services when authorizations do not align with assessed needs, and doing so places both participants and providers in untenable positions.

I strongly urge the State of Nebraska to withdraw the proposed 70-hour weekly cap and reductions to live-in caregiver hours and to reevaluate these changes through a provider-informed, CMS-compliant lens. Any revisions to A&D regulations should support realistic

service delivery, workforce sustainability, participant health and safety, and continued compliance with 42 CFR §441.301.

Thank you for the opportunity to provide public comment and for consideration of the operational and compliance impacts these proposed changes would have on providers, participants, and the A&D system as a whole.

Sincerely,
Caroline Anuh-Ndumu

From: katie hill
To: DHHS HCBS Public Comments
Subject: Public comment for ad waiver
Date: Friday, December 19, 2025 11:22:32 AM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

To Whom It May Concern,

I am writing with deep concern regarding the proposed plan to cut hours under the Nebraska Adult Developmental Disabilities (AD) Waiver.

I have personally seen how effective this waiver is when it is allowed to function as intended. I was raised in a home where my mother struggled to care for my brother and me while managing my brother's severe disabilities. As he grew older, his care needs intensified, and outside providers were often unable to support him without making his behaviors significantly worse. I watched my mother cry, trying to balance work, caregiving, and state-mandated school placements that were traumatic for him and devastating for our family.

Caregivers coming into the home were not a solution. Either my mother could not leave the property because he could not be left alone with them, or she remained on site supervising while I—still a child—did much of the hands-on work. Each year his aggression and agitation increased.

Then COVID changed everything.

My brother was removed from school, and outside caregivers were no longer coming into our home. With stability, routine, and consistent family care, he became calmer, less aggressive, and noticeably happier. My mother was finally able to take over his care full-time through paid caregiver hours, and our lives improved dramatically.

Because of that stability, we were able to move into a larger, accessible home. My mother used the income she earned—not state purchases—to provide critical supports: a larger bedroom, a roll-in shower, a new bed, a stair track chair, and other essential equipment. My brother is thriving today because of this care model.

He requires 24-hour supervision. He has a feeding tube, which legally requires nursing involvement. He is completely dependent for all activities of daily living and functions at a toddler level, requiring constant monitoring for safety. Many aspects of his care require two caregivers, including when he leaves the home—meaning my stepfather also loses work hours to assist.

I want to be clear that our family is not relying on unpaid labor to make this work. I am an adult, I do not live in the home, and while I do my best to be present when I can, I am working hard to build my own future. I work as a paraprofessional supporting behavioral and special needs students, and I am enrolled full-time in college pursuing a degree in education to become a teacher. Despite my professional training and willingness to help, I cannot replace the level of paid, consistent care my brother requires—and no family should be expected to sacrifice education, employment, or long-term stability to compensate for reduced services.

Having outside caregivers is not an option. It is not safe, it is not effective, and we will not return to a situation that caused him harm.

The state claims these proposed cuts are a budget issue. However:

- Nebraska is willing to pay over $160,000 per year for nursing-home placement.
- Nebraska is willing to pay approximately $400 per 10-hour shift for agency or nursing care.
- Under this proposal, the state would allow 40 hours at $15.35/hour for a parent and 30 hours of outside care, but will not allow 70 hours of parent-provided care at the lower rate, even though this saves the state tens of thousands of dollars.

My brother is a legal adult. Allowing family providers to meet his needs at a lower cost keeps him in his home, in compliance with Olmstead, the HCBS Final Settings Rule, and basic human dignity.

Maintaining 112 hours of care allows our family to cover critical expenses not paid by Medicaid, including dental care, additional equipment, and the second caregiver required for safe care. Cutting these hours does not reduce need —it shifts risk, increases harm, and ultimately costs the state more.

These are not numbers on a spreadsheet.
They are not pages in a policy manual.
They are not budget games.

They are real people, real families, and real lives.

Reducing care for individuals with the highest needs will put people at risk of serious harm and force families toward institutionalization that is both more expensive and more damaging.

I urge you to stop this proposal and allow medically necessary, cost-effective, family-provided care to continue for those who depend on it.

Please do not take away what is keeping people safe.
Sent from my iPhone

From: Kellie Quinlin
To: DHHS HCBS Public Comments
Subject: Public comment for AD waiver
Date: Sunday, January 4, 2026 8:50:56 AM

You don't often get email from [redacted]. Learn why this is important

When you become a parent, you imagine a certain future.
You picture babies growing into children, children growing into adults, and eventually watching them leave the nest to start families of their own. You imagine becoming an empty nester, enjoying retirement, traveling, relaxing, and hosting grandchildren for sleepovers. You imagine school days, playdates, babysitters, and the occasional night out with friends. You don't imagine daily phone calls from school asking you to come pick up your child.

When you have a child born with severe disabilities, your world changes completely.
Your dreams don't disappear—but they do change. Everything changes.

From the beginning, parenting looks different. You rely on your own parents more than expected. The grandparent role shifts—from fun visits and sleepovers to becoming a steady source of backup, stability, and emergency support. Emergency trips become routine. Calling a teenager to babysit is nearly impossible. Illnesses are constant, so you miss events and isolate more than most families ever have to. School calls become frequent. Siblings grow up faster, often becoming helpers, while you try desperately to preserve their role as just siblings.

As your child grows, the challenges grow too.
They become physically larger, and it takes more planning and effort to keep them safe outside the home. They become more aware of their wants and needs, yet may not be able to communicate them. Frustration builds. Sometimes they are trying to tell you something important, but they can't—and that frustration comes out as anger. They are stuck.

Slowly, you begin missing more and more of your own life—not because you want to, but because you are working tirelessly to protect theirs.

What makes life manageable for them is familiarity and trust.
They can communicate when they are surrounded by people who truly know them—people who understand their routines, their triggers, their signs of pain, stress, or illness. With family, they don't spend their day struggling to be understood. They feel relief. They feel safe.

Because of that safety, they can experience the world.
Family is willing to pack up the entire house just to make an outing possible. Family knows when to push forward and when to pull back. When illness strikes, family knows when to isolate to protect them from life-threatening risks. They know they will be protected.

But parents age.
Grandparents age. Supports shrink. And the fear of "what happens when I can't do this anymore?" becomes constant.

Parents adjust their retirement plans—not for comfort, but to prepare for their child's future. As their child becomes an adult, help from outside the family may slowly be introduced, often with the parent still present to guide and protect. The adult child notices these changes. They

are not unaware. They see their parent aging. They see siblings stepping into new roles. They begin to understand the future that is coming.

Over time, routines form—whether that means living with a sibling, receiving part-time help, or full-time assistance. There is no single right answer. There is no one-size-fits-all solution.

For some individuals, outside care is extremely difficult or even traumatic.
In those cases, family-provided care is not a preference—it is a necessity. It is what allows them to live with the least stress, the most freedom, and the greatest sense of safety.

Parents of children with severe disabilities willingly sacrifice their own dreams—not because they are forced to, but because making their child's life safe, meaningful, and dignified matters more. The goal has always been the same: to give their child the fullest life possible, surrounded by people who love them, understand them, and protect them.

Nebraska cannot lawfully deny waiver services by redefining extraordinary, medically necessary care as "normal family duties." Twenty-four-hour supervision, incontinence care, feeding, seizure monitoring, behavioral intervention, and constant safety oversight are not ordinary parental responsibilities—they are intensive supports that must be authorized based on need, not family relationship. Policies that ignore this reality violate the person-centered requirements of Olmstead and the HCBS Final Settings Rule and create a direct risk of unsafe care and unnecessary institutionalization. If Nebraska does not allow paid family caregiving with meaningful, individualized exceptions under its AD and HCBS waivers, it risks CMS noncompliance findings, loss of federal funds, and Olmstead-based litigation.

We also as family of these high needs have to be their voice! They can't just stand up and yell for themselves to be heard. So as much as you want to say it's just the families and parents saying stuff. That's how it is going to be! We are the ones who have to be their everything for them! If we don't speak out for them no one will! They will get walked on like this proposal is set out to do! It's not taking care of them or protecting them it's exactly the opposite. This proposal is designed to leave them hanging! Leave them with no option but be stuck in a facility! Leaves them without choice! You are trying to take away their voice with this proposal!

-Kellie Quinlin

From: Waylon Vajgrt
To: DHHS HCBS Public Comments
Subject: Public comment for HCBS proposals
Date: Friday, January 2, 2026 11:35:11 PM

You don't often get email from [redacted] Learn why this is important

I respectfully submit this comment to express concern and opposition to the implementation or continuation of rigid hour caps on in-home caregiver services within the proposed Aged and Adults and Children with Disabilities (A&D) 1915(c) HCBS waiver renewal.
The stated purpose of this waiver is to provide community-based services that allow individuals who meet nursing facility level of care to remain in their homes and avoid institutionalization. The proposal further emphasizes person-centered planning, participant direction, cost-effectiveness, and rebalancing long-term care away from institutional settings. Fixed or insufficient hour caps on in-home caregiving directly undermine these goals.
In-home care is a proven, cost-effective alternative to institutional care.
Nebraska's waiver is explicitly designed to prevent or delay nursing facility placement. Artificial limits on caregiver hours, when not aligned with an individual's assessed needs, increase the risk of hospitalization, caregiver burnout, unmet health and safety needs, and ultimately institutionalization—outcomes that are both more costly to the state and contrary to the waiver's intent.
Federal statute and CMS guidance support services based on individual need, not arbitrary limits.
Section 1915(c) of the Social Security Act permits states to waive comparability specifically so that services can be tailored to individuals who would otherwise require institutional care. CMS has consistently emphasized that HCBS waivers must be implemented in a manner that is person-centered and sufficient to assure health and welfare. While states may establish utilization controls, those controls cannot effectively deny medically necessary services or function as a de facto barrier to community living.
Hour caps conflict with person-centered planning requirements.
The HCBS regulations at 42 CFR §441.301 require that services be driven by a person-centered plan reflecting the individual's strengths, preferences, and support needs. Predetermined caps that override assessed need weaken the integrity of the person-centered planning process and limit meaningful choice, particularly for individuals with complex physical disabilities or limited informal supports.
Hour caps raise serious concerns under the Olmstead decision.
The U.S. Supreme Court's decision in Olmstead v. L.C. requires states to administer services in the most integrated setting appropriate to an individual's needs. When in-home services are insufficient due to capped hours, individuals may be placed at risk of unnecessary institutionalization, potentially placing the state out of alignment with its Olmstead obligations.
Flexibility already exists to manage costs without rigid caps.
The waiver includes individual cost limits tied to institutional cost neutrality, service authorization processes, reassessments, and safeguards. These mechanisms allow Nebraska to control costs while still meeting individual needs. Rigid hour caps are not necessary to achieve fiscal responsibility and may, in fact, increase long-term costs by accelerating institutional placement.
Recommendation
I urge the Department to remove or revise hour caps on in-home caregiver services and instead ensure that authorized hours are based on individualized assessments and person-centered

plans, consistent with the waiver's purpose, federal statute, and Nebraska's stated commitment to community-based care.

Thank you for the opportunity to comment and for considering the lived experiences of individuals and families who rely on in-home services to remain safely and independently in their communities.

Sincerely,

Waylon Vajgrt

Public comment for proposed AD waiver changes
This is NOT about Medicaid work requirements.

Why are big changes to the AD waiver being made by an anonymous committee, whereas a change to allow a guardian to be a shared living provider with the DD waiver has to be made by the legislature? Why doesn't the legislature have to approve the removal of support from vulnerable people? Who decides who is allowed to make such changes and why?

In the proposal, if a parent cannot continue to afford caring for an adult child at home the adult child will be placed in a facility. There are a number of problems with this plan:
-There aren't facilities with beds available that are able to meet the medical and/or behavioral needs of these people. There literally is no where that they will be accepted. It is immoral, unethical, and probably illegal to propose changes that can't be fulfilled. That's like saying, "You can have orange juice if the apple juice is too expensive. But...we don't actually have any orange juice."
-My daughter requires a ventilator while she's sleeping. Medicaid's definition of "ventilator dependent" is at least 10 hours of use a day. My daughter averages 9.5 hours. I suspect that means that Medicaid won't pay a facility the higher ventilator rate. So the facility is supposed to care for her and her ventilator at a lower rate, while still requiring placement in a ventilator unit with nurses and respiratory therapists. That's even less incentive for them to accept her to their facility. Without the ventilator we'll have to decide if she just never sleeps again or we just don't worry about her breathing while she's asleep because she can't do both simultaneously..
-Other parents have already submitted data that shows it is less expensive to pay guardians to care for these disabled adults than to pay an institution. Furthermore, if no nursing facility is available then those who are medically complex will have to live in a hospital. That definitely is significantly more costly than paying guardians to care for them at home (which is the whole point of the waivers). It's illogical. Paying guardians is an awesome bargain for you.

There are major ethical issues with requiring families to provide "informal support" for their disabled family member. That is underdeveloped/3rd world country thinking and practice. In those countries, if the family can't support a disabled person, that person is either left homeless or put in an understaffed, over crowded institution where there is likely terrible neglect and abuse. The United States is a developed/1st world country. Developed countries take care of their most vulnerable people. What do you want your future relatives to think about you when they read the history of this time? There's two options. If *evil* wins, you'll be a hero, a family legend, for killing those "worthless" people. That's what will happen. Taking services away will lead to unsafe and unsustainable conditions for disabled people. It's not quite as direct as Hitler's method, a bit more passive aggressive, but the end result will be the same: Disabled people will die. However, if *good* wins, your future relatives will be ashamed and appalled by the decisions you made that caused such awful consequences. If you don't believe me or think I'm being dramatic please read about the similarities between what is happening now and the holocaust. Note: *good* won that time, but not until a massive number of vulnerable people were murdered.

It's a slippery slope. These battles have already been fought. Why are you trying to go back

in time? Developed countries aim to advance and develop, not regress.

At this time, 95% of people served by the AD waiver use a budget within the 150%-175% facility rate maximum. That shows that it's working for the majority of people. That's a good result, and you should be proud. So why are you proposing to remove resources? For the 255 people who are over the cap, we need to accept that there will always be a small number of people who require more resources than others. Fair and appropriate does not necessarily mean equal.

What caused the 322% increase in spending? Where did that money go? The answer is not to remove needed services. When the AD waiver was developed and approved by the legislature it specifically said that anyone eligible for Medicaid with nursing home level of care needs was eligible for the AD waiver. No waitlist. The law requires Medicaid and the waivers to provide health and safety to Nebraska adults who are unable to care for themselves. It's not ambiguous. Law makers recognized the severe vulnerability of these people and designed the waivers to care for them with dignity in their community. This is not new. It's not a surprise. Just find the necessary money. It's there. Stop cutting taxes if financial responsibilities aren't being met.

People need to realize that they or a loved one are only one accident or illness away from needing these services themselves. If you think you could pay for everything a brain injured child needs for the rest of his/her life I suggest you find out the cost of one month in an Intensive Care Unit and the cost of several months of inpatient rehabilitation. Also, a specialized wheelchair, a special bed, modifications to your house, a wheelchair van, respiratory equipment and supplies , feeding tube equipment and supplies, home nursing care, multiple specialty doctors' visits, hospital admissions for illness, surgeries, etc. No matter how rich you are, your money isn't endless, but the needs of a disabled family member are.

I understand that a person doesn't qualify for a waiver if they are living in a facility, in which case Medicaid pays for their care, rather than the waiver. I know...it's all Medicaid money, but Medicaid waivers have a budget that is separate from regular Medicaid. Therefore, placement in an institution is financially beneficial for the AD waiver budget. It is a conflict of interest to allow the waivers to benefit financially by NOT accepting eligible people for waiver services.

Mr. Pillen recommends that we use community resources and neighbors to care for our disabled adult children. This is ignorant and insulting. Obviously we already ARE using all services available to keep our adult kids safe at home. We are very resourceful out of necessity. People served by the AD waiver have significant medical and/or behavioral complications. The teenager down the street who took a babysitting class is not prepared to safely care for someone with such high needs. My daughter breaths through a tracheostomy tube in her neck. If it becomes plugged or displaced, her caregiver has four minutes to resolve the problem before she dies. It is not safe for her to be left with random untrained people.

No one is being paid to do normal "grandma" things. It is not normal for a grandma to change a 24 year old adult grandchild's diaper. Or give her a tube feeding. Or change her

tracheostomy tube in an emergency. Furthermore, those aren't normal things for a parent to do for their 24 year old adult child either.

I care for my daughter 24 hours a day, seven days a week (168 hours). She is approved for 20 hours a day (140 a week) that initially I could bill for. Soon that dropped to 16 hours a day (112 a week). Who watches her those other 8 hours when I'm supposed to be sleeping? Well me, of course. I sleep in her room, and she is connected to five pieces of equipment that alarm if a problem is detected. She's in the bathroom with me when I shower. She can't be unattended. In the proposal I could only be paid for 40 hours a week, and a stranger can come into our home for 30 hours a week as a "companion." Do you know anything about the people who are served by the AD waiver? My daughter is paralyzed. She can't talk. She can't eat. She breaths through a tube in her neck. She can't sleep and breathe at the same time. She can't do anything by herself. A companion cannot do any hands-on caretaking, so I couldn't even leave to run errands while he/she was here. Therefore, you want to pay someone to come sit at my house to do what? Turn a video on for my daughter? Turn music on for her? Watch me do all the actual work? And this is fiscally responsible? No, it absolutely is not. It just doesn't make sense.

My recommendations for proposal decision makers.:
1) Come to our house and watch what it takes to keep my daughter safe and alive. She requires extraordinary care for her complex medical needs. I'm sure you can also visit a family whose son or daughter has complex behavior needs.
2) Meet with a pediatric pulmonologist and respiratory therapist at Children's Hospital to learn the requirements needed to bring a person with a tracheostomy home. Caregivers receive extensive education, training, practice, and testing before going home. It is intense. My daughter breaths through a little tube in her neck. If it becomes clogged or comes out her caregiver has about four minutes to resolve the problem before she dies. She proved this to be true in the hospital when her tracheostomy tube came out, wasn't properly replaced, and she required 27 minutes of cardiopulmonary resuscitation. This resulted in her severe anoxic brain injury.
3) My last recommendation is not specifically for the AD waiver, but for welfare in general: Do some research about the cycle of poverty and how difficult it is for people to escape that cycle. Then be thankful for the privileged situation that you were born into. There is not a single person on this earth who is more "worthy" than any other, no matter their circumstances.

Diana Lundquist

From: Melanie Henderson
To: DHHS HCBS Public Comments
Subject: Public Comment for proposed HCBS changes
Date: Tuesday, January 6, 2026 12:10:22 AM

You don't often get email from [redacted]. Learn why this is important

Please see my submission below for public comment regarding the proposed changes to the Aged and Disabled (AD) Waiver, specifically focusing on the proposed reductions in hours of individual care provided by live-in caregivers.

As a mother and full time provider, I am disheartened and appauled by this proposal. To think the state expects family caregivers to provide care to these individuals for 'free' is insane. Life is not free. We all have mortgages, car payments, insurance, taxes etc. I cannot imagine you would work over 40 hours a week without expecting pay, including overtime, if you were an hourly employee. You would not hesitate to call the Department of Labor.

So why would the state expect some of the most hard working people to work for no compensation?

If you proceed with these changes, there will be families that lose their homes, cars, safety, security, dignity and quite possibly, their loved ones.

The funds family caregivers receive are primarily spent on the needs of the individuals on the waiver. The average cost of a basic minivan with a ramp is $65,000. Home modifications cost money. Basic needs such as diapers and wipes are not always covered by insurance. I am not telling you anything you don't already know.

There are many AD participants that only have 1 caregiver due to circumstances out of their control. Not everyone has 2 physically capable parents to care for them. Not everyone has a network of family and friends that can and will help care for them.

What happened to the person-centered care planning and allowing the participant to decide who cares for them? I don't know of any individuals that would want a stranger from an agency coming into their home to take care of them. Would you?

You are penalizing individuals and the ones that love them most for fiscal mistakes the state and DHHS have made. It is not the individuals needing the care that overspent, it was DHHS.

Now, let's focus on the fiscal side of this proposal.

Yes, the number of individuals on the waiver has increased. This would be expected with getting rid of the waiting list. So then costs have increased as well. Also expected. The numer 332% has been mentioned repeatedly, but there has been no specific breakdown or explanation of where the increase has come from.

It was also mentioned that specifically 255 participants have a larger than average spend.

I am assuming these individuals are receiving care by agency caregivers.

I have been informed that several agencies have reimbursement rates around $40/hour, and yet the highest pay rate i have seen is $21/hour.

This leads to 2 questions:

1. Why has DHHS not set a standard reimbursement rate for agencies? Since 2023, all new agencies have been told the reimbursement rate is capped at $28. So why not make this the standard rate across the boards? I have been informed there is an agency currently getting reimbursed $40/hour for over 100 participants. Most of whom have 112 hours of care per week. How is this finally responsible when there are other agencies getting $28/hour and still paying caregivers the same as the agency getting $40/hour? I think you need to do your research. There are other ways to fix the budget without penalizing the people who need the care. The need for 24/7 care doesn't go away because you need to fix your budget.

2. Please explain why DHHS is capping family caregivers hours at 40 per week and then mandating an outside agency caregive provide the additional hours? This makes no sense financially. Agency staff is always going to cost more than/the same as a family caregiver. Most AD participants do not do well with change or unfamiliar people/places. This rule will only cause fear and uncertainty for not only the participant, but the family as well.

The AD Waiver exists to prevent institutionalization and promote dignity, stability, and independence. Any changes to it should reflect that mission and should not come at the expense of the very people it was designed to protect.

Thank you for the opportunity to provide public comment and for considering the impact this will have on the lives of the most innocent and vulnerable members of Nebraska.

Thank you

Public Comment for Renewal of AD Waiver, with Planned implementation July 2026
by Heidi Sommer, parent of 22-year-old son with complex needs

I strongly oppose the proposed changes to the AD Waiver and feel it violates the HCBS Final Settings Rule.

Background for understanding: My son was on DD waiver waitlist and denied AD for many many years. In 2020, he landed in hospital with autoimmune encephalitis and Children's Hospital was appalled that a child with such need (he has always required 24-care and help with ALL ADLs) was not on a waiver. They assisted us with expediting a new application and he was on it a short couple months later. This was when my son was newly 17 years old. Him not being on a waiver all along was due to many procedural mistakes that I honestly see continue to happen to others. While it was very tough on our family, we made it and never gave up.

Now that we have the waiver, it has helped us create more family normalcy and allow us to keep working but me only very part-time. We also have another neurotypical child, who is 4 years younger than Hayden. Hayden has Phelan-McDermid Syndrome, which is on the Social Security Administration compassionate allowance list. The list is supposed to make processes easier, because it is a known life-long condition. Our son's is regressive and he has been accessing a hospice care approach to healthcare in order to create quality of life for a couple years now. In the last month, while all this DHHS news was dropped, my son has also declined further and can no longer walk without assistance or he will fall. He requires lifting to get in car too, and we recently bought him a $5,000 wheelchair not covered at all by insurance.

Here are my questions/concerns/comments with the proposed changes to the AD Waiver:

*In the first public comment meeting and Olmsted emergency public meeting I asked if parents and caregiver agencies were a part of the planning process. Were any? The silence after my questions, leads me to believe no parents or agencies were asked to provide valuable information to guide these changes. How do you plan correctly without those who live it at the table? I volunteered and have NEVER been called.

*Which nursing homes in Nebraska are equipped to provide care in the event someone's budget goes above the 175% of the $92K average for nursing home care. I was told by DHHS that this $92K is the average Medicaid paid for a nursing home bed last fiscal year. This was based on the number of people paid for through Medicaid and divided by the amount spent. I asked were any of these with complex special needs? This question has yet to be answered. I'd like to share that I have called around and found NONE of the places

would take our son, Hayden. NONE. And when I asked how much it would cost, they said they couldn't give me that because they have no idea since they don't provide that type of care. SO, HOW ARE YOU THROWING A NUMBER OUT THERE WHEN IT IS NOT A POSSIBILITY EVEN? And if it is a possibility, can I have names of these nursing homes? Is it dangerous to plan for vulnerable Nebraskan's care on a number that has nothing to do with the type of care they need?!?! Yes. It. Is.

*I was told that when Nebraska looked at changes to DD when they added in Tiers that it took an entire algorithm and almost a year to do. The individuals on the DD do not have as severe or complex of needs, so help me understand why there is **LESS** planning for those on AD? To me, this screams **discrimination**. It screams forced institution for some. It screams SHAME ON ALL OF YOU.

*In the Omsted meeting on Friday, December 19, Tony Green said "we will have to implement a waitlist if we don't do this." And "we successfully eliminated the waitlist in 2025." Did you SUCCESSFULLY eliminate it if you are making drastic cuts, just so more have a little?" The "more" are some children that are receiving services during the day, so they are not getting nothing. If you pull hours that parent caregivers are providing you are going to have sick parents, you are going to have adult children that have nothing to go to during the day not having there needs met. These changes will be on the backs of the special needs adults' parents and siblings. **You are robbing Peter to pay Paul. Period.** Waitlist or unmet needs, you still have a problem that is not solved appropriately. You do have a governor that can check a box saying he "ended the waitlist" on the backs of parents and those with disabilities.

*You say we need to utilize informal supports? Both my and my husband's dads passed from cancer at age 65 over 10 years ago. Our moms are not capable of helping, and our siblings work. Our neighbors work and have families. I was told as my son's main caregiver, I AM THE INFORMAL SUPPORTS. So on some days, that means I stay up for more than 48 hours at a time. We have 1 caregiver that helps me twice a week for a total of 14 hours. We had another caregiver, but she just disappeared. The other people we've had from agencies you are paying close to $40 an hour for have zero skills and many of them have stolen from us. Parents provide the best care and if done right, it can be less than an agency.

*Which leads me to a valid point. Why not pay parent independent providers which is at nearly half what you pay an agency (savings there big time). If you paid a parent majority of the hours it would likely cost half as much as agencies. So when you cap a parent at 40, but will pay an agency for 30 more, the math doesn't make sense. That costs more than paying a parent 1.5 for the extra 30, or up to 112. Period. And what happens to this adult child

when the parent cannot take care of them? What is the plan? There are no nursing homes equipped to do this, so that needs to be fixed before this plan is put into place.

*You say this is needs based? It was stated by DHHS in public comment meeting. If you don't cap those on the DD waiver, then this is pure discrimination based on need/costs. Many on the DD waiver have higher budgets than those on the AD waiver. How can this be if the needs are not at the same level? Why are they entitled to their needs-based care, but those on the AD are not. You may want to look at Iowa and Indiana; there is a discrimination case very similar.

*Children on the AD waiver are entitled to more with LRI. Is this also **age discrimination**?

*CHORE and COMPANION. If you require nursing home level of care how is someone able to only come in and be a "companion"? or do chores? Who is doing all the ADLs during this time? Why not only provide personal care and all of that falls under that, like currently? Or if you have individuals that only need companion, do they need the waiver? Likely not. Weed that out.

*No plan in event "family" or informal supports cannot care. This is flat out dangerous. Shame on you Nebraska.

*There is a huge shortage of caregivers, which puts even more pressure on parents that have had to quit their jobs (I could make 6 figures in PR, but had to quit years ago to care for my son). We want to care for our adult children with needs, but we do need the help of the waiver. It allows us to pay for the many things that are not covered for our adults and still try to plan for our retirement (likely for 3).

*There are 168 hours in a week. You are asking us to provide unpaid care for 77 percent (less 40 hours) of that. If you were asked to work unpaid for 77 percent of your time, could you? Most of us "would", but the real question is can we? Can we risk our health? Can we go without retirement income, sick time, vacation time? The pay we get for caring for our adult children helps with all of that, which most do NOT ever have to even think about.

-why not consider those parents that are independent to continue that. And if you want your current budget it must be independent, not through an agency to save the State that money. My son's annual budget with me doing the most care is still less than many DD budgets. Why are those budgets not compared to institutionalization costs? Do YOU value other human life more? Sounds like more discrimination.

*It seems my son is "too" disabled for nursing homes, and "too" disabled for me to be paid to care for him, and "too" disabled to be PROPERLY PLANNED FOR by the Department of Health and HUMAN services. If you force institutionalization, that goes against the Nebraska Olmsted plan, correct?

*The Final Settings Rule requires meaningful choice of providers and respect for individual needs identified through person-center planning. First, I am the one that has done all his person-centered planning and had to request it be used and discussed. Furthermore, my son is currently on hospice and needs and wants to be around his family and cared for by them in his home. The proposed plan limits family-provided care and ignores individualized assessments and replaces person-centered planning with rigid caps.

PLEASE CONSIDER each human life as valuable, please consider our time we sacrifice to care for our adult children. You need us, and we need this waiver to not be cut. It will no doubt cost Nebraska more.

Thank you,
Heidi Sommer
[redacted]
[redacted]
Adult child, Hayden on waiver

From: Joni Thomas
To: DHHS HCBS Public Comments
Subject: Public comment for the aged and disabled waiver renewal
Date: Sunday, January 4, 2026 8:59:40 PM

You don't often get email from [redacted]. Learn why this is important

To Whom It May Concern,

I am writing to submit public comment regarding Nebraska's renewal application for the Aged and Disabled (A&D) Home and Community-Based Services Waiver.

I am deeply concerned that, in the effort to standardize Nebraska's Home and Community-Based Services (HCBS) waivers, the renewal application fails to adequately address a critical structural issue: the growing use of the Aged and Disabled waiver as a substitute for gaps and limitations within the Developmental Disabilities (DD) waiver—specifically, the inability of the DD waiver to consistently support individuals who require both custodial and habilitative services.

As a result of these limitations, families with adult children who have significant medical needs in addition to intellectual or developmental disabilities—often while waiting on long DD waiver waitlists—have been moved onto the Aged and Disabled waiver. However, this shift fundamentally alters the original intent of the A&D waiver.

The Aged and Disabled waiver was designed to support individuals who are able to direct their own lives and services, with assistance primarily through personal care, transportation, and limited supports—allowing them to remain safely in their homes and communities of choice. Using the A&D waiver to compensate for unmet DD waiver needs places individuals with complex medical requirements into a system that was never designed to meet those needs adequately. This misalignment has serious and dangerous consequences.

For individuals like myself—who live, work, and participate fully in our communities—the proposed limitations and service modifications create a very real risk of unnecessary institutionalization. When people cannot access sufficient overnight support or medically appropriate services in the community, the default outcome becomes placement in a nursing facility. This directly contradicts the purpose of HCBS waivers and undermines decades of policy progress toward community integration.

I am particularly concerned that the renewal application does not appear to fully account for the true costs associated with institutional placement for individuals with high medical needs, such as those who are ventilator-dependent or individuals living with dementia. These populations require specialized, intensive care in nursing facilities—care that is significantly more expensive than providing adequate supports in the community. It is unclear whether these costs were accurately included in the fiscal assumptions presented.

This leads to my second concern: I do not believe the nursing facility cost averages presented in the renewal application reflect the actual populations most likely to be forced into institutional care as a result of these changes. Individuals who would be displaced from the community are not average nursing home residents. They include people with ventilator dependence who are currently cared for by aging parents, and individuals like myself who have worked throughout adulthood, purchased and sold homes, paid taxes, and built lives in

our communities with the expectation that community-based supports would allow us to age in place.

I never believed that, after decades of employment and independence, I could be forced into a nursing facility simply because I cannot obtain enough waiver hours to cover overnight support and a limited number of daytime visits. Yet that is precisely the outcome these waiver modifications could create. I respectfully request transparency regarding the methodology and calculations used to arrive at the cost figures included in this renewal application.

Third, I am troubled by the broader fiscal context in which these changes are occurring. At the same time that Nebraska legislators have publicly questioned the sustainability of large tax cuts benefiting the state's wealthiest residents, the Aged and Disabled waiver is being rewritten in response to the very budget deficits those tax policies have contributed to. This raises serious concerns about whether fiscal priorities are being balanced equitably.

Finally, and most importantly, budget shortfalls should not be resolved on the backs of elderly individuals and people with disabilities. We want the same thing as everyone else: to remain in our homes, participate in our communities, maintain our independence, and live with dignity. That is the fundamental purpose of a Home and Community-Based Services waiver.

I urge CMS and the State of Nebraska to reconsider the proposed changes to the Aged and Disabled waiver, to fully evaluate their real-world impact on people with complex medical and disability-related needs, and to ensure that cost containment efforts do not result in unnecessary institutionalization or the erosion of civil rights guaranteed under federal law.

Thank you for the opportunity to submit public comment and for your consideration of these concerns.

Respectfully,

Joni Thomas
Lincoln, Nebraska

Joni Thomas
Pampered Chef &
www.pamperedchef.com/pws/jonithomas1957
Norwex Consultant
www.norwex.com/jonithomas
[redacted]

From: amanda Vick
To: DHHS HCBS Public Comments
Subject: Public Comment from a Primary Caregiver
Date: Monday, December 29, 2025 10:57:12 AM

You don't often get email from [redacted] Learn why this is important

Dear Chairman Hardin and members of the HHS Committee

. I am the mother and legal guardian of a 25-year-old son with traumatic brain injury due to a car accident. I am deeply concerned that the proposed changes leave no realistic or safe path for my son to continue living at home.

My primary concern is simple and urgent: under the proposed limits, the care hours are insufficient to keep my son safely at home, yet there is no realistic alternative placement available for him.

Based on my son's skilled nursing level of care needs, he would likely qualify in the 150–175% cost of care category. Despite

being in the highest need category , I would be limited to 40 paid hours per week as a family caregiver. That is not enough income to support my son, my other children, or myself—especially given the lack of benefits, paid time off, health insurance, retirement, or overtime.

At the same time, it is not realistic for me to take on one or two additional full-time jobs. My son requires constant supervision and skilled care. He cannot initiate communication, cannot feed or care for himself, cannot reliably indicate pain, and has seizures, autonomic dysreflexia, a G-tube, and a suprapubic catheter that he pulls out. His vitals must be monitored and medications administered as needed to keep him stable. Placing

him in an unfamiliar environment would be devastating to him and, in my opinion, cruel. There is also no viable placement option.

There are no nursing homes in my rural area that will accept my son. The only facility that has even considered accepting him is QLI in Omaha (2+ hours away), where he has been on a waitlist since 2017. He has been denied other placements because he requires a skilled level of care (not simply custodial) and because he is only 25 years old. The assumption that agencies or nursing can simply fill gaps is not reality.

In rural Nebraska, there is no reliable provider workforce. From 2017–2020, I was unable to fill even one-third of my son's approved nursing hours. After 2020, none were filled. There are

no nurses
available in my area. Agencies and I advertised for years with no success.
I currently have four caregivers besides myself:

- Two have full-time jobs elsewhere

- One works daytime hours but has missed many days and may soon leave for full-time work elsewhere at much higher pay

- My adult daughter works full-time three hours away and helps on weekends when possible, but if I reach my 40 hours, she cannot be paid

. If an agency is required to provide care but staff call out—as they frequently do—my son only has me. That does not result in care

being provided; it results in families being abandoned.

The idea that parents are not providing 24/7 supervision is deeply offensive.

Comments made during a recent Zoom meeting suggested that caregivers do not have “eyes on” their children at all times. Aside from brief moments such as using the bathroom, I am always monitoring my son. If I had access to more qualified caregivers, I would absolutely use them. The issue is not unwillingness—it is lack of access.

I sleep in a bed one night a week if I am lucky when have overnight staff. My son often does not sleep for days at a time due to his brain injury. I recently underwent two knee surgeries this year, both times without consistent staff coverage during

recovery. I am 45 years old with knees comparable to someone in their 60s. I cannot destroy my body indefinitely for free, no matter how much I love my son. That is not sustainable and only delays an inevitable crisis. Families need flexibility and choice.

Hours should belong to the client—not be restricted by who provides them. If a client is approved for a certain number of hours, it should not matter whether those hours are used by a family caregiver, one agency, or multiple agencies. Guardians should be allowed to decide how approved hours are allocated based on what actually works. Limiting family caregivers to 40 hours while restricting agency use to a single provider removes the flexibility families rely on to survive.

Finally, families like mine are saving Medicaid significant money.

If my son were in a nursing facility, routine care such as G-tube replacements or catheter changes would require ambulance transport, emergency room visits, and hospital procedures.

At home, these are managed safely and at far lower cost. These savings do not appear to be factored into current decision-making.

In closing:

The proposed changes leave families like mine with no safe option—unable to earn enough to keep our children home, unable to find staff, and unable to access placement. I am asking you to reconsider policies that remove flexibility, ignore workforce realities, and push families toward crisis rather than stability.

Thank you for listening to the lived experience of those of us doing this work every day.

Thank you for your time reading this, and I truly hope you hear my concerns and see how these changes will significantly cost taxpayers more money.

Amanda Vick

[redacted]

From:	bakerjo
To:	DHHS HCBS Public Comments
Cc:	Sen. Ben Hansen, B.
Subject:	Public Comment of Changes to Aged and Disabled Waiver
Date:	Wednesday, December 17, 2025 1:46:07 PM

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To Whom It May Concern:

The Aged and Disabled Waiver program is a lifeline to some of the most vulnerable persons in the Nebraska community. This program assists those families and caregivers to give the best care to their loved ones and clients. This allows guardians/caregivers to take care of those needs in a cost effective manner at home. These vulnerable persons need all the hard work and love that can be given to them.

When it is determined, because this program has not been addressed by the legislature according to the Medicaid HCBS waivers, that the hours that these dedicated people use to care for these individuals are to be cut is incredible. All of these people sacrifice more than just their time and energy. They actually care about the outcome that these individuals receive in their lives.

This program should have been funded at the same rate as the DD waiver. The difference in cost is amazing. Providers that are available to persons on the DD waiver are not available at the same rate as persons on the AD waiver. The DD waiver gets one to one attention while the AD waiver individuals get a less ratio rate. All of these individuals are all vulnerable individuals and they should be treated the same.

Guardians and Caregivers choose the AD waiver for a multiple of reasons. These reasons have to do with the ability and disability that each of these individual has. The individuals on the AD waiver probably will never attain the opportunity to hold a job, which is part of the DD waiver, but they should be able to have a wonderful, secure and happy life with the people who love them the most.

Under the Medicaid HCBS Waivers in Nebraska both the Aged and Disabled Waiver (AD Waiver) and Traumatic Brain Injury Waiver (TBI Waiver) falls under the Nursing Facility (NF) level of care and to help these individuals live safely in the community. One of many issues with cutting these Medicaid HCBS waivers there are little to no facilities that offer this type of care that accepts these waivers. The cost would become even greater if there were enough facilities that could take them and would they get the same wonderful, secure and happy life that the caregivers and love ones give them. I believe that it may not be the same.

Each of these caregivers know what the needs are for these individuals. There are many medical and disability issues with which these individuals and their service coordinator would know about. These are the front line people that come and visit with each of us all year long.Just because Medicaid HCBS group is looking at a dollar and cents issue, that does not take care of these individuals. Cutting these hours is not taking care of these individuals in the most safe and efficient manner.During the zoom call one of the presenters mentioned many are family members. That does not mean that our lives are any easier taking care of these vulnerable adults and children.

I would like to request that the hours for these vulnerable adults and children not be cut. It is in the best interest for the vulnerable individuals, families, guardians, caregivers and much more cost efficient for the state.

Joe Baker

From: Rocky Baker
To: DHHS HCBS Public Comments
Subject: Public Comment of Changes to Aged and Disabled Waiver
Date: Sunday, January 4, 2026 7:43:07 PM

You don't often get email from [redacted]. Learn why this is important

To Nebraska DHHS Leadership,

I am responding to the recent AD and TBI Waivers proposed policy changes that are going to be impacting families across the state of Nebraska. The Nebraska Department of Health and Human Services (DHHS) announced the 30-day public comment period for the renewal of the 1915(c) Medicaid Home and Community-Based Services (HCBS) Aged and Adult and Children with Disabilities (AD) Waiver (NE.0187) and an amendment to the Traumatic Brain Injury (TBI) Waiver (NE.40199) on an email dated Thursday, December 4, 2025. That email was sent out to a select group of individuals. If it wasn't for those select individuals sharing the email with other families very few Nebraska families would have been unaware of what was taking place. It was very convenient to host four (4) ZOOM calls in one of the busiest months of the year. When families called their Service Coordinators, they were unaware of any said proposals taking place and unable to provide any additional information.

As a member of the AD Waiver community, I am a parent to my special needs son, who is one of my pride and joys. I am my son's translator, advocate, teacher, nursing care and administration of medications, personal care, and many more and the list goes on as it does for many other family providers. We do this for our children out of love but give up a huge part of our own lives such as careers, friends or even dinner dates with their spouses. Respite is unheard of in our house. We have made many attempts to get a Respite or day services provider that accepts the AD Waiver only for the center to state our son needs more attention than the AD Waiver allows and they are not staffed for that type of support.

What I understood from the Zoom calls I attended the proposed policies are a movement to remove parents from providing care. DHHS is placing Nebraska families in positions they never thought would happen. During the Zoom call, the presenters were asked if they ever took care of a special needs family member. After a long pause, one said they provided care briefly. Members of DHHS should spend time with families and actually experience real life experience. Many families during the ZOOM calls offered to have someone come to their homes; this would be a wonderful educational opportunity for DHHS members before proposing policy changes.

DHHS is asking families to allow contracted care providers to take care of vulnerable individuals without understanding their needs. This will not help us parents, since we will have to be there instructing or translating for them because they will not be able to understand their wants and needs. I have been down that path many times and the care provider never came back or they informed me they cannot give medications or unable to interact with my son or they don't have proper staffing.

DHHS's other option is nursing facilities. Some nursing facilities can't support the needs of these vulnerable individuals, either. Some Nebraskans don't have a nursing facility within 100 miles, let alone bed openings in one that accepts Medicare or Medicaid residents. The Nursing workforce data states "The Nebraska Center for

Nursing projects that Nebraska will experience a workforce shortage of 5,436 nurses by 2025, with nearly 1,000 nurses between the ages of 24 and 55 being “very likely” to leave their employment over the next 12 months.” (*Nursing workforce data*. Nebraska Center for Nursing. (2025, September 7). https://center4nursing.ne.gov/data/).

I suggest the DHHS members visit the nursing facilities they list as taking the AD Waiver. After their visit look into a mirror and honestly answer the following questions. Do I feel safe here? Would my needs be taken care of at the same level of care received at home? Would I have my family members stay here? Just be reminded that you or someone close to you may need the AD Waiver one day. Human lives are more valuable than any dollar amount.

I would like to request that the hours for these vulnerable adults and children not be cut and not to change caregivers. It is in the best interest for the vulnerable individuals, families, guardians, caregivers and this is more cost efficient for the state.

Roxanne Baker

From: Craig Peterson
To: DHHS HCBS Public Comments
Subject: Public Comment on A&D Waiver
Date: Thursday, January 1, 2026 2:17:54 PM

> You don't often get email from [redacted]. Learn why this is important

This A&D Waiver is so important to my family in order to provide services to our 26 year old quadriplegic and ventilator dependent daughter. She is dependent on our 24/7 care, mostly from my wife. The A&D waiver has allowed my wife to provide the caregiver services in our rural home rather than needing to move our family to a more populated area that could provide institutional services.

Cutting in home care hours from what is required for proper care for our daughters needs will be detrimental to our family. Because of the shortage of qualified in home nursing care we have gone from having three nurses in the past to zero, meaning my wife and I have had to pickup those hours at the same time having the number of hours allowed reduced. This has started to affect the health of my wife in providing additional hours.

Like many families in our position, we struggle with the financial weight of providing the level of care our daughter deserves. Keeping her at home, surrounded by the family who knows her needs best, is vital. This support system is the foundation of her health and safety, and preserving it is the only way to ensure the best possible outcome for everyone involved.

Rather than reducing our authorized services, I am asking for your help in either maintaining or increasing our current hours. Our family is already at a breaking point, and preserving these hours is the only way we can continue to provide the 24/7 care our daughter requires to survive.

Craig L. Peterson
[redacted]

From:	Randy Wattermann
To:	DHHS HCBS Public Comments
Cc:	Sen. Ben Hansen, B.
Subject:	Public Comment on AD Waiver Renewal (NE.018.08.00)
Date:	Sunday, January 4, 2026 7:39:47 PM

You don't often get email from [redacted] Learn why this is important

Dear Nebraska Department of Health and Human Services,

Thank you for the opportunity to submit public comment on the proposed renewal of the Aged and Adults with Disabilities (AD) Waiver. As primary caregivers for our adult daughter, we are current participants in the AD Waiver and are deeply appreciative of the essential role it plays in enabling individuals with disabilities to remain safely in their homes and communities. I have copied Senator Ben Hansen, our state senator, for awareness of constituent feedback during the public comment period.

We want to begin by acknowledging the difficulty of the task before the Department. Balancing responsible stewardship of taxpayer funds with the obligation to administer a person-centered, effective waiver program is complex. We recognize and respect the effort required to manage this program at scale while maintaining fiscal accountability.

We also generally support the use of a cost cap informed by average nursing facility costs. In aggregate, AD Waiver services are delivered at a cost below comparable institutional care, while also producing better outcomes for waiver participants and their families. From both a fiscal and quality-of-life perspective, the waiver has demonstrated value to the state.

One aspect of the proposed renewal, however, raises concern for us and warrants reconsideration or additional clarification. As presented, the draft would establish a combined maximum of 70 hours per week for personal assistance services, live-in personal assistance services, and companion services, with an additional limitation that no more than 40 of those hours may be provided by a live-in provider.

While we understand the intent to manage service utilization within an overall cap, it is unclear why this further restriction on live-in services is necessary or how it aligns with current workforce conditions. For many families, the primary constraint is not over-utilization of authorized services, but rather the ongoing difficulty of recruiting and retaining qualified providers. In our own situation, even with a relatively large family network available to assist, a single individual in the home currently provides the majority of authorized service hours simply due to the lack of other available providers. Limiting the number of hours that may be delivered by a live-in provider—even when total authorized hours remain within the overall

cap—may unintentionally reduce access to necessary services.

We acknowledge that the proposal references an exception process for situations involving immediate health and safety needs. However, the criteria, process, and timeliness for granting such exceptions are not clearly articulated. Participants and families need confidence that medically necessary and safety-critical services will be authorized promptly and without undue administrative burden.

We respectfully urge the Department to reconsider this specific limitation, or at a minimum, to provide clearer justification and guidance regarding its application. Greater flexibility in how authorized hours may be delivered would better reflect workforce realities, support families, and continue to advance the waiver's core objective of preventing unnecessary institutional placement while maintaining sound fiscal stewardship.

Thank you for your continued work on behalf of individuals with disabilities and their families, and for considering the perspectives of waiver participants and caregivers directly affected by these proposed changes.

Sincerely,

Randy & Trina Wattermann

[redacted]

[redacted]

DHHS – Public Comment on A&D Waiver Changes

I am the parent of an adult with disabilities who lives at home. The proposed reduction in personal care hours is not only unethical and reckless—it is fundamentally unconstitutional. These changes demonstrate a complete disregard for the safety, dignity, and basic human rights of disabled adults and their caregivers.

This decision will directly force thousands of disabled adults into nursing homes because in-home caregivers will be unable to continue providing care without adequate compensation. Many of us are already financially strained. Most caregivers do not work outside the home, and those who do—like myself—are limited to part-time work. I work approximately 30 hours per week, earn an acceptable hourly wage, and yet receive **no benefits, no paid holidays, and no paid vacation**. This policy ignores economic reality entirely.

It is absurd to cap in-home caregivers at 40 hours while simultaneously paying outside agencies higher hourly rates for nearly the same amount of care. This exposes a complete lack of understanding of the caregiving workforce. There are not enough resources available. The assumption that families can simply "find help" or rely on relatives is inaccurate and insulting. I have no parents and no immediate family who can assist.

I have used agencies in the past, and the results were unacceptable. I have had staff show up untrained and unqualified to care for a disabled adult. I have had caregivers fail to show up without notice, resulting in lost money and canceled plans. This is not reliable or safe care.

It is infuriating that individuals sitting in offices are deciding the fate of the most vulnerable population without any apparent firsthand experience. I would like to know how many of you care for a disabled adult every single day. Our lives are repetitive, exhausting, and relentless—365 days a year, year after year. There are no days off. Caregivers deserve fair compensation for this work.

If families are forced to relinquish care, the state does not have anywhere near the capacity to absorb these adults into facilities. You are focusing only on rising numbers instead of acknowledging that DHHS itself expanded A&D waiver enrollment simply to eliminate waiting lists—without planning for long-term sustainability.

There is **no law** stating that in-home caregivers must absorb part of the cost of caring for a disabled adult. This narrative is being pushed solely to justify cutting essential care hours. It is disingenuous and unacceptable.

You are willing to pay higher rates to outside agencies or nursing homes—staffed by people who do not know or genuinely care about these individuals—while undervaluing those who provide constant, attentive, and knowledgeable care. In-home caregivers can recognize subtle changes, anticipate needs, and detect medical issues immediately. Agency staff cannot do this when they rotate shifts and care for multiple individuals at once.

DHHS needs to hire an independent CPA firm to conduct a real cost analysis, because the current financial assumptions are clearly flawed. Paying an in-home caregiver $20 per hour for 112 hours equals $2,240 per week. Nursing homes and agency care will cost the state **significantly more**, far beyond what you are projecting. You are presenting numbers that make DHHS appear informed, but they do not reflect reality.

If these changes are implemented, many parents will have no choice but to turn their adult children over to the state. These individuals are legally adults, and families are not legally required to continue care under impossible conditions. You should begin preparing immediately for the necessary space and resources that will result from your own policy decisions.

From: Kelly Wagner
To: DHHS HCBS Public Comments
Subject: Public Comment on DHHS AD Waiver Renewal – Impact on Family Caregivers and Waiver Participants
Date: Friday, January 2, 2026 2:59:06 PM

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To Whom It May Concern,

I am writing to submit public comment regarding Nebraska DHHS's proposed changes to the Adult Developmental Disabilities (AD) Waiver as part of the five-year renewal with CMS.

My husband and I are full-time caregivers to our two adopted adult children with special needs: Allyson, age 25, and Brayden, age 20. We have structured our lives around meeting their complex daily needs safely and consistently in a home-based setting. Beginning January 1, our approved caregiving hours were significantly reduced, and we are now facing the possibility of additional, substantial cuts.

These proposed reductions raise serious concerns—both personally and legally—regarding compliance with federal Medicaid requirements and the long-term health, safety, and stability of waiver participants.

Person-Centered Care and Sufficiency of Services
Federal law requires that waiver services be sufficient in amount, duration, and scope to meet each individual's assessed needs and to be determined through person-centered planning. Blanket caps on caregiving hours, particularly when imposed without regard to medical complexity or functional need, undermine this requirement. My children's care needs do not diminish because their caregivers are parents, nor can they be safely met within an arbitrary hourly ceiling.

Relationship-Based Limits on Parent Caregivers
The imposition of a 40-hour cap on paid care for live-in parent caregivers functions as an assumption of unpaid labor that federal Medicaid law does not permit. Adult beneficiaries should not be required to rely on uncompensated care simply because of family relationship. This approach conflicts with HCBS requirements that prohibit substituting unpaid "informal supports" for covered services.

Freedom of Choice and Constructive Denial of Services
Federal Medicaid law guarantees beneficiaries meaningful freedom of choice among qualified providers. Policies that make parent caregiving financially or logistically unsustainable eliminate that choice in practice. For many individuals with disabilities—particularly those with higher or more complex needs—parent caregivers are not merely a preference, but the safest and most stable option. Hour and compensation caps that force families to abandon this arrangement amount to a constructive denial of services.

Access, Workforce Stability, and Health & Welfare Risks
Nebraska already faces significant workforce shortages, particularly in rural areas. Arbitrary compensation caps and hour reductions increase instability, turnover, and unsafe gaps in care. These outcomes directly conflict with federal requirements to protect beneficiary health and welfare and to ensure access to services comparable to that of the general population.

Risk of Institutional Bias
The cumulative effect of hour and pay caps increases the likelihood that individuals will be pushed toward institutional placement—not because it is appropriate, but because home-based care becomes unsustainable. This runs counter to the intent of HCBS waivers and raises concerns under the Americans with Disabilities Act and the Supreme Court's Olmstead decision, which require services in the most integrated setting appropriate.

Advocacy and Retaliation Concerns
It is also essential that beneficiaries and caregivers be able to speak openly and advocate without fear of retaliation.

Federal Medicaid regulations and constitutional protections safeguard the right to public comment, advocacy, and due process. Any reduction, scrutiny, or adverse action taken in response to protected advocacy activity would be deeply concerning.

Request for Review and Corrective Action
I respectfully urge Nebraska DHHS to:
- Reevaluate relationship-based hour caps for parent caregivers
- Ensure services are determined by individual assessed need, not caregiver relationship
- Reconsider compensation caps that undermine access and workforce stability
- Protect meaningful freedom of choice of caregiver
- Ensure full compliance with federal Medicaid, HCBS, ADA, and constitutional requirements

Families like mine are not asking for special treatment. We are asking for policies that reflect reality, uphold federal law, and allow adults with disabilities to remain safely cared for in their homes.

Thank you for your time and consideration of this public comment.

Respectfully,

Kelly Wagner
Parent and Full-Time Caregiver
[City, Nebraska]

Sent from my iPhone

From:	Steven Libby
To:	DHHS HCBS Public Comments
Cc:	Sen. Rita Sanders; Merv Riepe; Dan Quick; gmeyer@leg.ne.gov; Sen. Ben Hansen, B.; Sen. Beau Ballard; Sen. John Fredrickson; Sen. Brian Hardin
Subject:	Public Comment on DHHS Proposed Changes to A&D Waiver 5 Jan 2026
Date:	Monday, January 5, 2026 9:11:09 PM

You don't often get email from [redacted]. Learn why this is important

I have one issue to address in my formal feedback to DHHS proposal for changes to the AD Waiver in 2026. These limitations on page 53 of the draft application must be withdrawn:

"Personal Care and LRI Personal Care are limited to a combined maximum of 40 hours per week (for live-in caregivers).

Personal Care, LRI Personal Care, and Companion services are limited to a combined maximum of 70 hours per week for non-live-in caregivers.

Exceptions to both limits may be approved by DDD Central Office to meet the immediate health and safety needs of a participant."

All participants of the AD Waiver require equivalent to "nursing facility level of care." What does this mean practically? It means supervision and execution of activities of daily living (ADLs) both day and night, and this is done to keep them out of more expensive nursing facilities. To the degree possible, Personal Care at home under the AD Waiver must be made available similar to how care is made available in nursing facilities. Nursing facilities do not shut down at night or on the weekends, and Personal Care providers are not punching a clock on a 9-5 desk job from Monday to Friday.

Secondly, artificially limiting the workforce otherwise eligible to provide care for family members based on where they live strikes as discrimination. Should not the individuals needing Personal Care hours (or their guardian) have the maximum flexibility to choose those who can best care for them? Some of the Personal Care tasks include toileting, bathing, and other tasks which would seem invasive to the dignity and privacy of a "normal" person who can perform such tasks themselves. Would you prefer to have a stranger from outside the house bathe your disabled adult daughter or son? What if your external provider changes frequently, through no fault of your own? How many different people would you trust to perform these tasks on your family member in your own home?

The second and third order effects of discriminating against parental providers will be detrimental to Personal Care providers, AD Waiver recipients, and the taxpayers of Nebraska. Why? Because parental providers are in most cases unable to work outside the home. To put some numbers to this, assume a current parental provider earns $15/hour (minimum wage) for 40 hours a week for a year. This is $31,200 a year. The difference between that and a 112-hour week ($87,360/year) is over $1000/week. Yet the maximum pay for the 112-hour week is still less than the State of Nebraska's Institutional cost calculation of $92,438. *("Institutional costs are based on the total State Fiscal Year (SFY) expenditures divided by the average number of recipients. In SFY2025, Nursing Facility costs were $92,438 per person.")*

In summary, In-home Personal Care providers will see their income reduced by ~64%

($56,160 out of $87,360 in this example). What happens next? Will some leave the state? Perhaps, but they risk losing Medicaid. Will some seek care from home health provider agencies? Perhaps, but the costs of these services will far exceed what DHHS currently pays in-home Personal Care providers. Will some seek placement in a nursing facility? Not likely – there are too few beds available, too few caregivers, greater costs for families, and overall lower quality of care (if required levels of care can be provided at all.) Community assistance programs or organizations – few and far between in many rural areas – are unlikely to be in a position to help with the dozens, hundreds, or thousands of new individuals who require help each and every day of the week.

All acknowledge that care in the home is better for the participant, his or her family, parents and/or guardians. These families are being put in a horrific position by the State of Nebraska and DHHS, being forced to choose between gaining external employment and caring for their family member. There are no good alternatives available for the thousands of disabled affected by this inane policy decision. What is likely to happen next is an increase in demand for SNAP, TANF, LIHEAP assistance programs. What will the State of Nebraska do with these new demands? So while it appears there may be some cost savings to the State from the AD waiver in-home provider reductions, in fact costs are likely to rise alongside the suffering in families with disabled family members.

It seems in this disastrous policy change for the AD Waiver, DHHS is undermining all the good done through the Governor's backing of 2024's *Nebraska DHHS HCBS Waiver Transformation Strategy*. The vision for this strategy concludes with the following:

"*Ultimately, the transformation is focused on delivering services that empower participants to live more independent, fulfilling lives in their own communities. This ongoing effort reflects a deep commitment to building a* ***future where all Nebraskans with DD have access to the right supports, at the right time, in the right way****.*

The end goal of this transformation is to establish a "Needs-Based, Participant-Driven Service Model," ***which prioritizes individual needs and preferences in service planning and delivery.*** *Under this model, every service plan will be rooted in interRAI assessment data,* ***ensuring individuals receive the right supports based on their unique circumstances****.* ***This approach moves away from a one-size-fits-all framework, fostering greater autonomy and choice for participants****.*

A quick review comparing the DHHS vision to this AD Waiver policy change is striking. First, this new DHHS policy reduces services and cuts provider hours – as opposed to "delivering services and empowering participants." - as many predicted with the desire to eliminate the DD Waitlist in Nebraska. AD Waiver participants are not being given the opportunity to voice, let alone "prioritize individual needs and preferences" in this decision to eliminate a potential pool of already approved and capable providers. "The right supports" for many AD Waiver participants is their in-home or parental provider. The State of Nebraska and DHHS in this action will act in opposition to this pledge. Finally, the overarching policy to reduce all hours by all in-home Personal Care providers is exactly and by definition a "one-size-fits-all framework."

In summary, any policy proposal that establishes limits foIr hours of in-home care Personal Care providers must be withdrawn. DHHS must translate their vision for DD

Waitlist elimination to the AD Waiver application. All that needs to be said regarding limitations is the following:

"Personal Care and LRI Personal Care limits are developed on a case-by-case basis to enable a balance between AD Waiver participant needs and AD Waiver Provider capabilities. *[Note: this is line with current policy.]*

No individual Personal Care provider may work more than 112 hours per week, and no AD Waiver participant receiving Personal Care can receive more than 168 hours per week. *[Note: this is line with current policy.]*

There is no limit to the number of independent caregivers AD Waiver participants may use as long as there is no overlap between caregivers (i.e., only one caregiver may bill at any one time.) *[Note: this is line with current policy.]*

These limitations apply to both live-in caregivers and any other independent caregivers. *[Note: this is line with current policy.]*

I am happy to discuss any of the above at a mutually convenient time with representatives of DHHS or others. Thank you.

Steven W. Libby

[redacted]
[redacted]
[redacted]

From: Carissa Haney
To: DHHS HCBS Public Comments
Subject: Public Comment on Disability Care
Date: Saturday, December 27, 2025 7:38:21 AM

You don't often get email from [redacted] Learn why this is important

Dear DHHS,

I am writing as a concerned member of the public and a nurse practitioner certified in public health. I urge you to stop the proposed caps on home and community-based service hours and the policies that would force people out of their homes and into institutional care.

These changes will not save money. They will cost the state far more.

Adults with severe disabilities who require constant one-on-one care cannot work and cannot live independently. Medicaid-funded home care is not optional for them—it is the only way they can safely live in the community. When adequate in-home care is available, these individuals remain stable, healthier, and out of costly institutions.

High-level care facilities and nursing homes routinely cost the state well over $150,000 per year per person, often much more. In contrast, family-provided in-home care costs a fraction of that amount. Families provide care at lower rates than agencies or institutions, without overhead costs such as buildings, administrative staff, or profit margins. The state saves money while the individual receives better care and quality of life.

Capping hours does not reduce the need for care. It only shifts the cost.

When in-home care hours are cut, families are pushed into crisis. Caregivers lose income and often become eligible for Medicaid, food assistance, and other state-funded programs themselves. Homes become less safe as families can no longer afford upkeep, equipment, or necessary modifications. Hospitalizations increase. Burnout increases. Eventually, many families have no choice but to turn to institutional placement—the most expensive option possible.

Forcing families to use agencies to access additional hours is also fiscally irresponsible. Agency care costs two to three times more per hour than family-provided care, and agencies are already unable to staff the needed hours. This policy increases spending while reducing continuity and quality of care, especially for individuals who cannot tolerate unfamiliar caregivers. Save agency hours for people who truly need agency hours.

Most importantly, these policies take away the only way of life that people with severe disabilities are supposed to be able to count on—the right to live in their homes, with their families, in their communities. These individuals cannot advocate for themselves. We have a responsibility to stand up for them.

I urge you to reject arbitrary caps and forced agency or out-of-home care. Preserve needs-based services. Protect both vulnerable individuals and taxpayer dollars by keeping people safely in their homes.

Please do not pass policies that will increase costs, increase harm, and violate the promise of

community-based care.

Respectfully,

Carissa Haney, DNP, MSN, APRN-BC, CPH
Nurse Practitioner

From: Brian Y
To: DHHS HCBS Public Comments
Subject: Public Comment on HCBS Waiver Changes – Importance of In-Home Chore Care
Date: Thursday, December 25, 2025 11:59:30 PM

You don't often get email from [redacted]. Learn why this is important

am writing to submit a public comment regarding the proposed changes to Nebraska's Home and Community-Based Services (HCBS) waivers. My name is Brian, and I live in Lincoln, Lancaster County, Nebraska. I am currently applying for the Nebraska Chore Care program for myself.

I am visually impaired and rely on assistance to complete essential daily activities. I also have a serious lung condition, pulmonary fibrosis, which significantly limits my mobility and makes it difficult for me to leave my apartment or perform certain physical tasks. Because of these limitations, in-home and community-based support is critical for me to live safely and independently.

Chore Care services would help me with essential tasks outside my home, such as getting groceries, picking up prescription medications, and retrieving my mail. I also need help inside my apartment with basic daily tasks like food preparation, laundry, and cleaning. Without this assistance, managing my health and daily living would become increasingly difficult.

If access to Chore Care or similar in-home services were reduced, restricted, or delayed, it would be much harder for me to continue living independently. I would struggle to obtain food and medications, which could negatively impact my health. If my situation worsened without adequate support, I would likely have no choice but to move into assisted living. I like where I live and strongly want to remain in my apartment for as long as possible.

I respectfully ask Nebraska DHHS to maintain strong funding and availability for in-home services such as Chore Care, avoid reductions in service hours or stricter eligibility requirements, and continue supporting policies that allow people with disabilities to remain in their homes and communities. In-home care is not only essential for quality of life, but it is also often more cost-effective than institutional care.

Many disability, aging, and health advocacy organizations have consistently emphasized that Home and Community-Based Services help prevent unnecessary institutionalization, reduce long-term Medicaid costs, and improve health outcomes. These principles apply directly to my situation and to many others across Nebraska who rely on HCBS supports to live independently.

As DHHS considers the future of these programs, I encourage the state to explore sustainable funding solutions rather than service reductions. Potential options could include prioritizing HCBS funding due to its cost savings compared to facility-based care, seeking additional federal matching funds or demonstration grants, reinvesting savings from reduced institutional placements back into HCBS programs, and continuing collaboration with advocacy organizations to identify efficiencies that do not reduce services. Protecting and strengthening in-home care programs benefits both individuals and the state as a whole.

Thank you for the opportunity to comment and for considering the real-world impact these decisions have on Nebraskans like me.

Sincerely,
Brian
Lincoln, Lancaster County, Nebraska

From: Kierstin Reed
To: DHHS HCBS Public Comments
Subject: Public Comment on HCBS Waiver Changes
Date: Friday, January 2, 2026 9:49:57 AM
Attachments: image001.png
Comments from LeadingAge Nebraska FINAL.pdf

You don't often get email from [redacted] why this is important

Comments from LeadingAge Nebraska are attached and listed below.

To: Nebraska Division of Developmental Disabilities
From: Kierstin Reed, Chief Executive Officer LeadingAge Nebraska
Re: Public Comment on Proposed Changes to the Aged and Disabled (AD) Waiver and Traumatic Brain Injury (TBI) Waiver
Date: January 2, 2026

LeadingAge Nebraska is a nonprofit association representing approximately eighty aging services providers across the state, including nursing homes, assisted living communities, and Home and Community-Based Services (HCBS) providers serving individuals through Nebraska's Medicaid waiver programs.

We appreciate the opportunity to comment on the proposed changes to the AD and TBI Waivers (Draft NE.018.08.00). While we understand the need to modernize waiver language and align services with current practices, several proposed changes will **reduce access to care, destabilize families, and increase Medicaid costs** by shifting individuals into more expensive institutional settings.

Terminology Updates – Appendix B-5 (Evaluation/Reevaluation of Level of Care):

The change from "assisted living" to "supported residential living" is understandable. However, the waiver must clearly state that supported residential living **may only be provided in a licensed Assisted Living facility**. While Title 175 is referenced throughout the waiver, the limitation of this service to a licensed setting is not explicit and creates risk of misinterpretation in service authorization and delivery.

Individual Cost Limit (Appendix B-2: Individual Cost Limit):

The waiver proposes a hard cap at **175% of the Institutional Cost Limit ($161,766)** and requires service reductions or referrals to institutional care when needs exceed this amount. Although DHHS has stated that approximately 95% of participants fall below this threshold, **no analysis has been provided regarding participants who exceed the cap** or the impact of this change on those individuals.

For participants with needs above 175%, this policy will **increase Medicaid spending**, not reduce it. These individuals typically have significant medical complexity and:

- Do not qualify for assisted living
- Require nursing facility placement
- Often cost **more in institutional settings** than they do under current waiver services

This cap replaces individualized, cost-effective decision-making with an arbitrary limit that will push a small number of high-need participants into **more expensive care settings**.

Requested Alternatives (Appendix B-2):

1. Set the limit at the **highest level currently utilized**.
2. Apply the 175% cap **prospectively to new applicants only**.
3. Allow for **individual exceptions** for high-need participants where home-based care remains the most cost-effective option.

Limits on Personal Care and LRI Personal Care (Appendix C: Participant Services):

The waiver proposes new combined limits:

- **40 hours/week** for live-in caregivers
- **70 hours/week** for non-live-in caregivers

Currently, LRI Personal Care allows up to **112 hours per week** for live-in caregivers. This proposal represents a **64% reduction** in caregiving support for families providing intensive, daily care. This change alone will increase the number of participants requiring a higher level of care because it devalues the services being provided by in-home caregivers and will prevent them from being able to continue this valuable service.

DHHS has acknowledged there is **no way to identify how many participants will be affected**, yet this change will have immediate and predictable consequences:

- Families will be unable to maintain care at home
- Caregivers will be forced into outside employment
- Participants will move into nursing facilities due to lack of support

LRI Personal Care is among the **most cost-effective services in the waiver**. Reducing access will not eliminate need—it will **shift costs to higher-priced institutional care**.

Requested Alternatives (Appendix C):

1. Maintain the current **112-hour weekly maximum** for Personal Care and LRI Personal Care.
2. Require **targeted review** when use exceeds **84 hours/week (75%) for three consecutive months**.
3. Allow families to provide Personal Care hours in place of Companion services, which are often less useful and more expensive when delivered by agencies.

Natural Supports Are Not a Viable Substitute:

(Appendix C – Service Definitions; Appendix D – Person-Centered Planning)

The waiver emphasizes reliance on "natural supports," and public statements have suggested families should rely on **other family members, churches, and neighbors**.

This is **not a viable or realistic policy expectation**.

Natural supports are **intermittent and voluntary**—such as help with errands or occasional meals. They are not a substitute for:

-

Daily assistance with bathing, toileting, eating, and dressing
- Constant supervision and redirection for safety
- Management of complex medical needs

Churches, neighbors, and extended family **cannot provide scheduled, daily, hands-on care**, nor can they replace the consistency required for individuals with significant disabilities. Expecting this level of support ignores:

- Workforce shortages already affecting HCBS providers
- Caregiver burnout and family financial instability
- The reality that many families have already exhausted informal support networks

Ongoing caregiving for individuals who are totally dependent is **not natural support**. It is skilled, continuous labor that fills a systemic gap in the service delivery system.

System-Wide Impact:

Workforce (Appendix C):

Nebraska does not have the workforce capacity to absorb the loss of paid family caregiving. Reducing these services removes care from the system—it does not replace it.

Placement Availability (Appendix B & C):

Medicaid nursing facility placements are increasingly difficult to secure due to closures and inadequate reimbursement. Many affected participants—especially those with complex medical needs or pediatric populations—will have **few or no placement options** in Nebraska.

Shifting Costs (Appendix B &C):

These changes shift costs, increase institutional reliance, and reduce access—without addressing underlying system constraints. Our nursing homes in Nebraska are closing at an alarming rate due to the inadequate reimbursement rates. Many of them also need to limit their capacity due to workforce shortages.

LeadingAge Nebraska urges DHHS to reconsider the proposed cost caps and service limits in the AD and TBI Waivers. These changes undermine family stability, increase institutional placements, and raise overall Medicaid costs—while relying on supports that do not exist at the scale required.

We support thoughtful modernization of the waiver. However, rigid caps and reduced caregiving hours are not aligned with Nebraska's workforce realities, provider capacity, or the stated goal of supporting individuals in their homes and communities.

We respectfully request DHHS modify these proposals to preserve flexibility, recognize the true role of family caregivers, and maintain access to cost-effective home-based care.

Kierstin Reed
CEO LeadingAge Nebraska
[redacted]

From:	David Tagart
To:	DHHS HCBS Public Comments
Cc:	Green, Tony; Clark, Jennifer J; Adam Tagart; Linda; Coralie Lang; Alana Schriver
Subject:	Public Comment on Proposed A&D Waiver Changes - ABLED
Date:	Monday, December 22, 2025 1:14:28 PM

Some people who received this message don't often get email from [redacted]. Learn why this is important

Dear DHHS Team,

I am writing to express my disappointment and significant concerns regarding the proposed changes to the Aged & Disabled (A&D) Waiver. ABLED has provided A&D Waiver services for six years, and the changes as outlined will have serious negative consequences for participants, providers, and continuity of care.

Background on Our Services

Our agency began by supporting an elderly woman with **high medical needs** who could be safely supported in a home-based environment. She lived with ABLED staff in a Shared-Living-style arrangement. When establishing her rate, we matched it to the DD Services Advanced Tier rate at that time, based on our assessment of her level of care. Over the years, our rate increased only through modest annual adjustments, and our current Personal Care (5761) rate is $44.59.

We now support four A&D Waiver participants, with **three in in-home arrangements** similar to Shared Living. Most have needs consistent with the Advanced Tier level under DD Services. As a result, even at $44.59, our current A&D Waiver rate structure is substantially lower than what would be provided for comparable needs through DD Services.

Key Concerns

1. Lack of recognition of differing levels of care

A&D Waiver participants have significantly different levels of need. The proposed rate structure does not acknowledge this variance, which is neither person-centered nor, in our view, compliant with federal person-centered planning requirements. High-needs individuals will be placed at immediate risk under a “one-size-fits-all” model.

2. Providers offer very different levels of support

ABLED is a Risk Tier provider, capable of delivering the highest level of staff and participant support in the state. Our team includes two Registered Nurses, an LIMHP, and nine additional professional administrative staff. Many providers do not offer this level of clinical capacity, and the proposed **rate** structure fails to reflect the meaningful differences in provider qualifications, staffing, and operational requirements.

3. Participants will lose their homes and stability

If rates are lowered, the staff supporting two of our current participants will be forced to give notice. As a result, these long-term A&D participants—who have lived in stable, supportive homes for years—will likely be displaced. Removing participants from their homes unnecessarily would be traumatic, disruptive, and entirely preventable.

4. Staffing model is inconsistent with Shared Living realities

Many A&D Waiver staff provide support in their own homes, often up to 168 hours per week. Without the ability to treat these arrangements as Shared Living subcontracting relationships, the overtime burden makes these arrangements financially unsustainable. A&D Waiver staff should be permitted to operate as Shared Living Providers and subcontractors, consistent with actual service delivery models.

Conclusion

For these reasons, I respectfully urge DHHS to reconsider the proposed A&D Waiver rate and structural changes. A rate model that does not account for level of care, provider capabilities, and real-world delivery realities will lead to participant displacement, staff turnover, and reduced quality of care. The individuals we support deserve stability, continuity, and person-centered services tailored to their needs.

Thank you for the opportunity to submit public comments. I would welcome further discussion and am available to provide case details or additional information upon request.

Sincerely,

David D. Tagart

CEO, ABLED, Inc.
Attorney At Law (NE Bar #21415)
JD, MBA, CPA Certificate #5616
7562 Upton Grey Lane, Lincoln, NE 68516
(402) 202-2284
tagart@abledinc.com

From: Lorene Kelly
To: DHHS HCBS Public Comments
Subject: Public Comment on Proposed A&D Waiver Changes
Date: Friday, January 2, 2026 2:44:14 PM

You don't often get email from [redacted]. Learn why this is important

My name is Lorene Kelly. I am a resident of Omaha and live-in caregiver to my 21-year-old daughter, Moira, who receives services through Nebraska's Aged and Disabled (A&D) Waiver.

I am submitting this comment to express serious concern regarding DHHS's proposed changes to the A&D waiver, including the financial cap, the 70-hour weekly limit on personal care services, and the proposed 40-hour cap on care provided by live-in or relative caregivers. These changes do not reflect person-centered care principles and would have significant negative consequences for individuals with complex medical needs.

My daughter is profoundly disabled, nonverbal, and medically fragile. She requires continuous supervision and complex medical care, including seizure response, respiratory support, oxygen, suctioning, and catheter care. She cannot be left alone at any time. My husband and I are her primary caregivers, and we do not have extended family nearby. Attempts to secure outside caregivers have been unsuccessful due to staffing shortages and the level of medical care required.

Moira currently receives up to 96 hours of personal care services per week. Under the proposed changes, her support would be reduced to no more than 70 hours—and in practice, likely 40 hours—out of the 168 hours per week she requires care. This reduction places her health and safety at serious risk and increases the likelihood of preventable hospitalizations or institutional placement. Providing care at home has repeatedly prevented prolonged ICU stays and avoided Medicaid expenditures that can quickly escalate into the tens or even hundreds of thousands of dollars.

I respectfully request that DHHS revise the proposed changes as follows:

- Grandfather current A&D waiver recipients at their existing support levels and personal care hours.

- Meaningfully involve A&D waiver stakeholders in policy development and planning.
- Implement truly person-centered budgets that allow individuals or guardians to determine how funds are best used.
- Eliminate the proposed 40-hour cap for live-in or relative caregivers.
- Allow multiple relative or live-in caregivers to each provide and be reimbursed for separate hours of care.

Maintaining individualized, home-based supports for people with complex disabilities is both humane and fiscally responsible. I urge DHHS to reconsider these proposed changes to ensure the A&D waiver continues to meet the needs of Nebraska's most vulnerable residents.

Thank you for the opportunity to submit this comment.

Sincerely,
Lorene Kelly

From: Morgan Cuttlers
To: DHHS HCBS Public Comments
Subject: Public comment on Proposed AD Wavier changes
Date: Monday, January 5, 2026 11:31:56 AM

You don't often get email from [redacted]. Learn why this is important

Hello,

I am an adult currently enrolled in Nebraska's Aged & Disabled (AD) Waiver program, and I was also supported by family caregivers as a child. I strongly disagree with the proposed reduction in claimable caregiver hours.

If these cuts force me into a nursing facility, I would stop actively seeking employment. Living in an institutional setting would remove my ability to manage my own schedule, participate in the community, and work toward independence. The resulting loss of autonomy would significantly impact my mental health and social engagement. Many of us on the AD Waiver want to eventually reduce our reliance on the system—not become permanently institutionalized because of policy changes.

Reducing or limiting caregiver hours will ultimately cost the state more in the long term. Nursing facility placement is far more expensive than home- and community-based care. These cuts also threaten caregiver jobs and could force home health agencies to close, leaving participants with fewer service options and further increasing the likelihood of institutional placement.

I am also deeply concerned about the proposed limits on hours paid to family caregivers. I have peers with immunocompromised conditions who, since COVID, cannot safely rely on caregivers outside their household. Family caregivers are not providing "part-time" support—this is a 24/7 responsibility. They deserve compensation that reflects the level of care provided, especially when it prevents costly nursing facility placement. No one is more knowledgeable or attentive to a participant's needs than a family member who has provided care from the beginning.

I strongly urge DHHS to reconsider the proposed caps on caregiver hours and to preserve flexibility for family caregiving and medically necessary exceptions. These changes risk harming participants, increasing state costs, and undermining the goals of community-based care.

Thank you for the opportunity to submit public comment.

Sincerely,
Morgan Cuttlers
AD Waiver Participant
Morgan Cuttlers

From: Faith, May
To: DHHS HCBS Public Comments
Subject: Public Comment on Proposed Aged & Disabled (A&D) Waiver Changes
Date: Monday, December 29, 2025 3:41:39 PM
Attachments: [redacted]

Good afternoon,

I appreciate the opportunity to provide public comment on the proposed changes to Nebraska's Aged & Disabled (A&D) Home and Community-Based Services Waiver. After reviewing the proposed updates and the impacts of the 2025 addendum, I would like to raise several concerns regarding person-centeredness, communication, cost assumptions, and level-of-care oversight.

1. Person-Centered Planning Concerns

The Waiver Description emphasizes that the A&D Waiver is based on a *person- or family-centered approach*. However, the 2025 addendum introduced changes that appear to move the waiver away from those core principles—most notably the shift to fixed dollar caps on certain services over a five-year period.

For individuals with fluctuating, progressive, or high-acuity needs, these caps limit the ability to access supports at the intensity and timing required to maintain independence and well-being. This approach is not aligned with longstanding person-centered planning standards, which rely on flexible, individualized service plans that adjust to changes in needs, goals, and preferences over time.

2. Public Awareness and Accessibility of Information

I am also concerned that these substantial changes were not clearly communicated to participants and families, particularly in rural areas. Many individuals have expressed that they were unaware of the implementation of service caps until after the changes had already taken effect.

3. Questions Regarding Annual NF-LOC Re-Evaluations

The waiver requires that Nursing Facility Level of Care (NF-LOC) re-evaluations be completed person-to-person, ideally in the participant's home. To support transparency and accountability, I respectfully request clarification on the following:

- What specific measures are being taken to ensure that annual NF-LOC re-evaluations are conducted person-to-person as required?
- How does the state verify that these re-evaluations were completed in person rather than remotely?
- What corrective actions occur when a person-to-person evaluation is missed or

completed incorrectly?

3. Questions Regarding Annual NF-LOC Re-Evaluations

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- What specific measures are being taken to ensure that annual NF-LOC re-evaluations are conducted person-to-person as required?
- How does the state verify that these re-evaluations were completed in person rather than remotely?
- What corrective actions occur when a person-to-person evaluation is missed or completed incorrectly?

5. Question Regarding the Reason for Implementing Service Caps

It appears that the most consequential change in the proposed waiver is the introduction of individual service caps. I request clarification on the underlying rationale:

- Is the implementation of service caps related to the requirement to pay overtime wages to direct care workers who provide more than 40 hours per week of care?
- If overtime costs have increased Medicaid administrative expenditures, is this influencing the decision to impose participant service caps—despite overtime not being part of a participant's individual budget?

Thank you for the opportunity to provide comment on these important issues. I appreciate the state's ongoing efforts to improve long-term services and supports and encourage continued dialogue to ensure that the waiver remains truly person-centered and responsive to the needs of Nebraskans.

May

May Faith
ATP Program Supervisor
Office: 500 S. 84th Street
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P: (531) 207-9028
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From:	Katie Novakoski
To:	DHHS HCBS Public Comments
Subject:	Public Comment on Proposed Amendments to Nebraska Aged and Disabled Waiver Nebraska
Date:	Saturday, January 3, 2026 1:20:51 PM

Dear Nebraska DHHS and CMS Reviewers,

I am submitting public comment regarding the proposed amendments to Nebraska's Aged and Disabled (AD) 1915(c) Waiver, specifically provisions that would cap personal care services at 40 hours per week for participants who require 24/7 support.

These proposed changes raise significant concerns regarding compliance with federal Medicaid law and HCBS requirements.

Under 42 CFR §441.301(c)(1), HCBS must be delivered through a person-centered planning process that is based on each individual's assessed needs, preferences, and goals. Service plans must reflect informed choice and may not be driven by programmatic or budgetary limits rather than individual need. A fixed cap on personal care hours fails to account for participants whose documented assessments demonstrate a need for continuous support and therefore conflicts with person-centered planning requirements.

Additionally, Medicaid HCBS waivers are authorized as alternatives to institutional care. When service limits render community-based care insufficient to meet health and safety needs, participants face increased risk of unnecessary institutional placement. CMS has consistently held that HCBS must be adequate to support participants in the most integrated setting appropriate, consistent with the Americans with Disabilities Act and the Olmstead decision.

While states may propose service limitations, CMS approval is contingent upon compliance with federal Medicaid law. Waiver provisions that effectively deny needed services based on arbitrary caps—rather than individualized assessments—are inconsistent with HCBS assurances required under 42 CFR §§441.302 and 441.303.

For these reasons, I respectfully urge DHHS and CMS to reconsider or reject provisions that impose rigid hourly caps on personal care services for individuals requiring 24/7 support and to ensure that the AD Waiver remains compliant with federal HCBS requirements and person-centered planning standards.

Thank you for the opportunity to comment.

Sincerely,
Katie Kuecker

From:	Jeanine Amaro
To:	DHHS HCBS Public Comments
Subject:	Public Comment on Proposed Changes to the Nebraska Aged and Disabled (AD) Waiver – Caregiver Hour Reductions
Date:	Wednesday, December 24, 2025 8:51:00 AM

You don't often get email from [redacted] Learn why this is important

To:
Nebraska Department of Health and Human Services
Division of Developmental Disabilities

From:
Jeanine Amaro
Omaha, Nebraska
Parent

Date:
12/24/25

Dear Nebraska Department of Health and Human Services Waiver Review Team,

I am writing during the public comment period to express serious concerns regarding the proposed changes to the **Nebraska Aged and Disabled (AD) Waiver**, specifically the proposal to reduce allowable paid caregiver hours from **up to 112 hours per week to 40 hours per week**.

This proposed reduction is not only unrealistic—it is **dangerous** for many individuals who rely on the AD Waiver to remain safely in their homes and communities.

Many AD Waiver participants require **round-the-clock supervision or hands-on assistance** due to medical fragility, cognitive impairment, behavioral needs, mobility limitations, or a combination of these factors. For these individuals, reducing paid caregiver support to 40 hours per week creates an immediate and significant risk of neglect, injury, medical crises, and caregiver burnout.

The assumption that the remaining hours can be filled by "informal supports" is deeply concerning and does not reflect the lived reality of many Nebraska families.

In practice:

- Many individuals **do not have extended family nearby**
- Many families **do not have relatives willing or able to provide unpaid care**
- Some caregivers are elderly, disabled themselves, or working full-time
- Others are already providing significant unpaid care beyond what is sustainable

Informal supports cannot simply be created where they do not exist. Expecting families to replace up to **72 hours per week of paid care with unpaid labor** places an unreasonable and inequitable burden on caregivers and ignores the realities of poverty, geography, workforce shortages, and caregiver health.

If these changes move forward, many families will be left with **no viable option other than placement in nursing facilities or other institutional settings**. This outcome directly contradicts the purpose of the AD Waiver, which is to support **community-based care** and prevent unnecessary institutionalization.

Institutional placement:
• Is often **less safe and less appropriate** for individuals with disabilities
• Results in **loss of autonomy, stability, and quality of life**
• Frequently leads to **worsening health outcomes**
• **Costs the State of Nebraska significantly more** than providing adequate home- and community-based services

Reducing caregiver hours may appear to be a cost-saving measure on paper, but in reality it is likely to **increase long-term Medicaid expenditures** through higher rates of institutionalization, emergency room use, and hospitalizations—while causing irreparable harm to individuals and families.

I strongly urge DHHS to:
• Reconsider any reduction in allowable caregiver hours
• Acknowledge that informal supports are not universally available
• Ensure that waiver participants with high and complex needs can continue to receive adequate paid support
• Evaluate the full fiscal and human cost of forcing individuals into institutional care

The AD Waiver should protect health, safety, and dignity—not place individuals at risk or force families into impossible decisions. I respectfully ask DHHS to revise the proposed changes to ensure that Nebraska's most vulnerable residents can continue to live safely in their homes and communities.

Thank you for the opportunity to provide public comment and for considering the very real consequences these changes may have for Nebraskans who depend on the AD Waiver.

Sincerely,
Jeanine Amaro
Omaha, Nebraska

From:	Danielle Carlson
To:	DHHS HCBS Public Comments
Subject:	Public Comment on Proposed Changes to the Nebraska Aged and Disabled (AD) Waiver – Caregiver Hour Reductions
Date:	Wednesday, December 31, 2025 5:00:39 PM

You don't often get email from [redacted]. Learn why this is important

To: Nebraska Department of Health and Human Services, Division of Developmental Disabilities

From: Danielle Carlson | Omaha, NE

Date: December 31, 2025

Dear Nebraska Department of Health and Human Services Waiver Review Team,

I am writing during the public comment period to express serious concerns regarding the proposed changes to the Nebraska Aged and Disabled (AD) Waiver, specifically the proposal to reduce allowable paid caregiver hours from up to 112 hours per week to 40 hours per week.

This proposed reduction is not only unrealistic, it is dangerous for many individuals who rely on the AD Waiver to remain safely in their homes and communities. Many AD Waiver participants require round-the-clock supervision or hands-on assistance due to medical fragility, cognitive impairment, behavioral needs, mobility limitations, or a combination of these factors. For these individuals, reducing paid caregiver support to 40 hours per week creates an immediate and significant risk of neglect, injury, medical crises, and caregiver burnout.

The assumption that the remaining hours can be filled by “informal supports” is deeply concerning and does not reflect the lived reality of many Nebraska families. In actuality, many individuals do not have extended family nearby; do not have relatives willing or able to provide unpaid care; caregivers are elderly, disabled themselves, or working full-time; or are already providing significant unpaid care beyond what is sustainable.

Informal supports cannot simply be created where they do not exist. Expecting families to replace up to 72 hours per week of paid care with unpaid labor places an unreasonable and inequitable burden on caregivers and ignores the realities of poverty, geography, workforce shortages, and caregiver health.

If these changes move forward, many families will be left with no viable option other than placement in nursing facilities or other institutional settings. This outcome directly contradicts the purpose of the AD Waiver, which is to support community-based care and prevent unnecessary institutionalization.

Institutional placement is often less safe and less appropriate for individuals with disabilities; results in loss of autonomy, stability, and quality of life; frequently leads to worsening health outcomes; and costs the State of Nebraska significantly more than providing adequate home- and community-based services.

Reducing caregiver hours may appear to be a cost-saving measure on paper, but in reality it is likely to increase long-term Medicaid expenditures through higher rates of institutionalization, emergency room use, and hospitalizations—while causing irreparable harm to individuals and families.

I strongly urge DHHS to:

- Reconsider any reduction in allowable caregiver hours
- Acknowledge that informal supports are not universally available
- Ensure that waiver participants with high and complex needs can continue to receive adequate paid support
- Evaluate the full fiscal and human cost of forcing individuals into institutional care

The AD Waiver should protect health, safety, and dignity, NOT place individuals at risk or force families into impossible decisions. I respectfully ask DHHS to revise the proposed changes to ensure that Nebraska’s most vulnerable residents can continue to live safely in their homes and communities.

Thank you for the opportunity to provide public comment and for considering the very real consequences these changes may have for Nebraskans who depend on the AD Waiver.

Sincerely,

Danielle Carlson

Omaha, NE

From: Peggy Reisher
To: DHHS HCBS Public Comments
Subject: Public Comment on Proposed Changes to the Nebraska Aged and Disabled Waiver and Brain Injury Waiver
Date: Sunday, December 21, 2025 5:11:01 PM

You don't often get email from [redacted]. Learn why this is important

The Brain Injury Association of Nebraska strongly opposes the proposed changes to the Medicaid Aged and Disabled Waiver and the Brain Injury Waiver that would cap community-based services and significantly restrict the use of paid family caregiving.

These changes will have a devastating impact on individuals living with brain injury and their families across Nebraska. Brain injury is a lifelong condition that often requires intensive, highly individualized supports to maintain health, safety, and stability in the community. Many individuals with brain injury rely on family members as paid caregivers—not by choice, but because consistent, trusted support is essential and the workforce shortage leaves few viable alternatives.

Restricting the amount of paid family support and imposing rigid spending caps ignores the realities of brain injury and undermines the purpose of these waivers: to prevent unnecessary institutionalization and support people in living safely in their homes and communities.

The proposed thresholds—triggering a high utilization review at 150% of nursing facility costs and capping services at 175%—create a clear pathway toward forced institutionalization. For individuals whose needs cannot be met within these artificial limits, the "choice" becomes no choice at all. Being referred to a nursing facility because community supports are capped is not person-centered, trauma-informed, or consistent with Nebraska's commitment to community integration.

Approximately 8,300 Nebraskans rely on the Aged and Disabled Waiver. Many of these individuals are living with brain injury, often invisible, complex, and poorly understood. These proposed changes would disproportionately harm them by disrupting stable caregiving arrangements, increasing caregiver burnout, and placing individuals at greater risk of hospitalization or institutional placement.

We urge the Nebraska Department of Health and Human Services to pause this proposal, engage transparently with the disability community, and fully assess the impact on individuals with disabilities and their families. Any changes to these waivers must prioritize health, safety, self-determination, and the ability to remain in the community—not cost containment at the expense of human dignity.

The Brain Injury Association of Nebraska strongly urges the Division to withdraw these proposed changes and work collaboratively with stakeholders to develop solutions that truly support Nebraskans with disabilities.

Peggy Reisher, MSW | **Executive Director**
Brain Injury Association of Nebraska
Board Member, Brain Injury Association of America
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destroy all copies of the original message.

From: Holly Steidlmayer
To: info@arc-nebraska.org; DHHS HCBS Public Comments
Subject: Public Comment on Proposed Nebraska HCBS Waiver Policy Changes
Date: Monday, January 5, 2026 7:46:27 PM

You don't often get email from [redacted]. Learn why this is important

Thank you for the opportunity to comment on proposed changes. I am a parent and guardian of a participant on the AD Waiver whose needs are currently being met at current levels and whose needs have increased in the last two years, and will be harmed by a reduction in services.

42 CFR Compliance and Health & Welfare Concerns

I am writing to object to the proposed changes identified in the application.

Nebraska has broad discretion to design its Medicaid Home and Community-Based Services (HCBS) waivers; however, that discretion is bounded by federal statute and regulation. Under **42 CFR Part 441**, waiver services must be person-centered, needs-based, voluntary with respect to natural supports, and must continuously assure participant health and welfare. The proposed policy changes conflict with these requirements and create foreseeable and preventable risks to waiver participants.

Federal Assurances and State Obligations

When submitting waiver applications, Nebraska must provide CMS with assurances that it will comply with all applicable HCBS requirements, including protection of participant health and welfare (**42 CFR §441.302(a)**) and provision of services consistent with an individual's assessed needs (**42 CFR §441.302(b)**).

Federal regulations do not permit states to assume the availability of unpaid or informal caregivers to meet unmet service needs. Any policy that relies on assumed unpaid care as a condition of remaining safely in the community undermines the state's required assurances to CMS.

Person-Centered Planning Requirements

(42 CFR §441.301(c))

HCBS waivers must be implemented through a **person-centered service planning process** that is driven by the individual's assessed needs and preferences—not by cost controls or uniform service caps (**42 CFR §441.301(c)(1)**).

The person-centered service plan must:

- Reflect services and supports (paid and unpaid) that are **voluntarily** chosen by the individual (**§441.301(c)(1)(vi)**);
- Be based on a **comprehensive assessment of functional need** (**§441.301(c)(2)**);
- Include services necessary to ensure health and welfare (**§441.301(c)(4)**).

Natural or informal supports may be identified in the planning process, but they must not be **imposed** on the participant or their caregivers. Treating family members as default or required caregivers violates the voluntary nature of unpaid supports embedded in the person-centered framework.

Hard caps that override individualized service plans convert a needs-based program into a budget-based one, contrary to **§441.301(c)**.

Voluntariness of Natural Supports and Prohibition on Exploitation

Federal HCBS regulations contemplate natural supports only as voluntary contributions chosen by the participant and their family (**§441.301(c)(1)(vi)**). Caregivers retain the right to decline unpaid care and to determine when and how they provide assistance.

Policies that shift state responsibility onto families without consent effectively coerce unpaid labor and exploit family relationships for cost savings. This violates the intent and structure of HCBS regulations, which are designed to support—not replace—necessary paid services.

Discriminatory Impact on Individuals With Higher Needs

The proposed service caps disproportionately impact individuals with higher or more complex medical, physical, or cognitive needs, in violation of the requirement that services be tailored to individual levels of need (**§441.301(c)(2)**).

Individuals requiring continuous supervision cannot meaningfully separate care into “hands-on” and “hands-off” time. As a result, they receive fewer authorized hours than individuals with lower needs who can segment care tasks more easily. This creates a discriminatory outcome inconsistent with individualized assessment and planning requirements under **§441.301(c)**.

Informal Supports and Inequitable Outcomes

There is an inverse relationship between need level and availability of informal supports. Individuals with fewer needs are more likely to have voluntary assistance from friends or family, while those with higher needs often do not.

Reliance on informal supports as a substitute for authorized services therefore systematically disadvantages individuals with higher needs and undermines equitable access to HCBS, contrary to the individualized service delivery model required by **§441.301**.

Nursing-Level Care and Institutional Bias

(42 CFR §441.302)

Participants in the Aged and Disabled Waiver qualify because they meet nursing facility level-of-care criteria, not because they need simple supervision or "babysitting". If adequate services are not authorized in the community, the state is obligated to provide institutional care. We asked for lists of nursing facilities that have contracts with the state, actual availability, and staffing in December and are still waiting for those to materialize. They appear to be theoretical not functional, on paper only.

Policies that cap services below what is necessary to meet assessed needs increase the risk of institutionalization, directly conflicting with the purpose of HCBS waivers and the state’s assurance that waiver services are sufficient to maintain individuals safely in the community

(**§441.302(a)**).

Lack of Evidence and Failure of Safeguards

(42 CFR §441.301(c)(4))

States must implement safeguards to protect the health and welfare of waiver participants (**§441.301(c)(4)**). Nebraska has provided no peer-reviewed or empirical evidence demonstrating that the proposed caps will not jeopardize participant health and safety.

Unproven policy changes that knowingly create service gaps constitute an experiment on vulnerable populations. An experiment is not evidence-based policy and does not satisfy federal safeguard requirements.

Continuous Health and Welfare Assurance Failures

Federal regulations require that the state assure participant health and welfare **at all times**, not only during authorized service hours (**§441.302(a)**).

If a participant cannot be left alone, authorizing only 40 hours of service in a 168-hour week leaves 128 hours without assured coverage. This is not a minor service gap—it is a systemic health and welfare failure.

Reliance on assumed, unpaid, or unvetted informal supports—such as neighbors or friends who are not trained or background-checked—cannot satisfy the state's health and welfare assurance obligations under **§441.301(c)(4)** and **§441.302(a)**.

Issues Requiring CMS Review and Clarification

CMS should require Nebraska to address the following prior to approval:

1. How does Nebraska demonstrate compliance with **§441.301(c)** when hard caps override individualized person-centered service plans?
2. What evidence supports the claim that proposed caps meet health and welfare safeguards under **§441.301(c)(4)**?
3. How does Nebraska assure continuous health and welfare under **§441.302(a)** when service authorization ends before needs are met?
4. How are individuals with higher or 24-hour care needs protected from disproportionate harm?
5. How does the state reconcile a 40-hour personal care cap with its assurance that services are sufficient to prevent institutionalization (**§441.302**)?
6. Does the state's responsibility for a participant's health and welfare stop when the 40 hours of authorized service ends?

Actions:

1. Remove the hard cap of 40 hours for personal care. For complex individuals, whose hands on tasks are intertwined with hands off time, and cannot be separated, move the 30 companion care hours to personal care, with

participant freedom to choose a provider or providers.

2. Add assurances that the state will follow federal regulations with regard to the voluntary nature of informal/natural supports. Informal/ natural supports can choose how much support to provide.

3. In SFY 2025 Annual reports it indicated that these services are tailored to multiple levels of beneficiaries needs. Prove how a 40 hour blanket cap doesn't conflict with this?

4. Provide written (actual not theoretical alternatives), naming nursing facilities that have contracts with the state and other resources that are vaguely referred to in the application so that participants can have an informed choice.

5. Document and recognize the inverse relationship with availability of caregivers and the complex level of needs of the individual. All is not equal.

Conclusion

The proposed waiver changes are inconsistent with **42 CFR Part 441**. They undermine person-centered planning, rely on involuntary unpaid family labor, discriminate against individuals with higher needs, and fail to assure continuous health and welfare. CMS should not approve a waiver application that replaces individualized need with arbitrary caps and shift the state's responsibility onto families in violation of federal HCBS requirements.

Thank you,

Holly Steidlmayer

parent and guardian of an over 18 age participant

From: Dorothy Ackland
To: DHHS HCBS Public Comments
Subject: Public comment on the behalf of a friend
Date: Friday, December 19, 2025 9:47:41 PM

You don't often get email from [redacted] Learn why this is important

Public Comment on Waiver Structure and Access to Habilitative Supports

I am submitting this comment to express serious concern about how the current Aged and Disabled (AD) Waiver limits access to habilitative and community support services. Although the waiver provides important daily living assistance, it leaves people vulnerable by excluding the supports they need to build and maintain adaptive skills, independence, and participation in their communities.

Age should never determine who can receive habilitative services. Learning and personal growth are lifelong processes. Adults and older individuals with disabilities continue to benefit from structured supports that help them live more independently, communicate effectively, and manage their daily environments. Denying those opportunities based solely on age or waiver category contradicts the principles of person-centered planning and community inclusion outlined in federal Home and Community-Based Services (HCBS) guidance.

Moreover, people should not be forced to choose between habilitative supports and medical or daily living assistance. These needs are interconnected—one sustains life, while the other sustains quality of life. Requiring an individual to pick one over the other is like saying you can have either air to breathe or food to eat, but not both. Every person deserves comprehensive, coordinated supports that address the full scope of their disability-related needs.

I urge decision-makers to revisit the waiver design to allow individuals to access habilitative, adaptive, and community-based learning supports regardless of age or medical condition. True equity and inclusion demand that we recognize all people’s capacity for growth and self-determination.

From: Katherine Rall
To: DHHS HCBS Public Comments
Subject: Public Comment on the proposed changes to HCBS Waiver
Date: Monday, December 29, 2025 8:56:59 AM

You don't often get email from [redacted] Learn why this is important

To the Division of Developmental Disabilites:

I am submitting this public comment to raise serious concerns regarding Nebraska's administration of its Medicaid Home and Community-Based Services (HCBS) Aged & Disabled (A&D) Waiver, specifically the enforcement of a rigid 40-hour weekly service cap.

This cap has the practical and foreseeable effect of forcing individuals with disabilities—many of whom meet nursing facility level of care—out of their homes and into institutional settings. This outcome directly conflicts with the requirements set forth in Olmstead v. L.C., 527 U.S. 581 (1999), and undermines the fundamental purpose of the HCBS waiver program.

Under Olmstead, states are required to provide services in the most integrated setting appropriate when:

1. Community-based services are appropriate to the individual's needs,
2. The individual does not oppose community placement, and
3. Community placement can be reasonably accommodated.

Nebraska's 40-hour cap fails this standard. It is not based on individual need, medical necessity, or person-centered planning. Instead, it functions as a systemic barrier to community living and creates a direct pipeline to institutionalization solely due to service limits, not clinical appropriateness.

The fiscal justification for this cap is also unsupported by data.

The average annual cost of a nursing home placement in Nebraska last year was approximately $92,000 per individual, excluding additional costs related to hospitalizations, emergency room use, behavioral crisis interventions, and increased state liability.

By contrast, community-based care under the A&D Waiver is reimbursed to providers at $32.15 per hour.

At a 70-hour per week cap, the annual Medicaid billable cost would be:

- $32.15 × 70 hours × 52 weeks = approximately $117,026 per year.

Once the well-documented costs of hospitalizations, emergency room utilization, behavioral crises, and increased state liability are included, institutional placement

routinely exceeds the cost of a 70-hour-per-week community-based care model while delivering worse health and safety outcomes.

Even at significantly higher service levels:

- 112 hours per week equals approximately $187,000 annually
- Importantly, Medicaid reimbursement does not increase for overtime
- Agencies are responsible for staffing costs and overtime obligations, meaning the state's financial exposure remains capped at the hourly rate

Institutional placement, by contrast, transfers full financial, operational, and legal risk to the state.

Publicly stated figures indicate that approximately 10,000 individuals are currently enrolled in Nebraska's Aged & Disabled Waiver, with 8,156 living at home with their families. Nebraska has only approximately 13,000–14,000 Medicaid-certified nursing facility beds statewide.

If families are forced into institutional placement due to waiver caps, Nebraska lacks both the physical capacity and the workforce to absorb this population. No funding mechanism has been identified to build, staff, or operate the additional nursing facilities that would be required.

Moreover, nursing homes are not clinically appropriate or safe settings for many individuals currently served under the A&D Waiver, including those with complex behavioral needs, developmental disabilities, or medical fragility requiring consistent one-to-one supports. Nebraska's own history— to include the challenges associated with the Beatrice State Developmental Center—demonstrates the risks of relying on congregate care for populations it is not designed to serve.

Families who have maintained loved ones at home have saved the state millions of dollars by avoiding institutional placements, reducing hospital utilization, and preventing the abuse, neglect, and litigation risks that frequently accompany congregate settings. Arbitrary service caps penalize these families and dismantle stable, cost-effective care arrangements that align with federal HCBS policy.

CMS oversight is urgently needed to evaluate whether Nebraska's Aged & Disabled Waiver, as currently implemented, complies with Olmstead and HCBS Final Rule requirements. A waiver that systematically forces institutionalization due to inflexible hour caps cannot be considered a true home- and community-based alternative.

I respectfully urge CMS to review Nebraska's waiver administration, require person-centered, needs-based service determinations, and ensure that individuals with disabilities are not unnecessarily segregated due to administrative limits that prioritize cost containment over civil rights, safety, and federal law.

Thank you for the opportunity to submit this comment.

Sincerly,
Katie Rall

From: Sandra Miller
To: DHHS HCBS Public Comments
Subject: Public Comment on the Proposed Waiver Budget
Date: Thursday, December 18, 2025 2:05:56 PM
Attachments: Outlook-foo2tsil.png

> You don't often get email from [redacted]. Learn why this is important

I wanted to voice my concern with the new budget as it pertains to the elderly in our community. I attended the first three open forums, but the main topic was the 40-hour limit that is going to be placed on family caregivers. This is going to be devastating to so many families, but the changes are also going to affect our seniors. Currently we care for seniors that have little to no support in their home and reducing their hours is going to make an impact on their quality of care. Our senior population is only going to grow each year, and I feel we are poorly prepared to meet their needs. I understand the importance of maintaining a budget, but I believe there are better ways to address the issue. '

I feel many people that will be affected voted for the current administration, both local and federal, and I hope they are looking at how that vote is now impacting their very lives.

Warm Regards,

Sandra Miller, BSW MBA
712.310.3496
https://trustedlifechoicesllc.com/personal-care/

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Public Comment on The Renewal of the Aged & Disable Waiver and the TBI Waiver

Submitted by Lorie Regier, parent of Adrian Regier

I am deeply concerned about the Renewal of the Aged & Disabled and the TBI Waiver.

1. DHHS released notice in December with very little time for public comment, being a very busy time of year. Please extend the public comment period so that families have time to understand the changes and make appropriate public comments.
2. DHHS did NOT notify the Olmestead Committee nor the Governor's Advisory Committee before public comment. Families and advocates were caught off guard with SIGNIFICAN changes. This is deeply concerning about the transparency with families, and recipients of the A&D and TBI waivers. Please ensure that this never happens again, and DHHS notifies the Olmstead Committee and the Advisory Committee ahead of releasing the renewal/public comment time period.
3. These changes are so drastic that individuals may not be able to remain in their own homes. Living in their own homes is essential to their health, safety and happiness. Nebraska does not have sufficient facility-based options for those who could be displaced by these drastic reductions in home-based services. Please make changes to the financial caps and the hours per week a live in caregiver can be paid for giving care.
4. The caps placed on personal care hours conflict with person-centered planning and do not consider the individuals unique needs. This is a serious issue for the individual's safety and health. Please reconsider all of the caps and find another way to contain costs.
5. The cost caps tied to nursing home costs are not realistic, as they are only an average of what the State currently pays. The high need individuals are NOT reflected in these caps.
6. The caps on hours a live in family member can be paid for giving care are totally unrealistic. Our loved ones who have 24-hour care needs will continue to need care for 24 hours. A nursing home will not be able to provide that. Nursing homes won't even accept most of the high-need individuals. Our loved ones are the healthiest and happiest in their own homes and reducing the current 112-hour limit to 40 hours per week is destructive to their lives. Not only that, if the State wants to spend less, then leave individuals at home where the costs are FAR less than in any institution. If my son would need to be in a facility for his care, he would die in a few weeks. He was in a facility for a few months, and the staff did not feed him regularly, did not take him to scheduled activities, and left him in his room by himself with no one to be with or to listen to. He is legally blind, quadriplegic, and cannot speak…HOW IN THE WORLD WOULD I EVER CONSIDER A NURSING HOME OR FACILITY FOR HIS care??????

   This proposal plans to have neighbors and non-live in people care for folks over the proposed 40 hour work week, but that is not realistic at all. If it were, there would not be a shortage of caregivers, which there are. It is unrealistic to believe that other people will start to give care, because care is difficult and constant. We have never worked a "typical work week" because that is not possible. It is totally unfair and morally wrong to be willing to pay live in care givers 40 hours per week and expect them to provide the necessary 24 hour care without pay. Since the State is willing to pay up to 70 hours per week (which is still not enough for many) at the minimum, allow live in caregivers to provide care for whatever the person needs.
7. There is no clear process for high-utilization reviews. This raises the question of fairness. For example, combining waiver costs with "Medicaid state plan services" is ambiguous. This needs to be clarified so that families understand what process is available to them. Please define high-utilization and clinical process review processes, including qualifications, timelines, and criteria.

8. The clinical review is undefined also. Who is qualified to complete the review? Are proper care-givers and family members included so that the needs are clearly stated and considered?
9. The proposed 175% cost limit fundamentally changes the waivers' purpose-from serving ALL individuals who meet the nursing home level of care to exclude those with the highest needs. Institutional care is NOT an acceptable substitute for living at home and undermines Nebraska's obligations under the Olmstead decision.
10. While EVV is a federal requirement, Nebraska is the ONLY state that requires 100% compliance with out the ability to manually make corrections. Even when the error is technology or weather related, and not an error on the providers' part, the amount of time it takes to request from DHHS a correction that they approve of is out of line. DHHS has purposely made this process difficult so that care givers don't request corrections. This also is morally wrong. I would ask that the 100% compliance be reduced to a reasonable percentage, more in the range of 75% which is what other states require.

I am a member of the Olmstead Committee and the Governor's DD Advisory Committee. I have attended the presentations concerning these changes and have heard many voices raising the same concerns. I appreciate the time you have taken to read my comments and greatly appreciate consideration of the suggestions I have made. If you would like more information, please contact Lorie Regier, at lorieregier@gmail.com.

From: Holly Wedemeyer
To: DHHS HCBS Public Comments
Subject: Public Comment Opposing Caregiver Hour Cuts
Date: Saturday, December 27, 2025 7:54:23 PM

You don't often get email from [redacted]. Learn why this is important

To Whom It May Concern:

I am writing to oppose the proposed changes to Nebraska's Aged & Disabled (AD) Waiver that would sharply reduce paid caregiver hours. As a member of the public, I am against cutting caregiver hours for disabled and elderly Nebraskans and for individuals with traumatic brain injuries, because these reductions will make it harder for people to remain safely in their homes and communities.

Pushing people into nursing facilities will likely be more costly for the state and less healthy for the individuals affected. Home- and community-based services are specifically designed to help people who meet a nursing facility level of care stay at home, and research shows that these services can be more cost-effective than institutional care while maintaining or improving outcomes. (HHS/ASPE report on home- and community-based long-term care)

My family has personal experience with how important these caregiver hours are. My sister-in-law has multiple disabilities and qualifies for caregiver support through Medicaid. She is successfully being cared for by family members at home, where she is loved, understood, and surrounded by people who know her needs and routines. I cannot imagine her being forced to leave her home; it would break her heart and almost certainly worsen her physical and mental health.

The stress of having her live elsewhere would also tear my brother-in-law apart. He is deeply committed to her care, and the current level of in-home support is what makes their arrangement sustainable. Reducing caregiver hours to the proposed level would push families like mine toward impossible choices: unsafe gaps in care, financial collapse, or institutional placement that nobody wants.

For these reasons, I urge DHHS to reject the proposed reduction in caregiver hours and to maintain or strengthen home- and community-based services under the Aged & Disabled Waiver. Protecting these services respects the dignity and wishes of disabled people, older adults, and people with traumatic brain injuries while also making better use of limited Medicaid dollars.

Thank you for considering my comments.

Sincerely,
Holly Wedemeyer
[redacted]

From: Katie Novakoski
To: DHHS HCBS Public Comments
Subject: Public comment opposing the proposal changes to the AD wavier
Date: Wednesday, December 31, 2025 5:01:59 PM

You don't often get email from [redacted] Learn why this is important

Dear Department of Health and Human Services,

I am writing to formally express my opposition to the proposed changes on the AD wavier to Personal Care Service hour caps and to request clarification on several aspects of these proposals that raise serious concerns.

My adult daughter, who has significant disabilities, is served under the AD Waiver. Until these proposed changes, our experience with the waiver has been overwhelmingly positive. The services provided have allowed my daughter to live in our home with dignity and respect, while receiving consistent, reliable care from those she trusts most—her parents.

My daughter requires assistance in every area of her life, all day, every day. She prefers care from her father and me, which is essential given the level of trust involved in her daily care. She depends on us to safely transfer her without injury, to prepare and provide meals when she is hungry, to administer medications accurately and on time, and to ensure her overall safety and well-being. This level of care is built on familiarity, consistency, and trust that cannot easily be replaced.

Even with personal care services, we already provide substantial informal, unpaid care—approximately eight hours per day. The proposed caps would further reduce critical support and place our daughter at risk by limiting care hours or requiring unfamiliar caregivers, creating unsafe and unsupported environments for individuals with severe disabilities.

Capping live-in caregivers at 40 hours of personal care services does not align with the realities of caring for individuals who require continuous support. Reducing compensated hours does not reduce care needs; it shifts responsibility onto unpaid caregivers and increases the likelihood of caregiver burnout and gaps in care.

In light of this proposal, I respectfully ask:

- How was the 40-hour cap for live-in caregivers determined, and what data or analysis supports the conclusion that this amount meets the needs of individuals requiring live-in care?
- Why are any hours granted as exceptions to the 40-hour cap required to be provided by non–live-in caregivers, rather than allowing continuity of care from those already meeting the individual's needs?

Additionally, the proposed 70-hour cap for the most vulnerable and highest-need individuals is deeply concerning. Individuals with complex medical and functional needs often require care far beyond this limit. Rigid caps fail to account for wide variations in need and undermine the core purpose of the waiver: preventing institutionalization and supporting individuals in their homes and communities.

Placing the most severely disabled individuals—those identified as the 5% high-utilization population—into the same tier system as individuals with more minor needs further compounds these concerns. Equity in care requires proportional support, not uniform limits that disregard severity and complexity of need.

I also respectfully ask:

- What alternative cost-saving measures have been considered that do not involve reducing direct care hours for individuals with the highest needs?
- Has DHHS considered adjusting, reducing, or eliminating LRI for minors, given that minors typically have additional natural supports and that parents are legally responsible for their care—unlike disabled adults on the AD Waiver who rely on these services for safety, stability, and independence?

These proposed changes place vulnerable individuals at risk and may ultimately increase costs through higher rates of hospitalization or institutional placement. I strongly urge DHHS to reconsider these proposals and to pursue alternative cost-containment strategies that do not compromise the safety, dignity, and well-being of people with severe disabilities.

Thank you for your time and consideration. I urge you to listen to the voices of families and caregivers who live these realities every day.

Sincerely,
Katie Kuecker

From: Holly Steidlmayer
To: info@arc-nebraska.org; DHHS HCBS Public Comments
Subject: Public comment question
Date: Monday, January 5, 2026 7:58:30 PM

You don't often get email from [redacted]. Learn why this is important

With regard to the institutional average given as $92, 438 does that account for and/ or include the 81 residents (census at end of 2024) of the Beatrice State Developmental Center whose cost is listed as $385,655 per person?

The number $385,655 was taken from the Division of Developmental Disabilities Fiscal Year 2024 Annual report, page 16.

Thank you

Holly Steidlmayer

From: Rachel H
To: DHHS HCBS Public Comments
Subject: Public Comment RE: Proposed amendments to A&D and TBI waivers
Date: Monday, January 5, 2026 8:22:48 PM

You don't often get email from [redacted] Learn why this is important

January 05, 2026

Dear all concerned,

I'm writing as a concerned constituent (tax-payer), disability advocate, and extended family member of a TBI waiver participant to formally express my strong opposition to the proposed amendments to the Aged and Disabled (A&D) and Traumatic Brain Injury (TBI) waivers, specifically the introduction of utilization thresholds and spending caps. The proposal to initiate a "high utilization review" at $138,657 and impose a hard spending cap of $161,766.50—175% of "regular" nursing facility costs—poses a serious threat to the independence, safety, and well-being of Nebraskans with disabilities who rely on home- and community-based services. I apologize in advance for the hasty preparation of this response. I don't feel that a one month period of time, when such drastic proposals have been made (especially over the holidays) is really adequate. It isn't fair to the citizen taxpayer or to waiver participants.

This policy represents an **appalling** step backward for Nebraska for several reasons:

• It forces institutionalization. By capping home-based care at a percentage of **regular** nursing facility costs, the state is effectively forcing individuals with complex needs into institutional settings when their care "costs too much" to provide at home. For many of these individuals, there is no appropriate or available skilled nursing facility capable of meeting their needs.

- Additional points, regarding the "hard cap" :
  - I have a Bachelor's degree in Business Administration. It appears there has been no *legitimate* cost-benefit analysis conducted **at all**. I have *never* seen or heard of a proposal to save money that did NOT obtain appropriate estimates for the most accurate financial assessments (required to make the best financial decisions possible). Without even the proper planning/anticipation of where participants will go if forced to be institutionalized, how is **any** planning or financial assessment even possible? It was mentioned at one of the Zoom meetings that "a nursing home" was contacted to obtain the monetary figure. WHICH nursing home? I'll give credit that it *was* caveated that the figure presented was for "regular" nursing home care. But that's also deeply embarrassing and insulting that not even a ballpark figure was obtained for skilled nursing. Ideally, when making a proposal you would attempt to obtain a good-faith, ballpark figure for plans requiring the most complex medical care for participant safety. It appears that *no* information regarding the costs that are applicable for medically complex participants was obtained.
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and apply that same monetary figure to the exponentially higher cost of a skilled nursing facility (which is required for **basic safety** of waiver participants that have complex medical needs. This alone should nullify any proposals that have been made as it shows an inability to logically foresee the exponentially higher cost to taxpayers when individuals with complex medical needs will be forced into (Hospitals? Skilled nursing facilities? Who knows—it appears that they (the nursing homes and skilled nursing homes **in Nebraska**) were not contacted to obtain estimates because once contacted, they relayed that they were not informed, contacted, and no information was requested of them regarding these proposals- they were shockingly unaware these proposals had been made)

• It unfairly penalizes family caregivers. Families who have worked tirelessly to support their loved ones in their homes and communities are now being told that home is no longer a viable option due to arbitrary financial limits rather than clinical need.

- Additional points of consideration regarding unfair penalization of family caregivers:
  - **Safety of waiver participants is highest priority of family caregivers**. Not only does Nebraska lack “regular” nursing homes and skilled nursing facilities, the aforementioned facilities often experience high turn-over and due to the nature of their jobs (multiple patients, different patient assignments for different shifts, etc.) employees logically are not able to develop the type of relationship required to communicate (non-verbally, minimally verbal, etc.) with participants that have complex medical needs and may be non-verbal or minimally verbal . Example of participant-centered benefit of home care: my nephew with a severe TBI experiences aphasia. My sister and his regular caregivers can understand him when he is able to try to speak, and his body language when he is unable to speak. They know how to obtain information (directly from him) that affects his well-being (such as when he is in pain, where the pain is located, etc.) Logically, this is a safety aspect.
  - Quality of life **should** be a consideration. My nephew (and many, if not all other waiver participants) experience higher quality of life when they are surrounded by people that truly love and care about them. Example: When my nephew was approved for home-based care he made progress with his TBI (such as: ability to hold his head up, ability to improve communication, ability to eat by being fed rather than solely through a G-tube, home caregivers provide opportunities to work on standing, assisted walking, improving talking—all which add to his quality of life and diminish negative aspects of things like being totally bedridden and incurring pressure sores). **Cost benefit** associated with this type of home care: With home-based care, my nephew does not experience bed sores, infections such as MRSA, VMR, C-Diff—all of which he had when he was in nursing facilities. All of the aforementioned infections and complications that are associated with inpatient care also increase costs of care.

• Lack of basic planning: if family caregivers are no longer able to care for waiver participants in their own homes, **where will waiver participants go?** I was only able to attend one of the few Zoom meetings (because of work constraints and this whole proposal being dropped with such disrespectfully short notice). In that meeting, no solutions were offered! It's as if this MAJOR COMPONENT was totally overlooked. Where is there availability for all of the waiver participants to go when they are **forced** out of home-based care? What planning and steps were taken to ensure that individuals with complex medical needs requiring complex cares have a **safe** place to be institutionalized? (Many against their wishes [Olmstead violation?], **and again-at greater cost to taxpayers**)

• Proposals appear to have been designed to discourage home-based care. Did anyone think it through that requiring a contracted caregiver to "clock in" with a multiple (up to six step process!) in itself is ridiculous? Expecting someone to come into your home, "clock out" if the waiver participant happens to take a nap or sleep, and "clock back in" if a medical emergency would arise (Real world example, applicable to my nephew: sitting straight up and attempting to get out of bed due to muscle memory even though he is unable to independently stand, self-support, or walk—this is a major fall risk; sudden silent seizures requiring immediate care, etc.)? Not only would it be impossible to "clock in" prior to such a medical emergency, it would be totally negligent and inhumane for a caregiver to delay the immediate response needed for safety. Are you seriously proposing that contracted caregivers violate the necessity of immediate care and responding to safety issues or risk not getting paid? Also, the whole proposal of staying in the home & "clocking in", "clocking out", "clocking in", "clocking out" repeatedly over a set amount of time (that staff won't even know how much of the time they will be paid for) is preposterous! When I babysat as a teenager, I was still paid once the kids went to sleep, nobody would have found babysitters if they didn't pay for all hours we were required to be there. Does anyone truly believe that a skilled caregiver deserves less than the basic decency and respect given to teenagers babysitting non-medically complex children? Again, these proposals are preposterous!

• It lacks transparency and meaningful stakeholder engagement. Announcing these life-altering changes on December 5 with a public comment period ending January 5 does not allow adequate time for impacted individuals, families, and advocates to fully understand or respond to the proposal. This is yet another shocking aspect of this whole ordeal. When our state is facing such a tremendous budget deficit, the abject failure to obtain realistic cost estimates displays total disregard for responsible financial stewardship of taxpayer funds **in addition** to blatant disregard of waiver participant **safety and well-being.**

Additionally, there are reports that the proposed reduction(s) in hours have already been implemented in some cases, even though nothing has been approved. This undermines the safety and well-being of vulnerable Nebraskans. I hope that this is looked into and proves to be a misunderstanding; as if true, the implications are grossly negligent.

I'd like to add just a basic humanitarian, compassionate plea (although based on this proposal I don't think compassion or concern for life is a driving factor). Do you know what it is like to watch a 16 year old go from placing/winning swim meets, being an avid fisherman, hunter, athletic "normal" 16 year old child doing what teenagers do, and one day the world is turned upside down when they incur a severe traumatic

brain injury through no fault of their own? Watching a child you love deeply experience being totally bed-ridden, not knowing if they will live or die, once stabilized realizing things will never return to “normal”, that the only thing you can do to ensure their progress and quality of life is to advocate for them and provide the best possible care you can (day in and day out, with too many sleepless nights to even begin to count)? My basic care for fellow humans makes me care about that for anyone really, I feel for *all* individuals that endure the difficulties of any challenges that leave them eligible for the waivers we are discussing. I cannot begin to imagine what it is like as the primary family caregiver, as it is for my sister. I am a Veteran, when we would have 24 hour shifts or extended shifts, eventually we would get “down time” to recover. She does not get “down time” or meaningful time to recover. She tirelessly cares for my nephew. His brain injury will cause him to be awake literally days at a time (up to 4 days so far), with Doctors explaining it is due to both sides of his brain being affected (this causes the medications they would typically use to help induce sleep to be ineffective). All parts of his brain are affected, the brain stem is damaged which causes autonomic issues (blood pressure issues, tremors, inability to regulate temperature at times- she isn’t paid to keep windows open in the winter because he is overheating and sweating profusely, also requiring frequent changes of clothes and bedding due to sweat- again, she is not paid for. She endures watching her child in pain which no medication will alleviate, knowing there is nothing she can do about it, and she somehow finds the strength to stay strong providing whatever comfort she can, knowing that is all she can do. She will replace his supra in the Emergency Room when they would rather have her do it because they don’t do it as often as she does (another example of savings for tax-payers: she provides the transport to ER if necessary; I’m sure many ER visits are *not* necessary due to her diligence in home care as well as the diligence of skilled staff she has been fortunate to find). On my nephew’s “good days” he can experience being outside or being fed food he enjoys, or to joke around with people that truly love him. These are experiences that he would not have if institutionalized. I know that they seem trivial to anyone else that has never experienced the hell of being bedridden, in chronic pain, etc. But for a human being that does have to endure those extreme challenges, those small blessings mean the world. Why would we deprive them of that, especially when it will end up costing taxpayers so much more for institutionalized care? For over a decade prior to her son’s TBI she cared for vulnerable adults in a group home setting, providing assistance with ADL’s. She knew the clients she served, learned to communicate with those that were non-verbal, to recognize their needs. She also has a deep understanding of the pitfalls and detriment to their well-being and overall health when transferred to institutions. She has sat with them when they ended up hospitalized, as they were dying, on her own time- unpaid. I can unequivocally say that she has served our fellow citizens equally if not more selflessly and honorably than most Veterans I know (and I am the spouse of a Combat Veteran, daughter of an Infantryman in Vietnam, Granddaughter of an Army Tanker that entered the European theater through the shores of Normandy). Which brings me to another area of personal concern: how many non-service connected Veterans will potentially be negatively affected by the proposed cuts?

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I strongly urge you to remove these spending caps from the final waiver application and instead focus on expanding community-based resources for Nebraskans with disabilities to live in their own homes.

Nebraska must ensure that the safety, rights, dignity, independence, and overall well-being of people with disabilities are protected.

I look forward to your response and a public commitment to protecting the rights of the disability community.

Concerned citizen,

Rachel Holmes

Lincoln, NE

From: Rachel H
To: DHHS HCBS Public Comments
Subject: Public Comment RE: Proposed amendments to A&D and TBI waivers
Date: Monday, January 5, 2026 8:22:48 PM

You don't often get email from [redacted] Learn why this is important

January 05, 2026

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I look forward to your response and a public commitment to protecting the rights of the disability community.

Concerned citizen,

Rachel Holmes

Lincoln, NE

From:	Beth Libra
To:	Kayla Walnofer; Mary Phillips; DHHS HCBS Public Comments
Subject:	Public Comment Regarding AD Waiver Proposal – Staffing, Person-Centered Planning, Safety, and Individual Rights
Date:	Thursday, January 1, 2026 7:34:16 AM

You don't often get email from [redacted]. Learn why this is important

Happy New Year,

I am submitting this public comment to express serious concerns regarding the proposed AD Waiver changes, particularly those outlined on pages 127–128, and the real-world impact these changes will have on individuals, families, and the already strained direct care workforce.

My primary concern is staffing. Nebraska, like many states, is experiencing significant workforce shortages in home and community-based services. The proposal appears to assume that when family caregiving hours are reduced, individuals can seamlessly transition to agency or non-family providers. This assumption does not reflect current realities. In many areas, staffing simply does not exist to fill those gaps. Cutting hours without available replacement staffing directly threatens health and safety.

Additionally, the proposal introduces caps on personal care hours that conflict with the principles of person-centered planning. Individuals who are currently authorized for hours above the proposed caps have those hours because their assessed needs require them. Reducing authorized hours to meet a predetermined limit, rather than honoring documented needs, undermines individualized service planning and places people at risk.

Pages 127–128 acknowledge that exceptions may be granted to address health and safety needs, yet the structure of those exceptions appears temporary and discretionary rather than aligned with ongoing, long-term needs. Individuals who require continuous supervision or hands-on support cannot have their health and safety met through short-term exceptions layered on top of hard weekly caps. This internal inconsistency places individuals with the highest needs at the greatest risk.

These changes also raise serious concerns regarding individual rights to remain in their own homes. For many people served under this waiver, home-based supports are not a preference but a necessity. Nebraska does not have sufficient facility-based options to meet the needs of individuals who would be displaced by reduced in-home services. Policies that reduce or cap hours without viable alternatives fail to protect the right of individuals to live safely in their own homes and communities.

Further, cutting hours that individuals currently rely on will directly undermine existing safety plans. Authorized hours are not arbitrary; they are tied to assessed risks, supervision needs, and documented health and safety requirements. Reducing those hours will create gaps in coverage that place individuals at increased risk of harm, medical emergencies, and crisis interventions. A safety plan cannot remain effective if the supports required to implement it are reduced or eliminated.

The proposal also applies unequal treatment based not on need, but on who provides care. Individuals with identical assessed needs may receive fewer hours solely because their caregiver is a family member or live-in provider. This is not needs-based policy; it is provider-based restriction. For individuals who cannot tolerate unfamiliar caregivers due to disability-related needs, this effectively penalizes them for requiring stable, trusted care.

From a fiscal standpoint, limiting family caregiving hours is also counterproductive. Family providers are a lower-cost option than agency care and significantly less expensive than institutional placement. Restricting family care while failing to ensure adequate staffing alternatives increases the likelihood of nursing facility placement, driving higher costs and contradicting the stated goal of fiscal responsibility.

In summary:

- Health and safety are acknowledged, yet caps make safety unattainable for some individuals.
- Person-centered planning is referenced, but blanket limits override individualized needs.
- Existing safety plans will be compromised by reductions in authorized hours.
- Individual rights to remain in their own homes are not adequately protected.
- Provider choice is restricted in ways that penalize family-based care.
- Cost containment goals conflict with increased risk of institutionalization.

I strongly urge the state to reconsider these provisions and to align waiver policy with staffing realities, person-centered planning, individual rights, and the practical requirements of maintaining health and safety in the community.

Thank you for the opportunity to comment and for your consideration of these concerns.

Respectfully,

Beth Libra

From:	Liz Lochner
To:	DHHS HCBS Public Comments; Sen. Brian Hardin; Sen. Beau Ballard; Sen. John Fredrickson; Sen. Ben Hansen, B.; gmeyer@leg.ne.gov; Dan Quick; Merv Riepe; Green, Tony; Clark, Jennifer J; Houseman, Karen; Smith, Kristen; Boss, Stacey; dlonowski@leg.ne.gov; vrountree@leg.ne.gov; Sen. Dave Murman; gethelp@aclunebraska.org
Subject:	Public comment regarding the proposed changes to the Aged and Disabled Waiver
Date:	Sunday, January 4, 2026 7:09:52 PM

You don't often get email from [redacted] Learn why this is important

Elizabeth Lochner

402-416-1461

Hello,

I am writing to submit a public comment regarding the proposed changes to the Aged and Disabled (AD) Waiver, specifically the proposed reductions in individual care and services due to an asserted financial shortfall.

First let me apologize as I am not going to be very concise or linear in this email. I am a family provider for my son on the A&D waiver. He is 45 years old. I am not parenting him in the usual sense. I am providing him with care over and above any parenting of any age. He has a trach, uses a ventilator, has a gastro feeding tube, uses a wheelchair, and needs total care. That means I change his diaper, I feed him via his gtube,I shave him, I brush his teeth, I do his multiple breathing treatments. I transfer him to his wheelchair and back to his bed. I order his meds and medical supplies. I schedule his appointments and attend most of them; Dad does a few without me. Dad is also a provider when I'm not available. But guess what he's fun. He loves watching roller derby, going to movies, and going on vacation. He is primarily nonverbal except for once in a great while he gets the word mom out. Parenting him at this age should be me calling him to come help his dad with the lawn or asking him when he'll make me a grandma. That's not happening now or ever unless God grants us a miracle. And speaking of grandmas, Mr. Pillen his grandparents have been dead many years. They are not volunteering to help. If he is sick and must be hospitalized, he goes straight to ICU.

The draconian changes proposed to the A&D waiver are over the top wrong. 40 hours a week for live in providers, really who's providing care the rest of the time? I already get up numerous times overnight off the clock to attend to his ventilator alarming or his pulse ox alarming or his feeding pump alarming. He has a non-live in provider who cares for him while I work out of the home. Yes, I'm a working taxpayer. So, 30 hours a week for a non-live-in companion does what? She works 40 hours a week now to support her own family. It's my understanding that a companion cannot do any hands-on assistance or medical needs. Well, he has a sitting protocol and needs to lay down in his bed after being up for 3 hours. He gets gtube fed multiple times while she cares for him. She must be able to change the inner cannula on his trach and to change the trach in an emergency. She gives him medicine via his gtube. He must have his incontinence brief changed multiple times during her time with him. How's that gonna work? He needs a hands-on provider while I work.

Has anyone checked with Madonna or The Ambassador for a cost of what it would be if

we didn’t take care of him? Or is the plan for families to give up and let their loved ones be moved there to languish by themselves with no one who knows them until they die. That would certainly save the state money, wouldn’t? Or is that the plan? Do I sound cynical? You better believe it. The comments from the governor leads me nowhere else.

I sincerely hope you who are in charge of this and our State Senators step up and do better. Guess what the people getting services are citizens of this state. I keep hearing how Nebraska is a right to life state, then prove it. Right to life doesn’t stop at birth.

Yes, I know the state budget has issues. Well, maybe some of the corporate tax breaks should be rolled back. And let's look at the tax revenue we are losing by not legalizing marijuana. Also why not just do a 1% rollback of provider pay.

The A&D proposal would only cover 40 hours a week. So that's about 25% of the hours in a week. Let’s pay the company building the new prison 25% and tell them the rest is volunteer. Or let's tell every state worker they only get paid for 25% of the work that they do; fair is fair after all.

Please reconsider the changes in the proposal for the A&D waiver.

Elizabeth Lochner

From: teresa stewart
To: DHHS HCBS Public Comments
Subject: Public Comment
Date: Tuesday, December 16, 2025 4:42:50 PM

You don't often get email from [redacted]. Learn why this is important

I am here to advocate for my adult disabled son.
The back story:

My son was born Oct 1st 1996. He was born healthy, happy and loved. He contracted meningitis at 20 days old, its is believed that he was bitten by a mosquito carrying the West Nile virus while attending the funeral of my grandfather in rural Nebraska. I knew within hours something was terribly wrong with him. His brain hemorrhaged, leaving him physically and mentality devastated.

Those first 10 years were non-stop extended hospital stays in and out of the state of Nebraska. His father could not take the incredible responsibility the comes along with the diagnosis. He has CP, cortical blindness, Intractable epilepsy, baclophen pump (to keep the rigidity at a manageable place), a vagal nerve stimulator, trach, g-button, non-verbal, quadriplegic, vent dependent and unable to do anything on his own. I never had anymore children because I didn't feel it would be fair to either child. I have been caring for my son almost 30 years now. As such, I feel****no, I KNOW, I can provide a level of care the far surpasses care he could get anywhere else. This includes hospitals, care facilities and untrained respite workers.

DHHS insisted that I either get a full time job, or go to college, I did both, which took me 8 years to accomplish. I finally found that terrific cooperate job, that offered great pay, health insurance for myself and ability to contribute to my retirement.

Your saying that an additional 30 hours can be provided but by who??? Agencies that have the staff, will not staff those hours because of medical severity. It is a liability for them to do so. Therefore I would still have to make myself available to suction, prepare and administer medications, handle ventilator issues, administer rescue seizure medications, etc. Where would that staff come from?

Additionally, If my son were to go to a extended family home, they will get paid (For my son's level of need at high risk) 693.00 a day, 20,790 per month, and 249,480 per year. far more that I can make??? Why???

Also, are you saying that a live in caregiver is maxed out at 40, with an additional 30 by a outside provider, or can the parent get that additional 30 hours? And at what pay scale? Do you realize this will be a devastating financial blow to most of us? With our economy becoming increasingly more expensive (seems like) by the day with rising homeowners taxes and insurance rising, utilities rising, food costs rising, goods and service prices rising, how will this be sustainable for us? There has to be a better answer than this. Shameful.

From: Katie Thompson
To: DHHS HCBS Public Comments
Subject: Public Comment to AD Waiver proposed caps on hours-Strongly urge a pause and update
Date: Monday, January 5, 2026 10:11:00 PM
Importance: High

You don't often get email from [redacted]. Learn why this is important

Dear Fellow Nebraskans and NE DHHS Team,

I am writing as a Nebraskan, a family member, and a caregiver to urge you to pause and reconsider the proposed cuts to the Nebraska Aged & Disabled (A&D) Waiver, specifically the plan to cap waiver services at 70 hours per week, down from the current allowance of up to 168 hours for individuals with complex needs.

These proposed cuts come on the heels of more than $400 million in tax cuts, followed now by a declared budget shortfall. I am deeply concerned that, rather than addressing this shortfall with care and foresight, the state is proposing a change that would fundamentally dismantle home- and community-based services (HCBS) for Nebraska's most vulnerable citizens; without a viable alternative plan.

Real families, real consequences
Two of my family members currently rely on the A&D Waiver to remain safely in their homes.
One is 91 years old, has advanced dementia, is wheelchair-bound, and requires 24-hour care. Her waiver services cover essential needs: feeding, toileting, bathing, medication administration, transfers, fall prevention, and overnight supervision. Under the proposed cap, she would immediately lose 98 hours per week of essential care. There has been no explanation from policymakers as to how those hours would be replaced; or whether her safety would simply be compromised.
My second family member, age 68, would lose 35 hours per week of critical care under the same proposal.
Both individuals would technically qualify for institutional placement if these cuts proceed. But qualifying for a nursing facility does not mean it is appropriate, humane, or fiscally responsible; nor does it reflect the intent of the A&D Waiver program, which was created to support independence and keep Nebraskans in their homes whenever possible.

The flawed cost assumptions behind this proposal
State discussions have cited an "average" nursing home cost of approximately $92,438 per year, with a proposed cap of 175% of that amount. This framing is deeply misleading.
That average does not reflect:

- Patients with advanced dementia
- Individuals requiring round-the-clock supervision
- High fall risk or total assistance with activities of daily living

These are not "average" patients; and Nebraska does not have sufficient nursing facility capacity, staffing, or specialized care options to absorb a forced influx of high-acuity residents. Pushing people out of their homes does not save money; it shifts costs to more expensive and less appropriate settings, often resulting in higher Medicaid expenditures through institutional care or avoidable hospitalizations.

Workforce and safety realities

Caregiving is already a strained workforce. My family members rely on multiple caregivers, and recruiting and retaining staff is increasingly difficult. While a 70-hour cap might be technically “staffable,” it would be unsafe. Caregivers have already indicated they would leave under these conditions, compounding instability and risk.

Federal policy and legal implications
Federal Medicaid policy has long encouraged home- and community-based services over institutionalization, recognizing both the cost-effectiveness and the human dignity of keeping people integrated in their communities.
This proposal appears to violate the spirit, and potentially the letter, of federal HCBS policy, as well as the principles established under the Americans with Disabilities Act and the Olmstead decision. Federally, states are required to provide services in the most integrated setting appropriate to an individual’s needs.
Moving forward without individualized assessments, transition planning, or exceptions for complex cases exposes Nebraska to federal scrutiny, compliance risk, and potential legal challenge.

What I am asking
I respectfully but urgently ask that you:

1. **Pause any action** on the proposed A&D Waiver hour caps
2. **Conduct a formal impact assessment**, particularly for individuals with complex medical and cognitive needs
3. **Meet with affected families and caregivers** before advancing policy changes
4. **Create clear exceptions or alternative pathways** for those who cannot safely survive under a one-size-fits-all cap

Nebraska can, and must, balance fiscal responsibility with compassion, legality, and common sense. Cutting life-sustaining home care without a plan does not solve a budget problem; it creates a humanitarian one.

Thank you for your time and for your service to our state. I would welcome the opportunity to discuss this further or share additional detail about how these changes would affect real Nebraskan families.

Sincerely,

Kathryn (Katie) & Tyler (Ty) Thompson
Lincoln, NE

Get Outlook for iOS

From: Kellie Quinlin
To: DHHS HCBS Public Comments
Subject: Public comment
Date: Tuesday, December 30, 2025 5:31:49 AM

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Public Comment – AD Waiver Proposal

The proposed AD Waiver changes claim to be aligned with the **HCBS Final Settings Rule**, yet the actual provisions in this proposal clearly contradict that requirement.

The Final Settings Rule requires **individualized, person-centered planning based on assessed needs**, not blanket caps or one-size-fits-all limits. Establishing what functions as a **de facto 40-hour cap** on family or independent providers — regardless of medical necessity, functional need, or health and safety — is the opposite of individualized planning. A blanket limit ignores the reality that many individuals on the AD Waiver require **substantially more care to safely remain in their homes**.

Further, the proposal places **explicit restrictions on who a participant may or may not choose as their provider**, even when those providers are willing, qualified, trained, and already delivering care **at a cost far below nursing facility placement or agency rates**. The Final Settings Rule explicitly protects a participant's **right to choice of providers**, including the right to choose family or trusted caregivers when appropriate. Restricting provider choice for administrative convenience or budget predictability does not meet federal HCBS standards.

These changes do not advance independence or integration. Instead, they **force individuals toward institutional models of care** by making home-based care increasingly unworkable — even when home care remains **well within the Medicaid cost cap and significantly less expensive than nursing home placement**. This directly undermines the cost-effectiveness argument and sacrifices quality of life without achieving meaningful savings.

By limiting hours and restricting provider choice rather than assessing and meeting individual needs, this proposal risks **violating the Olmstead decision**, which requires states to administer services in the most integrated setting appropriate to the individual. Policies that make community living unsustainable, despite cost neutrality and available supports, functionally push people toward institutionalization — exactly what Olmstead prohibits.

This proposal does not reflect person-centered planning, does not honor participant choice, and does not prioritize health and safety. It prioritizes administrative control over individual need, despite federal requirements stating that **waiver services must be based on the needs of the participant, not arbitrary limits**.

Nebraska can and should maintain fiscal responsibility **without violating federal HCBS requirements**. When individuals can safely receive care in their homes, with trusted providers, at a cost far below institutional care, restricting that option is not responsible policy — it is a step backward that harms the very people the AD Waiver is designed to protect

This plan needs to be we wrote! Do not put Nebraska on the map for being inhumane! We are

supposed to take care of our own! This plan is not the way to go about it.
Thank you!
Kellie Quinlin

From: Sarah Rasby
To: DHHS HCBS Public Comments
Subject: Public Comment: Impact of Proposed Medicaid Waiver Changes
Date: Sunday, December 28, 2025 7:38:51 PM

You don't often get email from [redacted] Learn why this is important

To Whom It May Concern,

I am submitting this comment as a Nebraska resident and former family caregiver to a loved one with a severe disability. And, as a PhD scholar who studies family caregiving burden and well-being.

Until age 35, I was not a caregiver and had no connection to disability services. That changed suddenly when my twin sister suffered a cardiac arrest that caused a severe anoxic brain injury. She lost the ability to care for herself in any capacity. Our family entered the world of caregiving overnight- without preparation, without warning, and without choice.

I am deeply concerned that proposed changes to Medicaid waivers, particularly reductions in caregiver hours, will cause real harm to families like mine. These changes do not simply "adjust services." They increase caregiver burnout, isolate disabled individuals, and push families into crisis. Many caregivers are already providing care 24 hours a day while working and parenting. Further reductions will only increase instability and long-term costs.

Disability and caregiving are not rare experiences. They are a part of being human. Policies that weaken community-based care do not reflect efficiency- they reflect a failure to protect our most vulnerable residents.

I urge DHHS to reconsider any changes that reduce access to Medicaid HCBS waivers and to prioritize policies that support families, caregivers, veterans, and disabled individuals in remaining safely at home and in their communities.

Thank you for considering my public comment.

Respectfully,
Sarah Rasby

Lincoln, NE 68512

From: Jazmine Marie
To: DHHS HCBS Public Comments
Subject: Public Comment: Oppose Proposed Caps on HCBS In-Home Care Services
Date: Monday, December 29, 2025 9:20:49 AM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Dear Nebraska Department of Health and Human Services Leadership,
My name is Jazmine Rannells, and I am a Nebraska resident from Fremont, NE.
I am writing to submit a public comment in opposition to the proposed caps on Home and Community-Based Services (HCBS) hours and related policy changes that would reduce access to in-home caregiving for adults with disabilities. These proposed changes will harm Nebraska families and will ultimately cost the state more, not less.
More than one in eight Nebraskans lives with a disability, and many adults with severe disabilities rely entirely on in-home care to live safely in their homes. For these individuals, home care is not optional—it is essential. Reducing or capping care hours does not eliminate the need for care; it only shifts the cost to more expensive systems.
When families lose necessary in-home care hours, they are pushed into crisis. Caregivers are often forced to leave the
workforce or reduce work hours, increasing reliance on public assistance programs. Health and safety
risks increase, emergency room visits become more common, and many families are eventually forced to place their loved ones into institutional care.
Institutional care is the most expensive outcome possible. Nursing facilities can cost the state well over $150,000 per person each year, while family-provided in-home care costs a fraction of that amount. Keeping people in their homes
is both more humane and more fiscally responsible.
I respectfully urge Nebraska DHHS to reject arbitrary caps on HCBS hours, preserve needs-based services, and avoid policies that force people out of their homes and into higher-cost institutional care.
Thank you for the opportunity to provide public comment.
Sincerely,
Jazmine Rannells
Fremont, Nebraska

From: Nicole Mattson
To: DHHS HCBS Public Comments
Subject: Public Comment: Opposition to Proposed Aged & Disabled Waiver Cuts
Date: Thursday, December 25, 2025 2:34:47 PM

You don't often get email from [redacted]. Learn why this is important

To Whom It May Concern,

I am writing to voice my strong opposition to the proposed changes to Nebraska's Aged and Disabled Medicaid Waiver, specifically the reduction of reimbursable caregiver hours from 112 per week to 70, and the cap limiting live-in family caregivers to 40 paid hours.

This proposal places some of our most vulnerable Nebraskans at risk — elderly individuals, disabled adults, and children whose safety, stability, and well-being depend on consistent, trusted care. Caregiving is not a luxury. It is an essential, intensive service that keeps people alive, safe, and at home rather than in institutional settings that are often understaffed, overcrowded, and far more expensive.

Families do this work out of love. But love does not replace the reality of lost income, burnout, medical complexity, or the sheer time it takes to care for someone who cannot function independently. Reducing hours means reducing care. Reducing care means increasing preventable hospitalizations, institutional placements, exploitation risk, and caregiver collapse. That is not sustainable for families — financially or emotionally.

If the stated goal is program sustainability, cuts of this magnitude do not accomplish that. They shift costs elsewhere: to hospitals, to long-term care facilities, to communities unprepared to absorb them. Institutional care is not cheaper, nor is it better for quality of life. The waiver exists precisely because home-based family care is humane, effective, and ultimately cost-conscious. Restricting it is short-sighted public policy.

Every person deserves the dignity to remain in their home with the people who know them best whenever possible. Policies that discourage family

caregiving undermine that dignity. For many, losing 72 hours of reimbursable care is not a minor adjustment — it is the difference between staying home and being forced into facility placement. It is the difference between a family holding together or breaking under financial and emotional strain.

I have personally witnessed the importance of these services in my own family. My disabled nephew depends on care and consistency, and my aging grandparents benefited greatly from waiver services prior to their passing. I cannot imagine how families like ours would bear the burden of sudden hour reductions without severe consequences to safety, mental health, and financial stability.

Nebraska should be proud to support families who keep loved ones safe at home. We should not balance budget gaps on the backs of disabled people and their caregivers. These individuals are Nebraskans, taxpayers, community members, and human beings who deserve more than minimum survival. They deserve quality of life.

I urge DHHS to reconsider these changes, seek alternative funding solutions, and prioritize the voices of families, caregivers, and the disability community before making decisions that will affect thousands of lives.

Please protect the integrity of the Aged & Disabled Waiver and the people who depend on it.

Sincerely,

Nicole Mattson

[redacted]

Aunt to a disabled nephew; granddaughter of aging family members previously served by waiver support

From: [redacted]
To: DHHS HCBS Public Comments
Subject: Public Comment: Proposed Changes to AD/TBI Waivers – Hour Caps. Formal Opposition to AD Waiver Amendment - Personal Care Limits
Date: Tuesday, December 23, 2025 10:34:39 AM

You don't often get email from [redacted] Learn why this is important

I am writing to express my strong opposition to the proposed 40-hour weekly cap on paid caregiving for live-in family members.

Currently, many families provide over 100 hours of specialized, life-sustaining care per week. Reducing these hours to 40 will create an immediate financial and safety crisis for our most vulnerable citizens. For many, this compensation is the only thing allowing a primary caregiver to remain in the home rather than seeking outside employment.

If these cuts are implemented:

Risk of Institutionalization: Families will no longer be able to sustain the cost of home care, forcing loved ones into nursing facilities against medical advice.

Increased State Costs: The cost of facility-based care far exceeds the cost of home-based caregiver hours. This change is fiscally counterproductive for Nebraska.

Safety: A 40-hour cap does not reflect the 24/7 medical reality of many waiver recipients, potentially leading to caregiver burnout and patient neglect.

I urge DHHS to maintain the current flexible hour structure that allows Nebraskans to receive high-quality care in their own homes.

Please accept this formal comment regarding the proposed amendments to the Aged and Disabled (AD) Waiver. I am writing to oppose the 40-hour limit for live-in caregivers and the 70-hour combined limit for personal care services.

These arbitrary caps fail to account for the "Level of Care" assessments already used to determine medical necessity. By capping hours regardless of a patient's actual clinical needs, the state is effectively incentivizing institutionalization, which contradicts the goals of the Olmstead Act and the preference of Nebraskans to age in place.

Furthermore, these cuts will disproportionately affect rural families who have no access to secondary agency providers to "fill the gap" created by these caps. I request that DHHS reconsider these limits and prioritize individual need over blanket hourly restrictions.

Sincerely,
Ryan Johnston
Lincoln NEBRASKA

Public Comment on Nebraska' plan to renew the 1915(c) Medicaid Home and Community Based Services (HCBS) Aged and Adult and Children with Disabilities waiver and amend the Traumatic Brain Injury waiver

Disability Rights Nebraska

January 5, 2026

Disability Rights Nebraska is the state's designated Protection and Advocacy system. Disability Rights Nebraska uses a combination of strategies to promote, protect, and advocate for the legal and human rights of all people with disabilities. We support people to gain full inclusion in home, community, education, and employment beginning with those who learn, live, or work in isolated, segregated or congregated settings. We submit this public comment on the State of Nebraska's proposed changes to the Aged and Disabled Waiver and the Traumatic Brain Injury Waiver.

The Nebraska Department of Health and Human Services Division of Developmental Disabilities announced in early December of 2025 its intention to drastically change the terms of the Aged and Disabled and Traumatic Brain Injury waivers. The Division of Developmental Disabilities (Division) provides funding and oversight for Medicaid Home and Community-Based Services (HCBS) Waivers, **including** determining eligibility, providing service coordination for eligible people, monitoring services, and paying providers. In its draft application to the United States Centers for Medicaid and Medicare Services (CMS), the Division seeks to drastically reduce the number of hours participants may receive and dramatically change how these services may be provided to the most vulnerable Nebraskans with disabilities. Disability Rights Nebraska has received numerous calls to our intake line from families and people with disabilities who will be impacted by these changes. We have attended listening sessions and public meetings hearing first hand from people who fear for the safety and wellbeing of their loved ones if these changes are approved.

In its attempt to push through these changes, the Division quietly posted to its website a notice for public comment along with the 238-page Medicaid Waiver applications. Without notice to any disability groups, advisory committees or the public, Nebraskans with disabilities face the prospect of being forced into institutional care.

The complete lack of transparency by the Division is astonishing, especially considering it meets monthly with the Governor's Developmental Disability Advisory Committee and closely works with the Olmstead Advisory Committee and workgroups monthly. The Division did not disclose to the disability community, stakeholders or families that it had been working on this plan to alter the waiver programs over the last six months. Disability Rights Nebraska categorically disagrees with the Division that Olmstead and the Americans with Disabilities Act are not impacted by the proposed changes, especially when the language of the waiver application states that

participants will have the "option" of returning to nursing homes or other institutions if their needs cannot be met in their own home.

Families fear changes will force institutionalization

Disability Rights Nebraska has heard from many families and individuals who will be impacted by the proposed waiver changes. The 238-page proposal to the state's Aged and Disabled Waiver would limit the need-determined reimbursable hours of caregivers from a current cap of 112 hours to 70. Of those hours, a paid live-in family caregiver could be reimbursed up to 40 hours, a part of the program with no current cap. Families report that a reduction in hours will make it impossible to keep their loved one at home. While nursing home level of care is a requirement to participate in the Aged and Disabled waiver, the needs of many people with disabilities are highly specialized and require intensive care that most institutions, including nursing homes, are not equipped to provide. Families struggle to find an outside option because there are not enough care providers in their community to meet the demand for services if hours are capped for families at 40 hours per week.

Excluding family care providers does not save money

The Division argues the need for fiscal responsibility to maintain the longevity of the Aged and Disabled Waiver and avoid a waitlist. If families are capped at forty hours a week, how does paying an outside agency provider for the additional 30 hours, instead of the family, save money? It simply shifts the cost to another entity. Families reported that their care hours are billed at a lower rate than agency providers. Many families and people with disabilities are unable to find outside providers in their communities. This is particularly acute in rural areas. The lack of ~~capacity for~~ care providers is a state-wide crisis in Nebraska. These proposed waiver changes would shift 30 hours of care to providers and a workforce already stretched too thin. Families and advocates report that the lack of capacity and reliability of providers have forced many parents of adult children to leave jobs and take on the role of care provider so their loved one can receive the care they need at home and not in a nursing facility.

Many families reported that the current 112 hour limit is critical for them and their loved one to afford to live in the community. The proposed reductions would impose yet another financial strain for many families. Many families spoke at the public meetings stating that they have figured out a way to provide adequate and safe care for their loved one; these regulations would serve to undermine an already working, yet precarious, situation for families of the most vulnerable.

Nursing facilities not equipped to meet needs of people with disabilities

Disability Rights Nebraska has heard from people with disabilities, families and advocates that nursing facilities and in-home care agencies cannot meet the needs of people with disabilities who have high medical needs. One family reported that there is not a facility in or near their community that could serve the needs of their loved one. Families voiced that care facilities in their area will not accept or cannot

adequately serve their loved one. Several families spoke at public meetings about the lack of training, equipment, and staffing at nursing/care facilities for people with complex medical conditions— they have checked. A family stated at the Olmstead Committee meeting that their daughter cannot wait for staff to get to her when her tracheostomy tube gets clogged. One family relayed that the in-home care agency staff cannot treat their daughter when she is having a seizure.

Other families told stories about not only a lack of *formal* care and support, but also informal supports (e.g., siblings or other family members who live elsewhere, friends who are unable or unwilling to provide care). These proposed waiver changes assume that all families have a robust and substantial informal support system (if not formal supports in their area).

One advocate reported that there is a shortage of facilities who have Medicaid funded beds available. Another advocate reported that institutions like nursing facilities and assisted living facilities have a variety of payment rates based on the individuals' complex level of need. Using the average yearly nursing facility cost does not accurately represent the need of many individuals who use the Aged and Disabled Waiver. The average yearly nursing facility cost assumes bare minimum custodial level of care. Individuals who face leaving their homes to enter a nursing facility who need high levels of care would easily exceed daily rates of $1,000.

Families also voiced strong concern for the safety and security of their loved one— new caregivers can be a safety risk. Revolving care staff invites inconsistency and changes of providers and/or venue can create unnecessary stress for their loved one.

One family said in the Olmstead committee meeting that essentially the proposed changes would force families to place *children* in *nursing facilities*.

Uncertain how many people will be impacted

The Division reports that approximately 255 people meet the high utilization criteria requiring a review to reduce hours under the cap. Families have been told to contact their service coordinator to find out if their hours exceed the cap. Disability Rights Nebraska has heard from families who have contacted service coordinators with questions and received little guidance. Service Coordinators did not have the information requested, were not aware of the proposed Aged and Disabled Waiver changes and had no information about where their loved one would live if they could not meet the cap.

Families voiced significant concern about the timing of these proposed waiver changes and the lack of input from families and advocates. Families were also concerned that there would be insufficient time for them to make new arrangements for care between the final approval of these waiver changes and the implementation date.

Referrals to other community services

The language of the Aged and Disabled Waiver application indicates on page 26, when the participant's health and safety cannot be met within the 175% cost limit,

the SC (service coordinator) will provide the participant with "referrals to other community services, including institutional services." The Division has not adequately provided information to families and individuals with disabilities as to what other "community services" are available to avoid institutional care.

Lack of transparency by the Division

Advisory Committee on Developmental Disabilities

The Division of Developmental Disabilities leadership meets with the Advisory Committee on Developmental Disabilities pursuant to Nebraska Statue. One of the key functions of the Advisory Committee is to advise the Nebraska Department of Health and Human Services on the funding and delivery of services. Over the last 18 months the Division of Developmental Disabilities informed the Advisory Committee of changes to its Home and Community Based Developmental Disability Waivers. The Committee and the public were informed of the Divisions intention to amend its waivers to eliminate the waitlist for services. As a member of this committee, Disability Rights Nebraska, along with other advocacy groups, family members and people with disabilities received detailed updates about the changes and the need to amend the waivers to accomplish this change. The lack of communication by the Division to this committee on its plan to abruptly change the Aged and Disabled Waiver is glaring. Its decision to hold public comment (December 5, 2025-Janauary 5, 2026) over the busy holiday season was equally perplexing. We heard from numerous people about the lack of information from the Division and how their own service coordinators were not prepared to answer even basic questions on how the proposed changes would affect them. People with disabilities and their families are frustrated and scared.

Olmstead Advisory Committee

Pursuant to Nebraska State Statute §81-6122, the Nebraska Department of Health and Human Services, along with other state agencies, are required to develop and implement an Olmstead plan. According to the most recent iteration, the plan is "grounded in the belief that all individuals with disabilities should have the opportunity to live, learn, work, and thrive in the most integrated setting of their choice."[1]

The Olmstead Advisory Committee was established under this same statute. The Committee meets at least quarterly and five workgroups meet monthly. The Advisory Committee was not informed of the proposed changes or even alerted to any issues occurring within the Aged and Disabled Waiver. The Olmstead Advisory Committee held an emergency meeting on December 19, 2025, to find out why the Committee had not been informed and to press the Division for more details about the impact the changes will have on people with disabilities. Over 120 people attended the emergency meeting. During this meeting, the Division could not adequately explain

[1] https://nebraskalegislature.gov/FloorDocs/109/PDF/Agencies/Health_and_Human_Services__Department_of/832_20250729-120921.pdf at pg. 3.

why the Committee had not been informed but stated it did not believe the Olmstead Committee needed to be notified.

From: Katie Novakoski
To: DHHS HCBS Public Comments; Green, Tony
Subject: Public Comment
Date: Saturday, January 3, 2026 1:17:12 PM

Dear DHHS,
This is an email sent to the HHS committee. Add this to public comment.

"I wanted to reach out again about these proposed changes to the AD Wavier. I understand you all are not voting on this proposal and it will be sent to CMS for final approval but I also know you have understanding and sway with DHHS prior to things being sent into CMS.

I am fairly upset as I have learned some more information about the funding for the DD and AD waivers. I was informed by an employee at DHHS that DD has always gotten more funding for their loved ones because they are louder advocates. That does not seem right to me. It is not fair. Those on the AD waiver require just as much if not more care than some of the individuals on the DD wavier. Yet I can see in the 2024 annual fiscal report that DD wavier actually received significantly more funding than the AD waiver YET they have half the amount of people on that wavier. The 2025 annual fiscal report is not posted on the DHHS website so I am not able to see that yet.

In 2024, the DD wavier had 5,023 served and the AD waiver had 10,054. The DD budget was $467,342,835 and the AD budget was $335,112,544. That is a $132,230,291 difference for 5,031 LESS recipients. The average recipient on the CDD wavier costs the state on average 3 times the amount as those on the AD wavier. Not to mention those that live and are served at the Beatrice State Developmental Center (BSDC) cost on average 100 times the amount of someone receiving the AD wavier. The cost of the BSDC is its own issue that needs to be addressed as well (the average annual cost of someone at the BSDC is $385,655).

So please help me understand how those who are on the AD wavier are going to be capped at 40 hours of personal care when there are recipients that need 24/7 hour care. 40 hours a week at the new minimum wage is $31,200. That is not a livable wage for their caregivers. It leaves 128 hours of unpaid care a week that is just expected for families to do because we love our family members.

Parents, caregivers, and loved ones of those who utilize the AD waiver are upset and hurt. Rightfully so. So please know this is not the last time you will hear from us. We will be advocating for our loved ones.

Let me know what information would be helpful. You are all more than welcome to our home and if you are not near us, I can find a family who would welcome you into their home to see what our lives are like and why we haven't had time to advocate for more funding like those

on the DD waiver.

Talk to you all soon,
Katie Kuecker"

From: Ashley Wagner
To: DHHS HCBS Public Comments
Subject: Public comment
Date: Monday, January 5, 2026 9:01:40 PM

You don't often get email from [redacted]. Learn why this is important

As a full time caregiver to a special needs family member, I am devastated at the apparent lack of support by the State towards the most vulnerable of people. People who are unable to advocate for themselves, most being unable to provide any of the most basic of needs for themselves. Family members have chosen to care for them, many to the detriment of their own health and financial security because they see the value and importance of in home support. No one knows these special needs individuals like the people that have watched them grow; there's no rest. Sure, you can say well we sleep at night…but what about the times when my paraplegic sister has a colostomy blowout and requires an entire bath, bed change, etc which will take no less than hour? Or when my brother gets up multiple times during the night, because he wet his bed and also needs a full assist with shower, bedding changed and washed, etc. It's easy for someone to come into our home and talk for an hour but they don't see the other 23 hours that revolves completely on that individual's needs. If that said individual can not, under circumstance, be left alone for any certain amount of time, it is negligence to the family for you all to act as if this is just another 9-5 job that we can clock out of and kick our feet back and relax at the end of our shift. It was literally said that the State is granting us 40 hours just like a normal job, as if it's a prize we won and we should be grateful, but this in no way resembles a "normal job".

The paid hours help families provide quality care, supplies and overall better life for their loved ones. No one is going on luxury holidays or buying sports cars. We are fighting to be able to have the ability to care for our loved ones to the very best of our ability. By cutting hours, it means that our ability to buy medical items not covered by insurance, pay for extra gas when we need to take two vehicles because of adaptive equipment, taking otherwise homebound children to special extracurricular activities once in awhile and so on, becomes majorly restricted. You say that you want our loved ones to remain in our home because you want the best quality of life, but if we're all required to get another job because of income cuts…that is exactly what will happen. We will be forced to institutionalize our loved ones because most of us do not have any access to any type of respite care.

I implore you to seriously to reconsider a decision that will have a devastating impact on hundreds of families all across Nebraska.

From: Ishmael Keyzer
To: DHHS HCBS Public Comments
Subject: Public comment
Date: Monday, January 5, 2026 9:06:20 PM

> You don't often get email from [redacted]. Learn why this is important

Please read this article and watch this video (again if needed) as my public comment.

What you are trying to do to my brother (Simon Keyzer)and my mother (his caregiver) is pretty messed up. Do not move forward with caping the hours for live in caregivers to 40 or 70 or whatever. It doesn't even make sense. Why did you bother to send someone to the house to see my brother and do his yearly review, if you weren't gonna give us services based on his needs?? (He was reapproved for 112 hours by the way)

Isn't DHHS a agency created to help take care of the disabled of our state? Is this how you are trying to take care of my Disabled brother? It doesn't seem like it to me.

Nebraska Medicaid waiver changes feared by families
https://share.google/FeFauqNefBzZKdqub

https://www.facebook.com/share/v/17y5Cwg5Pf/

Make a better choice.

Ishmael Keyzer
[redacted]

From: Holistic Group, Inc.
To: DHHS HCBS Public Comments
Subject: Public Comment--A&D Regulations, 70-Hour Weekly Cap, and Live-In Caregiver Reductions
Date: Friday, January 2, 2026 10:56:24 AM

You don't often get email from [redacted]. Learn why this is important

To whom it may concern,

Please accept this email as formal public comment regarding the proposed changes to the Nebraska Aged and Disabled (A&D) regulations, including reductions to live-in caregiver hours and the proposed cap limiting total participant services to 70 hours per week. I submit this comment from a provider perspective and strongly object to these changes due to their impact on service delivery, workforce sustainability, and compliance with CMS Home and Community-Based Services (HCBS) requirements under 42 CFR §441.301.

HCBS regulations require that waiver services be authorized based on individualized, person-centered assessments rather than fixed caps or generalized limits (42 CFR §441.301(c)(1)). From a provider standpoint, a universal 70-hour weekly cap is incompatible with the needs of many A&D participants currently served and creates service plans that are not operationally feasible or clinically appropriate.

Providers are responsible for ensuring participant health and welfare and for delivering services consistent with authorized plans. Under 42 CFR §441.301(b)(1) and (c)(2), the state must provide assurances that services are sufficient to meet assessed needs. A 70-hour cap results in predictable gaps in coverage—particularly overnight, during high-risk periods, or when participants require hands-on assistance or supervision. These gaps place participants at risk and expose providers to increased liability, incident reporting, and service failures that are outside of provider control.

CMS HCBS regulations also emphasize the obligation to prevent unnecessary institutionalization and to support individuals in the most integrated setting appropriate (42 CFR §441.301(c)(4)). From a provider perspective, authorizing services at levels that do not meet actual participant needs increases the likelihood of crisis events, hospitalizations, and eventual placement in nursing facilities or other institutional settings. These outcomes undermine the purpose of the A&D waiver and increase long-term system costs.

The proposed reductions also raise serious concerns regarding provider capacity and workforce stability. Live-in caregivers and high-hour service models are already difficult to staff. Reducing authorized hours and imposing a 70-hour weekly cap makes many service models financially and operationally unsustainable, leading to increased turnover, inability to staff cases, and potential provider withdrawal from the A&D program altogether. This directly conflicts with CMS expectations that states maintain a sufficient and qualified HCBS workforce.

From an operational standpoint, these proposed changes shift risk from the state to providers while limiting providers' ability to safely meet participant needs. Providers cannot ethically or effectively deliver services when authorizations do not align with assessed needs, and doing so places both participants and providers in untenable positions.

I strongly urge the State of Nebraska to withdraw the proposed 70-hour weekly cap and

reductions to live-in caregiver hours and to reevaluate these changes through a provider-informed, CMS-compliant lens. Any revisions to A&D regulations should support realistic service delivery, workforce sustainability, participant health and safety, and continued compliance with 42 CFR §441.301.

Thank you for the opportunity to provide public comment and for consideration of the operational and compliance impacts these proposed changes would have on providers, participants, and the A&D system as a whole.

Sincerely,

Caroline Anuh-Ndumu
CEO

--
Holistic Group Inc.
9001 Arbor St Ste #206
Omaha NE 68124
P:402-718-6900
f: 402-763-9126

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From: Dorothy Ackland
To: DHHS HCBS Public Comments
Subject: Public Comment
Date: Saturday, December 20, 2025 11:30:01 AM

You don't often get email from [redacted] Learn why this is important

Public Comment on Aged and Disabled (AD) Waiver Renewal rural Family Struggles with Pediatric Personal Care and EPSDT Nursing

Dear Nebraska DHHS Waiver Team,

I am a mother and caregiver in Crab Orchard, Nebraska (Johnson County), and former Certified Nursing Assistant (CNA), raising my 19-month-old daughter on the AD Waiver. She has relied on a feeding tube 24/7 for at least a year requiring constant supervision for feeds, monitoring for complications like aspiration or clogs, and hands-on care that exceeds typical parenting duties. As a former CNA, I feel like I have a full nursing home in my own home—especially at the beginning of our journey when it was truly round-the-clock and incredibly overwhelming. This is not a minor or hysterical statement; it is our lived reality. Now reduced to just one hour of feeds and minimal formal support, it doesn't feel quite as overwhelming—but our family still struggles. This might sound simple, but I want to be a parent—I don't want to be a nurse. I want to focus on playing with my daughter, teaching her words, and helping her learn new skills, not constantly monitoring if she's hooked up correctly or dealing with the feeding pump.

The state argues this falls under "parental responsibility," but this view fundamentally misunderstands the distinction between ordinary parenting and the skilled, nursing facility-level medical care my daughter requires. Typical parental duties involve feeding a child with a spoon, changing diapers, or comforting during illness—these are universal and expected. In contrast, managing a 24/7 feeding tube demands clean techniques to minimize infections, precise pump programming to avoid under- or over-feeding, vigilant monitoring for silent aspiration (which can lead to pneumonia or worse), troubleshooting clogs or alarms at all hours, and immediate response to emergencies like tube dislodgement. These are tasks I never provided as basic care as a CNA—they were classified as professional nursing jobs at the facility where I worked, done under supervision with shift changes and backups. Expecting parents to do this solo, unpaid, around-the-clock ignores the physical exhaustion, sleep deprivation, and mental health toll that leads to family breakdowns or institutionalization—the very outcomes waivers aim to prevent. EPSDT nursing is even harder to secure, demanding exhaustive physician documentation and prior authorizations that rural families like ours rarely overcome due to provider shortages and living at least 30 minutes from Lincoln. Meanwhile, AD Waiver personal care caps and adult-focused assessments deny us the hours needed to prevent burnout or institutionalization.

For the July 2026 renewal, I urge:Child-specific personal care expansions with higher caps for tube-fed kids.

Simplified EPSDT nursing pathways and rural provider incentives.Recognition that equity means supporting families beyond "parental duty," so parents can actually parent.

These changes would keep families whole. Thank you for considering my comment.

Sincerely,
Dorothy Ackland

Subject: Public Comment on Proposed Aged & Disabled Waiver Changes – Live-In Care, Hour Caps, and Caregiver Pay

To Whom It May Concern,

I am submitting this public comment regarding the proposed 2026 changes to Nebraska's Aged and Disabled (AD) Waiver.

This care is for my daughter, who has multiple chronic disabilities and requires **round-the-clock care**. Her medical needs do not stop after five 8-hour days. She is sick **24 hours a day, seven days a week**, including nights and weekends. Limiting paid care to 40 hours per week does not reflect the reality of her condition and places her health and safety at risk.

My daughter's care requires constant supervision and hands-on assistance. Because of this, it is **not possible for me to maintain outside employment**. Care-giving is not a shift I clock out of — it is continuous, medically necessary care.

Under the current system, Medicaid authorizes approximately **$36 per hour**, yet as a caregiver I receive **$17 per hour** through an agency. A significant portion of the authorized funding is retained by agencies, largely to "run payroll," leaving caregivers with wages that are not livable.

Rather than reducing authorized hours or shifting the burden onto families, DHHS should closely examine:

- How many hours agencies are billing for,
- How much of the authorized Medicaid rate is being retained by agencies, and
- Whether this structure results in waste, fraud, or abuse at the administrative level.

Families providing direct care should not lose services while agencies continue to take a large percentage off the top.

DHHS should consider:

- Setting **clear, transparent limits** on how much agencies may retain from authorized hourly rates,
- Establishing **clear statewide standards** for caregiver wages under the AD Waiver,
- Ensuring caregivers are paid a **livable median income wage**, and

- Allowing individualized hour determinations based on medical necessity rather than fixed caps.

At **$17 per hour for 40 hours per week**, a caregiver cannot meet basic living expenses, afford health insurance, or sustain long-term caregiving. For many of us, this is our **only source of income**, and leaving caregiving to “get another job” is not an option when our loved one requires care at all times. If the 40 hours are enforced a livable median hourly wage should be established and paid directly to the caregiver and not be allowed to be skimmed by any agency.

The proposed hour caps risk forcing families into crisis and pushing individuals into institutional care — which is more costly to the state and directly contradicts the purpose of Home and Community-Based Services and Nebraska’s obligations under the Olmstead decision.

I respectfully urge Nebraska DHHS to reconsider these proposed limits and instead focus on protecting medically necessary care, supporting family caregivers, and addressing inefficiencies at the administrative level rather than reducing services to those providing direct care.

Thank you for the opportunity to provide public comment.

Sincerely,
Shannon & Shawna Aitken
Elkhorn, NE.
Parent and Caregiver of a Child with Multiple Chronic Disabilities

From: Kerigan Juracek
To: DHHS HCBS Public Comments
Subject: Public comment
Date: Saturday, December 27, 2025 4:19:27 PM

You don't often get email from [redacted]. Learn why this is important

Greetings,

I am writing to oppose the proposed changes to the AD Waiver personal care program, including the reduction of weekly service hours and limits on compensation for live-in caregivers.

These changes would significantly reduce continuity and quality of care for people with severe disabilities while placing an unsustainable financial burden on family caregivers. For many individuals, 70 hours of care per week is simply not enough to meet basic daily needs, let alone ensure safety for medically complex conditions that require constant supervision. For many live-in caregivers, 40 hours a week of pay will not be financially sustainable.

Family or live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes. Cutting hours and limiting paid time will force many families to seek skilled nursing or institutional care, which is far more expensive for the state and often provides worse outcomes. These proposed cuts risk increasing hospitalizations, institutional placements, and overall taxpayer costs.

If cost containment is necessary, there are better alternatives:

- Maintain current hour limits for existing participants (grandfathering).
- Remove or revise the 40-hour cap for live-in caregivers.
- Use a needs-based assessment rather than a one-size-fits-all cap, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable individuals, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. I urge DHHS to withdraw or significantly revise these changes and pursue thoughtful, needs-based solutions instead.

Thank you for considering my comment.

From: Diane Kiichler
To: DHHS HCBS Public Comments
Subject: public comment
Date: Wednesday, December 31, 2025 1:04:53 PM

> You don't often get email from [redacted]. Learn why this is important

I cannot believe caregivers are being restricted to 40 hrs if they live with the disabled person. They have to bring in someone else??? I do not understand this. Who are you to make this decision? Are farmers restricted to care for their livestock to 40 hours? Governor Jim Pillen states he puts in long hours should we limit him to 40hrs. Are we to work for free if we choose to love and care for our disabled. I am sad this is how we treat our caregivers and disabled. I understand controlling a budget, but this is not a good thing. How would you like to have a stranger in your house that is taking care of you or in your house while you want to have a normal life? Most of us did not choose this. It just happened. Please we cannot limit the hours to 40 Hours and what about weekends. Most of these caregivers do not even get days off. If they do it is very rare. Worst of all. To find good help is almost impossible and scary. Please we cannot let this happen!!!
May God Bless You

From:	Mark Kuecker
To:	Clark, Jennifer J
Cc:	DHHS HCBS Public Comments
Subject:	Public Comment
Date:	Thursday, December 18, 2025 9:39:54 AM
Attachments:	image001.png

Some people who received this message don't often get email from [redacted]. Learn why this is important

Jenn,

Thank you for hosting the meeting yesterday and for providing the opportunity for public comment. I appreciate the way you facilitated the discussion and addressed challenging questions. I know these forums can be difficult, and you did an excellent job.

Although I previously submitted written feedback to the public comment email address, I wanted to summarize my remarks from yesterday and add one additional consideration based on my professional experience—caregiver hiring and turnover. I am also copying the public comment email address here for the record.

As President of Dads Appreciating Down Syndrome (DADS Omaha)—a nonprofit supporting fathers and father figures of individuals with Down syndrome—and as a long-time professional in the care industry, I am deeply concerned about the proposed 40-hour cap on paid live-in caregiver hours.

Consistency in care is critical. Medically complex individuals rely on caregivers who understand their routines, medications, communication cues, and early warning signs. A parent or long-term live-in caregiver develops this deep, intuitive knowledge. Allowing up to 70 hours to be provided by a single live-in caregiver preserves this continuity and results in safer, more stable outcomes.

Caregivers are not interchangeable. Dividing hours among multiple individuals creates gaps in communication, increases anxiety for the person receiving care, and raises the risk of preventable medical emergencies. For many families—particularly those caring for medically fragile children—**introducing multiple caregivers is not merely disruptive; it can be dangerous**.

The only restriction being proposed is *who* can provide those hours. Limiting a live-in caregiver to 40 hours does not reduce the amount of care needed or save money. Instead, it forces additional caregivers into the home, creating unnecessary disruption and **increased safety risks**.

An additional and critical concern is the **growing difficulty of recruiting and retaining qualified caregivers for medically fragile individuals**. Requiring families to replace a consistent, primary caregiver with multiple outside providers places an unrealistic burden on families and the system. Caregiving is already a strained workforce serving both individuals with disabilities and seniors. In the senior care industry—where I work—we are experiencing significant challenges in hiring, training, and retaining qualified staff. This proposed change would further exacerbate these workforce shortages, increase turnover, and introduce **serious continuity-of-care and safety risks**.

This is fundamentally a quality-of-care and safety issue. I respectfully urge DHHS to reconsider the 40-hour cap for live-in caregivers and to allow up to 70 hours (or more!) for a primary caregiver. This approach supports consistency, safety, and dignity while enabling individuals with disabilities to remain healthy and stable in their own homes.

Thank you again for your time, your willingness to listen, and your thoughtful consideration of these concerns. I am happy to meet with anyone to discuss further if that would be helpful.

Sincerely,

Mark Kuecker – President
D.A.D.S. -Dads Appreciating Down Syndrome
Cell 402-686-9858 | www.dadsomaha.org | www.facebook.com/dadsomaha

D.A.D.S. Omaha is recognized by the IRS as a 501c3 organization
D.A.D.S. mission is to assist and support, through fellowship and action, the fathers and families of individuals with Down syndrome.

From: Isabelle Stallbaumer
To: DHHS HCBS Public Comments
Subject: Public Comment-Reduction in Caregiver Hours
Date: Monday, December 22, 2025 8:53:47 PM

You don't often get email from [redacted] Learn why this is important

Nebraska Department of Health and Human Services,

My grandfather was diagnosed with Lewy Body Dementia when I was in 4th grade. I lived part-time with my grandmother and grandfather, and aided in his caretaking beginning at age 11 until his death from the disability. My grandmother dedicated her life to his 24/7 care, even though she was in her late 70's and early 80's. Because of her altruism, his humanity, dignity, and light remained. My grandmother refused to risk her husband experiencing neglect in long-term institution.

Though there are economic and morally dubious reasons to reduce the eligible hours (thus reducing necessary financial support) of 24/7 caregivers, I ask: What is the value of a human life? It cannot be measured with a formula, nor is it prudent to reduce necessary financial support for dedicated caregivers in an attempt to prevent abuses of this welfare system.

How do you measure the value of your loved one's lives? And what should happen to them when they become disabled in their old age, should they be blessed enough to reach it? Do you believe these families who will be impacted do not deserve the amount of necessary financial support they are now receiving, if not more?

This Department of Health and Human Services is not an entity separate from humanity, it is a cooperative of people who will never be exempt from the moral implications and consequences of their actions.

Please consider my grandmother's and grandfather's case, as well as the cases of American families before making a decision to reduce the necessary financial support of dedicated caregivers.

Thank you,
IS

From: Dustin Franklin
To: DHHS HCBS Public Comments
Subject: Public comments about proposed AD waiver changes.
Date: Saturday, January 3, 2026 9:33:44 AM

You don't often get email from [redacted]. Learn why this is important

My name is Dustin Franklin, and I am commenting today out of deep concern for my sister Emily Brooks. Emily is a disabled adult who prior to our mother's passing in 2021 was cared for by her(our mother). Since my mother's passing I have taken the responsibility and do everything I can to care for Emily on a full time basis. Emily requires very specific care due to her rare neurological condition called Aicardi Syndrome. She is fully non-verbal and is dependent on others for her every need. She currently gets to stay in her home where she is kept safe and healthy, with her family that loves her. I fear that with the proposed changes to capping in-home caregiver hours it would be very hard, if not impossible to continue the current level of care she has now. It would require lifestyle changes such that I would need to outsource her care in order to make up for the cut in hours I would receive. I strongly feel that having to do this would be a direct threat to Emily's health and safety. Taking care of Emily is a full time job, she requires around the clock care and I am grateful that I am able to provide that for her, as she deserves nothing less. Emily loves her family and her family loves her, and it would be doing her a disservice if we were forced to seek outside support for her care. Emily deserves to be home, where she is well taken care of, safe, and healthy, and most importantly loved. The current AD waiver allows Emily (and many many more like her) to remain in their homes, around their loved ones. I take care of Emily because I love her, she is not my child, this wasn't forced on me, I CHOSE it because Emily deserves the best and I will give it to her. My mother would have it no other way. These proposed changes jeopardize Emily's health and safety in a way that is very new and very scary. We have always been under the assumption that these programs are in place to protect those among us that are the most vulnerable. Those without a voice of their own. Today I will be her voice. These changes would be deeply harmful to Emily and so many like her and I would ask that you strongly reconsider the suddenness and harshness of them. For all of our disabled loved ones and the ones who care for them please consider how damaging this would be to their health and safety. Please do the right thing and don't cut funding to an already very vulnerable group of people.

From: Allen Hoffman
To: DHHS HCBS Public Comments
Subject: public comments DHHS AD Waiver
Date: Tuesday, December 30, 2025 12:21:52 PM
Attachments: state cut funding letter 2025.docx

You don't often get email from [redacted]. Learn why this is important

Please see and read below our comment concerning the budget cuts effects for DHHS AD Waiver .:

Subject Public Comment on Proposed Changes to Medicaid Home and Community Waivers

This letter is to express the profound concern my family and many others in our community have
regarding the proposed changes to the Medicaid Home and Community-Based Services (HCBS)
waiver program. These changes would be devastating to individuals with significant disabilities
and the families who care for them.
Our family includes our 29-year-old son, Nicholas, who has global developmental delays and functions at the level of an 11-month-old child. He is nonverbal and unable to communicate verbally or through assistive devices. Nicholas has complex medical needs, including tube feedings through a G-button, daily bowel flushing using a Chait button, urinary catheterization,
and respiratory support through a BiPAP machine at night because his brain does not consistently
signal him to breathe. He relies on specialized equipment such as a stander to maintain muscle tone and is fully wheelchair dependent. Nicholas is unable to perform any of his daily care independently.
For many years, I struggled to maintain employment while ensuring Nicholas received the care
he needs. When his grandmother was no longer able to assist, I reduced my hours to part-time and used FMLA to protect my job until I no longer qualified due to reduced work hours. Ultimately, I was forced to leave a well-paying job I held for 25 years. Becoming Nicholas's in-
home care provider has allowed us to keep him healthier, meet his medical and daily care needs
consistently, and ensure he attends necessary medical appointments.
Nicholas does attend a day center a few days a week to help him adapt to others providing care,
as we know that one day we may have no choice but to rely on outside caregivers. However, these centers cannot meet all of his daily needs. Staffing shortages, high turnover, and inconsistent care are ongoing issues. For individuals like Nicholas—who are nonverbal, medically fragile, and wheelchair dependent—this creates a heightened risk of unmet needs, neglect, or abuse.
Over the years, despite extensive efforts, we have had only three outside care providers complete
the requirements and follow through to provide respite care. Even at his day center, frequent staff

turnover negatively impacts the quality and consistency of his care. We have found that keeping
Nicholas at home with family caregivers ensures his needs are met daily and has been essential
to maintaining his health and safety.
The proposed reductions in care hours and limitations on family-provided care would be deeply
harmful to vulnerable individuals like Nicholas. It is difficult to understand how it is more effective—or humane—to pay non-family caregivers more while restricting family caregivers who are already providing consistent, knowledgeable, and loving care. Many families are single-
parent households or lack extended family support. The level of care required for individuals with complex needs is overwhelming, and it is most often sustained by those who love them unconditionally.

I also have personal experience with institutional care. My mother resided in a nursing home due
to dementia, and the level of care she received was so poor that I often left in tears. When parents
and guardians are willing and able to provide care at home, restricting their ability to do so only
increases the likelihood of institutional placement and poorer outcomes.
Individuals with disabilities deserve to receive care in their homes, surrounded by family, whenever possible. I respectfully urge you not to restrict care hours or further limit family caregivers. Our son’s life—and the lives of others like him—deserve the highest quality of care
from those who know and love them best.
Thank you for considering my comments.
Brenda & Allen Hoffman
[redacted]

From: Brad Thompson
To: DHHS HCBS Public Comments
Subject: Public Comments for AD waiver due Jan 5,2026
Date: Friday, January 2, 2026 1:37:57 PM

> You don't often get email from [redacted] Learn why this is important

Bradley and Debra Thompson
[redacted]

Subject: Aged and Disabled Waiver- 40 hour cap for live-in caregivers

Dear Nebraska Representatives,

This email is in response to the open public comment period for the proposed changes to the Aged and Disabled Waiver due by January 5, 2026.

President Ronald Reagan said it best when he said the most terrifying words you'll ever hear is "I'm from the government and I'm here to help." If Nebraska HHS implements the proposals set forth, we will become a nanny state similar to the mandatory mandates during Covid-19 pandemic. These proposals would be like Dr. Fauci saying, take the shot it will protect you, stand 6-feet away to prevent spread, we here to protect the vulnerable, if implemented these proposals would also be a future case study of the failure of Nebraska leaders mandating a one size fits all which will be disastrous to the families of Nebraska.

Brad has experience working at the state level with the Autism Council in Wisconsin, appointed by Governor Jim Doyle (D) and Governor Scott Walker (R) from 2004 to 2008 when the insurance mandate was implemented and the "waitlist" was removed. With appropriate representation at the state level, these proposals would never be adopted as written without parental input from state councils or advocates, and from public comment period. These proposals also fail to follow guidance in the Olmstead Act (1999) and from Supreme Court instruction, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life" and "confinement in an institution severely diminishes the everyday life activities of individuals, social interactions, work options, economic independence, educational advancement, and cultural enrichment."

It's obvious these heavy handed top down type proposals have the intentional effect of destroying the only reliable safety net our severely disabled son has in place:
- By capping live-in caregiver hours at 40 hour, while restricting non-family providers the remaining hours up to 70 hours per week. What drives these changes?
- In this waiver, the state specifies 175% of the institutional average cost as the cost

limit threshold. Limiting and capping resources.
- Intent of removing self-centered or individually directed care from the home to state institutions. Removing the parents and/or court appointed guardians.

Note: a recent 7th Circuit Court of Appeals decision affirmed a preliminary injunction on similar proposals in Indiana. Recognizing that the children deserve to live at home with their families, not being forced into institutions. The decision reinforces the understanding that children with complex medical needs are best served when they can remain in the home and that there are steps that must be taken to help ensure these children remain safely in their families homes.

Our son is 33 years old and successfully living at home. His complex needs are being met at home with his family. He is non-verbal autistic, has Graves Disease, PICA, severe GI issues with specific diet, extensive medication routine and requires 24/7 supervision, and one on one supervision in all community settings including transportation. Our son does not understand safety risks and is an elopement risk. Our son deserves to have input to the self-directed in-home care he receives, whether family or non-family. His behavior is evident when providers are not attentive or are haphazard when providing care, it directly affects his well-being.

Nebraska HHS needs to train their moderators during public comment to be respectful and not have condescending attitudes and speak in a professional manner to those parents and organizational managers on the zoom calls. I've never heard so much disrespectful tone and unprofessional language towards parents.

It is our recommendation that Nebraska HHS keep in place the currently paid 112 hours to family members and keep in place language that would be flexible with managing these hours based on provider and respite availability as there are currently no agencies that we've contacted available to assist us. The written language should give the parents the ability to be paid and to use those hours when appropriate to pay non-family providers. Our son deserves to have input in his self directed care.

Thank you for your attention.

Respectfully,

Brad and Deb Thompson
Lincoln, Nebraska

January 4, 2026

Nebraska Department of Health and Human Services
301 Centennial Mall South
Lincoln, NE 68509
email: dhhs.hcbspubliccomments@nebraska.gov

RE: Public Comment regarding proposed hours cap/caregiver restrictions for A&D Waiver

My name is Danielle Ohlman, and I am the mother and, along with my husband, caregiver of my 24-year-old son, Logan, who has profound developmental disabilities and complex health care needs. Logan's challenges began as a newborn when he suffered from meningitis, resulting in significant brain damage and several health conditions. At age ten, he experienced fulminant liver failure due to his seizure medication, requiring a liver transplant. Logan cannot dress himself, use the toilet, or prepare his own food. His speech is limited to repetitive phrases, and he has the mental capacity of a toddler. While he can walk, he does not understand how to cross a street, ask for help, or communicate about his day. He is among the most vulnerable individuals you could encounter.

Despite his limitations, Logan is constantly moving and requires round-the-clock supervision. He knows how to unlock doors, open cabinets, and climb stairs, and he puts everything in his mouth. If left alone, even briefly, he will find something to open or dismantle. We have no respite; we cannot find anyone willing to watch him due to the intensity of care required and the low reimbursement rates associated with the A&D Waiver. One agency accepted him, but only for two days a week, leaving us to provide care every remaining hour. Our attempts to enroll him in other day services have been unsuccessful, as many agencies are unwilling to take on the responsibility of caring for Logan for the compensation offered.

Logan rarely leaves our sight. Shortly after moving into our home in 2017, Logan managed to leave the house, enter a neighbor's home, and sit on their couch. Thankfully, the neighbor recognized his disabilities and returned him safely. This incident could have ended tragically and is just one example of the constant vigilance Logan requires.

Doctors have told my husband and me that our care is the reason Logan has survived this long. The quality of life he enjoys is due to our dedication and love. When I learned about the proposed changes to the A&D Waiver, I was devastated. We have been providing a tremendous service to the state by keeping Logan at home and caring for him ourselves.

This is why I urge you to stop the assault on Nebraska's most vulnerable citizens and their families. We play a vital role and will not subject our loved ones to neglect or abuse in a facility simply because it is deemed more cost-effective by Governor Pillen and NE DHHS. This is not a pro-life stance. The sanctity of these lives should be valued and protected. If Governor Pillen and his administration truly uphold pro-life values, they would cease targeting this small, vulnerable group and instead address those who truly exploit the system. We did not choose this path for our children; our dreams for them changed the moment they were born with disabilities. Since then, our only wish has been for them to live, to feel joy, and to know they are loved. We have fought tirelessly against the fragmented and discouraging NE DHHS system, striving to secure the health and safety our children deserve.

Our lives have been dedicated to battling a system that changes rules without notice or opportunity for response, deceiving us into believing our children deserve the best while simultaneously stripping away the care that ensures their quality of life. Advocates have fought for decades to move away from institutionalization, only to see policies now making it the last resort due to the state's refusal to support their care at home.

Nebraska's current approach, simply stated, is not pro-life. Governor Pillen's policies suggest that only those born healthy are valued. Those with disabilities are deemed too costly and not worth the investment of their families' expertise and dedication. This is a cruel reality for families like mine. Nebraska should be ashamed of the reputation it is creating for itself with this proposed plan.

What will your response be when families are forced to place their loved ones in understaffed nursing homes, where they may be neglected, abused, or worse? My son cannot communicate if he is harmed. He suffered injuries in day services as a child. He was scratched, bitten and kicked in the head among other injuries. I can only imagine how severe the injuries could be as an adult. How will you answer families when preventable tragedies occur in facilities, when these individuals could have been safe at home?

This is the human cost of reducing hours for family caregivers. **Governor Pillen and NE DHHS are attempting to balance the budget on the backs of the most vulnerable.** There is nothing honorable about this. In fact, it is disgraceful.

Nebraska is not a business. The government has a moral and legal obligation to care for all its residents. Running the state like a business, where profit outweighs people, is not only misguided but dangerous. I have included links to recent stories outlining the potential for mistreatment and even death that individuals with disabilities will be at increased risk for should you cap hours for parent caregivers and force their hand where they have no other option than to institutionalize their adult children. Nebraska should prepare to be identified in articles such as these should they decide to move forward with the proposed changes. Governor Pillen will be judged accordingly for lowering the state's ethical standing, making it very clear that he as the Governor of the State of Nebraska does not value human dignity for all its people. NE DHHS will fare no better.

I implore you to reconsider these policies and to recognize the invaluable service that families like mine provide that deserve to be compensated. Please ensure that the most vulnerable Nebraskans are protected and supported, not sacrificed for budgetary convenience. Do not allow these budgetary pressures to eclipse your moral and legal obligations. Reject any policy that would force families into impossible choices that would institutionalize those who can and should be cared for at home. The decisions you make in this moment will have irreversible consequences for our families. I urge you to recognize that these are not abstract policy changes—they are matters of life, dignity, and fundamental human rights. To proceed with these cuts is to knowingly place individuals at risk, to undermine the very values of compassion and justice that should define our state, and to shift the burden of care onto those least able to bear it. Please act with the integrity, and humanity this moment demands.

Stepping back from the proposed reductions and caps is absolutely necessary to prevent further harm to waiver participants and Nebraska families. We will not rest until our children are treated with the dignity and respect they deserve.

Respectfully,

Danielle M. Ohlman

Cc:

Sen. Brian Hardin, Chairperson: bhardin@leg.ne.gov
Sen. John Fredrickson, Vice Chairperson: jfredrickson@leg.ne.gov
Sen. Beau Ballard: bballard@leg.ne.gov
Sen. Ben Hansen: bhansen@leg.ne.gov
Sen. Glen Meyer: gmeyer@leg.ne.gov
Sen. Dan Quick: dquick@leg.ne.gov
Sen. Merv Riepe: mriepe@leg.ne.gov
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jeff.powell@Nebraska.gov

My Son Logan

Please explain to us why you think it would be better to cap the hours we care for him. He is living the best life possible in a home where he so loved and receives the best care. And he is happy and healthy. And it is still more cost effective for him to receive this care at home than putting him in a facility.

Below are a multitude of regulations the proposed changes would be in violation of. The proposed policies conflict with federal law and regulations governing Medicaid Home and Community-Based Services (HCBS) waivers, including:

- **42 U.S.C. § 1396n(c)** and **42 C.F.R. § 441.302**: Require that waiver services be determined through person-centered planning, based on individual assessed need, and sufficient in amount, duration, and scope to meet those needs. **Blanket caps on hours or compensation based solely on family relationship are not permitted**.
- **42 C.F.R. § 441.301(c)(1), (4)**: Mandate that services be determined through person-centered planning and not rely on required unpaid "informal supports." States **may not presume that parents of adult beneficiaries must provide uncompensated care** as a condition of waiver participation.
- **42 U.S.C. § 1396a(a)(30)(A)** and **42 C.F.R. § 441.302(a)**: State payment methodologies must ensure access to covered services comparable to the general population. Payment limitations that render providers unavailable or unwilling to serve waiver participants undermine access, health, and welfare assurances.
- **42 U.S.C. § 1396a(a)(23)** and **42 C.F.R. §§ 431.51, 441.301(b)(1)(i)**: **Guarantee waiver participants the right to choose among qualified providers, including individual caregivers**. **Policies that make parent caregivers financially or logistically unsustainable effectively eliminate that choice.**
- **42 C.F.R. § 440.230(b)**: Requires that services be sufficient in amount, duration, and scope to reasonably achieve their purpose. Policies that systematically prevent services from meeting assessed needs violate this standard.
- **Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. §§ 12131–12134**, and the Supreme Court's decision in **Olmstead v. L.C., 527 U.S. 581 (1999)**: Prohibit unnecessary institutionalization and require services to be provided in the most integrated setting appropriate.
- **CMS Oversight**: Approval of the A&D Waiver is conditioned on Nebraska's compliance with federal assurances. CMS retains authority to require corrective action where state policies violate federal requirements or place beneficiary health, welfare, or rights at risk.

Additional Information:

As a reminder of what has happened in Nebraska's somewhat recent past, I have included the link to the LR283 Report of the DD Special Investigative Committee regarding Beatrice State Development Center (BSDC) from 2008: https://nebraskalegislature.gov/pdf/reports/committee/select_special/ddsi/DDSI_2008_LR283.pdf.

Check out pages 13, 14, 15, 22, 23 for just some quick reminders of the potential for abuse and neglect when ICF's are understaffed/not monitored. This is not meant to place any shadow on BSDC now, as I've been told things have improved there. This is to show you what can (and

eventually will) happen if we start to institutionalize all our disabled because their parents can't afford to care for them. This is not the 60's when families didn't want to deal with their loved ones. This is 2026 where the government gives families no choice but to consider institutionalization because families can't afford to care for their loved ones at home.

I am also including a link to the DOJ's letter to Governor Pillen in May of 2024 regarding violations of Title II of the Americans with Disabilities Act. While the letter addresses Nebraska's administration of its behavioral health service system, it discusses Nebraska's attempt to segregate individuals with severe mental illness in assisted living facilities and segregated day programs. It is interesting to note that the DOJ stated in its letter only 18 months ago that, " the state has underdeveloped its workforce necessary to provide access to community-based services." Yet DHHS wants to cap a family caregivers' hours at 40, in certain cases allowing 70 hours only allowing those extra hours to be performed by someone other than the family member. With an underdeveloped workforce to provide these services, how easy does the state think it will be for family members to find someone to take those 30 hours of care?
https://www.justice.gov/crt/media/1351746/dl

Lastly, I have attached articles regarding individuals with disabilities being abused and neglected in institutionalized settings. These are all within the last few years. We are foolish to think this could never happen here again.

New Hampshire Bulletin

State senators to file legislation addressing abuse and neglect in NH's disability care system

BY: **WILLIAM SKIPWORTH** - DECEMBER 26, 2025 2:22 PM

Sen. David Rochefort said he and his colleagues are "still working out the finer details" of the bill. (Photo by William Skipworth/New Hampshire Bulletin)

State Sen. David Rochefort, a Littleton Republican, said he and the state's legislative staff are in the process of drafting a late bill aimed at addressing systemic abuse and neglect issues in New Hampshire intellectual and developmental disability care system.

In November, the Bulletin published a series of articles outlining abuse and neglect — sometimes fatal — committed by caretakers against people with disabilities. The stories also uncovered systemic failures of oversight and prevention that allowed the abuse and neglect to happen. State records obtained by the Bulletin show that from January 2023 through the first six months of 2025, 467 credible reports of abuse, neglect, and exploitation against people in the system were investigated by the state. The records also show 119 deaths occurred across the system during that time.

People with intellectual and developmental disabilities are legally entitled to care funded and overseen by the state. In New Hampshire, the Department of Health and Human Services'

Bureau of Developmental Services contracts with 10 private area agencies, each responsible for a region of the state, to coordinate the care.

While investigating these tragedies, the Bulletin spoke with several family members of people within this system who were abused or neglected, their attorneys, and advocates within the community. Rochefort, who is chairman of the Senate Health and Human Services Committee, said the series alarmed him and pushed him to look into the issue.

> "I don't think there's any opposition to making change here," Rochefort said. "I think there's a real desire to do something now from everyone involved, even senators who are not on (the Health and Human Services Committee), who approached me on this."
>
> He said colleagues from both parties have expressed support for the effort.
>
> "I think that you're going to see action happen sooner rather than later," Rochefort said. "Nobody wants to kick the can here."
>
> Rochefort said he and his colleagues are "still working out the finer details" of the bill, but it'll seek to strengthen oversight and improve data sharing to allow officials to better identify issues.

"Data on these things would be shared automatically, rather than the way that it's shared now," he said. "And it would give the state a better way to either respond to complaints or take action if there's an issue."

He also said the bill changes the composition of the Incapacitated and Vulnerable Adults Fatality Review Committee — a panel established by state law to review concerning deaths and make recommendations on how the state can prevent similar deaths in the future — to allow for "better representation of the communities affected and the people that would actually be able to affect change."

The Bulletin previously reported on the December 2022 death of Stephen Weidlich Jr., a man with physical and developmental disabilities who was found dead behind the care home where he lived. Additionally, in July 2019, Christine Marie Bill, a woman with disabilities, was found dead after overheating in a hot, sealed car, according to the Bulletin's reporting. Before the Bulletin published its findings, the co-chairs of the Incapacitated and Vulnerable Adults Fatality Review Committee, Vanessa Blais and Francesca Broderick, said they hadn't been told about either death and that each should have been reviewed by the committee.

New Hampshire Bulletin

A series of tragedies exposes patterns of abuse and neglect in New Hampshire's disability system

BY: **WILLIAM SKIPWORTH** - NOVEMBER 10, 2025 5:00 AM

Community Bridges, based in Concord, is one of 10 nonprofit area agencies in New Hampshire serving people with disabilities. The agencies "operate within the guidelines and regulations established by the Department of Health and Human Services." (Photo by Allegra Boverman/For the New Hampshire Bulletin)

This is the first in a three-part series on New Hampshire's intellectual and developmental disability care system. Click here to access the full series. This story was updated to clarify the Lyme caregiver's licensure; she was an LNA not an RN.

A VIDEO RECORDED at a Dunbarton care home for people with intellectual and developmental disabilities in February 2019 captured caretakers pinning Lucas Houle to the ground and slapping him repeatedly. Amid his pain and fear, Houle made a tearful plea: "I want to go home."

A System Of Harm

Four months later, Christine Marie Bill was found dead after several hours in a hot, sealed car in Andover, according to the lawsuit filed in the wake of her death and a State Police incident report. Bill, due to her cognitive disabilities, had a history of leaving the house, and it was her caretaker's job to check on her every 15 to 30 minutes.

In March 2023, a woman named Laurie Raymond, who has cerebral palsy and is nonverbal, was living at a residential facility in Lyme when she suffered second-degree burns to her abdomen, legs, and genital area. An employee caring for Raymond placed her under scalding water and then scrubbed the burns, resulting in a $45,000 medical bill, according to a malpractice lawsuit filed by the family.

While every story of abuse and neglect within New Hampshire's intellectual and developmental disability care network is unique in the harm caused, collectively they point to the state's systemic failures in oversight and accountability. Over the past several months, the Bulletin has learned about people like Houle, Bill, Raymond, and others through court filings, law enforcement documents, state records, and conversations with lawyers, advocates, and family members. Their stories are being reported for the first time here. Each individual tragedy is illustrative of the consequences of repeated breakdowns in care — care that is paid for and overseen by the state.

DO YOU HAVE information or experience with New Hampshire's intellectual and developmental disability system you'd like to share?
The Bulletin would like to speak with you. Please email wskipworth@newhampshirebulletin.com or send an encrypted message via Signal to WillSkipworth.80.

According to state records obtained by the Bulletin, New Hampshire investigated 1,405 complaints of abuse, neglect, and exploitation committed against people with intellectual and developmental disabilities receiving state services from January 2023 through the first six months of 2025. Of those, 467 were deemed credible after a state investigation, according to the records. Some of those complaints include physical and sexual abuse. Eighteen of the complaints were withdrawn before the investigations were complete, and 28 complaints were ongoing investigations when the records were produced.

Additionally, state records show 119 people died in New Hampshire's intellectual and developmental disability system from January 2023 through the first six months of 2025. Of those deaths, 79 were deemed "anticipated" by the state — state officials wouldn't answer the Bulletin's questions about how they defined anticipated — and at least 22 were categorized under "unknown" cause of death.

📷 This mortality report, obtained by the Bulletin through an open records request, details deaths within New Hampshire's intellectual and developmental disability care system. The state declined to provide more documentation to add context to the nature of the deaths.

Holly Haines, a Manchester attorney who represented the Bill family, said that case taught her a lot about New Hampshire's disability care system.

“The state is hiring vendor private agencies,” she said. “The private agencies are hiring private people, and not training them or educating them adequately, and it’s ultimately the disabled individuals who are harmed.”

There is more “fingerpointing,” she said, than taking responsibility.

“I don’t think the state knows what’s actually going on in the households,” Haines said. “I’m not sure the vendor agencies even are aware.”

In a written statement issued in response to the Bulletin’s requests for an interview with Department of Health and Human Services Commissioner Lori Weaver, among other state officials, for this investigation, DHHS spokesman Jake Leon said that the department can’t comment on individual cases but “has a process in place to review and investigate complaints made against providers and vendors licensed or certified through the Department.”

The office of Gov. Kelly Ayotte shared a similar statement: “DHHS has a process in place to review and investigate complaints, and the Governor will be monitoring this issue closely.”

Daily beatings

When Lucas Houle, who has intellectual and developmental disabilities, was pinned to the ground and slapped by his caretakers, he screamed, “Please stop, please stop, don’t beat me up.”

> The incident was captured in a video taken surreptitiously in February 2019 by an employee of Houle’s care agency and described in detail in a Dunbarton Police Department report obtained by the Bulletin. The video, according to the report, shows an obscured view of Houle’s live-in caretakers, Bikash Shrestha and Dilux Timsina, pinning Houle to the floor of their Dunbarton home while he cries. As the caretakers straddled Houle and repeatedly slapped him across the face, they advised each other on where and how to strike him in a way that wouldn’t leave bruising.

The video, as described in the police report by an officer, shows a caretaker bending Houle’s finger backward as punishment for brandishing his middle finger, ostensibly what sparked the incident. Houle cries out, “Please don’t break my finger” in response.

Houle can be heard crying and screaming: “I won’t do it again, I won’t do it again”; “I’ll be good! I’ll be good! I promise!”; and “No, no, no, please stop.”

At the end of the video, Shrestha tells Houle he isn’t allowed to use a toilet and that he must urinate in the living room. Timsina tells Houle he must remain on the ground. Pitambar Thapa, who recorded the video, told police the two made Houle lie in his own urine for half an hour after the video ends.

Pitambar Thapa told police the physical, verbal, and psychological abuse continued on a daily basis for at least 10 months. He told police he was initially afraid to report the abuse and provide the video to authorities out of fear of retribution.

Houle, in his 40s when the abuse happened, has the mental capacity of a child. He's been diagnosed with intellectual disability, ADHD, mood disorder, schizophrenia, intermittent explosive disorder, and other disabilities. He has behavioral issues as a result.

Dunbarton Police Department
SUPPLEMENTAL NARRATIVE FOR DETECTIVE LAURA J CATTABRIGA
Ref: 19-257-OF

I then started the recording and asked Pitambar to walk me through what was happening at the time, if he could recall. At the beginning of the recording it is only audio as Pitambar has the phone in his pocket. Lucas can be heard saying, "I won't do it again, I won't do it again" and then screaming "owwwww." Pitambar said he could not remember what was happening at that moment but that it was Bikash SHRESTHA's voice he hears on the recording first. Lucas is then heard yelling, "I'll be good, I'll be good, I promise." I pointed out that Lucas' voice sounded muffled and asked if he was on the ground at that point, Pitambar said that one of the guys had his hand over Lucas' mouth but he could not recall which one. Bikash then says "You are not going home Tuesday" and Lucas replies "I want to go home." You then hear Bikash ask why he put up his finger and Lucas replies "I won't do it again" and then another "why?" in a raised voice followed by a slapping noise. I ask Pitambar what that noise was and he said that Bikash hit Lucas in the side of the face and demonstrated it with an open hand. Lucas is heard immediately reacting to this slap by crying loudly and saying "I won't do it again" over and over again and then saying "no no no please stop." I asked Pitambar what was happening then and he said they were now on the ground and that they would both straddle over his chest and slap him. He said that they would change positions, sometimes Dilux TIMSINA would be in front and sometimes Bikash SHRESTHA was in front. Pitambar said that during this incident Dilux TIMSINA hit Lucas as well. Pitambar then demonstrated how Lucas was laying on the ground and Dilux would grind his foot into the back of his calf. Lucas is then heard crying and saying "I'll be good I promise" over and over again and another slap can be heard. Pitambar said that Dilux was the person who slapped him that time in the face and in the body. He said the hits were always open handed. Lucas cries out a few more times and you can hear the two men talking. I asked what they were saying and Pitambar said it was Bikash saying "hit this side, don't hit on the other side" and demonstrated hitting in the thigh area because "day guys hit too much" and that Lucas was going to his mom's tomorrow and if they hit too much on one side it would be bruising. Lucas then continues to cry out and says "please stop please stop don't beat me up." Pitambar said he does not remember who was hitting Lucas at that time. Lucas then says hes on his way down and to stop. He still continues to cry out and sounds pained. I asked Pitambar decided to start taking this video because it was not a one day or two day thing, it was every single day they would hit him and he did not like that.

The end of the video Bikash tells Lucas he cannot go to the toilet but that he would have to pee in the living room. You then hear two more slapping sounds and Pitambar says that both, Bikash and Dilux were slapping him. Bikash then says "give me that finger" and Lucas says "please don't break my finger," and cries out. Pitambar says that one of them was bending his middle finger backwards but did not remember which one of the two did. The camera is then taken out of the jacket pocket and Bikash SHRESTHA is seen straddling over Lucas' chest. Lucas is lying face up on the floor. Dilux TIMSINA is standing to the left of Lucas' body. The incident seems to be calming down and Lucas is saying "sorry" and Dilux tells him to roll over and stay on the ground for an hour. I asked if they would make him stay on the ground for an hour, and Pitambar said that it was half an hour that time. The video then ends.

In the above graphic, excerpts from pages four and five of the Dunbarton Police Report detail the brutal abuse from the police officer's perspective. (Graphics by Molly Rains/New Hampshire Bulletin)

He was living in and receiving care at a home operated by the care agency Summit New Hampshire at the time of the abuse. In New Hampshire, people with intellectual and developmental disabilities are entitled to receive services through the Department of Health and Human Services' Bureau of Developmental Services, which has contracts with 10 private

area agencies, each responsible for a region of the state, to coordinate care. Those area agencies sometimes subcontract with other vendor agencies to provide that care. In Houle's case, the area agency Community Bridges hired Summit to provide care and a Vermont-based organization called Aspire Living and Learning to provide behavioral support. The care is paid for through Medicaid and other state and federal dollars.

> Pitambar Thapa told police Houle's two caretakers — along with a third named Uttam Thapa — would regularly hit Houle with an open hand, step on his calves, and strike him in the arch of his foot. He said the three would lie about their whereabouts, pretending to be in the community when they weren't, police records indicate.

Houle's family sued Summit, Community Bridges, Aspire, and several officials at those organizations. The parties settled the case in July. In separate criminal cases, Shrestha and Timsina pleaded guilty to simple assault in 2020 and Uttam Thapa entered a special plea in which he accepted conviction for simple assault but didn't admit guilt. Shrestha and Timsina were sentenced to nine months in jail while Uttam Thapa was fined $500, according to court records. Pitambar Thapa was not charged.

Houle is now living with his mother.

Kristin Ross, an attorney representing (along with her law partner Cristina Rousseau) Houle's family and speaking on their behalf, told the Bulletin when she first heard what happened to Houle, "I was physically sick to my stomach."

"It was incredibly difficult to listen to the video and audio and hear Lucas begging for them to stop," she said.

There were plenty of red flags regarding Houle's care that the state missed.

Community Bridges' relationship with Summit was new when it hired the agency to care for Houle in 2018. Internal documents from Community Bridges made public during litigation show the formal vetting process for Summit wasn't completed until May 2019, months after Houle was placed in its care.

Also, the caretakers were required by state regulations and the service agreement to submit reports each month detailing their activities with Houle, what progress was being made on his behavioral and developmental goals, and any incidents that occurred. Many of those reports, which were also made public as part of the litigation, are verbatim, or near verbatim, copies of one another. The language appears to be copy and pasted (with the same typos) and small, very

specific details repeated. The caretakers' supervisors and Houle's behavioral team were required to review those reports, but no one appears to have questioned why they never changed.

📷 These progress reports, revealed during litigation, show Houle's care team writing verbatim, or near verbatim, copies of notes that are supposed to document Houle's progress on his goals.

Additionally, Matthew Green, an Aspire employee, was assigned to be Houle's behavior analyst and was responsible for his care plan. Green told police he saw the video of Houle being abused, according to the police report. While he reported it to the Bureau of Adult and Aging Services, Green and his colleagues didn't remove Houle from his abusers until almost a month after he was made aware of the footage. Green, who was a defendant in the lawsuit but never criminally charged, didn't respond to the Bulletin's requests for an interview or comment, though the July settlement barred him from speaking about the case.

Under the terms of the care plan, Green was required to spend an average of six hours each month observing Houle's care team. But billing records revealed during litigation show he spent just 2.5 hours with Houle and his team in total over the roughly eight months between the day of the video and Houle's removal from the home. The defendants argued during litigation more time spent with Houle wouldn't necessarily have increased the likelihood that someone would've discovered he was being abused and that Aspire may have failed to log all of Green's time spent observing. They also noted he could spend less time one month and more another if it all averaged out to six hours, but no evidence brought in court shows Green provided enough hours the other months to bring the average up.

When the parties in the lawsuit settled under undisclosed terms, they were barred from speaking about the case. The Bulletin reached out before and after the settlement, but Community Bridges and Aspire didn't respond to requests for comment, while Summit declined to comment. The Houle family's lawyers, Ross and Rousseau, spoke to the Bulletin before the settlement, but stopped commenting on the case afterward.

Overheating in a hot car

It was a July evening when Christine Marie Bill, 46, was found unresponsive in a hot car, the doors and windows closed, in the driveway of the Andover home where she lived, according to both the lawsuit and police records. She'd been there for roughly six hours and was pronounced dead at approximately 7:10 p.m. after EMS, State Police, and a medical examiner responded.

Ten years earlier, an insulin overdose left Bill with a number of disabilities, including cognitive/memory deficit, brain dysfunction, and a seizure disorder; as a result, she had a history of leaving the house for unexplained reasons, according to the suit. Security footage from the home showed Bill leaving the house and walking toward the car that day herself unbeknownst to the caretakers, according to the police report. It was the caretakers' job, as

outlined in the care agreement, to check on Bill frequently. A wrongful death lawsuit filed by the family alleges they weren't properly trained on what those check-ins entailed.

For Bill's care, Community Bridges contracted with Independent Services Network, which hired the caregivers. The care plan, created by the two organizations in collaboration with the Bill family, explicitly said, "She cannot be left alone and requires 24/7 supervision in the home with eyes-on in the community as her safety skills are minimal," according to the suit.

The case was settled in 2023, with the defendants maintaining they weren't negligent. The terms of the settlement are confidential and, according to Haines, the plaintiffs' attorney, barred the parties from speaking about it. Neither Community Bridges nor Independent Services Network responded to the Bulletin's requests for comment or an interview.

"What was very clear," Haines, who couldn't comment on Bill's case but did discuss the system at large, said, "is just the complete lack of oversight that there is in the system itself. Just a complete systemic breakdown. Everyone is checking boxes to try to comply with administrative regulations, but no one is doing anything substantive."

The biggest part of this breakdown, she said, is the lack of change after tragedies to prevent future tragedies.

"Incidents are reported because they have to be reported," she said. "But nothing is done to do any sort of root cause analysis or investigation and change to the system. … It really doesn't matter how many incident reports you file if no one's doing anything in response to them."

Burned by scalding water

Malpractice reports from January 2023 to March 2025, obtained by the Bulletin through records requests, reveal that claims of abuse, neglect, and exploitation are common. While state officials said they couldn't say which reports were substantiated upon further investigation, citing state statues, many involve reports of physical, verbal, sexual, psychological, and emotional abuse.

One complainant reported that a resident was “kicked in the ribs” and had her “wrist broken by her aide.” Another said the caretaker “punched (the resident) in the eye and the jaw.” Another said the caretaker “grabbed her by the shirt pushed her and kicked her.” In another, “staff hit him in the face.”

Staff were having sexual relations with those in their care, others reported. Multiple others described staff sexually assaulting residents or not preventing residents from sexually assaulting one another.

Several claimed people who require 24-hour care and supervision for their disabilities were left unattended. There were reports of staff sleeping on the job, intoxication, and drug use. Some cited concerns about unsafe living quarters, including mold in the shower, exposed live wiring, lack of running water, roaches and rodents, and feces or urine on beds and furniture.

Raymond was the subject of one of the reports. Her family ultimately filed a lawsuit. In March 2023, Raymond’s caretaker — a licensed nursing assistant from Mississippi hired by travel nursing agency TLC Nursing — allegedly put her under scalding water in the shower at her Lyme care facility, resulting in second-degree burns, according to a malpractice lawsuit filed by the family.

The caregiver, seemingly oblivious to the damage Raymond suffered to her abdomen, legs, and genital area, saw redness on Raymond and allegedly proceeded to scrub the burned areas clean. The caretaker reportedly noted that skin peeled off during the scrubbing, but still didn’t realize she was scrubbing burn wounds, according to the lawsuit.

Three round burns, the size and shape of the showerhead, were discovered on Raymond by another caregiver, according to the suit. Raymond was subsequently taken to Dartmouth Hitchcock Medical Center, where she was reportedly treated in the burn unit, and incurred $45,000 in medical costs, per the lawsuit.

The facility where Raymond lived was operated by the area agency PathWays of the River Valley. Like that of Houle and Bill, Raymond’s care was overseen by the state’s Bureau of Developmental Services and paid for through state and federal dollars.

The family’s lawsuit, filed in October 2024, named PathWays, TLC Nursing, and the woman who reportedly burned her as defendants. A settlement reached in March bars the family from speaking about the case. PathWays didn’t respond to the Bulletin’s request for an interview or comment, though they were similarly barred from speaking after the settlement.

Coming Wednesday in A System of Harm, Part II: *In December 2022, the body of Stevie Weidlich Jr. was found in the woods of the Allenstown house where he was being cared for. His family remembers a once-joyful young man who hoped to one day have a place of his own, a girlfriend, and,*

above all, a normal life. But those dreams were dashed within a disability care system that was supposed to keep him safe.

MISSOURI INDEPENDENT

Developmentally disabled Missourians suffer abuse, death in state's dysfunctional system

From 2017 through 2023, roughly 2,680 people with developmental disabilities died under the care of the state of Missouri — on average, one person every day

BY: **WILLIAM SKIPWORTH** - FEBRUARY 24, 2025 5:55 AM

A registered nurse, Dina Lester left her job working for the state in part over concerns about its poor level of care (Anna Spoerre/Missouri Independent).

This story was commissioned by the River City Journalism Fund.

After Ronald Scheer was found suffocated to death by the straps of his own wheelchair, an autopsy determined his cause of death was "hanging."

Scheer, a man with developmental disabilities and mobility issues who used a wheelchair, was living at the state-run St. Louis Developmental Disabilities Treatment Center in St. Charles in June 2020 when one of his caretakers allegedly failed to secure all the safety belts keeping him in his wheelchair, according to court documents in a wrongful death lawsuit filed by his legal guardian.

Then, the caretaker allegedly left Scheer alone despite the fact that his prescribed care plan required them to check in on him every 30 minutes and reposition him every two hours. During

that time, Scheer reportedly slipped down the wheelchair, his neck fell into one of the straps and he suffocated.

Scheer's caretakers were not held responsible for his death because a court ruled that, as public employees, they were immune from civil suits regarding negligence on the job.

But Scheer is not the only Missourian with disabilities whose death raised troubling questions.

A review of state records, court documents and department policies, as well as interviews with frontline employees working in the state, reveal a dysfunctional developmental disability system riddled of accusations of abuse, neglect, and in some cases, concerning deaths.

From 2017 through 2023, 74 people with developmental disabilities died in some sort of accident while in state care, according to state records obtained by the River City Journalism Fund. Additionally, nine homicides and seven suicides occurred amongst this population during that time, according to the records. Another 2,200 died of natural causes and 392 had an "undetermined" cause of death.

In total, from 2017 through 2023, 2,682 people with developmental disabilities died under the care of the state of Missouri — on average, one person every day.

Lisa Goodman, 57, died at Center for the Developmentally Disabled in 2019 after choking on a hot dog (Anna Spoerre/Missouri Independent).

Lisa Goodman, a 57-year-old Warrensburg woman with developmental disabilities, is another one of those people. Two months after moving into a Kansas City group home, she choked on a hot dog given to her by her caretakers and died.

Goodman's group home was run by an agency called the Center for Developmentally Disabled. Her disabilities meant she required a special diet with non-solid food so she wouldn't choke.

Yet on this day in July 2019, her caretakers, who'd been briefed on her diet, gave her a hot dog. At the time she choked and died, the caretakers had stepped outside, despite the fact that her prescribed care plan required a caretaker to supervise her while she ate, according to multiple employees who worked with Goodman or had direct knowledge of the situation but asked to remain anonymous out of fear of retribution from their superiors.

An investigative report provided by the Jackson County Medical Examiner's Office confirms that Goodman died from asphyxia due to choking on July 27, 2019.

Goodman was a ward of the state, meaning the state of Missouri, via a public administrator, was her legal guardian. As with Scheer and around 7,500 others with disabilities like Down syndrome or severe autism, the Missouri Department of Mental Health's Division of Developmental Disabilities was responsible for her care and well-being through residential services.

That care is paid for with Medicaid. Most of these people, including Goodman, live in private facilities contracted by the state; about 250 live in state-run facilities like Scheer, according to the department.

The Department of Mental Health declined to provide any documentation on Goodman's death including medical records, law enforcement documents, event reports or death notifications, citing various state statutes.

The Center for Developmentally Disabled did not respond to requests for comment.

Goodman and Scheer died two and three years, respectively, after a high-profile death involving another ward of the state's Division of Developmental Disabilities. That death sparked calls for change. But people with knowledge of the department's workings say that never happened — and as result, people with disabilities remain at risk.

Brandy Sisk of Forrest City has a son with disabilities who was under the state's care until she successfully fought for his return home.

"These people are treated less than human," Sisk said.

Carl DeBrodie

When Carl DeBrodie's caretakers discovered him convulsing, screaming and bleeding from the nose one night in 2017, they did not call 911, according to court documents in a wrongful death lawsuit filed by his family. Instead, they put him in a bathtub and left him under running water.

DeBrodie died that night.

He was living at a facility in Fulton operated by Second Chance Homes, a private care agency contracted by the state, according to the suit. Two caretakers at that facility, Sherry Paulo and Anthony Flores, forced DeBrodie multiple times to leave the facility and come to their home to do chores. He slept on the basement floor. At their home, DeBrodie was even forced to fight another Second Chance resident for their amusement, the lawsuit alleged.

It was on one of the nights as DeBrodie was sleeping on the basement floor of their home that he died of a seizure, according to the court documents.

The lawsuit, which named the state, Second Chance Homes, the caretakers and several others as defendants, ended in 2018 with a settlement to the family. Paulo and Flores were convicted on civil rights and obstruction charges – including willfully failing to provide necessary care resulting in injury and death, healthcare fraud and falsifying a document to impede, obstruct and influence a federal investigation – and sentenced to 17 ½ years and 15 years and 8 months in prison respectively.

DeBrodie's death was highly publicized, and calls for reform came from the Missouri Developmental Disabilities Council, a federally funded council appointed by the governor to advocate for people with developmental disabilities.

"The Council has been following Carl DeBrodie's story and has high expectations that once all investigations are completed that there will be justice for Carl and that there will be necessary systemic changes implemented so that others may avoid such a gruesome death and lived experience," their 2018 statement read.

However, interviews with people working in the field as well as a close look at department policy suggest those systemic changes never happened. Similarly, state and court records show that stories of abuse, neglect and death within Missouri's developmental disability system are common.

Jessica Bax, the director of the Division of Developmental Disabilities – who, since being interviewed by the River City Journalism Fund, has been nominated by Gov. Mike Kehoe to be the next director of the Missouri Department of Social Services – and Debra Walker, a spokesperson for the Department of Mental Health, declined to discuss any specific deaths or incidents due to privacy laws, including those of Scheer and Goodman.

However, when asked about the number of people dying in state care, Bax questioned whether the rate of deaths was actually high, pointing to the fact that the division has a steadily aging population.

State records also show 1,858 reports of verbal, sexual or physical abuse from 2017 through 2023. Bax said she thinks the high number of reports is, in some ways, a good thing.

"You always want, if someone sees something, to say something," Bax said. "We definitely want anyone who has any sort of concern to make sure, no matter how small they think that is, to be reporting it."

The state declined to provide further records to clarify the circumstances of any of the deaths including event reports, law enforcement reports (even on the homicides), medical records, autopsies or any other administrative documentation, citing various state statutes.

However, the Department of Mental Health said in an email that it only investigated two of the 10 most recent accidental deaths (at the time of the records request) for abuse or neglect. One investigation was ongoing and the other reportedly found no substantiated abuse.

It also investigated two of the five most recent suicides, and both found no substantiated abuse, it said. The department declined to provide records on any of the investigations it did complete.

Dina Lester

Dina Lester is a registered nurse from Kansas City who worked within the system for almost 10 years. She left in 2020 partially because she was disappointed with the poor level of care and lack of change following DeBrodie's death.

"There's been no changes into the processes that allowed that to happen in the first place," Lester said.

In DeBrodie's situation, multiple safeguards meant to protect him failed. None of those have been significantly amended since his death.

First, according to division policy, the abuse and neglect suffered by DeBrodie, which went on for months or perhaps years, should've been reported and corrective action taken long before his death.

Procedures for how complaints of abuse and neglect — in addition to misuse of funds or property — should be reported and investigated are outlined in Division Guideline No. 68. While it's been amended several times since DeBrodie's death, Bax acknowledged the changes "have not been substantive in terms of how things were done." She said the changes were "more to update in terms of clarifying or reflecting our changes in structure and process."

Lester said the reporting system is completely flawed. She made multiple reports via email and phone about abuse and neglect and saw no change. She provided the River City Journalism Fund with screenshots of such emails. She suspects regional offices investigating reports are incentivized to say deaths weren't preventable and abuse or neglect incidents weren't serious enough to warrant action.

Lester believes the reported number of abuse incidents is an undercount. She's seen abuse and neglect happen without an event report created, even when a mandatory reporter witnessed it, and she's seen reports she believed were serious go uninvestigated.

When asked what measures are in place to ensure incidents are actually reported, Bax said staff at facilities are mandated reporters and are required to undergo training on abuse and neglect. Division policy also requires a case manager to make face-to-face visits monthly to check on residents and verify their well-being.

In DeBrodie's case, this system failed.

Tiffany Keipp, with Callaway County Special Services and the Department of Mental Health, and Melissa DeLap, a registered nurse, were required to conduct visits with DeBrodie. Neither of them did in the final months, and the lawsuit alleges they filed false reports claiming they did. DeLap eventually pleaded guilty to health care fraud and admitted to signing seven months worth of false reports claiming she'd seen DeBrodie when he was already dead.

Still, there have been virtually no changes to this process.

Missouri's Department of Mental Health building in Jefferson City (Annelise Hanshaw/Missouri Independent).

Like DeLap, Lester was tasked with performing these monthly meetings. She said they've always been flawed.

She said she'd give a facility staff a list of things to be done, and they often just wouldn't do them. There was no system to ensure nurse recommendations are taken and no consequences when they aren't, she said.

"It was simple stuff like calling and making a dentist appointment or a physical or going in and getting labs done," Lester said. "I mean, it's not difficult. It wasn't rocket science, but month after month after month, the same stuff would be on the list."

Bax said the division has a monitoring process and an annual review system. She also said every case manager has at least one of their cases reviewed each year.

Lester called this "ridiculous" and questioned whether it's comprehensive enough. She also said there's a culture of fear within the system. People who speak up about the poor level of care are retaliated against by their superiors, she said. "What happens is people start speaking out and complaining, and then they find a way to get rid of them and basically push them out."

The River City Journalism Fund spoke with four other nurses, caretakers and frontline staff members who wouldn't go on the record or requested anonymity out of fear of retaliation from their superiors. They made statements similar to Lester's.

Randy Vought

Randy Vought has seen the flaws in the system firsthand.

Vought, who lives in Independence, worked as a support coordinator and then program director at Missouri Mentor and Heritage Residential, private agencies like the ones that cared for Goodman and DeBrodie, from 1986 until he retired in 2020. His job was to advocate for people with developmental disabilities in state care, help their families navigate the system and determine the best care options.

Over his decades-long career, Vought grew disillusioned. He said many deaths "slip through" the state's processes.

Missouri Mentor, which has merged with Heritage Residential, did not respond to requests for comment on Vought's allegations.

For example, state policy says that an autopsy should be done by a medical examiner if there is concern about the death. However, Vought said this happens "rarely." During the 34 years he worked in Missouri, he only heard about one time a medical examiner got involved, and that was because a facility wanted to know whether the person was using drugs before their death.

"If there is a suspicious death that occurs in Kansas City, the police do the report and then the coroner is called and a coroner makes the determination of what was the cause of death," he said. "But if it's an individual in the [care of the] Department of Mental Health, that doesn't occur."

> These people are treated less than human.
>
> *– **Brandy Sisk, who has a son who was under state care until she fought for his return home***

State policy requires the facility's staff to complete an event report after someone dies, along with other documentation given to the Department of Mental Health. Vought said, in his experience, this leads to staff providing the state with an incomplete picture.

"There are way too many agencies that are for profit, that want to make money off the backs of these individuals," he said. "They're not about to turn in a report that says 'Hey, our staff may have missed this.' Who's going to do that? Who's going to admit that 'Hey, my staff made a mistake, so we may be liable for the death?' Nobody. Not even myself … You're going to turn in a report that looks like your staff did everything they possibly could do. That's what you're going to turn in. And that's what they do turn in, and that's what DMH swallows."

For example, Vought said he knew of an instance where a man with developmental disabilities was put into a tub of water so hot he was scalded to death. To his knowledge, no one was criminally charged for that death.

“They reported that he went to bed and woke up and he was in a coma,” he said. “This is crazy. Nobody just goes to bed and wakes up into a coma with third-degree burns on his body. The third-degree burns were because he was put into scalding water. You forgot that part of the report, didn’t ya?” After that incident, staff were required to do temperature checks before baths, he said.

Vought said the state workers who typically review the event reports are both underqualified and overworked.

“You’re relying on a nurse and not a medical review team,” he said. “I do think a medical examiner should be the one that really gets to determine what was the cause of death.”

He said when deaths occurred under his watch, the Department of Mental Health took most of what he said at face value with very little verification.

Overall, Vought said Missouri’s developmental disability system is “criminal” and “a bureaucratic nightmare.”

Vought explained that while the state updates its rates to reflect inflation and market increases, they’re only updated when a patient first enters the agency. This means agencies are incentivized to push clients out to make space for new ones that will bring higher rates, even if it’s not in the client’s best interest. This leads to inadequate care. One of his clients, he said, had been moved around to 32 different group homes in a 12-month period before she came to him.

Vought said abuse, neglect and death has been happening in Missouri’s developmental disability system, and he believes it will continue.

As recently as 2023, deadly incidents of abuse have been substantiated.

That March, Joseph Wyckoff, a man with developmental and physical disabilities including a lack of teeth and abnormal tightening or narrowing of the esophagus choked to death in a Saline County group home, much like Goodman.

According to a wrongful death lawsuit filed by his family, Wyckoff’s disabilities required his caretaker to cut his food into “bite-size pieces” and encourage him to drink an adequate amount of fluids. He reportedly choked and died eating chicken, macaroni, and green beans after his caretakers allegedly failed to follow these procedures.

The lawsuit ended in voluntary dismissal by the parties after the defendants’ legal team argued the caretaker, as a state employee, was officially immune from claims of negligence, court

records show.

In an autopsy of Wyckoff, the coroner confirmed: "I viewed the body of the deceased on Saturday morning and observed food particles in Mr. Wyckoff's mouth," adding, "It was reported by the staff that they heard Mr. Wyckoff 'snoring' at approximately 6:15 p.m. and I'm not sure that this time frame is accurate. Staff stated that he liked to sit 'with a blanket over his head' and that there was mottling noted when they moved him from the chair to the floor to begin CPR... the opinion of this office is that Mr. Wyckoff had been deceased for a longer period of time than thought by staff... I believe that the 'snoring' sound heard was probably Mr. Wyckoff aspirating (choking) at that time since he had a blanket over his head, no attention was given at that time."

'Not unique to Missouri'

Asked whether Missouri's developmental disability system has an abuse and neglect problem, Bax declined to answer. However, Walker stated, "This is not unique to Missouri."

National data on abuse and neglect in other state-run developmental disability care systems is not publicly available, but reporting from states like Iowa, Illinois and West Virginia reveal numerous anecdotes of alleged abuse and neglect.

In Illinois, a 2022 ProPublica and Southern Illinoisian investigation found that, over the course of a decade, there were 200 state police investigations into employees at developmental disability care facilities. There were also nearly 4,000 allegations of neglect and abuse investigated by the state health department's inspector general over that time period.

Bax noted that the Department of Mental Health is asking the state legislature for additional funding. She hopes to use the funds on enhanced oversight, quality assurance, staff development, improving the quality of employees, and increased wages.

In 2023, Republican lawmakers blocked a proposal to spend $900 million shoring up the Division of Developmental Disabilities, though the legislature passed a budget that included $171 million to boost pay for employees serving people with developmental disabilities. The following year, then-Gov. Mike Parson asked legislators for $79.4 million for the Division of Developmental Disabilities, but the legislature cut the funding before the end of session.

But people who've worked within the system say the problems with the homes supervised by Missouri's Division of Developmental Disabilities and Department of Mental Health go beyond a lack of funds.

Lester, the Kansas City nurse, says she believes that the state has failed to address problems that put people at risk, despite people dying in preventable ways.

Lester has a grandson with special needs. She said there's "no way in hell" she'd put him in one of Missouri's facilities.

"Nobody in their right mind would," she added. "When you go to the hospital, there's some quality control in a hospital setting. If you go to have a surgery, it's not just doctors and nurses and medical professionals playing every man for himself. There's some sort of oversight and they have to answer to somebody. And there's not that in this industry."

This story was commissioned by the River City Journalism Fund, which seeks to advance journalism in St. Louis. See rcjf.org for more information.

Health Care

We Found Widespread Abuse of Disabled Patients at an Illinois Facility. The DOJ Is Investigating.

A federal probe into Illinois' treatment of disabled people will examine abuse and neglect allegations at state-run residential institutions — including Choate, the subject of a yearlong Capitol News Illinois and ProPublica investigation.

The Choate Mental Health and Developmental Center in Anna, Illinois, is one of three state-run institutions that the federal Department of Justice says it will investigate. Whitney Curtis for ProPublica

by Beth Hundsdorfer and Molly Parker, Capitol News Illinois

Co-published with Capitol News Illinois

March 24, 2025, 6:00 am

This article was produced for ProPublica's Local Reporting Network in partnership with Capitol News Illinois. Sign up for Dispatches to get stories like this one as soon as they are published.

The U.S. Department of Justice has opened a wide-ranging investigation into Illinois' treatment of people with developmental disabilities, examining whether the state provides adequate resources for community living and protects residents from harm in public institutions.

Tonya Piephoff, director of the Illinois Department of Human Services' Division of Developmental Disabilities, informed employees of the investigation in a letter dated March 13 that was obtained by Capitol News Illinois.

"The investigation will examine whether the state unnecessarily institutionalizes, or puts at serious risk of institutionalization, adults with intellectual and developmental disabilities," the letter stated. Illinois has long had one of the highest populations of people with developmental and intellectual disabilities living in state-run institutions in the nation.

The letter said the investigation also will look into abuse and neglect allegations of patients at three of the seven state-operated residential institutions run by IDHS, including the Choate Mental Health and Developmental Center, in rural southern Illinois, which was the subject of an investigative series by Capitol News Illinois and ProPublica starting in 2022. The news organizations launched the series after the arrests of Choate staff members for abuse and neglect of residents; the articles documented instances of mistreatment by staff.

Gov. JB Pritzker said Friday that Illinois has already made significant changes to improve the safety of people with developmental disabilities living in state-run institutions, including installing cameras to help investigate mistreatment allegations. Pritzker said that individuals had moved to other institutions, and that the state had also enhanced the services provided to residents in those places. He did not address parts of the federal investigation focused on whether Illinois is relying too heavily on institutions to provide care instead of supporting people in community-based settings.

“The work has been done already,” Pritzker said of the DOJ investigation, speaking at an unrelated news conference. “It’s fine if there’s an investigation, but the reality is that things have moved significantly in the right direction, and I have done what I said I should do, and that I think we all agree should be done, which is keep everyone safe.”

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IDHS issued a written statement on Wednesday that read: “As always, the department will cooperate in full with the independent investigation and continue, as permitted and appropriate, to keep staff and interested stakeholders updated.”

It added: “IDHS has made unprecedented investments in home and community based options to empower Illinoisans with disabilities to live in the least restrictive setting of their choosing.”

A spokesperson for the DOJ did not respond to a request for comment.

The latest investigation also promises to be far broader than a previous DOJ inquiry. The new effort will review how the state provides services to all people with intellectual or developmental disabilities, including those who live in the community or at home.

The DOJ had previously investigated Choate in 2007. In a report released two years later, it found the facility had not provided proper transition planning for those wanting to move into the community; and for those living inside the state-run facility, had failed to protect residents from abuse and neglect, and did not meet their health, education and treatment needs, in violation of constitutional and federal statutory rights. The DOJ ended its monitoring in 2013.

In its investigative series a decade later, Capitol News Illinois and ProPublica detailed cases documented in internal reports and police and court records where staff had beaten, choked, whipped, sexually assaulted and humiliated residents. Those cases included the 2014 beating by staff of a man with intellectual disabilities for failing to pull up his pants. They also included the verbal abuse of a resident with developmental disabilities in 2020, including a threat by staff to break one of his fingers, captured on a recorded 911 line, according to court records, police reports and IDHS watchdog findings.

The reporting also documented a culture of covering up abuse and neglect at the facility, findings later echoed by IDHS’ Office of Inspector General — the watchdog arm that investigates abuse and neglect allegations at state-run facilities and provides agency oversight.

In the wake of the reporting, Pritzker called the abuse detailed in the stories “awful” and “deeply concerning.” The agency promised to make systemic changes to keep Choate home to the nearly 230 people with developmental disabilities who lived there at the time.

But as the news organizations continued to report on the abuse and neglect at Choate that was documented in internal and state police reports, Pritzker and his leadership team at IDHS changed course, announcing plans to move at least half of Choate’s residents to community placements or to one of the six other state-operated facilities.

“We are at a point today where all of those things weren’t working to the degree we wanted them to, so today we are making transformational changes,” he told reporters at a news conference.

In December, Equip for Equality, a legal advocacy organization monitoring the transition of Choate residents, found the state falling short of its promises, with many individuals ending up in other institutions instead of community settings, according to a report.It said the state needed to do more to help people find community group homes and prepare them for the transition.

Illinois' reliance on institutions represents "an antiquated and oppressive model of serving people with developmental disabilities," said Andrea Rizor, an Equip for Equality attorney, who also said the group hopes the investigation will ultimately help bring more resources to community-based care.

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The U.S. Supreme Court found in 1999 that confining people with disabilities in state institutions constituted discrimination, holding that patients with mental disabilities should be placed in community settings if they are medically cleared to do so and expressed a desire to live outside a facility.

Illinois largely failed to do that and ended up under a federal consent decree, which a judge ruled just last year should stay in place until the state made more progress.

Today, accusations of abuse and neglect also have continued to grow, at Choate and across the system. A December 2024 report by the Office of Inspector General said it had received over 15,000 complaints from individuals in institutions and community-based settings, a 24% increase from the previous year and an 80% jump since fiscal year 2020. The office has struggled to keep up, even after growing from 73 to 91 employees in a year. The report said the Office of Inspector General "still lacks enough staff to handle rising caseloads efficiently, estimating it needs at least 120 workers."

In addition, two years after Pritzker's announcement that 123 residents with intellectual or developmental disabilities would be moved out of Choate, 81 have been relocated, with most moving to other state-operated developmental centers. Not included in the governor's initiative are 111 patients with developmental disabilities who are living in specialized units at Choate.

There currently are nearly 1,600 people with developmental disabilities living in state-run facilities in Illinois, with 242 residents stating they want to explore living in the community.

What We're Watching

During Donald Trump's second presidency, ProPublica will focus on the areas most in need of scrutiny. Here are some of the issues our reporters will be watching — and how to get in touch with them securely.

From: Brent Toalson
To: DHHS HCBS Public Comments
Subject: Public Comments Proposed Changes to AD Waiver
Date: Friday, January 2, 2026 4:54:20 PM

You don't often get email from [redacted] Learn why this is important

To Whom It May Concern,

My name is Brent Toalson. My wife, Colleen, and I are AD Waiver approved caregivers for our 30-year-old son, Alex, who has Duchenne Muscular Dystrophy. We are his only caregivers. We have been approved for more than 40 hours a week to provide care for Alex in our home. If the proposed changes go into effect, our reimbursable caregiver hours could be reduced significantly. These comments expand on the brief comments I submitted via chat during one of the online presentations.

Alex depends on us for all his daily needs. He is ventilator dependent with a tracheostomy. We do all his trach cares and monitor his oxygen and heart rate to make sure his ventilator is working. We clear mucus from his trach and airway throughout the day and night. I stay in his room each night to make sure his equipment is working, to clear his airway, to respond to breathing, O2 and heart rate alarms and reposition him. We give Alex all his feedings and medications through a feeding tube. I change his Foley catheter weekly. He is wheelchair dependent, but unable to move, so we drive his chair for him and use a lift to transfer him from his chair to his bed and commode. He is recovering from a cardiac/respiratory event that injured his brain due to low oxygen, requiring additional support.

If Alex is required to get the care he needs from someone outside the home, they would have to possess skilled nursing and respiratory therapy training and credentials. My wife and I are paid $16 an hour to provide this level of care for Alex. The State of Nebraska will end up paying considerably more to pay someone outside the home to provide care for Alex. Most nursing facilities will not take people who are ventilator dependent because they don't have respiratory therapists on staff. The cost to care for Alex at a rehab hospital with respiratory therapy support is way above the nursing facility institutional cost limits.

Colleen and I and the other families who receive AD Waiver reimbursements are doing the very best we can to care for our loved ones. We are grateful that the Medicaid waiver program has allowed us to care for Alex in our home.

Brent Toalson
[redacted]

From: Jorgensen, Shelley
To: DHHS HCBS Public Comments
Subject: public comments
Date: Monday, December 29, 2025 12:48:24 PM

> You don't often get email from [redacted]. Learn why this is important

In regard to the proposed changes for the AD waiver. My son has duchenne muscular dystrophy and is unable to complete any tasks on his own. He requires 24/7 supervision and assistance as he cannot be left alone. I highly suggest you do not remove the 24/7 care as he primarily receives assistance from an outside agency as he lives at his own apartment for the majority of the time. My husband and I provide for his care on the weekends and during holidays, etc.. Both my husband and I have FT jobs and would be unable to provide for his care 24/7 365 days a year, therefore the outside agency is a must. Obviously an outside agency is not going to provide 24/7 care if they do not get paid for it. You need to realize that some of these individuals simply will not survive without 24/7 care. I hope that you will review each case individually and make necessary changes based on your findings instead of making a blanket change to all AD waiver individuals.

Thank you.

Shelley Jorgensen

From: Tobi Davis
To: DHHS HCBS Public Comments
Subject: PUBLIC COMMENTS
Date: Tuesday, December 16, 2025 6:22:15 PM

> You don't often get email from [redacted]. Learn why this is important

First of all can you tell me how (my son) a human being is in a vegative state who can NOT do anything on his own. Can't eat, can't talk, can't move his arms and legs, can't have bowel movements without help, can't shower and the list goes on and on.... will survive with ONLY 40 hours of paid care? I'm not having a stranger come in that to care for him since his requirements are very challenging. An INSTITUTION is NOT an option. Every single dr he has had and he has had SO many from all around the world has said the Only reason he is alive is because of how I take care of him around the clock. How is this cut humane to a disabled person who literally can't do anything? I understand cuts but not cuts on a disabled person that can't do one thing on their own. How about cutting the people that milk the system who dont work or work for cash so they qualify for every benefit. When my son was in the hospital for all the months he was there he faught bed sores, pnemonia, Uti's and even ecoli from a nurse not caring about the feeding tube being submerged in feces. This is not Ok, I will not give up on my son, I will reach out and do whatever I need to do to continue his services of 24/7 care.

Thank You

From: Mary O"Callaghan
To: DHHS HCBS Public Comments
Subject: Public Comments--HCBS Aged and Adult and Children with Disabilities waiver
Date: Monday, January 5, 2026 4:53:07 PM

You don't often get email from [redacted] Learn why this is important

I am writing to submit a public comment regarding the proposed changes to the Aged and Disabled (AD) Waiver, specifically the proposed reductions in individual care and services due to an asserted financial shortfall.

Reductions in individual care hours often shift costs to emergency rooms, hospitals, institutional care, or family caregivers, increasing risks to vulnerable individuals and leading to higher long-term state costs.

Additionally, the proposed changes greatly reduce reimbursable care hours, particularly for live-in family caregivers. This would create a greater reliance on non-family or agency providers. Many family members become caregivers because it is difficult to find and retain non-family or agency providers. It is not clear that Nebraska has a sufficient workforce to handle the increased workload.

Further, if family caregivers are unable to continue to care for their family member at home due to the proposed changes, it is not clear that Nebraska would have sufficient facilities and staff to provide care for these individuals. Nebraska is experiencing a shortage of nursing-home level care facilities and access to skilled nursing care, especially outside of urban areas. This is driven by both facility closures and workforce challenges. Many counties in Nebraska do not have nursing homes, leaving significant areas without local long-term care options.

Thank you for the opportunity to provide public comment and for considering the impact these proposed changes will have on this population.

Mary O'Callaghan

From: Jorgensen, Shelley
To: DHHS HCBS Public Comments
Subject: public comment
Date: Thursday, December 11, 2025 10:01:56 AM

> You don't often get email from s[redacted]. Learn why this is important

I attended the 12/11/25 public comment meeting. Obviously, I do not understand the changes that are being suggested based off of everyone else's reaction. I would like to know how this is going to personally impact my son's care. I care for him on the weekends and an outside agency provides care for him during the work week. he requires 24/7 care. Are you telling me he will be reduced to only getting care 40 hours/week????? If so, that is unacceptable. His level of care needed has not changed. I need some clarification on how this is going to impact my son so I can begin to prepare for these changes. Thank you.

From:	Nick Hightree
To:	Governor; DHHS PIO
Cc:	KLKN TV Channel 8 Lincoln; 1011 Now; Powell, Jeff; Strimple, Laura; DHHS HCBS Public Comments
Subject:	Public Concern and Request for Review: Draft NE.018.08.00
Date:	Wednesday, December 24, 2025 8:48:45 AM

You don't often get email from [redacted] Learn why this is important

Dear Governor Pillen, Secretary Corsi, and Members of the Media,

I am writing to formally submit my strong objection to Draft NE.018.08.00, the Nebraska Department of Health and Human Services' proposed renewal and amendment of the 1915(c) Medicaid Home and Community-Based Services (HCBS) Aged and Adult and Children with Disabilities Waiver, currently open for public comment.

As proposed, Draft NE.018.08.00 outlines how Nebraska intends to continue delivering Medicaid HCBS services to seniors, adults with disabilities, and children with special needs beginning July 1, 2026. These services—including case management, personal care, respite, assisted living supports, transportation, and other community-based assistance—are essential to keeping individuals safely in their homes and communities rather than in institutional settings.

While the stated intent of the waiver is to maintain access to community-based care, the draft introduces unnecessary complexity, administrative burden, and ambiguity that place real risk on the very populations it is meant to serve—particularly children, elderly Nebraskans, and individuals with disabilities.

Policies governing essential services must be clear, accessible, and predictable. Draft NE.018.08.00 instead relies heavily on layered administrative processes, monitoring frameworks, and compliance mechanisms that may appear sound on paper but are disconnected from the lived reality of families, caregivers, and seniors navigating these systems. Increased complexity does not equate to better outcomes—it often results in delays, inconsistent application, and reduced access to care.

Children with disabilities are especially vulnerable to disruption. Any increase in procedural friction, service uncertainty, or administrative delay directly affects their stability, development, and long-term well-being. Yet the draft does not clearly demonstrate how its expanded requirements measurably improve outcomes for children, while the risk of disruption is evident.

Similarly, elderly Nebraskans—many of whom manage fixed incomes, declining health, or limited mobility—depend on systems that are straightforward and reliable. Draft NE.018.08.00 places additional burden on seniors and caregivers who are least equipped to absorb bureaucratic complexity, increasing the likelihood of service gaps or misapplication.

Equally concerning is the lack of clear justification for many elements of the draft. The proposal does not sufficiently explain:

- What specific deficiencies in the current waiver are being addressed
- Why existing structures are inadequate
- What measurable benefits these changes deliver to participants

Without this clarity, Nebraskans are asked to accept increased cost, confusion, and risk without evidence of improved quality, safety, or accountability.

Public policy—especially policy governing essential health and disability services—should reduce barriers, not create them. It should protect those with the least margin for error, not expose them to additional risk. Draft NE.018.08.00, as written, does not meet that standard.

I respectfully urge the Governor's Office and the Department of Health and Human Services to withdraw or substantially revise this draft and to engage more meaningfully with families, caregivers, advocates, and service recipients before advancing any revised proposal. I also encourage members of the media to examine the downstream impacts of this draft so the public can better understand what is at stake for Nebraska's most vulnerable citizens.

Thank you for your time and attention to this important matter.

Sincerely,

Nicholas Hightree

[redacted]

[redacted]

From: Holly Steidlmayer
To: info@arc-nebraska.org; DHHS HCBS Public Comments
Subject: Public Input
Date: Monday, January 5, 2026 7:55:48 PM

You don't often get email from [redacted] Learn why this is important

Suggestions

I have several suggestions regarding changes to the structure of public input. To improve efficiency and save time, a recorded slideshow could be shared in advance outlining the proposed changes, along with a link to the formal document. Participants could then be invited to submit questions by email, allowing common or recurring questions to be grouped together. During the webinars these grouped questions could be addressed in the first half hour, leaving the remaining hour for additional comments or new questions. An evening webinar would be appreciated as well.

Additionally, strictly limiting each question or comment to three minutes per raised hand would help ensure that more participants have the opportunity to be heard. As you know, at the end of each webinar there were still multiple hands raised that had been waiting for quite some time.

Thank you for the opportunity to comment,

Holly Steidlmayer

From: Holly Steidlmayer
To: info@arc-nebraska.org; DHHS HCBS Public Comments
Subject: Public Input
Date: Monday, January 5, 2026 7:55:48 PM

> You don't often get email from [redacted]. Learn why this is important

Suggestions

I have several suggestions regarding changes to the structure of public input. To improve efficiency and save time, a recorded slideshow could be shared in advance outlining the proposed changes, along with a link to the formal document. Participants could then be invited to submit questions by email, allowing common or recurring questions to be grouped together. During the webinars these grouped questions could be addressed in the first half hour, leaving the remaining hour for additional comments or new questions. An evening webinar would be appreciated as well.

Additionally, strictly limiting each question or comment to three minutes per raised hand would help ensure that more participants have the opportunity to be heard. As you know, at the end of each webinar there were still multiple hands raised that had been waiting for quite some time.

Thank you for the opportunity to comment,

Holly Steidlmayer

From: teresa stewart
To: DHHS HCBS Public Comments
Subject: Purposed A7D and TBI Waiver Cuts
Date: Wednesday, December 17, 2025 4:28:09 PM

> You don't often get email from [redacted]. Learn why this is important

Questions: When will we be advised what the final acceptance of policy change will be?
Can I have a list of those on the committee who wrote these waiver changes?

Comments:

This is not a "family forward" purposal. Where is the moral character of this administration?

A family caregiver going from 112 hours to 40 hours per week is absolutely not sustainable. It is not only financially devastating and unsustainable but providing "the best option for care" is abolished. Families will lose (Or have to forfeit) handicap modified homes and vehicles (due to not being able to afford the payments) but wouldn't most of these families then qualify for Medicaid health insurance, snap and liheap? Essentially putting them at at least right at poverty level for a family of 2?

Additionally, if you ok extra hours over 40 for complex recipients to be preformed by "others" this will not only disrupt the consistency, continuity and compassion of care, exposing the most venerable to additional illness and viruses by adding introducing more potential carriers of local illnesses? Expect more hospital stays. And this is if I could even staff it considering my son's "risk" level of cares needs.

Furthermore, with my son's level of needs, finding staff to cover him would be damn near non-existent. Agencies cannot provide staff to do extensive medical cares on my son. This includes suctioning trach, drawing up and administering medications, administering life saving medical interventions such as respiratory rescue inhalers, rescue nasal spray for seizures, maintaining and troubleshooting ventilator issues, providing **urinary** catherization. And the list goes on.

So, in essence, If by some miracle I find staffing, I would still have to be available all the time to do those cares.

TAs a ageing parent/caregiver of 61, finding additional employment would be difficult. Ive been out of the workforce for over a decade now. With the unemployment rate at a 4 year high (4.6), how employable do you think I am, physical limitations put into this mix. I am currently in contact with a bankruptcy attorney to prepare for this atrocity.

Please don't do this.

Merry Christmas.
May you be rewarded for fairness.

Peace, Love & May God Bless You !
Best Regards,
Teresa Stewart

From: Sandra Miller
To: DHHS HCBS Public Comments
Subject: Question on the new proposed budget
Date: Friday, December 19, 2025 4:20:14 PM
Attachments: Outlook-dzaetw4f.png

> You don't often get email from [redacted] Learn why this is important

We have hired several older caregivers at the request of the Medicaid Waiver consumer that I am not sure can physically go through the training or be strong enough to effectively perform CPR. We have also in the past employed individuals that had some physical impairments but were perfectly good caregivers that might not have been able to perform CPR.
Do we need to fire these individuals if they cannot meet these new Waiver requirements?

Warm Regards,

Sandra Miller, BSW MBA
712.310.3496
https://trustedlifechoicesllc.com/personal-care/

woman owned

TRUSTED LIFE CHOICES LLC | key home care
Where Compassion is Key

From: Marissa Sims
To: DHHS HCBS Public Comments
Cc: Lexy Beck
Subject: Question regarding proposed Waiver Changes - CPR
Date: Thursday, January 1, 2026 5:22:32 PM

> You don't often get email from [redacted]. Learn why this is important

I am writing to submit a public comment and request clarification regarding the CPR and First Aid (FA) training requirements for agencies under the proposed waiver changes.

Specifically, I am seeking guidance on what CPR and First Aid certification requirements will look like for agency staff. Will online-only training platforms be considered acceptable and compliant with DHHS requirements, or will in-person or blended (online plus skills demonstration) training be required?

For example, would certifications obtained through online platforms such as the National CPR Association, National CPR Foundation, or CPR Certification Institute be considered acceptable or approved by DHHS for agency staff?

Clear guidance on acceptable training formats and approved or disallowed certification sources would be very helpful for agencies as they plan for compliance and staff training.

Thank you for the opportunity to provide public comment and for considering this request for clarification.

Marissa Sims

[redacted]

From:	Clark, Jennifer J
To:	"Hansen, Jennifer L"; Large, Colin
Cc:	Swanson, Sarah R; DHHS HCBS Public Comments
Subject:	RE: A&D waiver change clarification
Date:	Thursday, December 11, 2025 4:57:59 PM
Attachments:	image001.png

In this case it would be personal care hours.

Jenn Clark, LIMHP | *Deputy Director of Community Services*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-7909

From: Hansen, Jennifer L <jenniferl.hansen@unmc.edu>
Sent: Thursday, December 11, 2025 4:53 PM
To: Large, Colin <Colin.Large@nebraska.gov>; Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>
Cc: Swanson, Sarah R <sarah.swanson@unmc.edu>; DHHS HCBS Public Comments <DHHS.HCBSPublicComments@nebraska.gov>
Subject: RE: A&D waiver change clarification

Thank you both for the prompt replies! Please forgive me, what do you mean when you refer to “hours” (as in “state plan (MCO) hours and the waiver hours combined”)--hours of therapies, nursing care, personal care services, etc.? I appreciate the clarification!

Jennifer Hansen
Parent Resource Navigator
Munroe-Meyer Institute for Genetics and Rehabilitation
UNMC
BREAKTHROUGHS FOR LIFE.

University of Nebraska Medical Center
985450 Nebraska Medical Center | Omaha, NE 68198-5450
402.559.5759 | fax 402.559.5737
Jenniferl.hansen@unmc.edu

UNMC | Facebook | Twitter | Instagram | YouTube | Flickr

From: Large, Colin <Colin.Large@nebraska.gov>
Sent: Thursday, December 11, 2025 2:21 PM
To: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>; Hansen, Jennifer L <jenniferl.hansen@unmc.edu>
Cc: Swanson, Sarah R <sarah.swanson@unmc.edu>; DHHS HCBS Public Comments <DHHS.HCBSPublicComments@nebraska.gov>
Subject: Re: A&D waiver change clarification

Non-UNMC email

Jenn is correct.

We will consider this email as a Public Comment and will look to see if clarifying language is needed prior to CMS submission.

Thank you for bringing this to our attention.

Colin

Colin Large | *Policy Administrator II*
Executive Green Belt
he/him
DEVELOPMENTAL DISABILITIES & HOME AND COMMUNITY-BASED SERVICES

Nebraska Department of Health and Human Services
CELL: 402.853.1452 | WEB: DHHS.ne.gov

From: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>
Sent: Thursday, December 11, 2025 1:07 PM
To: 'Hansen, Jennifer L' <jenniferl.hansen@unmc.edu>; Large, Colin <Colin.Large@nebraska.gov>
Cc: Swanson, Sarah R <sarah.swanson@unmc.edu>
Subject: RE: A&D waiver change clarification

Colin can correct me if I am wrong.

I believe this means that whatever hours the state plan (MCO) hours and the waiver hours combined exceed the cost limit. For us it would really mean the waiver hours as we are not taking the hours that the MCO pays for/provides into consideration of the waiver cap.

Thanks.

Jenn Clark, LIMHP | *Deputy Director of Community Services*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-7909

From: Hansen, Jennifer L <jenniferl.hansen@unmc.edu>
Sent: Thursday, December 11, 2025 11:42 AM
To: Large, Colin <Colin.Large@nebraska.gov>
Cc: Clark, Jennifer J <Jennifer.J.Clark@nebraska.gov>; Swanson, Sarah R <sarah.swanson@unmc.edu>
Subject: A&D waiver change clarification

Good morning!

Firstly, I just want to thank you and Jenn for hosting the listening session yesterday and want to give you both so much credit for taking some not-so-positive feedback as the messengers. Please know that both of your dedication to the disability community is noticed and very, very much appreciated!

I was the one who asked the question regarding the **combination** of HCBS services and Medicaid state plan included in the individual's budget of 150%/175%, as noted below:

Page 12: "*All current waiver participants will continue to receive the services as outlined on their person-centered plan (PCP). Prior to the participant's next eligibility year, the Service Coordinator (SC) will meet with the participant to complete the high-utilization review. When the combined costs of waiver and state plan services exceed the applicable cost limit, the SC will work with the participant to reduce services below the 175% limit, while still ensuring health and safety are met. When the participant's needs cannot be met, referrals to other community services, including institutional services, are provided to the participant. The participant is provided with alternative options to meet their needs, including but not limited to nursing facility placement.*"

If I am misinterpreting this, could you please explain what the highlighted section does mean? Thank you, again!

Best,

Jennifer Hansen
Parent Resource Navigator
Munroe-Meyer Institute for Genetics and Rehabilitation

University of Nebraska Medical Center
985450 Nebraska Medical Center | Omaha, NE 68198-5450
402.559.5759 | fax 402.559.5737
Jenniferl.hansen@unmc.edu

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From: janell epp
To: DHHS.HCBSPublicComments@nebraska.go; DHHS HCBS Public Comments
Subject: Re: A/D Waiver
Date: Tuesday, December 30, 2025 4:09:49 PM

> You don't often get email from [redacted]. Learn why this is important

On Tue, Dec 30, 2025, 3:07 PM janell epp [redacted] wrote:

> To whom it may concern
>
> I am a individual Provider for my Grand daughter for several years now and I'm concerned about the proposed changes to reduce the amount of hours for her care.
> How can anyone dictate that all handicapped or special needs people will only require 40 hours of care? Each individual requires different types of care and quantity of care. Only a medical professional after testing and a full exam can determine what is needed for each individual. I understand that each individual medical history had to be submitted in order to qualify for DHHS assistance so is that information going to be considered to determine amount of care needed?
> The medical field has been severely under staffed for years so by forcing more handicapped individuals into nursing homes and such facilities is increasing the strain which affects the care they receive. Forcing these individuals to leave their homes and families is inhumane. When I asked a retired nurse how a facility would likely care for a person that is non verbal, needs to be fed, dressed, assisted with toiletries and with walking. She said they would more than likely heavily medicate that person. They don't have the staffing to give that kind of individual care.
> Imagine a family member of yours needing this kind of care. What would you want for them? Would you want them cared for by loving family members or in a facility that just can't give them the care they need. They deserve our best care from the time they wake in the morning till bed time. That's more than 40 hours a week.
>
> A concerned care giver and grandmother of a very special person.
>
> Janell Epp

From: Henny Kupferstein
To: bbartels@leg.ne.gov; Sen. Brian Hardin; DHHS HCBS Public Comments
Cc: Gonshorowski, Drew; Barrett, Nicole; Office, InspectorGeneral; AGO Medicaid Fraud; Brunssen, Jeremy
Subject: Re: Childcare licensing audit - ABA fraud
Date: Tuesday, December 23, 2025 7:19:03 PM
Attachments: [redacted]

> You don't often get email from [redacted]. Learn why this is important

Let the record reflect that I have advocated for a total ban of ABA under Nebraska's medicaid. Since my initial advocacy, Idaho became the first state to remove the ABA CPT codes from their state plan. Arkansas removed the classifier in their professional code that recognized ABA providers as allied health professions. This allowed for chiildcare liencesing to be enforced.

If Nebraska is taking the medicaid fraud into serious consideration, then your health department must also consider evidence from the field that ABA is not a therapy, is not medically necessary, is not a gold standard, and it directly linked to harm. We the autistics who have been harmed by ABA are begging you to take a stand and protect the next generation of vulnerable children from glorified babysitting, unlicensed fake autism therapy, and put this dark era behind us.

You may call me at 818-573-0005 -- yes I am willing to testify. Please be sure to review my published research, attached.

Sincerely,

Henny Kupferstein, Ph.D.
Hennyk.com & Doogri Institute
Qualified expert on informed consent for nonspeaking, ASL, and AAC users
8 www.BANABA.us

.. see my Amazon list.

On Mon, Sep 22, 2025 at 9:11 AM Henny Kupferstein [redacted] wrote:

> Dear Senator Hardin,
>
> Thank you for taking the lead on mitigating fraud, waste, abuse and neglect of autistic children. As an Autistic person, I have a heightened sense of justice, and as a parent, when my autistic children suffered in the hands of ABA fake autism therapy, I conducted research on the harms of ABA. As Nebraska has an opportunity to stop all abuse and fraud in one quick strategy, I welcome the opportunity to serve. I am your resource. You may reach me at 818-573-0005.
>
> I propose identifying Nebraska Medicaid-ABA clinics where these sessions may **violate childcare licensing laws**, but digital Medicaid record audits are required.

Key Audit and Licensing Criteria

- **Unrelated Children Onsite:** Nebraska law requires a childcare license when four or more unrelated children are present at a facility at the same time, regardless of whether their services are 1:1 or group. This applies if all are onsite for individual ABA sessions in separate rooms or with different staff, as long as the children are not related to one another or to the supervising adult.

- **Parent Exclusion:** Typical ABA practice is for parents to be excluded from the therapy sessions, which means children are left under exclusive supervision of clinic staff for prolonged periods.

- **Duration:** Clinics scheduling sessions for more than four continuous hours per child (e.g., treatment plans recommending 40 hours per week) must ensure they do not violate childcare licensing laws if four or more unrelated children are present during overlapping times.

Audit Process

- Digital search for concurrent claims per provider/clinic NPI.

- Cross-reference with client address/relationship data to verify unrelated status.

- Site inspection or request for attendance logs if patterns suggest a nonexempt childcare-type operation.

Intraagency Jurisdiction

Each office has statutory authority to investigate individual cases tied to complaints or incidents. Multi-clinic, systemic fraud or abuse investigations are exceptional events requiring special collaboration, data sharing, and oversight mechanisms that go beyond their usual jurisdiction and workflow. These offices are legally and operationally set up to process individual allegations or specific complaints. Regular workflow is limited to “case” investigations, not proactive cross-system data mining for broad violations.

Medicaid Fraud Control Unit (Attorney General's Office) - Investigations are typically triggered by first-person complaints, facility-level allegations, or evidence of fraud in an individual case. The unit does not have regular access to Medicaid's entire system data for proactive, broad reviews—systemic audits require special coordination and access granted through program integrity or legislative referral.

DHHS Child Care Licensing - Primarily responds to first-person, facility-specific complaints or allegations. The agency investigates specific locations after receiving an allegation, not broad patterns across multiple clinics, due to resource constraints and legal mandate

Nebraska Inspector General of Child Welfare (OIG) - Has the jurisdiction to provide independent oversight of Nebraska's child welfare and juvenile justice systems and investigates misconduct and systemic issues, making recommendations for improvement. Most inquiries begin with individual incidents or complaints (e.g., child death, serious injury, or direct reports of abuse). OIG can investigate systemic issues but often requires legislative, executive, or cross-agency referral to launch a broader inquiry; does not directly access all agency data without coordination.

DHHS Program Integrity (Medicaid) - Typically performs targeted audits based on complaints, billing anomalies, or periodic sampling, rather than sweeping system-wide investigations without higher-level authorization or external triggers

Conclusion:
The proposed investigation centers on the coincident presence of four or more unrelated children in an ABA clinic, each receiving medicaid "therapy", without their parents onsite, and for durations exceeding the childcare licensing threshold. Nebraska law protects unrelated children being under non-parental adult supervision, regardless of session type. Coordination for systemic investigations requires explicit legislative mandate, intraagency agreements, or advocacy-driven push for data access—otherwise, legal and privacy constraints limit cross-office sharing and scope expansion.

Sincerely,

Henny Kupferstein, Ph.D.
Hennyk.com & Doogri Institute
Qualified expert on informed consent for nonspeaking, ASL, and AAC users

.. see my Amazon list.

From: Melissa Cook
To: DHHS HCBS Public Comments
Subject: Re: Cook, Kaden
Date: Monday, January 5, 2026 10:43:49 PM

You don't often get email from [redacted] Learn why this is important

I thought our email was to be turned in by 5pm today. So I sent the email without finishing. I found out that's not the case, so I'm continuing our letter to you.

I went to Southeast Community College years ago and couldn't get daycare because they didn't have a full time nurse available. Only in the Fall, there was a nurse most days and when the children went on field trips the nurse went with. The school didn't have a vehicle that was wheelchair assemble. The Community College said they were not staffed for my son's condition. We have had so many struggles in life. I purchased a handicap vehicle on my own with no assistance. No co-signer, no state or federal assistance. Just my good credit and full time job. I've always had a full time job since I was 17 years old, minus when I was on pregnancy leave. The hours that will be taken away will cause so much pain and so many more struggles for us!! Kaden needs the continuous love and care he has been getting~The proper way of living. He is non verbal, total dependent for all his cares, bathing, feedings, medications. He has a G-Button for all nutrition and medications. He has seizures, he's developmentally delayed. Spastic

Quadriplegic, Ulcerative Colitis and so many more disorders that we didn't choose. There has not been any other reported family in the United States with the condition my boys have. THIS IS SO UNFAIR AND FRUSTRATING!!!!! When Michael Miller, Kaden's Service Coordinator from The Leage of Human Dignity gave us the 90 hours a week, my question to him was…"Will we ever loose these hours we are getting? He said, No!"

YOU CANNOT LIE!!! YOU CANNOT GIVE SOMETHING AND THEN TAKE IT AWAY!!! PEOPLE ARE GOING TO SUFFER!! IF THIS GOES THROUGH, PUTTING FAMILIES IN A POSITION TO FAIL ON PURPOSE! That's against the law!!

I will have to apply for all the assistance that is available for low income families to survive if you take our hours away. I was very happy when Kaden turned 19 years old. Finally my income wouldn't reflect on SSI. I could not have more than $2000.00 in my bank account. There was no way to save money of any kind without effecting Kaden's SSI. Our whole life we have had to live paycheck to paycheck. Now when life seems to be heading in a great direction, we hear the way of living is going to change after we finally have some money saved. I

planned our funeral arrangements so when it's time for my youngest son to go up and be with his brother in heaven, he will have a proper burial and can rest in peace with his brothers ashes by his side. Kaden will not be cremated! I'm sharing with you these different events of my life because I want you to know I'm doing the best I can with everything that's been thrown at me. I try to keep my head up high and do the best I can. Sometimes life just isn't fair. What is being proposed just isn't fair. You cannot take away a way of life and then not replace it with equally balanced opportunities!!

On Jan 5, 2026, at 5:04 PM, Melissa Cook [redacted] wrote:

Hello,

My name is Melissa Cook. I am Kaden Cook's Mom and Guardian. Life has been so difficult with all the personal changes throughout our lives. Now, when life keeps moving forward and improving mentally, physically, and medically; Kaden has not been in the hospital for Christmas in two years because of seizures, or a shunt malfunction. He is blossoming at 22 years old. He started communicating with me on his eye gazing Dynvox. He is improving more and more with family and friends. We finally have life going pretty good for us. He's going to start Hetra soon. Insurance doesn't cover this. We did the math and can afford Kaden to go twice a week. Our support and daily life will change drastically if our combined maximum 40 hours per week between Personal Care and LRI Personal Care changes. We are getting 90 hours per week now. Going down to 40 hours….we will not be able to keep our modified vehicle we still have 10,000 we owe. We rent an apartment in Greenwood Nebraska. Since we are in Cass County, we have not been able to find an agency to come and help us because two nurses need to be available for a client; for back up. When we did live in an area that we could receive outside help other than family and friends, when I worked 12 hour shifts as a med aide and cna…I had to switch my 8 hour days to 12 hour days so it would be worth the RN's time to come and replace me while I worked. I had a loveseat full of all different kinds of toys, activities, books for them to engage with Kaden while I was working. Nothing seemed to be touch very often. So I spoke with the Head Nurse that visited us every three months to see how everything was working out. Told her I wanted to set up a video camera. She thought that was a great idea. I was irate at what I was seeing!!!! I requested 6 of the RN's that was not welcome back in our home, and I had documentation to show and did. I have worked in the nursing field since

1999, the year I graduated. I can't fathom putting my son in an institution. Both of my boys were born with X-Link Recessive Congenital Hydrocephalus due to a pathogenic variant in the LICAM gene inherited by me.

1. X-linked recessive congential hydrocephalus (s/p VP shunt) due to a pathogenic variant in the LICAM gene inherited….
   This genetic change accounts for the findings in Kaden. A maternal half-brother, now deceased, and a maternal great-uncle were also affected.
2. Spastic quadriplegia
3. History of seizures
4. Profound intellectual disability
5. Non-verbal, although does utilize some signs for communication
6. Non-ambulatory, wheelchair dependent
7. Neuromuscular scoliosis
8. Ulcerative colitis

Genetic Counseling:
We again reviewed the X-linked inheritance pattern in X-linked hydrocephalus. His mother is a carrier, meaning that she has the L1CAM pathogenic variant on one of her X chromosomes, and a working copy of the L1CAM gene on the oth Female carriers for X-linked hvdrocenhalus

My boy is total dependent and has to have supervision at all times. He thrives off of all the activities and places we do and go!!
Please don't ruin our lives. It's been so hard, don't make it harder again. We have our vehicle that needs to be payed off before July of this year or we will loose it. We live paycheck to paycheck. The more money I make the more my health insurance is. So I purposely didn't want to increase my wages from $15.00 an hour because of that. I went to Southeast Community College years ago and couldn't get days care because they didn't have a full time nurse available.

Melissa

From: Houseman, Karen
To: "Katie Novakoski"
Cc: Green, Tony; DHHS HCBS Public Comments
Subject: RE: FORMAL OBJECTION to the AD wavier changes NEBRASKA
Date: Monday, December 29, 2025 8:48:22 AM

Good Morning –

I'm including DHHS HCBS Public Comment mailbox to ensure your response is received for public comment.

Best regards,

Karen Houseman | *DHHS Program Manager II, AD and TBI Waiver Service Coordination*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-9329 | CELL: 402-840-0869

From: Katie Novakoski [redacted]
Sent: Sunday, December 28, 2025 11:12 AM
To: Green, Tony <Tony.Green@nebraska.gov>
Subject: FORMAL OBJECTION to the AD wavier changes NEBRASKA

> Some people who received this message don't often get email from [redacted] Learn why this is important

Dear Nebraska Department of Health and Human Services and other interested parties,

I am writing to formally object to the proposed changes to the Nebraska Aged and Disabled (AD) Waiver Program, including reductions in authorized service hours, limits on compensation for live-in caregivers, and the increased reliance on unpaid "informal supports." These changes are contrary to Nebraska law, inconsistent with the purpose and structure of the AD Waiver, and incompatible with fundamental Medicaid waiver principles. If implemented, they will significantly reduce the safety, continuity, and quality of care for adults with severe disabilities while shifting unsustainable financial and caregiving burdens onto families.

Nebraska law is explicit regarding the age of majority. Once an individual reaches age 19, parents are no longer legally or financially responsible for that individual's care. The State of Nebraska already recognizes this distinction through its administration of Medicaid waiver services for adults. Any policy that assumes or relies upon parents, grandparents, or other family members to provide unpaid care to adults directly contradicts this established legal framework. Not only that, but many families do not have these informal supports to rely on, perpetuating the unsafe conditions these

changes would force upon families.

Equally important, informal supports, by definition, must be voluntary. They cannot be mandated, presumed, or relied upon to replace authorized Medicaid services. Parents, family members, and friends are not voluntarily providing this level of care for free, nor can they reasonably be expected to do so. The Department's apparent expectation that families will step in to provide uncompensated care fundamentally mischaracterizes both the nature of informal supports and the realities faced by families supporting adults with significant disabilities.

The AD Waiver exists for a specific and essential purpose: to provide medically necessary services that allow individuals with significant disabilities and complex medical needs to remain safely in their homes rather than being placed in institutional settings. Services authorized under the AD Waiver include mechanical transfers and lifting, incontinence care, suctioning, tube feedings, oxygen management, medication administration, and constant supervision. These tasks are skilled, hands-on medical and personal care. They are not casual assistance, and they are not acts of voluntary goodwill. They are labor.

Federal Medicaid waiver requirements mandate that services be based on assessed need and that they function as a true alternative to institutional care. Arbitrary reductions in authorized hours—while presuming unpaid labor from family members—undermine the waiver's role as an institutional diversion program. When services are insufficient to meet assessed needs in the home, the waiver fails its intended purpose and increases the risk of hospitalization or placement in more costly institutional settings.

For many individuals on the AD Waiver, 70 hours of care per week is not sufficient to meet even basic daily needs, let alone ensure safety for medically complex conditions that require constant or near-constant supervision. Many participants require care far exceeding 40 hours per week, with some needing continuous, 24-hour support. Hour caps and limits on paid family or live-in caregivers do not reduce need—they create unsafe gaps in care and place vulnerable adults at serious risk.

The expectation that family members will provide this care without compensation also ignores economic reality. Many parents and family caregivers work full-time, have their own households, and must earn income to survive. Most cannot afford to provide daily or round-the-clock care for free. This is not a matter of unwillingness; it is a matter of impossibility. When paid hours are reduced, caregivers are forced to seek employment outside the home, leaving adults with disabilities without necessary care during critical hours. It is unfair to expect families to take such drastic cuts in hours that they use to care for their loved ones while cost of living continues to rise every day.

The proposal further assumes that reduced hours can be offset by "outside help." This assumption is unsupported by current workforce conditions. Nebraska is experiencing a severe and ongoing shortage of direct care workers. Agencies are understaffed, and in many areas there is no available workforce to replace lost paid family caregiving hours. Authorizing services that cannot realistically be delivered

does not meet the State's obligations under the waiver.

Family and live-in caregivers provide high-quality, cost-effective care that keeps people safely in their homes and reduces overall Medicaid expenditures. Cutting hours and limiting compensation will force many families to pursue skilled nursing or institutional care, which is far more expensive for the State and often results in poorer outcomes. These proposed changes risk increasing hospitalizations, institutional placements, and total taxpayer costs—outcomes that directly contradict the purpose of the AD Waiver.

If cost containment is necessary, there are more responsible and lawful alternatives that would preserve safety and continuity of care, including:

- Maintaining current authorized hour levels for existing participants through grandfathering provisions.
- Removing or revising the 40-hour compensation cap for live-in caregivers.
- Implementing individualized, needs-based assessments rather than one-size-fits-all hour caps, with higher limits for individuals requiring constant care or supervision.

The AD Waiver was created to protect vulnerable adults, support caregivers, and use public funds responsibly. The current proposal undermines all three goals. DHHS has both a legal and ethical obligation to administer the AD Waiver in a manner consistent with Nebraska law, federal Medicaid requirements, and the actual assessed needs of waiver participants.

I urge DHHS to withdraw these proposed changes or significantly revise them to preserve adequate authorized hours and the ability for qualified family members to serve as paid caregivers. Failure to do so will place vulnerable adults at serious risk and undermine the integrity and purpose of Nebraska's Medicaid waiver system.

Thank you for considering my comment and protecting some of the most vulnerable adults in our communities.

Katherine Kuecker

From: Houseman, Karen
To: "nikki mann"
Cc: DHHS HCBS Public Comments
Subject: RE: HCBS waivers
Date: Monday, December 29, 2025 8:49:44 AM

Good Morning –

I'm including DHHS HCBS Public Comment mailbox to ensure your e-mail is received for public comment.

Best regards,

Karen Houseman | *DHHS Program Manager II, AD and TBI Waiver Service Coordination*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-9329 | CELL: 402-840-0869

From: nikki mann [redacted]
Sent: Sunday, December 28, 2025 8:29 PM
To: Houseman, Karen <Karen.Houseman@nebraska.gov>
Subject: HCBS waivers

> You don't often get email from n[redacted]. Learn why this is important

Dear Program Manager,

I am writing as a Nebraska resident to express my concern regarding proposed changes to Medicaid Home- and Community-Based Services (HCBS) waivers.

Medicaid waivers are a critical part of our state's care infrastructure. They allow children, adults, seniors, and veterans with disabilities or serious medical needs to receive care in their homes and communities, rather than in institutional settings. These services support not only individuals with disabilities, but also the family caregivers who make it possible for loved ones to remain safely at home.

Any reduction in caregiver hours or access to services places families in impossible positions, forcing them to leave the workforce, risk the safety of loved ones, or consider institutional care against their wishes. Caregivers are already under significant strain, and further reductions would increase isolation, burnout,

and long-term costs to the state.

I respectfully urge you to protect Medicaid HCBS waivers and to carefully consider the real-life impact these changes will have on families across Nebraska. Supporting community-based care is not only compassionate policy; it is fiscally responsible and reflects our shared values.

Thank you for your time and service to our state. I appreciate your consideration of this important issue.

Sincerely,
Nikki Mann
[redacted]

From: Julie
To: DHHS HCBS Public Comments
Subject: Re: Nebraska Disability Rights
Date: Tuesday, December 23, 2025 10:38:45 PM

> You don't often get email from [redacted] Learn why this is important

this is the comment I want on record please.

On Tue, Dec 23, 2025 at 10:26 PM Julie [redacted] wrote:

> The state needs to spend more to kee re they should be. Nursing home costs. Institutions are a poor choice for these people who have loving families caring for them. The problem is that DHS doesn't care. If they did they would be trying to get caregivers to help them get more money.

From: Jo T
To: DHHS HCBS Public Comments
Subject: Re: Nebraska Disability Rights
Date: Tuesday, December 30, 2025 10:10:51 AM

You don't often get email from [redacted] Learn why this is important

Nebraska can freeze the corporate tax cuts that are creating budget shortfalls.
A&D Waiver: Nebraska has the ability to suspend the corporate tax cuts that are contributing to budget shortfalls. Placement in a nursing home or institution typically involves higher expenses. What government assistance programs may families need to utilize, and what are the estimated costs to taxpayers?
Sincerely,
Julie S.

On Sun, Dec 28, 2025 at 2:01 PM Jo T [redacted] wrote:

> Dear DHHS,
>
> I have been a single mother caring for my adult child for 28 years. I can no longer work outside the home because he requires 24-hour care. Asking for free care is not an option—there are not enough providers willing or able to come into our home, not enough trustworthy staff to keep him safe, and we have had many difficult experiences with agencies in the past.
>
> DHHS says this about children: “Every child deserves a safe place to call home.” A child is generally a young human between birth and adulthood, characterized by growth, learning, and dependence. My adult child is a special-needs, medically fragile individual who remains fully dependent on someone else for care 24 hours a day. He has cerebral palsy, epilepsy, osteoporosis, scoliosis, developmental delays, and uses a wheelchair. I have provided him with a safe home, stability, dignity, and the chance to feel valued and hopeful about his future. But what does that future look like under your proposal?
>
> I invite you to come into the homes of families like mine. Look into the eyes of these adult children and tell them that you are no longer going to support the loved ones who care for them. Tell them that the bare minimum is all they are worth. Tell their parents—who sacrifice everything—that they must now suffer even more to provide the care their children cannot live without. Under your proposal, many of these children will lose the ability to remain in their loving homes and may be forced into nursing homes or institutions.
>
> Your proposal will cost the state far more than supporting families who provide care at home. Many families will lose their homes or their accessible vans and will be forced to rely on government transportation, housing assistance, SNAP, and other programs. How does this strengthen Nebraska’s future? What additional financial burdens will this place on taxpayers? And how will this not harm the care and safety of our most vulnerable

citizens?

I urge you to reconsider this proposal and meet with families directly before making decisions that will reshape their lives.

Sincerely,
Julie S.

From:	Large, Colin
To:	Newtson, Miranda D; Quiring, Hanna; DHHS HCBS Public Comments
Subject:	Re: Proposed Amendment cuts to the Nebraska Medicaid Home and Community-Based Services (HCBS) Aged and Disabled (AD) Waiver
Date:	Friday, January 2, 2026 10:14:28 AM

Sent to PC mailbox.

Colin

Colin Large | *Policy Administrator II*
Executive Green Belt
he/him
DEVELOPMENTAL DISABILITIES & HOME AND COMMUNITY-BASED SERVICES

Nebraska Department of Health and Human Services
CELL: 402.853.1452 | WEB: DHHS.ne.gov

From: Smith, Kristen <Kristen.Smith@nebraska.gov>
Sent: Friday, January 2, 2026 9:51 AM
To: Large, Colin <Colin.Large@nebraska.gov>; Newtson, Miranda D <Miranda.D.Newtson@nebraska.gov>; Quiring, Hanna <Hanna.Quiring@nebraska.gov>
Subject: FW: Proposed Amendment cuts to the Nebraska Medicaid Home and Community-Based Services (HCBS) Aged and Disabled (AD) Waiver

Please see below for a public comment.

Thank you!

Kristen Smith | *Deputy Director of Eligibility, Policy, and Quality*
DEVELOPMENTAL DISABILITIES

Nebraska Department of Health and Human Services
OFFICE: 402-471-8704

DHHS.ne.gov | Facebook | Twitter | LinkedIn

From: Mitch Hegg [redacted]
Sent: Thursday, January 1, 2026 3:54 PM
To: Smith, Kristen <Kristen.Smith@nebraska.gov>
Subject: Proposed Amendment cuts to the Nebraska Medicaid Home and Community-Based Services (HCBS) Aged and Disabled (AD) Waiver
Importance: High

> You don't often get email from mjhegg@cox.net. Learn why this is important

Dear Kristen Smith,

I felt it imperative that I voice my strong concern and opposition for the proposed cuts

to the Nebraska Medicaid Home and Community-Based Services (HCBS) Aged and Disabled (AD) Waiver service hours for the care of our most vulnerable people. These proposed draconian cuts reducing service hours to just 40 hours per week for live-in family members will be devastating and possibly life-threatening to the disabled persons and a significant financial burden on the family caregivers that care for these family members. These are our Sons, Daughters, Parents, Brothers, Sisters, Aunts and Uncles. How have we come to this, that we would introduce and move forward on budget cuts that adversely affect the already difficult lives that aged and disabled loved ones live? It's downright shameful.

I understand that budgets need to make sense, but to cut care hours for people that can't care for themselves. How can you convince yourself that is the right way to balance your budget. I'm sure their other areas that can be cut that don't affect the lives of people that can't take care of themselves.

I sincerely ask you to re-look at what is being proposed, close your eyes and imagine you are doing this to one of your loved ones to save a few dollars in the grand scheme of an entire budget where cuts can be made to things that don't affect the care of our most vulnerable people.

Every aged or disabled persons care is different; some require a lot of hours spent caring for and helping them to enjoy life and others require less hours. Lumping them all together and setting a maximum number of hours (the propose 40 hours) for all, is just not very caring or loving and frankly it's an easy way to make a cut without providing diligence to truly support and care for all involved, the aged, disabled and caregiver alike.

Our son is 28 years old and has many disabilities that would prevent him from surviving in a nursing home or a group home. He is blind, does not take anything by mouth (he is tube fed), he is incontinent, has cerebral palsy and is on life-saving medications. He requires 24/7 monitoring and care just to survive. Because of our diligent care we have kept him safe and out of the hospital. Bringing "outsiders" in to care for him would be devastating to his emotional state and his physical health and would be drastically more expensive then to just continue to provide the current 112 hours of in-home family care he receives now.

One DHHS employee is stated as saying "You'll be paid for a 40-hour work week, just like other working people" Our son and other aged and disabled people receiving care, don't just stop being disabled or needing care at the close of a 40-hour work week!

If this is all about the budget – what are you doing? How are you convincing yourself that this is somehow the right and prudent course of action?

Due to his emotional anxiety, routine and his life-saving medications he would never survive outside our care, we know him best and understand his unique medical condition that if not monitored throughout the day constantly, he would slip into a medical crisis and not survive. Because we are diligent and know him and his medical

crisis signs, we have avoided many hospital stays and emergency room visits over the last 28 years.

Please reconsider the proposed cuts to the A&D care hours! As you can see, we spend way more than 40 hours a week caring for our son. The loss of hours would be a financial burden to all his care givers and a strain on the health of those caring for him by requiring employment outside of caring for our son.

Being leaders requires you to not only evaluate and make decisions but to do it with compassion, care and what is right and not just easy and budget line cuts.

Thank you for taking the time to read and understand our concerns.

Sincerely,
Mitchell Hegg
Father and caregiver for Peter Hegg

From: Dorothy Ackland
To: DHHS HCBS Public Comments
Subject: Re: public Comment on ad waiver
Date: Friday, December 19, 2025 10:00:48 PM

You don't often get email from [redacted]. Learn why this is important

Please only submit the comment that's right before this email.Because the rest of them are essentially the same with minor adjustments.I'm so sorry

On Fri, Dec 19, 2025, 9:49 PM Dorothy Ackland [redacted] > wrote:

> Public Comment on Medicaid HCBS Waivers – Need for Habilitative Option at Nursing Level of Care
>
> Thank you for the opportunity to comment on Medicaid HCBS waivers, including Developmental Disabilities (DD) and Aged and Disabled (AD) waivers.
>
> My child qualifies for both: the AD waiver confirms her nursing facility-level medical needs due to her feeding tube, but limits services to ~$1,000—insufficient for her daily care. The DD waiver authorizes ~$10,000 for habilitative supports that enable her to remain stable at home.
>
> This forces a choice: select AD to reflect her medical reality and lose skill-building hours, or choose DD and understate her feeding tube requirements. Parents should not face tradeoffs between medical support and habilitation.
>
> My daughter's quality of life improves with habilitation, and that is only possible if therapy and waiver services work together. We are currently working on feeding her orally, and she went from 100% tube fed to now 75% tube fed, proving habilitation is possible and working. This is especially critical for non-school-age children who need consistent daily habilitation outside school hours to build foundational skills—and the same principle applies to adults who could benefit from habilitation at nursing level of care. CMS must require states to presume habilitation potential until assessments prove otherwise. I respectfully ask CMS to mandate a habilitative HCBS waiver for children and adults at Nursing Facility (Aged and Disabled) level of care. These individuals need both feeding tube management and habilitation to develop self-help, socialization, and adaptive skills—not a non-habilitative AD waiver with reduced hours.
>
> CMS should direct states to:
>
> Develop habilitative waivers for pediatric and adult nursing needs like feeding tubes.
>
> Address disparities where higher needs result in fewer services.
>
> Prioritize person-centered planning based on medical necessity, not waiver categories.
>
> This would ensure comprehensive support without artificial limits.
>
> Thank you.

On Fri, Dec 19, 2025, 9:46 PM Dorothy Ackland <[redacted] wrote:

> Public Comment on Medicaid HCBS Waivers – Need for Habilitative Option at Nursing Level of Care
>
> Thank you for the opportunity to comment on Medicaid HCBS waivers, including Developmental Disabilities (DD) and Aged and Disabled (AD) waivers.
>
> My child qualifies for both: the AD waiver confirms her nursing facility-level medical needs due to her feeding tube, but limits services to ~1,000—insufficient for her daily care. The DD waiver authorizes ~10,000 for habilitative supports that enable her to remain stable at home.
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> Address disparities where higher needs result in fewer services.
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> Prioritize person-centered planning based on medical necessity, not waiver categories.
>
> This would ensure comprehensive support without artificial limits.
>
> Thank you.
> Dorothy Ackland

On Fri, Dec 19, 2025, 7:57 PM Dorothy Ackland <[redacted]> wrote:

> Public Comment on Medicaid HCBS Waivers – Need for Habilitative Option at Nursing Level of Care
>
> Thank you for the opportunity to comment on Medicaid HCBS waivers, including Developmental Disabilities (DD) and Aged and Disabled (AD) waivers.
>
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This forces a choice: select AD to reflect her medical reality and lose skill-building hours, or choose DD and understate her feeding tube requirements. Parents should not face tradeoffs between medical support and habilitation.

I request CMS support a habilitative HCBS waiver for children at Nursing Facility (Aged and Disabled) level of care. These children need both feeding tube management and habilitation to develop self-help, socialization, and adaptive skills—not a non-habilitative AD waiver with reduced hours.

CMS should direct states to:Develop habilitative waivers for pediatric nursing needs like feeding tubes.Address disparities where higher needs result in fewer services.Prioritize person-centered planning based on medical necessity, not waiver categories.

This would ensure comprehensive support without artificial limits.Thank you.

Dorothy Ackland

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CMS should direct states to:Develop habilitative waivers for pediatric nursing needs like feeding tubes.Address disparities where higher needs result in fewer services.Prioritize person-centered planning based on medical necessity, not waiver categories.

This would ensure comprehensive support without artificial limits.Thank you.

Dorothy Ackland

From: Dorothy Ackland
To: DHHS HCBS Public Comments
Subject: Re: public Comment on ad waiver
Date: Friday, December 19, 2025 9:47:05 PM

> You don't often get email from [redacted]. Learn why this is important

Public Comment on Medicaid HCBS Waivers – Need for Habilitative Option at Nursing Level of Care

Thank you for the opportunity to comment on Medicaid HCBS waivers, including Developmental Disabilities (DD) and Aged and Disabled (AD) waivers.

My child qualifies for both: the AD waiver confirms her nursing facility-level medical needs due to her feeding tube, but limits services to ~1,000—insufficient for her daily care. The DD waiver authorizes ~10,000 for habilitative supports that enable her to remain stable at home.

This forces a choice: select AD to reflect her medical reality and lose skill-building hours, or choose DD and understate her feeding tube requirements. Parents should not face tradeoffs between medical support and habilitation.

My daughter's quality of life improves with habilitation, and that is only possible if therapy and waiver services work together. We are currently working on feeding her orally, and she went from 100% tube fed to now 75% tube fed, proving habilitation is possible and working. This is especially critical for non-school-age children who need consistent daily habilitation outside school hours to build foundational skills—and the same principle applies to adults who could benefit from habilitation at nursing level of care. CMS must require states to presume habilitation potential until assessments prove otherwise. I respectfully ask CMS to mandate a habilitative HCBS waiver for children and adults at Nursing Facility (Aged and Disabled) level of care. These individuals need both feeding tube management and habilitation to develop self-help, socialization, and adaptive skills—not a non-habilitative AD waiver with reduced hours.

CMS should direct states to:

Develop habilitative waivers for pediatric and adult nursing needs like feeding tubes.

Address disparities where higher needs result in fewer services.

Prioritize person-centered planning based on medical necessity, not waiver categories.

This would ensure comprehensive support without artificial limits.

Thank you.
Dorothy Ackland

On Fri, Dec 19, 2025, 7:57 PM Dorothy Ackland [redacted] wrote:

> Public Comment on Medicaid HCBS Waivers – Need for Habilitative Option at Nursing Level of Care
>
> Thank you for the opportunity to comment on Medicaid HCBS waivers, including

Developmental Disabilities (DD) and Aged and Disabled (AD) waivers.

My child qualifies for both: the AD waiver confirms her nursing facility-level medical needs due to her feeding tube, but limits services to ~1,000—insufficient for her daily care. The DD waiver authorizes ~10,000 for habilitative supports that enable her to remain stable at home.

This forces a choice: select AD to reflect her medical reality and lose skill-building hours, or choose DD and understate her feeding tube requirements. Parents should not face tradeoffs between medical support and habilitation.

I request CMS support a habilitative HCBS waiver for children at Nursing Facility (Aged and Disabled) level of care. These children need both feeding tube management and habilitation to develop self-help, socialization, and adaptive skills—not a non-habilitative AD waiver with reduced hours.

CMS should direct states to:Develop habilitative waivers for pediatric nursing needs like feeding tubes.Address disparities where higher needs result in fewer services.Prioritize person-centered planning based on medical necessity, not waiver categories.

This would ensure comprehensive support without artificial limits.Thank you.

Dorothy Ackland

From: teresa stewart
To: DHHS HCBS Public Comments
Subject: Re: Public Comment
Date: Tuesday, December 16, 2025 4:49:08 PM

> You don't often get email from [redacted] Learn why this is important

Also, I almost forgot, 20 days before my son turned 21, his nursing agency at the time notified me that his nursing hours would be cut greatly. I had 20 days to decide whether to place my son in a facility (of which none were available for his level of need) or quit my job and take care of him. Of course I chose to care for him because dhhs told me I could be a paid caregiver. Lets remember that I gave up a great paying job, with health insurance and 401k. The speaker that mentioned that this will greatly affect our social security is correct. At my age (61) this will be devastating.

I am certain I will think of more to add, for now this is all.

Peace, Love & May God Bless You !
Best Regards,
Teresa Stewart

On Tuesday, December 16, 2025 at 04:42:42 PM CST, [redacted]

I am here to advocate for my adult disabled son.
The back story:

My son was born Oct 1st 1996. He was born healthy, happy and loved. He contracted meningitis at 20 days old, its is believed that he was bitten by a mosquito carrying the West Nile virus while attending the funeral of my grandfather in rural Nebraska. I knew within hours something was terribly wrong with him. His brain hemorrhaged, leaving him physically and mentality devastated.

Those first 10 years were non-stop extended hospital stays in and out of the state of Nebraska. His father could not take the incredible responsibility the comes along with the diagnosis. He has CP, cortical blindness, Intractable epilepsy, baclophen pump (to keep the rigidity at a manageable place), a vagal nerve stimulator, trach, g-button, non-verbal, quadriplegic, vent dependent and unable to do anything on his own. I never had anymore children because I didn't feel it would be fair to either child. I have been caring for my son almost 30 years now. As such, I feel****no, I KNOW, I can provide a level of care the far surpasses care he could get anywhere else. This includes hospitals, care facilities and untrained respite workers.

DHHS insisted that I either get a full time job, or go to college, I did both, which took me 8 years to accomplish. I finally found that terrific cooperate job, that offered great pay, health insurance for myself and ability to contribute to my retirement.

Your saying that an additional 30 hours can be provided but by who??? Agencies that have the staff, will not staff those hours because of medical severity. It is a liability for them to do so. Therefore I would still have to make myself available to suction, prepare and administer medications, handle ventilator issues, administer rescue seizure medications, etc. Where would that staff come from?

Additionally, If my son were to go to a extended family home, they will get paid (For my son's level of need at high risk) 693.00 a day, 20,790 per month, and 249,480 per year. far more that I can make??? Why???

Also, are you saying that a live in caregiver is maxed out at 40, with an additional 30 by a outside provider, or can the parent get that additional 30 hours? And at what pay scale? Do you realize this will be a devastating financial blow to most of us? With our economy becoming increasingly more expensive (seems like) by the day with rising homeowners taxes and insurance rising, utilities rising, food costs rising, goods and service prices rising, how will this be sustainable for us? There has to be a better answer than this. Shameful.

From:	Aaron Kuecker
To:	Pillen, Jim
Cc:	Sen. Megan Hunt; DHHS HCBS Public Comments; Sen. John Cavanaugh, J.; Sen. Brian Hardin
Subject:	Re: Response to your concern
Date:	Friday, January 2, 2026 7:02:00 PM
Attachments:	image.png image.png

You don't often get email from [redacted] Learn why this is important

Mr. Pillen,

Thank you for your response to my public comment to DHHS. I will continue to submit comments and questions regarding the proposal through the appropriate channels. However, I feel it necessary to respond directly to several of your claims regarding the proposed waiver changes.

I agree with the intent of the AD Waiver updates, and I agree that we should manage resources effectively, protect taxpayer dollars, and avoid the creation of a Medicaid waitlist. To use a popular phrase, I believe in cutting "waste, fraud, and abuse," but this program is none of the above.

The proposed "reasonable budget parameters" are based on incomplete data. The AD Waiver cap of approximately $93,000 per year per person assumes that nursing facilities are the baseline cost of care, but it does not accurately reflect the real cost to taxpayers if nursing facilities become the primary means of care for individuals currently served under the waiver. With these proposed cuts, the use of nursing facilities would increase, along with overall expenditures.

As mentioned in my previous comment, live-in personal care is the least costly option for taxpayers. Most live-in caregivers earn approximately $15 per hour. If the state paid for 24-hour care at that rate, the annual cost would be $131,400. While this exceeds the proposed $93,000 budget parameter, it remains significantly less expensive than skilled nursing or institutional care.

The average hourly wage for a nurse in Nebraska is approximately $32. At that rate, a person could receive just over 11 hours of care per day within the proposed cap. However, care needs do not change based on the caregiver. If an individual requires 24-hour care, that need remains constant regardless of whether care is provided by a live-in caregiver, a nurse, or an institution. At $32 per hour, 24-hour nursing care would cost taxpayers $280,320 per year.

If a nursing facility is required for an individual with a severe disability—such as someone requiring a tracheostomy, ventilator support, or epilepsy care—the cost can reach $1,000 per day, or $365,000 per year, as reflected in the current DHHS contract with Ambassador Health of Omaha. This estimate is consistent with the state-run facility in Beatrice, which has an average annual cost of approximately $380,000 per person.

In summary, live-in caregivers cost approximately $131,400 per year, nursing care costs $280,320 per year, and nursing facilities cost upwards of $365,000 per year. While cutting the AD Waiver budget may appear to protect taxpayer dollars, it would ultimately produce the opposite result.

Additionally, the proposed updates to the AD Waiver would jeopardize high-quality, community-based supports rather than preserve them. If live-in caregivers are no longer paid a livable wage, more individuals will be forced into institutional settings. These settings are not as high-quality as the live-in supports already in place and remove individuals with disabilities from their communities. In effect, these changes would sacrifice the well-being of Nebraska's most vulnerable residents in the name of tax and budget cuts presented as fiscal responsibility and accountability. That may sound harsh, but I feel it is necessary to convey the gravity of the situation.

We would welcome the opportunity for you to visit our home in Omaha to see what day-to-day care looks like for our daughter. This program is not "grandmas getting paid to be grandmas," as you stated in a recent interview. It involves serious personal and medical care. Grandmothers get to bake pies and watch movies with their grandchildren, while we prepare specialized diets and administer medications that some physicians have never heard of.

I urge you to work with the Unicameral to temporarily pause future tax cuts and to identify actual "waste, fraud, and abuse" before making further reductions in critical services. To borrow an old carpentry adage, I urge you to "measure twice and cut once." Just as a carpenter cannot easily replace miscut wood, restoring essential supports to Nebraskans after they are cut will be extremely difficult and will cause unnecessary harm in the meantime.

Thank you for your time and consideration,

Aaron Kuecker

[redacted]

On Fri, Jan 2, 2026 at 11:57 AM Pillen, Jim <Jim.Pillen@nebraska.gov> wrote:

Jim Pillen
Governor

STATE OF NEBRASKA
OFFICE OF THE GOVERNOR
P.O. Box 94848 • Lincoln, Nebraska 68509-4848
Phone: (402) 471-2244 • jim.pillen@nebraska.gov

Dear Mr. Kuecker,

Thank you for contacting my office regarding the state's proposed changes to the Aged and Disabled Waiver. I appreciate you taking the time to share about your family's support needs.

The proposed AD Waiver updates include adjustments to cost coverage and the establishment of reasonable budget parameters to manage resources effectively, protect taxpayer dollars, and avoid the creation of a waitlist. The proposed AD Waiver updates are designed to preserve Nebraska's longstanding commitment to providing high-quality, community-based support while ensuring the program remains fiscally accountable and available to all eligible Nebraskans now and in the future.

Nebraskans are highly encouraged to submit public comments. Public comments are essential to the waiver renewal process as it is an opportunity for individuals, family members, caregivers, and all members of the public to contribute insights on what is important and necessary to fit the needs of all Nebraskans.

As part of the waiver update process, DHHS opened the public comment period on December 5, 2025. The public comment period will close January 5, 2026. After the public comment period closes, the department will review and post the public comments on the DHHS website. DHHS will also submit to the Centers for Medicare & Medicaid Services (CMS) a summarized response to public comment as part of the waiver application.

Public comments may be submitted by:

- Email: DHHS.HCBSPublicComments@nebraska.gov .
- Fax: (402) 471-8792.
- Mail: DHHS – Division of Developmental Disabilities, 301 Centennial Mall South, P.O. Box 95026, Lincoln, NE 68509

I encourage you to share your concerns with DHHS.

Thank you again for reaching out.

Sincerely,

Jim Pillen
Governor

Office of the Governor
PO Box 94848
1526 K Street, Suite 1
Lincoln, NE 68509
402-471-2244
governor.nebraska.gov | Facebook | Twitter

From: noreply@ne.accessgov.com <noreply@ne.accessgov.com>
Sent: Tuesday, December 23, 2025 2:51 PM
To: Pillen, Jim <Jim.Pillen@nebraska.gov>
Subject: A submission has been made to Write the Governor

Write the Governor

A submission has been submitted to the Office of the Governor. The submission can be viewed through the link: https://ne.accessgov.com/gov-admin/Admin/Submission/Review/contact-us?formId=347d48e5-b86c-4dbd-8bd3-4cbfdc8b4f35

First Name:	Aaron
Last Name:	Kuecker
Email:	[redacted]
Topic:	Health and Human Services
	I would like to include Mr. Pillen on my public comment to the Department of Health and Human Services regarding potential cuts to the Aged and Disabled Waiver personal care hours. See below: Greetings, My name is Aaron Kuecker, and I would like to leave a public comment on the proposed changes to the AD Waiver personal care program. In short, I am opposed to the currently proposed changes, but I would like to go into further detail as to why. I will start with my background and connection to the AD Waiver, then describe the problems I see with these changes, and finally offer alternatives for consideration. Background My daughter, Chitti Kuecker (age 19), has a severe disability and requires 24/7 care and supervision. She has a rare seizure disorder called Lennox–Gastaut syndrome (LGS). It is a drug-resistant form of epilepsy in which she can have any type of seizure at any time, for any reason. She is currently on four medications and has a medical implant called a vagus nerve stimulator (VNS), yet she still experiences 5–10 seizures per day. Chitti is non-verbal and requires full care, including assistance with administering medication, diaper changes, feeding, wheelchair mobility, bed turning, teeth brushing, dressing, and nearly every other personal care task. My wife, Katie Kuecker, and I are both caregivers through the AD Waiver, but Katie is her primary caregiver. She recently quit her job to become Chitti's full-time caregiver. Chitti is currently approved for the cap of 112 hours per week through the AD Waiver. As a side note, Chitti should probably qualify for 24 hours a day, or 168 hours per week, and the cap should be expanded in rare situations where individuals truly require constant care or supervision. Problems With the Proposed Cuts These cuts create a discontinuity and degradation of care for those on the AD Waiver, a financial hardship for caregivers, and will be more costly for taxpayers. Cutting weekly hours from 112 to 70 represents a 37.5% decrease in care and caregiver pay. However, because live-in caregivers are limited to being paid for only 40 of those hours, DHHS is effectively proposing a 64.3% decrease in pay for caregivers like my wife. Most employers provide cost-of-living adjustments tied to inflation —typically around 2–5% per year. DHHS is not only ignoring inflation but is dramatically reducing caregiver pay. We should be discussing how to increase compensation to keep up with rising costs of living, not cutting it. For my family, these cuts could mean that my wife can no longer remain a stay-at-home caregiver for our daughter, a choice we made because we knew this program existed. As a special education teacher for Omaha Public Schools, she brought home approximately $4,200 per month. Under the proposed cuts, her income would drop to $2,400 per month (40 hours per week × $15 per hour × 4 weeks). That leaves our family needing to find an additional $1,800 per month in our budget. Can we still afford our mortgage? Can we afford the wheelchair-accessible van we purchased to accommodate our daughter's disability? If my wife needs to return to work, who will care for our

Comment:

daughter? I believe the best caregivers for Chitti are the people who know her best—my wife and me. We have become quasi-experts in epilepsy due to her needs, and I would argue that we know more about her condition than the average certified nurse, unless that nurse works specifically in epilepsy care. This is not unique to our situation. In general, family caregivers provide the highest-quality care for their loved ones. By cutting hours, you are reducing the quality of care for individuals on the AD Waiver and potentially putting medically fragile individuals at risk for preventable hospitalizations. This change is also happening far too quickly for families who have come to rely on this level of income. If the cuts are accepted, we have roughly six months to either find an additional $1,800 per month or dramatically alter our budget. Cutting hours is the wrong choice, but if DHHS proceeds anyway, the reduction should at least be staggered to give families adequate time to adjust. Additionally, these changes will likely increase the overall cost to the state. My daughter requires care for 168 hours per week. Under the proposed cuts, only 40 of those hours could be covered by my wife or me, leaving 128 hours unpaid. Due to Chitti's medical needs, those remaining hours would require a registered nurse (RN) rather than a certified nursing assistant (CNA). At an average RN rate of $32.04 per hour in Nebraska, 128 hours would cost $4,101.12 per week. Combined with the 40 hours of family care, the total weekly cost would be $4,701.12. Currently, at 112 hours per week, the total cost is $1,680. This means the proposed cuts would cost taxpayers an additional $3,021.12 per week, or approximately $157,000 per year. If skilled nursing assistance cannot be adequately staffed, another option would be institutional care or a nursing home providing 24/7 intensive medical support. These facilities likely do not exist for someone with my daughter's needs, or they lack space or the specialized professionals required to serve her. This is where DHHS's average estimate for nursing home costs appears misleading. While I do not know the exact cost of such a facility, I am confident it exceeds the approximately $92,000 estimate DHHS is using for 2025. Even if that estimate were accurate, paying my wife to provide 112 hours of care per week would cost $87,360 annually—still roughly $5,000 less than institutional care. So between the three options, which is most financially responsible? Live-in caregivers provide the highest quality of care at a cost of approximately $87,360 per year under the previous AD Waiver limits. Nursing homes are more expensive and provide lower-quality care, assuming space is even available. Skilled nursing coverage would cost the state approximately $244,360 annually to replace the hours eliminated by the proposed cuts. So live-in caregivers are both higher quality and less expensive. I know which option I would choose. I understand that skilled nursing costs may come from a different budget than the AD Waiver, but this still represents a gross misuse of taxpayer funds and negligent stewardship by DHHS leadership. I recognize that the intent behind these cuts may be to prevent a waiver waitlist, but there must be a better approach. In the next section, I offer possible alternatives. Better Alternatives It is worth exploring all alternatives, as the proposed cuts represent a lose-lose-lose outcome for individuals with disabilities, caregivers, and taxpayers. Doing nothing is a valid option—DHHS could withdraw the proposal and continue the program as it currently exists. If the AD Waiver budget is strained, DHHS or the state legislature could explore reallocating funds from other programs. If changes are deemed unavoidable, one option is to grandfather in individuals who are currently approved for higher hours. Anyone newly entering the AD Waiver after July 1, 2025, could be subject to the 70-hour limit. This would protect families who rely on existing income

and care levels while gradually establishing a new norm. Additionally, eliminating the 40-hour cap on live-in caregivers would improve continuity of care and reduce unnecessary administrative complexity. Another issue with the proposed cuts is their one-size-fits-all approach. Individuals with disabilities have widely varying needs. Seventy hours of personal care per week will be insufficient for many people. Instead, the cap could remain at 112 hours, or increase to 168 hours for individuals with extreme needs. DHHS could then conduct audits of service needs assessments to determine appropriate hours. To reduce subjective judgment, a needs-based rubric could be developed, similar to the LRI program. Tasks could be assigned standardized time values—diaper changes at 15 minutes, bathing at 30 minutes, medication administration at 20 minutes, and so on. However, unlike the LRI program, supervision hours must be included for medically complex individuals whose conditions could rapidly deteriorate without monitoring, such as those with ventilators, tracheostomies, or severe epilepsy like my daughter. This approach would allow the AD Waiver to serve individuals based on actual need rather than an arbitrary cap. While some individuals' hours might decrease, meeting DHHS's cost-reduction goals, the most vulnerable would still receive the care they require. The best part is that at the end of this process DHHS would have an accurate budget for this program, not estimates or approximations based on nursing home averages or other metrics. You would know exactly how much money is needed to serve all individuals based on their needs. That would carry much more power in our legislature and DHHS would have many advocates, such as myself, in fighting for enough funding if allocations for the waiver were ever short of that amount. For what it's worth, I would like to rank these alternatives as a parent and caregiver: Continue personal care hours as they exist now. No changes. Re-evaluate every individual on the program using a needs-based rubric without a weekly hour cap. Continue with the proposed changes, but grandfather in those with an approved number of hours per week. But, make no differentiation between live-in and non-live-in caregivers for those new to the waiver. Summary In closing, I urge DHHS and our state leaders to step back and consider the human, financial, and ethical consequences of these proposed cuts. The AD Waiver exists to keep individuals with severe disabilities safe, dignified, and cared for in their homes, while also being a responsible use of taxpayer dollars. The current proposal fails on all three fronts. It places families like mine on the brink of financial collapse, reduces the quality and continuity of care for Nebraska's most vulnerable residents, and ultimately costs the state far more through skilled nursing or institutional care. This is not an abstract policy decision for us. It determines whether my daughter can remain safely at home, cared for by the people who know her, love her, and are best equipped to meet her complex medical needs. I ask you to reject these cuts and pursue thoughtful, needs-based alternatives that protect families, respect caregivers, and uphold the intent of the AD Waiver. Doing so is not only the compassionate choice, but the fiscally responsible one.

From: Kelsey Lahaie
To: DHHS HCBS Public Comments
Subject: Reasonable Adjustments and Options for In-Home Family Care
Date: Monday, January 5, 2026 4:27:24 PM

You don't often get email from [redacted]. Learn why this is important

**Reasonable Adjustments and Options for In-Home Family Care

Nebraska Aged & Disabled (A-D) Waiver**

In-Home Family Caregiver Hours

The proposed reduction in allowable hours for in-home family caregivers under the A-D Waiver is unreasonable and will place an undue burden on families who are already providing essential, high-level care. These reductions risk destabilizing care arrangements that currently allow individuals with disabilities and older adults to remain safely in their homes and communities.

Proposed Reasonable Adjustment

Rather than implementing immediate and sweeping cuts, the state should adopt a measured, transparent approach that allows families time to plan and avoids unnecessary disruption to care:

- Only when the state is within six (6) months of a verified funding shortfall, the following adjustment may be implemented.
- Allow families to provide up to 90 hours per week of in-home family caregiving at $15.00 per hour (or the prevailing livable wage at that time).
- Families may choose, but are not required, to use an agency for up to 30 of the 90 hours.
- Participation in agency-provided care must remain voluntary and based on the participant's preferences and needs.

This approach:

- Gives families adequate notice and predictability, allowing them to plan for potential changes.
- Recognizes that many individuals with high-level care needs are not comfortable with unfamiliar caregivers.
- Acknowledges the ongoing shortage of qualified direct care workers, especially for complex medical or behavioral needs.
- Supports the participant's right to remain in the least restrictive and most integrated setting, consistent with Olmstead v. L.C. and the Americans with Disabilities Act (ADA).

Because agency-provided care often costs two to three times more than family-provided care, this model:

- Allows participants and families to determine the most appropriate and cost-effective care arrangement.
- Preserves participant choice, autonomy, and dignity.
- Protects the state from unnecessary increases in overall Medicaid expenditures.

Nursing Home Care Reimbursement

The state must also reevaluate its approach to nursing home reimbursement.

The current proposed reimbursement structure:

- Provides no meaningful incentive for nursing facilities to accept or adequately serve individuals with high medical or behavioral needs.
- Fails to address chronic staffing shortages, including the lack of continuous access to licensed medical professionals.
- Does not ensure facilities can safely meet the level of care required by many A-D Waiver participants.

When nursing homes are unable to meet these needs:

- Families are forced to fill gaps in care that are legally the responsibility of the state, not unpaid caregivers.
- Individuals face increased risk of harm, neglect, or inappropriate placement.

The state must establish a higher, more realistic reimbursement rate that:

- Reflects the true cost of providing high-quality, appropriate care.
- Ensures facilities are properly staffed and equipped.
- Prevents unnecessary institutionalization or inappropriate placement due to financial constraints.

Disability Rights and Olmstead Considerations

Under Olmstead v. L.C., the ADA, and Nebraska's own Olmstead Plan, the state has an obligation to:

• Provide services in the most integrated setting appropriate.
• Avoid policies that effectively force institutionalization by reducing or destabilizing community-based supports.
• Respect the rights of participants and families to make informed decisions about their care.
Policies that significantly reduce in-home supports—without reasonable alternatives—risk violating these obligations and undermining the very purpose of the A-D Waiver.

Conclusion

A balanced, rights-respecting approach that supports family caregivers, preserves participant choice, and ensures adequate reimbursement for institutional care is not only fiscally responsible—it is legally required. The proposed adjustments offer a practical solution that protects Nebraska's most vulnerable residents while remaining consistent with federal disability rights law.

Our families and children are depending on you to do the right thing.

Kelsey Lahaie
Rett Parent

**Reasonable Adjustments and Options for In-Home Family Care

Nebraska Aged & Disabled (A-D) Waiver**

In-Home Family Caregiver Hours

The proposed reduction in allowable hours for in-home family caregivers under the A-D Waiver is unreasonable and will place an **undue burden on families** who are already providing essential, high-level care. These reductions risk destabilizing care arrangements that currently allow individuals with disabilities and older adults to remain safely in their homes and communities.

Proposed Reasonable Adjustment

Rather than implementing immediate and sweeping cuts, the state should adopt a **measured, transparent approach** that allows families time to plan and avoids unnecessary disruption to care:

- **Only when the state is within six (6) months of a verified funding shortfall**, the following adjustment may be implemented.
- Allow families to provide up to **90 hours per week** of in-home family caregiving at **$15.00 per hour** (or the prevailing livable wage at that time).
- Families may **choose**, but are **not required**, to use an agency for up to **30 of the 90 hours**.
- Participation in agency-provided care must remain **voluntary** and based on the participant's preferences and needs.

This approach:

- Gives families **adequate notice and predictability**, allowing them to plan for potential changes.
- Recognizes that many individuals with high-level care needs are **not comfortable with unfamiliar caregivers**.
- Acknowledges the ongoing **shortage of qualified direct care workers**, especially for complex medical or behavioral needs.
- Supports the participant's right to remain in the **least restrictive and most integrated setting**, consistent with **Olmstead v. L.C.** and the Americans with Disabilities Act (ADA).

Because agency-provided care often costs **two to three times more** than family-provided care, this model:

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- Protects the state from unnecessary increases in overall Medicaid expenditures.

Nursing Home Care Reimbursement

The state must also reevaluate its approach to **nursing home reimbursement**.

The current proposed reimbursement structure:

- Provides **no meaningful incentive** for nursing facilities to accept or adequately serve individuals with **high medical or behavioral needs**.
- Fails to address chronic **staffing shortages**, including the lack of continuous access to licensed medical professionals.
- Does not ensure facilities can safely meet the level of care required by many A-D Waiver participants.

When nursing homes are unable to meet these needs:

- Families are forced to fill gaps in care that are **legally the responsibility of the state**, not unpaid caregivers.
- Individuals face increased risk of harm, neglect, or inappropriate placement.

The state must establish a **higher, more realistic reimbursement rate** that:

- Reflects the true cost of providing high-quality, appropriate care.
- Ensures facilities are properly staffed and equipped.
- Prevents unnecessary institutionalization or inappropriate placement due to financial constraints.

Disability Rights and Olmstead Considerations

Under **Olmstead v. L.C.**, the ADA, and Nebraska's own Olmstead Plan, the state has an obligation to:

- Provide services in the **most integrated setting appropriate**.
- Avoid policies that **effectively force institutionalization** by reducing or destabilizing community-based supports.
- Respect the **rights of participants and families to make informed decisions** about their care.

Policies that significantly reduce in-home supports—without reasonable alternatives—risk violating these obligations and undermining the very purpose of the A-D Waiver.

Conclusion

A balanced, rights-respecting approach that supports family caregivers, preserves participant choice, and ensures adequate reimbursement for institutional care is not only fiscally responsible—it is **legally required**. The proposed adjustments offer a practical solution that protects Nebraska's most vulnerable residents while remaining consistent with federal disability rights law

From: Leslie Eads
To: DHHS HCBS Public Comments
Subject: Regarding cap to services for Developmentally Disabled Individuals
Date: Sunday, December 21, 2025 10:14:45 AM

You don't often get email from [redacted]. Learn why this is important

To Whom It May Concern,

I am writing to advocate for an individual who will be greatly impacted by your short-sighted decisions requiring a cap on care. This individual resided at BSDC when the Department of Justice (DOJ) investigated them after reports of abuse and neglect. They found serious violations and in March of 2008 initiated a lawsuit and reached a settlement agreement. This individual is one of the people who was affected by this abuse and neglect. She was in the papers on the news as a victim of care the Nebraska DHHS oversaw. She was hospitalized for a significant period and finally transitioned to HBCS. Her family was assured by NE DHHS that she would be cared and provided for, for the rest of her life.

The DOJ's involvement pressured Nebraska to reform its system, leading to fewer people living in institutional settings, and focused on community-based support. Due to this change in focus, the DOJ ended its involvement with the understanding that institutional focus would die out and Nebraska would continue to focus on HCBS.

The new guidelines that have been published, go back to a time when we threw DD individuals into an institutions and threw away the key. You are doing exactly what the DOJ found was a significant contributor to abuse/neglect of these individuals. I don't know how you can move forward in good conscience with how this will affect our disabled community. This will remove them from homes that have sacrificed to provide them a family. You will tear them away from people they love and trust. You should not pull them from homes of decades or more.

This is a travesty and an unconscionable choice. Do better.

Concerned citizen

From: Jodi Tolman
To: DHHS HCBS Public Comments
Subject: Remove 40 hr/wk limit for LIVE-IN INDEPENDENT PROVIDERS who save the state money
Date: Saturday, December 27, 2025 10:22:24 AM

You don't often get email from [redacted]. Learn why this is important

Dear DHHS,

I am an independent provider on the AD Waiver for my adult daughter with severe disabilities and complex medical needs, requiring 24 hour/day care. I have major concerns about the proposals presented in the renewal of the AD Waiver, specifically the 40 hour/week limit placed on live-in family caregivers.

AGENCY PROVIDERS COST THE STATE MORE THAN TWICE THE COST OF INDEPENDENT PROVIDERS

The AD Waiver renewal proposes that additional hours given to the participant beyond the 40 hour/week live-in caregiver limit must be provided by an outside agency provider. I urge you to consider the additional cost this puts on the state! As an independent provider, I am paid just $15/hr. Compare that to how much it costs the state to pay for an agency provider to work those same hours:

Cost to provide just 30 additional hours per week:

Live-in Independent provider: $15/hr x 30 hrs/wk x 52 weeks = **$23,400/year**

Agency provider: $35/hr x 30 hrs/wk x 52 weeks = **$54,600/year**

By paying an independent provider (live-in family caregiver) instead of an agency, the **state will save $31,200/year on just ONE participant!**

Those savings are magnified even further when you consider that my daughter, as well as many others on the AD waiver, will most likely qualify for more than 70 hours/week based on their level of medical complexity and their need for 24 hour/day care.

My daughter requires 24 hour care, but let's say that she is limited to 112 hours a week of paid care (72 hours beyond the 40 hrs allowed to live-in caregivers):

Cost to provide 72 additional hours per week:

Live-in Independent provider: $15/hr x 72 hrs/wk x 52 weeks = **$56,160/year**

Agency provider: $35/hr x 72 hrs/wk x 52 weeks = **$131,040/year**

By paying an independent provider (live-in family caregiver) instead of an agency, the **state will save $74,880/year on just ONE participant!** Multiply those savings by thousands of partipants and that is huge savings for the state.

It makes no financial sense to require ANY hours to be worked by agency providers who cost the state far more money than independent providers.

You have already grandfathered in parents like me who are parent independent providers, exempting us from the new policy that requires new parent caregivers to work through an agency. **Use this to your advantage as a way to save even more money by paying us instead of more expensive agency providers for additional hours.**

The other issue with requiring additional hours to be worked by agency providers is that most agencies do not have the providers to support the huge need that these waiver proposals will suddenly create, leaving huge gaps in care and increasing the need for institutional placement, which again, only costs the state even more money.

Live-in family caregivers are a valuable resource for the state. Utilize us appropriately! Pay us what we are worth! Don't disrespect us or take advantage of us by assuming we will provide care for free! Continue to compensate us reasonably and equitably, or risk losing a large portion of these family caregivers. Losing live-in family caregivers will only cost the state more to pay for agency providers, or create even bigger financial and logistical problems with a surge of participants suddenly requiring institutional care.

I plead with you to exempt live-in independent providers from the proposed weekly limits in the AD Waiver renewal.

Respectfully,

Jodi Ann Tolman

From: Katie Novakoski
To: DHHS HCBS Public Comments
Subject: Request for Information
Date: Thursday, January 1, 2026 4:40:48 PM

> You don't often get email from [redacted]. Learn why this is important

Hi,

I would like to formally request to see the document that breaks down the costs for institutional costs/nursing homes? In the 2024 DDD annual report, I see that the Beatrice State Developmental Center costs an average of $385,655 per person. I also have heard the contract with Ambassador Omaha and DHHS is $1,000 a day for Medicaid patients. I am formally requesting more in-depth information about how the **$92,438** average was determined for AD wavier participants. I am concerned this average does not accurately reflect averages for those who are more severely disabled.

Katie Kuecker

From: Katie Novakoski
To: DHHS HCBS Public Comments
Subject: Respite care AD waiver proposal changes
Date: Saturday, January 3, 2026 1:10:32 PM

Hello, I am concerned with and oppose the changes to language used around respite care in the proposal. It now seems to say that parents are unpaid caregivers instead of usual caregivers or other language like that.

From: Dawn Larson
To: DHHS HCBS Public Comments
Subject: Response to not lower the hours
Date: Wednesday, December 17, 2025 12:03:10 PM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

When someone is disabled for life then the state is trying to lower the hours which is not right at all because all the disabled people need this help for a reason especially when they really need 24/7 care so please exspecially single parents trying to make a living so please help us all by not lowering the hours
Sent from my iPhone

From: Tamar Polivka
To: DHHS HCBS Public Comments
Subject: Response to Proposed Changes to AD Waiver
Date: Friday, January 2, 2026 4:13:08 PM

You don't often get email from [redacted]. Learn why this is important

Do NOT move forward with this unjust and dangerous proposal to gap live-in caregivers. Please see how your own handbook says DO NOT DO THIS. It will hurt our most disabled Nebraskans.

Based specifically on the language on pages 127–128 of the AD Waiver proposal, there are several internal inconsistencies and conflicts when you line up personal care hour caps, exceptions, and who is allowed to provide the care.

—

1. Conflicting Hour Caps vs. "Health and Safety" Exception Language

What the proposal says

- 40-hour cap for Personal Care + LRI Personal Care when the caregiver is live-in
- 70-hour combined cap for Personal Care + LRI + Companion
- Exceptions may be approved by Central Office to meet immediate health and safety needs

Inconsistency
• The proposal acknowledges that some individuals have needs that exceed 40 or 70 hours for health and safety,
BUT
• It does not align those exceptions with 24/7 care needs, even when those needs are already documented and previously approved.

Why this is a problem
• A person who needs continuous supervision or hands-on care cannot have their health and safety met under a hard weekly cap.
• The exception language is written as temporary or emergency-based, not as recognition of ongoing, permanent high needs.

 Contradiction: The proposal admits higher hours are sometimes required, but structures the system so those needs cannot realistically be met long-term.

—

2. Provider Restrictions Conflict With Tolerance, Routine, and Disability Needs

What pages 127–128 do

- Strongly limit who can provide care:
- Live-in family caregivers capped lower
- Greater reliance implied on non-family or agency providers
- Treats family care as something that should be restricted, not individualized

Inconsistency
• The proposal:

- Claims to be person-centered

    - References health and safety

- But ignores the reality that:
    - Some individuals do not tolerate unfamiliar caregivers
    - Routine and trust are medically necessary, not preferences

 Conflict: You cannot claim person-centered planning while forcing care from providers the individual cannot safely tolerate.

—

3. Unequal Treatment Based on Provider Type, Not Need

What the proposal does

- Two people with the same assessed needs can receive very different hours depending on:
    - Whether care is provided by family
    - Whether they can tolerate outside staff

Inconsistency
- The waiver is supposed to be needs-based, yet:
    - The cap applies more harshly to family providers
    - Individuals who cannot accept outside providers are effectively penalized

 Result: The proposal creates artificial scarcity, not based on needs, but on provider category.

4. Cost-Containment Language Conflicts With Actual Cost Outcomes

What's implied
- Caps are justified as cost control

Inconsistency
- Family caregivers:
    - Are paid less than agencies
    - Cost far less than institutional care
    - Restricting family hours:
        - Pushes individuals toward nursing facilities or higher-cost settings
        - Violates the stated intent to be fiscally responsible

 Contradiction: The proposal limits the least expensive care option while risking the most expensive outcome.

—

5. Olmstead & HCBS Final Settings Rule Conflict (Indirect but Real)

Even though not named directly on pages 127–128, the conflicts are clear:
- Olmstead requires services in the most integrated setting
- Final Settings Rule requires:
    - Choice of providers
    - Services that support remaining in the community

Inconsistency
• Caps + provider limits:

- Reduce meaningful choice
- Make home care unsustainable for high-need individuals
- Increase risk of institutionalization

 This puts the state at odds with federal intent, even if not explicitly acknowledged in the proposal text.

—

6. Summary of Core Inconsistencies (Plain Language)
• The waiver says health and safety matter, but caps make safety impossible for some.
• It says person-centered, but applies blanket limits.
• It says choice of provider, but restricts family care.
• It says cost-effective, but undermines the lowest-cost option.
• It says community-based, but increases institutional risk.

Instead of taking funds from our most vulnerable citizens, please consider doing an audit of all the individuals receiving disability. I am convinced the amount of fraud going on would more than cover the shortfall in your budget.

My sister is the caregiver for my nephew who requires 24/7 care. They would be happy to have an auditor visit and see what is involved with caring for my nephew. There is absolutely no way you are going to find a cheaper way to care for him than the current situation. It is also impossible for her to find other caregivers who will work for the $15/hour she is paid. This is absolutely untenable. There has to be a better solution. Please care enough to find it.

To Governor Pillen, Nebraska DHHS Leadership, and Nebraska Lawmakers,

We are writing as individuals with a disability who rely on the Aged and Disabled Waiver to live safely, independently, and with dignity in our own home and community. We strongly oppose the State of Nebraska's proposal to reduce services from 112 hours per week to 70 hours per week, and to further limit family-provided care to only 40 of those hours.

My family caregivers are not just "providers." They are the people who know us best. They have always cared for us. There is no learning curve with our needs because they already understand them—physically, emotionally, and mentally. They know how we like things done, what we can do independently, and when we truly need help. They trust us, and we trust them.

Our family has a vested interest in our well-being. For them, this is more than a job. They have pushed us to better ourselves, encouraged our independence, and helped us stay engaged and mentally stimulated. Because of them, we feel safe, respected, and empowered to make choices about our own life. With family caregivers, we are able to do what is best for us in a place where we feel secure.

Having family caregivers gives us freedom. We can live in our home, remain active in our community, and go to work. We can have our service dogs. We can decide how we spend our day and who provides our care. These are not luxuries—they are essential to our quality of life.

The proposal to force 30 hours of care to be provided by a stranger is deeply concerning. Constantly rotating unfamiliar caregivers creates stress, fear, and risk. There is always a learning curve with new staff, and that learning curve puts our safety at risk. Many caregivers cannot truly relate to us or understand our needs the way our family does. For too many, this is just a job. We become a task—or worse, a paycheck.

If we lose the ability to use our family caregivers and are forced into an assisted-living facility, we know that once we go in, we will never come back out. It would feel like a prison. We would lose our independence, our voice, and our motivation to better ourselves. There is an increased risk of neglect or abuse. We would not have a say in who cares for us. We would not be able to work or fully participate in the community. Our lives would shrink.

Nebraska's disability services are supposed to support community-based living, not dismantle it. These proposed changes do the opposite. They punish families who have stepped up, reduce safety, and push people like us closer to institutionalization—something that is both more costly to the state and far more harmful to the individual.

We are asking you to reconsider these changes. Please protect our rights—and the rights of others like us—to remain at home, with the caregivers who know us, support us, and help us live full, meaningful lives.

Respectfully,

Sarah and Alex Troia
Concerned individuals with a disability

I am writing this on behalf of Cody Cullen, with the changes that could possibly be coming does worry me as Cody is a 24 hr Care. He is mentally handicapped and completely blind so he has to have Someone with him at all times. Even in the night hours when most are asleep he doesn't sleep but a few hrs all night than thinks it's time to get up. About 5 years ago he caught something called Necrotising fasciitis it's a flesh eating bacteria that is very deadly but he survived it. But along with that he now has problems walking good so with all the other things Cody faces he is just alot more care so Cutting hrs would be very unfair for him.

Thank You for Youre time

Ashley Shell

From: Cori Watkins
To: DHHS HCBS Public Comments
Subject: Statement regarding cuts to funding for the disabled
Date: Monday, December 29, 2025 10:56:54 AM

You don't often get email from [redacted] Learn why this is important

To whom it may concern : Here in Nebraska they have proposed deep cuts to all services for disabled people , in home , caregivers , reducing hours and pay for all involved , also breaking the law while at it , drastic funding cuts and staff cuts when we are already managing on a skeleton crew everywhere in this state with Caregivers , at all skill levels and after our DHHS dept here in Lincoln Nebraska lost somewhere between 30-40 million according to our state auditor , with inflation , prices going up , we need more help not less and this is putting the disabled population at great risk , danger and harm , Our Governors proposal to put these people in nursing homes , takes them away from their families , support systems , Consistency the list goes on ,plus the cost of a nursing home is outrageous , our nursing homes cannot absorb this , I'm a nurse of 36 and we already have dangerously understaffed skilled care homes , I know I've worked at them , almost all
Of them in and around lincoln as an agency nurse , this is a very serious matter and it's quite clear our leadership or lack thereof is targeting the most vulnerable of our community , this is intolerable and unacceptable to discriminate against them this way by making them suffer , families suffer , letters , complaints emails and calls have been not been enough for the powers that be to change course , we the parents of special needs children whether they be adults or still minors need help , this is not an acceptable solution to just lock them away , far from society , it's evil and inhumane , the test of how healthy a Society is , is how well we treat our elderly and disabled populations , and this is a disgrace , ask them where the money is , ask them why we need to cut services from the disabled ? Because they can't fight back , but we the parents will not stop fighting this , there is no way this is going to work anyway , this is ludicrous to think this is even feasible , especially when the lawsuits start flying against this state and I can assure you they will if this inhumane nonsense continues , I hope that you can be of some kind of assistance in this situation , we are reaching out to everyone and anyone who might be able to help , Thank you for your time and attention to this very important matter , I can provide more details if needed , Cori L Watkins 5356 Mission lane lincoln NE 68521402-904-0333

From:	James Summers
To:	DHHS HCBS Public Comments
Subject:	state"s plan to renew the 1915(c) Medicaid Home and Community Based Services (HCBS) Aged and Adult and Children with Disabilities (NE.0187) waiver and amend the Traumatic Brain Injury Waiver (NE.40199). The 30-day public comment period is from December...
Date:	Thursday, December 25, 2025 4:14:56 PM

[You don't often get email from [redacted]. Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Sent from my iPad,
I am the father of 21 year old mentally and physically disabled young man that this proposal will effect if approved. My son has had medical problems his entire life with multiple surgeries and weeks at a time in Childrens hospitals. He has the mind of a 6-8 year old and believes in anything and everything (Santa is real, elves are real, he flies in his sleigh all over the world delivering toys to all the boys and girls all over the world. He believes the Easter Bunny is real, Star Wars, he believes. My wife takes care of him 24-7-365 shes in his room cleaning picking up, washing clothes, changing his medical needs or emptying the stoma bags (he has 2 (two) a urostomy and an illiostomy. These require alot of work for SANITARY AND HEALTHCARE. His bag blows or gets tore off in bed or in the car its a big mess that has to be dealt with immediately no matter where you are or no matter what you are doing. He has a medical bed that raises and bends for comfort so he can eat and sleep in it. My wife attends to him several times through the night every night and its a job that exceeds what most cant even imagine. Her wages currently before these proposed changes are a direct effect of our budgeted expenses and above needed supplies that his insurance does not cover. We depend on it just like my income, its her job caring for him and his medical needs. When hes in the hospital, her care does not stop, she has to stay with him through the night most times showing nurses and aids how to empty, drain and dump his Ostomy bags and when it needs to be changed, she does it because most have never seen one before. Putting our 21 year old son in some facility is NOT WHAT WE WANT TO DO. Him being cared for at home is ALOT CHEAPER than in some facility that would 100% require 24-7-365 supervision and care. Cutting hours from 70-80 a week to 40 in her scenerio is absolutely ridiculous. She has 100% dedication to giving him the best comfort and medical needs he requires and works well over 80 hrs a week. If cutting hours is to cut back on spending to save money or disperse it else where is obsurd. The families that take care of there loved ones should not sacrifice and loose there homes because of this. Ive worked for a Government Municipality my entire life and i understand budgets and i understand why there needed but i also understand that theres some areas that you just have to work them into the amount needed and cut the FAT from other places like monetaries that are dispersed that no one knows what it is. Stop giving tax dollars to places that DO NOT NEED THEM they just can use the extra to benefit and make millions more. I know adults that ABUSE the system and recieve monitary help and are perfectly capable of taking care of them selves, they are just LAZY, (start by cutting the FAT).

My wife, im told by alot of people that know her or my son and they know what she does, how does she do it? How does she keep it up, she is amazing how she cares for him and that all children need a mom like her.

I am asking you to deny the proposed changes because not only is it going to put a hardship on us as a family, it will put mostly everyone involved in some type of negative situation. There are an uknown amount of people this will effect and dramatically change there lively hood. Your not just making a simple decision to save some money, your decision will be cutting some single mom or dads income in half and then what will happen? The answer is simple. (Proven medical and physical healthcare needs should never come after anything that doesn't need it). My sons needs was born with these issues and when we ADOPTED him, we didn't care but we also didn't know how bad it would be. His life does MATTER, hes not just a number, hes our son.

My sons needs are complex and complicated, his needs are not common at all. We have been told that no facility in Nebraska is equipped for his needs and that comes directly from his SERVICE COORDINATOR assigned to my son by the state.

Thank you for your time,
Sincerely, James Vernon Summers

From: Doug Grover
To: DHHS HCBS Public Comments
Subject: Stop the changes to AD Waiver
Date: Tuesday, December 30, 2025 11:01:12 AM

You don't often get email from [redacted] Learn why this is important

I am writing to strongly oppose the proposed changes to Nebraska's AD Waiver, particularly the limitation of paid hours for family caregivers. These changes raise serious legal, ethical, and fiscal concerns and will have devastating consequences for individuals with disabilities and the families who support them.

First, the assertion that 40 hours at minimum wage is "sufficient" is legally irrelevant. Federal Medicaid law requires services sufficient to meet medical necessity and to allow individuals with disabilities to remain safely in the most integrated setting appropriate. By reducing authorized hours and shifting thousands of dollars in disability-related costs onto families, the Department is denying meaningful access to Medicaid services and creating a serious risk of unnecessary institutionalization. This violates Title II of the ADA and the Olmstead v. L.C. decision. The policy creates a coerced choice rather than a voluntary one—amounting to constructive institutionalization, which Olmstead explicitly prohibits.

Second, limiting family caregivers to 40 paid hours per week while allowing non-related caregivers to work up to 70 hours—and simultaneously funding institutional care at $90,000+ per year—creates a two-tier system that penalizes family caregivers solely based on their relationship to the person receiving care. This distinction is arbitrary and discriminatory.

Third, family caregivers perform the same work—often more complex and more consistent—than non-family caregivers. The only difference is blood or legal relationship. Nebraska law does not require family members to provide caregiving after age 19, yet this policy assumes unpaid labor once the 40-hour cap is reached. Families are effectively being forced to subsidize the state through uncompensated care after already making significant financial sacrifices, including reduced employment, accessibility modifications, specialized transportation, and higher ongoing medical costs. This expectation is neither ethical nor sustainable.

Fourth, the policy is fiscally inconsistent. Family caregivers are paid approximately $15/hour, agency caregivers around $30/hour, and institutional care often exceeds $1,900 per week. Despite being the most cost-effective option, family caregiving is the most restricted. This contradicts basic principles of responsible use of taxpayer dollars.

Finally, if DHHS is concerned about budget predictability, there are reasonable alternatives:

- Individual reassessments based on medical necessity

- Standardized or capped agency reimbursement rates
- Equal hourly reimbursement regardless of provider relationship

Balancing the budget by relying on unpaid family labor is not a legitimate solution.

In summary, these policy changes discriminate against family caregivers, exploit unpaid labor, undermine cost-effective community-based care, and punish families for keeping loved ones at home. I urge you to oppose these changes and to request that DHHS halt implementation until a lawful, equitable, and fiscally sound approach is adopted.

Thank you for your time and leadership on this critical issue.

Respectfully,
Connie Grover
[redacted]

From: Clark, Jennifer J
To: DHHS HCBS Public Comments
Subject: Sue Cole Public Comments
Date: Monday, December 22, 2025 4:44:23 PM

Hi
She sent multiple emails to me and a whole bunch of other people, so I have combined them into one for public comment. Thanks
Jenn

When limiting hours to people that live in household, I was able to get my daughter Kristina, from Florida, to move in with us to help me out. This would mean that she would have to move because she would lose her income.

Even if it went to 70 hours, the income would drastically affect families. Now families have to pay alot of a clients expenses to enjoy life. For example traveling to Florida. DHHS would be preventing Tiffany from traveling because we could no longer afford it and DHHS would not pay expenses for others to take her.

When a client is profoundly handicapped and needs 24 hr care, you are already making parents volunteer some of their time each day.

It is also expected that parents have to cover a lot of expenses for the person they are caring for. How does putting parents at poverty levels of benefit for anyone?

Without enough pay to live, how does forcing a client into a alzheimer unit give them any quality of life. Hasn't the Supreme Court already ruled you can't do that? Yet if parents can't afford their adult individual to live in their home, isn't that what you are going to do?

When a client has been determined to need 24 hr care, why does it matter who provides the care? It is based on needs of the client.

How can DHHS stop individuals from enjoying life and doing g things with family and out in the community? That is what will happen if you take away the families income. Families will no longer be able to afford caring for their adult client. This is a lose lose situation. I took over a 50 percent cut in pay and lost all of my benefits by caring for my daughter. She was in and out of the hospital so much, that I couldn't work the hours needed and to keep her safe.

When individuals work full time jobs, most aren't minimum wage. To hire an agency in my area to help out, the wages would be over $50 and Hour and the want overtime for weekends, holidays and over 40 hrs a week. It is cheaper to pay the parent than an agency. Tiffany needs the same the same hours. Parents shouldn't have to go to work for an agency.

DHHS is already paying much less an hour for parents than what the pays rate in our state should be. If DHHS is going to require agencies to come into the home for

those hours, it will cost the state 2 to 3 times money than what they pay currently.

What will happen if I have to get outside job and use an agency and there is not enough people to cover all of the hours?

You say 40 hours is full time for one person, but you want 3 people to share those 40 hours, that isn't full time for anyone.

The clients have a set amount of hours of care that they need. How can DHHS say they will not pay for the hours a severely handicapped person requires?

When the states says they will only pay 40 or 70 hrs a week when the individual requires 24 hr care, no family homes will be able to keep individuals the family home. They would have to go to an alzheimer unit for that amount of care. This would be the same as locking up in an institution with absolutely no quality of life!!!

Aren't clients supposed to be able to choose their caregivers? Why is DHHS taking those rights away? Why does DHHS want to lock them up in an alzheimer unit away from their family and friends. That is what would happen if they lower hours to 40 or 70. Families not only have to pay the expenses of their household, but also pay the majority of expenses for the disable person also.

By being a full time caregiver, we are giving up paid health insurance, paid holidays, paid vacation, paid sick time, retirement benefits etc. They are also giving up their quality of life being able to do a lot of things.

When you consider how much it costs for all of those benefits a lot employees get, DHHS is not over paying live in caregivers. Consider how much it costs the state for employee benefits per person.

Nebraska DHHS is trying to force severely handicapped into alzheimer units and take them out of family homes. They are wanting to pay only $600 to $700 a week for families to live on. Health insurance would take 2 weeks paycheck for just health insurance. People can't live on 40 to 70 hours at almost minimum wage. DHHS isn't even paying the rates determined by the rate study. Families shouldn't have to volunteer more than the 56 hours. DHHS is trying to punish people who keep these individuals in their home. Why does Nebraska want to lock these individuals up? What have they done wrong. For a severely handicapped person, care without benefits should be $25-$30 an hour for the 70 hours. Each individual in the home should be able to get that at $25-$30 hour. We don't even get sick time, retirement holiday pay, vac etc. We give up alot to care for these individuals. Now Nebraska wants us to choose between bankruptcy or putting the individuals into an institution!!!

The state said 40 hours is full time, yet the want 3 people to share the 40 hours, which is only 13 hours per week per person, to live on. How can people live on 13 hrs per week? Then the state is expecting non parents to even volunteer hours if they live in household. When we already volunteer 56 hours a week, why do they

even expect us to volunteer more hours than this? They expect us to pay a lot of their expenses to the special needs person, in addition to the 56 hours we are expected to volunteer now.

We need to get a class action law suit for the state to try and force individuals into institutions and not allow them to live in homes and not able to choose their own caregivers.
They need to be able to choose whomever they want to care for them. They should not be punished for living with their family. The Supreme Court has already ruled that it is their legal right as an individual!

The State of Nebraska, DHHS, needs to be stopped!!

From: Becky Winters
To: DHHS HCBS Public Comments
Subject: This law is wrong. Do what"s right
Date: Thursday, January 1, 2026 10:54:42 PM

You don't often get email from [redacted]. Learn why this is important

To whom it may concern:
On December 5th DHHS released proposed changes to the AD waiver. Part of these changes was to LIMIT live in care giver hours to 40 hours per week. For some of these live-in providers and their clients, this change would be very detrimental. Some of the MOST disabled folks in our state receive the maximum amount of 112 hours per week for their paid care (payment for 16 hours per day of care). Of that group, live-in caregivers provide the majority of those hours. Many of these live-in caregivers are parents or spouses of these disabled people, and many of them have left careers to take care of their loved ones. Some have been caring for their loved ones for 30 years or more. To suddenly cut their hours and income by 72 hours per week is DANGEROUS and very destabilizing for these disabled clients. This could lead to the loss of homes, mental health crises, hospital stays, and possibly death for some of the most medically needy clients.
Families affected by these changes will face severe financial issues. A loss of 72 hours per week at $15.00/hour is a cut of $4320 per month for these households. How will they be able to find jobs that pay that much, as people who have been out of the work force for so long? These families must also balance doctor appointments, hospital stays and the stress of caring for their loved ones, which would make working outside of the home very difficult for them at times. This plan assumes that suddenly, after YEARS of searching, hiring, training and losing paid care givers, that they can find someone to do their jobs. This is further complicated by the fact that these paid caregivers aren't able to administer medications or provide the medical decision-making necessary to ensure proper care for clients at all times, which means our most disabled will be in danger.
This plan will NOT work for the most medically fragile and high needs disabled adults on this waiver. If you are to go forward with limiting live-in care givers to 40 hours per week, you will be forcing people to sell their homes and put their loved ones into nursing home facilities. The waiver program was created in order to stop this exact situation from happening. Also, moving disabled clients into nursing homes will be further complicated by a current shortage of Medicaid funded beds available.
Instead, we propose that since this waiver has enough funds to make it through this year, that you spend this year meeting with the families of these individuals and create a plan that will actually work. I believe there are solutions available in this situation! The current system that's in place was created for individualized care, and there are already evaluations that were created to determine services and hours. If you want to create caps, please do it moving forward--not retroactively and NOT so suddenly and NOT so drastically. Consider contracting with each family individually (perhaps less agency contracting and more live-in caregiver contracting?), consider a tiered system like DD services use to determine pay rates.
Also please consider seeking out the funds you need:
a. Find an agency or non-profit, or create one, and begin to hold an annual fundraiser that gives average Nebraskans and wealthy Nebraskans a chance to care for the disabled of our state.
b. Perhaps the Huskers could run a fundraiser at one home game a year where they advertise the needs of those who are disabled in our state and give a matching percentage of ticket sales that day.
c. Would the Volleyball team and their fans want to help protect the disabled of our state?

d. Ask the Nebraska legislature to allocate more money for this program, due to the rising number of individuals in this program. I believe this sort of thing happens (for example, asking for raises for state employees, you look at the cost of living and then approve a 3-6% raise for your employee). A request for additional funding seems appropriate.

I know a young adult that was once a great athlete until an accident took the life he lived and changed it forever. Now his family fights having time for their family because 24/7, 365 days a year they hand to think of Carson first. Meet this kid, Carson Hansen. Tell him you don't think he's worth helping
Can you do that????

Becky Stephens
Nebraska citizen for 15 years

From: Jim Wagner
To: DHHS HCBS Public Comments
Subject: To all who will listen
Date: Monday, January 5, 2026 8:35:00 PM

[You don't often get email from [redacted] Learn why this is important at https://aka.ms/LearnAboutSenderIdentification]

Not long ago we were informed that our family caregiver hours were cut for the 2nd consecutive year. We didn't understand why we started hearing the "informal support " phrase become the service coordinators excuse for changing the hours allowed for our two adult special needs adults.
Then, the proposal to cut everyone to a 40 hour maximum limit turned our future upside down.
For us, like hundreds of others, we cannot provide the quality of care that these precious family members deserve if we are forced to find additional work to make things work.
Some may think we make too much money with two kids on the AD waiver.
We have sacrificed all career opportunities, any hope of retirement, spent many years near bankruptcy to provide a rich family life for these children. We adopted these two and both have needed endless help. These kids were not our responsibility. We chose to make them our own despite knowing they were hard to place and had many serious mental and physical needs that would last a lifetime.
If the state guts the income for family caregivers how will you attract other adoptive families to take on the responsibility of the state?
Are we paid too much for never leaving the work of caring for some of the neediest people in our state?
Who else trains for decades, bovines the best caregivers available for these needy precious people, commits careers, retirement, every family vacation and even virtually every moment to a job? There are no other people more committed than our family caregivers. As adults, we are shouldering the responsibility of the state. We are not merely getting paid to be parents or grandparents. We are not stupid people who should be subjected to low wages for greater commitment than those trying to do this to our families.
These families should be able to live in some dignity and provide a dignified life to those they care for without absolutely burning themselves into despair and poverty.
Further, DHHS acted in the public zoom meetings as those they were gifting families 40 hours. In reality, the state is bilking families that are carrying the load for the state. 168 hours in a week and we are to cover 128 of those hours.
Do the DHHS executives work longer hours than we do? Are they more committed or better qualified than we are?
If you force us into low income crisis, we will still love these people in our care and fight to keep them from institutionalized care that will dramatically lower quality of life, happiness, safety and length of life.
Do any of the state people calling for these cuts have the same commitment? No possible way. If any of you faced these demands and cuts on your jobs you would quit. We cannot.
We are pro life in every way. Caring for these needy adults is our proof.
Their lives are precious and the way the state provides for them defines the quality of the state.

Further, we're supposed to be allowed 40 hours only. Possibly, 30 more hours that would have to come from outside the home. This shows that the state actively prefers that outsiders provide care. This is an attack on these families. Our care recipients cannot handle those interruptions in care or the separation from us. You are actively working against the well being of these people.
Why not give us the full 70 hours so that we can keep the home a home. Do you have caregivers come from outside and invade your homes?
Besides all that, there aren't outside providers or even institutions available to most families. We live in rural Nebraska. You know full well that any institution would jerk these people away from their families. Family is the entire wellbeing of our two grown up kids.
There's no guarantee in anything I've heard so far that says we'd even get approved for the full 40 hours. Our daughter is already cut to 68 hours a week. Seems like that will likely mean more like 20 hours will be what she will be allowed.
Further,
If the state didn't require agencies to be used the costs to the state could be cut in half without hurting the caregivers or the recipients.

I ramble to get these thoughts together but this is crushing to us. It will cause deep loss and decrease quality of life for many people.
Get the money somewhere else. Leave these most committed, loving and self sacrificing caregivers alone.
Sincerely, Jim Wagner.

Sent from my iPhone

From: Steve knotts
To: DHHS HCBS Public Comments
Subject: To Whom It May Concern My name is Steven Knotts and I am an independent provider caregiver for the AD Waiver. I became a provider for my disabled nephew who has no other caregivers besides my wife and his elderly grandmother/caregiver. He struggles in ...
Date: Thursday, January 1, 2026 7:34:15 PM

You don't often get email from s[redacted]. Learn why this is important

From: Jules
To: DHHS HCBS Public Comments
Subject: To whom it may concern
Date: Thursday, January 1, 2026 10:57:45 AM

You don't often get email from [redacted]. Learn why this is important

To whom it may concern:
On December 5th DHHS released proposed changes to the AD waiver. Part of these changes was to LIMIT live in care giver hours to 40 hours per week. For some of these live-in providers and their clients, this change would be very detrimental. Some of the MOST disabled folks in our state receive the maximum amount of 112 hours per week for their paid care (payment for 16 hours per day of care). Of that group, live-in caregivers provide the majority of those hours. Many of these live-in caregivers are parents or spouses of these disabled people, and many of them have left careers to take care of their loved ones. Some have been caring for their loved ones for 30 years or more. To suddenly cut their hours and income by 72 hours per week is DANGEROUS and very destabilizing for these disabled clients. This could lead to the loss of homes, mental health crises, hospital stays, and possibly death for some of the most medically needy clients.
Families affected by these changes will face severe financial issues. A loss of 72 hours per week at $15.00/hour is a cut of $4320 per month for these households. How will they be able to find jobs that pay that much, as people who have been out of the work force for so long? These families must also balance doctor appointments, hospital stays and the stress of caring for their loved ones, which would make working outside of the home very difficult for them at times. This plan assumes that suddenly, after YEARS of searching, hiring, training and losing paid care givers, that they can find someone to do their jobs. This is further complicated by the fact that these paid caregivers aren't able to administer medications or provide the medical decision-making necessary to ensure proper care for clients at all times, which means our most disabled will be in danger.
This plan will NOT work for the most medically fragile and high needs disabled adults on this waiver. If you are to go forward with limiting live-in care givers to 40 hours per week, you will be forcing people to sell their homes and put their loved ones into nursing home facilities. The waiver program was created in order to stop this exact situation from happening. Also, moving disabled clients into nursing homes will be further complicated by a current shortage of Medicaid funded beds available.
Instead, we propose that since this waiver has enough funds to make it through this year, that you spend this year meeting with the families of these individuals and create a plan that will actually work. I believe there are solutions available in this situation! The current system that's in place was created for individualized care, and there are already evaluations that were created to determine services and hours. If you want to create caps, please do it moving forward--not retroactively and NOT so suddenly and NOT so drastically. Consider contracting with each family individually (perhaps less agency contracting and more live-in caregiver contracting?), consider a tiered system like DD services use to determine pay rates.
Also please consider seeking out the funds you need:
a. Find an agency or non-profit, or create one, and begin to hold an annual fundraiser that gives average Nebraskans and wealthy Nebraskans a chance to care for the disabled of our state.
b. Perhaps the Huskers could run a fundraiser at one home game a year where they advertise the needs of those who are disabled in our state and give a matching percentage of ticket sales that day.

c. Would the Volleyball team and their fans want to help protect the disabled of our state?
d. Ask the Nebraska legislature to allocate more money for this program, due to the rising number of individuals in this program. I believe this sort of thing happens (for example, asking for raises for state employees, you look at the cost of living and then approve a 3-6% raise for your employees). A request for additional funding seems appropriate in this situation.
i. Or perhaps it would be a GREAT time for the legislators to PAUSE or freeze the corporate tax cuts that are creating some of these budget shortfalls?
e. Would Larry the cable guy be willing to help in some way as a Nebraskan with a HUGE platform? Would Warren Buffett want to help? We could ask some of the wealthiest Nebraskans to step up for those who are disabled in our state.

Please consider solutions that are PEOPLE focused, individualized and caring, not just focused on the dollar signs. Thoughtful policy making will ensure that those who are disabled, as well as their families, can continue receiving the care they need and avoid damaging and life-altering circumstances. This waiver program has blessed a whole lot of Nebraskans and allowed them to flourish. It has helped provide dignity and care for so many people! Please consider that as you move forward and make necessary changes.

Signed: (your name and address)

From: Katie D
To: DHHS HCBS Public Comments
Subject: Urgent — Pay Cuts to Family Caregivers
Date: Saturday, January 3, 2026 7:34:32 PM

> You don't often get email from [redacted]. Learn why this is important

To Whom It May Concern,

I am writing to express my deep concern about the recent reductions in family caregiver pay, which have significantly impacted my ability to receive safe, consistent in-home care. As someone with cerebral palsy who relies on Medicaid waiver programs to live a full and independent life, these changes have caused [brief concrete harm].

I kindly request that the Department of Health and Human Services (DHHS) review and restore family caregiver rates as soon as possible or provide transitional support. Additionally, I urge you to hold a stakeholder meeting that includes family caregivers to discuss this vital issue.

Please confirm receipt of this message and let me know the next steps. I can provide any necessary documentation and am available for a conversation at your convenience.

Thank you for your attention to this matter.

Sincerely,
Katie Durfee
[redacted]

From: MICHAELA DAVIS
To: DHHS HCBS Public Comments
Subject: URGENT !!
Date: Saturday, January 3, 2026 6:42:08 PM

You don't often get email from [redacted]. Learn why this is important

Dear Nebraska DHHS Team,

I am writing to formally express deep concern regarding the proposed major reduction in caregiver hours for my brother and others around the state. These hours are not supplemental or optional — they are essential to his health, safety, dignity, and ability to remain in his home.

My brother is unable to speak or communicate his needs in typical ways. Because of this, his care depends heavily on caregivers who can recognize his nonverbal cues, behaviors, and subtle changes that indicate pain, discomfort, distress, or medical concerns. My mother understands these cues better than anyone. Through the past year of daily, hands-on care, she has learned how he communicates, what his behaviors mean, and how to respond quickly and appropriately to keep him safe and comfortable.

This level of care cannot be taught quickly or replaced easily. My mother is not just his caregiver — she is his advocate, his voice, and the person who knows his needs best. Her ability to anticipate and respond to his needs is the reason he has been able to remain stable and well cared for in his home rather than being placed in an institutional setting.

Reducing caregiver hours would have devastating consequences. Without adequate paid caregiver support, my mother would be forced to seek full-time employment to financially survive. This would make it impossible for her to continue providing the level of care my brother requires, leaving institutional placement as the only option. This outcome would not only be traumatic for him but would also result in significantly higher costs to the state than maintaining appropriate in-home care hours.

Family caregivers are not a convenience — they are a critical, cost-effective solution that prioritizes the well-being of individuals with disabilities. Paying family caregivers acknowledges the skilled, constant, and emotionally demanding care they provide and allows individuals like my brother to live with dignity, safety, and stability in their own home.

My brother deserves the best possible care, and he is currently receiving it. These hours should

not be reduced. We respectfully ask Nebraska DHHS to reconsider this decision and maintain the caregiver hours necessary to support his needs, protect his safety, and preserve his quality of life.

My brother is only 21! This AVM rupture happened right after his 20th birthday. He has so much life to live and what this could do to him would be detrimental. Please reconsider and think of how these random things could happen to your loved ones and how you would want the best care for them.

Thank you for your time, consideration, and understanding of the serious impact this decision carries for our family.

Sincerely,

Michaela Davis

Family Member and Advocate

From: Cynthia Wiggins
To: DHHS HCBS Public Comments
Subject: urgent read before January 5th.
Date: Monday, December 29, 2025 6:44:08 AM

You don't often get email from [redacted]. Learn why this is important

Budget cuts that affect vulnerable adults should be illegal. It is neglect and dishonor of the most vulnerable people in the state

I am writing in regard to the proposed changes from the state to lessen the amount of money paid ***to in home private providers*** on the AD and DD waiver.

For many people including my husband and myself we quit our jobs, stopped going to school, rearranged our lives to care for our adult disabled children. Knowing that we were relying on the state funding that has helped us for the last 20 years.

We never had an issue of getting paid or fulfilling the obligations of the job and in turn ensured our loved ones were well cared for all while saving the state of Nebraska thousands and thousands of dollars.

The proposed changes will force us to look for work to supplement to help provide for our family. The question is who is going to care for the 1 to 1 people we care for during the hours we are not home. Who is going to diaper our kids, cook their meals during the hours we are off or having to work at a outside job?.

There were no issues with the waiver program until you made everyone get back round checked through Maximus which is costly. Then the last couple of years we started with Tellus and therap(EVV) all which is overhead coming out of the money designed to fund care for our loved ones with special need, not pencil pushers. Then the state went on to hire and sign sizable contracts with various companies because the billing was too difficult for some individuals. **All money being spent should be spent on care for the people we serve, not corporations doing other people's paperwork.** Corporations like these need to be having to suffer from the cutbacks not the private providers. We have already sacrificed our careers and lives for our to care for the ones we love.

I know all this was done to prevent fraud but in reality, all it did was get the people cheating on the system other ways to lie and steal. You're not hurting them you're hurting the people who loved their individuals enough to make the sacrifices needed to be able to care of their loved ones in their homes to keep them safe and out of group homes and nursing homes for as long as we can. **All while saving the state money.**

I would ask you how you and the others at the state level if someone told you in six months your pay is going to be cut by 65% or more, .how would you feel. Think about it how would

you and the other congress people feel.

Also, so many people that are qualifying for AD waiver should have to be nursing home level of care not some of the ones approved recently. I have heard from providers that are shocked people are being put on waiver.

My son had a stroke with the effects still evident and a heart transplant he qualifies because without me he will have to live out his days in a nursing home. If you were 38 would you want to live in a nursing home.

Budget cut somewhere else not with the most vulnerable people in Nebraska.

Cynthhia and Randall Wiggins [redacted]

From: Cynthia Wiggins
To: DHHS HCBS Public Comments; Pillen, Jim
Subject: URGENT THIS IS CAUSING AN EMERGENCY AMOUNT OF STRESS!!!!!!!!!!
Date: Tuesday, December 30, 2025 10:04:59 AM

Some people who received this message don't often get email from [redacted] Learn why this is important

Budget cuts that affect vulnerable adults should be illegal. It is neglect and dishonor of the most vulnerable people in the state

I am writing in regard to the proposed changes from the state to lessen the amount of money paid ***to in home private providers*** on the AD and DD waiver.

For many people including my husband and myself we quit our jobs, stopped going to school, rearranged our lives to care for our adult disabled children. Knowing that we were relying on the state funding that has helped us for the last 20 years.

We never had an issue of getting paid or fulfilling the obligations of the job and in turn ensured our loved ones were well cared for all while saving the state of Nebraska thousands and thousands of dollars.

The proposed changes will force us to look for work to supplement to help provide for our family. The question is who is going to care for the 1 to 1 people we care for during the hours we are not home. Who is going to diaper our kids, cook their meals during the hours we are off or having to work at a outside job?.

There were no issues with the waiver program until you made everyone get back round checked through Maximus which is costly. Then the last couple of years we started with Tellus and therap(EVV) all which is overhead coming out of the money designed to fund care for our loved ones with special need, not pencil pushers. Then the state went on to hire and sign sizable contracts with various companies because the billing was too difficult for some individuals. **All money being spent should be spent on care for the people we serve, not corporations doing other people's paperwork.** Corporations like these need to be having to suffer from the cutbacks not the private providers. We have already sacrificed our careers and lives for our to care for the ones we love.

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your pay is going to be cut by 65% or more, .how would you feel. Think about it how would you and the other congress people feel.

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My son had a stroke with the effects still evident and a heart transplant he qualifies because without me he will have to live out his days in a nursing home. If you were 38 would you want to live in a nursing home.

Budget cut somewhere else not with the most vulnerable people in Nebraska.

From: Charlotte and Kevin Endorf
To: DHHS HCBS Public Comments
Subject: Urgent!
Date: Friday, December 19, 2025 8:15:52 AM

You don't often get email from [redacted]. Learn why this is important

Please re-evaluate these life changing decisions...

I attended the meeting via Zoom this week. I also head up the Brain Injury Awareness group of Northeast NE. The numbers keep increasing but last I saw, in NE alone there are about 16,000 new brain injuries per year from falls, car and motor cycle accidents, strokes, aneurysm, etc

At some point nearly every sufferer I know has needed a caregiver. I feel more thought needs to go into the cuts being made. When I was hurt eight years ago, help in the well known facilities in NE wasn't available. We checked out of state also and since I could walk (holding onto walls), I couldn't get help in the well known places desired. Instead I spent 90 days in Omaha being shuttled by Uber and a long term hotel to three therapies three times weekly. I was nursing home material. However, I worked in a nursing home in the 80's. My siblings chose to place our parents there. Did I see improvement or even a decent quality of life for them? No, not like I saw in my own healing. I can tell you true horror stories of nursing home life. They are basically a place to go to die. Not many ever return home. So many have closed causing even more work for each nurse/CNA. When I worked myself through college as a CNA it wasn't uncommon to lift triple your weight. It wasn't uncommon to be responsible for over 30 people each eight hour shift. This obviously is worse care than being at home with living caregivers who know you well.

Double check the numbers. They do not add up. It's cheaper and better to keep the sufferer home. Add PTSD which many of us also suffer to the mix and this mass shift of living circumstances combined with the obvious stress of the parent/family caregivers is going to end in lots of sedation to simply mask the problems.

I am grateful on the progress I have made. I am one of the lucky or I call it blessed. I am speaking for a group from Yankton SD to Madison NE (North and South). ONeill to Oakland NE (East to West). The many abbreviations and small print on the screens yesterday were hard for both me and my caregiver husband who is fine. Not to mention how fast the leaders talked, the inability to type in chat and the dozen or so of us who had our hands up but we're not given any opportunity to talk.

Add the Medicaid volunteer and work changes to this mix and you have about the worst poverty guarantee Christmas gifts for many Nebraskans who worked their tails off before injury and are not asking for handouts but only fairness at a lesser cost. Note: I and many I know are not and have not received a cent of aid. We

simply scrimp and rely on half the household income we had before. It's not easy. Our thermostats in our homes are set low in the winter and high in the summer to save wherever we can.

In my writing and speaking interviews I worked with many who lived WWII and the Holocaust. Hitler chose to eliminate the handicapped. History is repeating itself. This is just a different tactic. It's not a good decision. Please reevaluate and forward this note to all making decisions on this.

Nebraskans are struggling. Many have been forced to get food from emergency shelters due to lack of funds and employment after the brain injury. My house taxes tripled this year after moving to a tiny house when our forever home became too expensive without me working. We should have contested it but I had horrible head pain at the time of the meeting to do so and just couldn't go.

I just took on a two hour a day job, six days a week. Some days are good but days like today with the high winds, the neuro fatigue is unbearable. I have to bow out of fun things on my agenda that are time sensitive to rest so I can function the next day.

I have worked for Humanities NE over two decades. I just received their newsletter and see our talks will be cut in half in 2026. Before injury I did 150 plus talks a year myself. My husband helps me now, but what we have worked back up to will be only about $7,000 next year if they don't decide to eliminate the speakers bureau completely like they have done twice in the past. My husband now commutes an hour a day to work and our vehicles have many miles on them. I take Cedar County Transit mostly when I need to go out of town. They just released new, higher rates because of the cuts they are enduring.

Something has to give! Please help.

Charlotte Endorf
Magnet NE

From:	Kaylee Murrell
To:	DHHS HCBS Public Comments; Green, Tony; Clark, Jennifer J; Sen. Robert Dover
Subject:	URGENT: Opposition to Proposed Spending Caps on A&D Waiver (Draft NE.018.08.00)
Date:	Monday, December 22, 2025 11:56:17 PM

You don't often get email from [redacted]. Learn why this is important

Dear CEO Corsi, Director Green, Deputy Director Clark, and Senator Dover,

I am writing today as a concerned constituent and disability advocate to formally express my strong opposition to the proposed amendments to the Aged and Disabled (A&D) Waiver, specifically the introduction of spending caps.

The proposal to trigger a "high utilization review" at $138,657 and implement a hard spending cap of $161,766.50 (175% of nursing facility costs) is a direct threat to the independence of Nebraskans with disabilities.

This policy is a setback for Nebraska because:
It Forces Institutionalization: By capping home-based care at a percentage of nursing home costs, the state is effectively forcing individuals with complex needs into institutions when their care "costs too much" to provide at home.

It Penalizes Family Caregivers: Families who have worked tirelessly to keep their loved ones in their communities are now being told their home is no longer a viable option due to arbitrary financial ceilings.

It Lacks Transparency: Announcing these life-altering changes on December 5th with a closing date of January 5th is an unacceptable way to engage with the disability community.

I urge you to remove these spending caps from the final waiver application and instead focus on expanding community-based resources that allow Nebraskans to live with dignity in their own homes.

I look forward to your response and a public commitment to protecting the rights of the disability community.

Sincerely,

Kaylee Murrell
[redacted]

From: Kris Huebert
To: DHHS HCBS Public Comments
Subject: URGENT: Opposition to Proposed Spending Caps on A&D Waiver (Draft NE.018.08.00)
Date: Wednesday, December 24, 2025 1:44:44 AM

You don't often get email from [redacted] Learn why this is important

Dear CEO Corsi, Director Green, Deputy Director Clark, and Senator [Your Senator's Last Name],

I am writing today as a concerned constituent and disability advocate to formally express my strong opposition to the proposed amendments to the Aged and Disabled (A&D) Waiver, specifically the introduction of spending caps.

The proposal to trigger a "high utilization review" at $138,657 and implement a hard spending cap of $161,766.50 (175% of nursing facility costs) is a direct threat to the independence of Nebraskans with disabilities.

This policy is a setback for Nebraska because:
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It Penalizes Family Caregivers: Families who have worked tirelessly to keep their loved ones in their communities are now being told their home is no longer a viable option due to arbitrary financial ceilings.

It Lacks Transparency: Announcing these life-altering changes on December 5th with a closing date of January 5th is an unacceptable way to engage with the disability community.

I urge you to remove these spending caps from the final waiver application and instead focus on expanding community-based resources that allow Nebraskans to live with dignity in their own homes.

I look forward to your response and a public commitment to protecting the rights of the disability community.

Sincerely,
Krystie Huebert
[redacted]

From: John Payton
To: DHHS HCBS Public Comments; Green, Tony; Clark, Jennifer J; Sen. Megan Hunt
Subject: URGENT: Opposition to Proposed Spending Caps on A&D Waiver (Draft NE.018.08.00)
Date: Wednesday, December 24, 2025 1:52:06 AM

You don't often get email from [redacted]. Learn why this is important

Dear CEO Corsi, Director Green, Deputy Director Clark, and Senator Hunt,

I am writing today as a concerned constituent and disability advocate to formally express my strong opposition to the proposed amendments to the Aged and Disabled (A&D) Waiver, specifically the introduction of spending caps.

The proposal to trigger a "high utilization review" at $138,657 and implement a hard spending cap of $161,766.50 (175% of nursing facility costs) is a direct threat to the independence of Nebraskans with disabilities.

This policy is a setback for Nebraska because:

1. It Forces Institutionalization: By capping home-based care at a percentage of nursing home costs, the state is effectively forcing individuals with complex needs into institutions when their care "costs too much" to provide at home.
2. It Penalizes Family Caregivers: Families who have worked tirelessly to keep their loved ones in their communities are now being told their home is no longer a viable option due to arbitrary financial ceilings.
3. It Lacks Transparency: Announcing these life-altering changes on December 5th with a closing date of January 5th is an unacceptable way to engage with the disability community.

I urge you to remove these spending caps from the final waiver application and instead focus on expanding community-based resources that allow Nebraskans to live with dignity in their own homes.

I look forward to your response and a public commitment to protecting the rights of the disability community.

Sincerely,

John Payton
[redacted]

From: Ron Lindquist
To: DHHS HCBS Public Comments; Green, Tony; Clark, Jennifer J; Robert Clements; Sen. Jana Hughes
Subject: URGENT: Opposition to Proposed Spending Caps on A&D Waiver (Draft NE.018.08.00)
Date: Wednesday, December 24, 2025 7:24:17 PM

You don't often get email from [redacted]. Learn why this is important

Dear CEO Corsi, Director Green, Deputy Director Clark, Senator Clements, and Senator Hughes

We are writing today as concerned constituents and disability advocates to formally express our STRONG OPPOSITION to the proposed amendments to the Aged and Disabled (A&D) Waiver, specifically the introduction of spending caps. We ask you to put yourself in the shoes of these vulnerable families these changes would adversely affect. Implementing these changes forcing some of your most vulnerable and defenseless constituents out of their loving homes into institutions to cut costs is morally corrupt.

The proposal to trigger a "high utilization review" at $138,657 and implement a hard spending cap of $161,766.50 (175% of nursing facility costs) is a direct threat to the independence of Nebraskans with disabilities.

This policy is a setback for Nebraska because:
It Forces Institutionalization: By capping home-based care at a percentage of nursing home costs, the state is effectively forcing individuals with complex needs into institutions when their care "costs too much" to provide at home.

It Penalizes Family Caregivers: Families who have worked tirelessly to keep their loved ones in their communities are now being told their home is no longer a viable option due to arbitrary financial ceilings.

It Lacks Transparency: Announcing these life-altering changes in the busy holiday season of December 5th with a closing date of January 5th is an unacceptable way to engage with the disability community, and gives the appearance of trying to "sneak" the changes through.

We urge you to remove these spending caps from the final waiver application and instead focus on expanding community-based resources that allow Nebraskans to live with dignity in their own homes.

We are constituents of Senator Hughes and are the concerned grandparents of severely disabled Jeremy Lindquist. Jeremy and his mother Maria Lindquist are constituents of Senator Clements in Lincoln.

We look forward to your public commitment to protecting the rights of the disability community.

Sincerely,

Ronald and Linda Lindquist

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From: tracycapalite
To: DHHS HCBS Public Comments; Clark, Jennifer J; dguereca@leg.ne.gov
Subject: URGENT:Opposition to Proposed Spending Caps on A&D Waiver (Draft NE.018.08.00)
Date: Tuesday, December 23, 2025 12:07:48 PM

You don't often get email from [redacted] Learn why this is important

Dear CEO Corsi,
Director Green,
Deputy Director Clark, and Senator Dunixi Guereca of District 7

I am writing today as a concerned constituent and disability advocate to formally express my strong opposition to the proposed amendments to the Aged and Disabled (A&D) Waiver, specifically the introduction of spending caps.

The proposal to trigger a "high utilization review" at $138,657 and implement a hard spending cap of $161,766.50 (175% of nursing facility costs) is a direct threat to the independence of Nebraskans with disabilities.

This policy is a setback for Nebraska because:
It Forces Institutionalization: By capping home-based care at a percentage of nursing home costs, the state is effectively forcing individuals with complex needs into institutions when their care "costs too much" to provide at home, I DO NOT want my daughter living in a nursing home with subpar care were her emotional and social needs will not be met because of some cap on spending. Enough has been taken from family with special needs, when does it stop?

It Penalizes Family Caregivers: Families who have worked tirelessly to keep their loved ones in their communities are now being told their home is no longer a viable option due to arbitrary financial ceilings.

It Lacks Transparency: Announcing these life-altering changes on December 5th with a closing date of January 5th is an unacceptable way to engage with the disability community.

I urge you to remove these spending caps from the final waiver application and instead focus on expanding community-based resources that allow Nebraskans to live with dignity in their own homes.

I look forward to your response and a public commitment to protecting the rights of the disability community.

Sincerely,
Tracy Monaghan
[redacted]

From: Presley Spencer
To: DHHS HCBS Public Comments
Subject: Video Submission
Date: Monday, January 5, 2026 10:52:26 PM

> You don't often get email from [redacted] Learn why this is important

https://youtu.be/nK7h8T-KnFA?si=Nq7bNgwJ1imWcCSt

Hello,
I am submitting a video as part of public comment regarding the proposed changes to the AD and TBI Waiver programs.
In a recent statement, these programs were described as “paying grandmas to be grandmas.” I understand concerns about program integrity, but the families in this video represent situations that go far beyond that. Many of them provide complex, high-level care that allows their loved ones to remain safely at home instead of in a nursing facility.
This video shares real stories from Nebraska families who will be directly affected by the proposed reductions and restrictions to care hours. These are not abstract budget decisions — they have real consequences for safety, dignity, and the ability to remain at home.
I respectfully ask that this video be viewed and considered as part of the decision-making process.
Thank you for your time.

From: Shawn Bellew
To: DHHS HCBS Public Comments
Subject: Wage cut
Date: Tuesday, December 23, 2025 9:53:23 PM

> You don't often get email from [redacted]. Learn why this is important

my name is shawn bellew. I speak for myself an my disabled son Shawn David Bellew II. I am very disappointed in ur system. I told u are goin to cut my wages. this is goin to be horrible for us,
I spend 7 days aweek 24 hours day for him in care giving for him. Maybe u should come n do what i do, U cut my wages i cannot get another job, i still have my son. ur system let his mom walk away, not paying nothing.

Why down"t u take out the middle man out? They are the problem. Ur giving them at least 200,00. I sure don "t get that. U are sure killing me n family, thankyou for beeing the biggest joke i've
ever seen. I still got to pay my bills. Please know I will never support any of u in future.

Very Ungratefull Shawn Bellew

From: Dajadela Chamblin
To: DHHS HCBS Public Comments
Subject: Waiver changes
Date: Monday, January 5, 2026 1:50:52 PM

You don't often get email from [redacted]. Learn why this is important

To whom it may concern,

My name is DJ I am a single mom of 3. My youngest is non verbal autistic and on disability. She has the a&d waiver but also qualifies for the d&d waiver. She is highest level of risk due to her being non verbal, elopes, and isn't potty trained. I normally don't follow the news or anything that I feel I don't or wouldn't have control over so I just change and adapt. But this change isn't something I can stand quietly on as I am my daughter's voice, her protector. Her mom. From the very beginning before her diagnosis we have had the chips stacked against us. The biggest obstacle has been care. Or help with care. We don't have any family or friends near us or that are really significant roles in our lives. Which makes working to provide for my children a task. I've always had child care help but centers are extremely limited and most with wait lists. However my biggest concern with centers or other providers came from when my daughter was abused at daycare while I was at work. They didn't understand her, didn't have patience for her and bruised her little body. And law enforcement unfortunately couldn't do much since the camera system happened to not record that day. So I found people who would come to my home as I have cameras in every area for safety which helps drastically when she runs away. I work 2 jobs at times 3 and do side jobs. My goal was to give my children a home with a yard. I did that! But unfortunately the more I make the more I loose. Food stamps, help with childcare (if I could find a place or person to accept my kiddo), Medicaid etc. I was told about the a&d waiver and when I was approved I was super hopeful to have found help possibly.

How ever that's not been the case. We have had the waiver for a year and have attempted to have multiple people approved to become providers with no luck. Either they decide it's not something they want to do because at times she can be a lot. Or they don't follow through with the weeks and weeks of steps to become approved or the worst did happen. The last person who was approved to help actually drugged my children to sleep by putting clonadine in their popsicles while I was at work. Again law enforcement not doing much on multiple counts of child abuse for whatever reason. You know how I see this? I see a flawed system and now we have to come together and hopefully be heard by the ones who don't understand our struggle, who don't walk days in our shoes as providers, care takers, parents…

The situation with my daughter has of course made it hard to work. But my health has taken a turn for the worse rapidly. I already worried about how I would meet my hour requirements for work, etc but the possibility of maybe finding someone to help always kept me going even the littlest nudge. And now someone wants to limit that even further. This isn't something to limit further it's something that is needed. And to be maybe adjusted on a case by case basis. I fall short a little every month on bills which a modification to the waiver that would be helpful would be to allow me to be her caregiver and get even a portion of pay so that I can continue to maintain home life, her safety, and her growth.

I know multiple families this will impact a close friend takes care of her son who's on a feeding tube with multiple other disabilities that requires 24/7 care that most wouldn't consider taking on a responsibility or nurturing care level required. Please consider these

factors among all the possibilities others may raise in concern of this matter. Please don't make our jobs as parents and caregivers harder with more restrictions and cutting the resources available.

Thank you for your time

Dajadela Onate
[redacted]

From: Dajadela Chamblin
To: DHHS HCBS Public Comments
Subject: Waiver changes
Date: Monday, January 5, 2026 1:50:52 PM

You don't often get email from [redacted]. Learn why this is important

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I know multiple families this will impact a close friend takes care of her son who's on a feeding tube with multiple other disabilities that requires 24/7 care that most wouldn't consider taking on a responsibility or nurturing care level required. Please consider these

factors among all the possibilities others may raise in concern of this matter. Please don't make our jobs as parents and caregivers harder with more restrictions and cutting the resources available.

Thank you for your time

Dajadela Onate
[redacted]

From: Randi Renee
To: DHHS HCBS Public Comments
Subject: Waiver max & personal care hours
Date: Monday, January 5, 2026 8:24:34 AM

You don't often get email from [redacted]. Learn why this is important

Dear representative:

My name is Paul & I have a rare chromosome abnormality. I lived in Louisville Nebraska for the beginning of my life. I am not able to independently sit up, walk, talk or be left alone. I cannot get myself out of bed, call for help or use a call button. My parents wanted to give me as much opportunity as possible, so we moved all my sisters, brother & parents to Omaha where I could attend a class A school. That helped a lot. I am 20 years old now, and although I learned to take my own shirt off, I am not able to put it back on myself & I often disrobe at inappropriate times. I use a wheelchair because I need help walking & sitting, a Dynavox because I cannot speak, use a gastronomy tube because I cannot swallow & I try to elope constantly when I am awake (I like to see what is going on in the neighborhood).

I created quite a challenge for my family, especially my parents. It's especially difficult in Nebraska because our State does not have adequate support systems in place for someone like me because of my medical needs & behavior. My Dad was a construction equipment Sales Representative for 30+ years here in Nebraska, then several years ago he learned he has cancer, became disabled too & has his own g-tube! My Dad still helps me, but both of us can only do activities for short periods before we have to take a break. That leaves my mom to take care of me most of the time. She had a hard time with attendance at work because often Agency providers call in or don't show up at the last minute to take care of me, so she stays home with me. She was a Certified Public Accountant. My mom liked her job, but she just couldn't go to it regularly, so she went back to school & became a Registered Nurse with a very flexible schedule. For the past 10+ years, she has been able to work a flex schedule at the hospital as a nurse & then come home to take care of me. I require 24/7 care and even with a flexible schedule, she often missed work. My parents love me so much that they cobbled together a way to get through all those years.

When I turned 19, my parents could start being paid through my personal care hours. Even though this was nowhere near the salary my mom was making, she was able to quit working at the hospital & just take care of me. Reducing the total hours and reducing the paid time my parents work, will

be very detrimental to me & my whole family.

The proposed changes to the HCBS waivers will cause a migration towards facilities. Therefore, the proposed changes are especially institutionally biased. People like me are very limited on appropriate facilities.

The proposed changes create more problems with continuity of care. My mom is still working for me because she is required to train my Agency caregivers due to excessive turnover. One of my parents is required to be on call 24/7. Due to the nurse practice act, no unlicensed caregivers can provide PRN (as needed) medications without a responsible adult's approval (my parents, because I am not able to decide) or a licensed provider's approval. Nebraska does not require a licensed person to work at the Agencies, write a care plan or provide training. So in order to be lawful, my parents are always on call for training & PRNs even when they are not being paid to care for me.

The proposed changes nearly eliminate my ability to choose my own providers.

The proposed changes do not consider individual needs. The $ cap on A&D is calculated using an average. As you can see, I am not average.

The proposed changes put my mom in a situation where she cannot work full time outside my house if my hours are reduced to the proposed 40 hours / week (I need help 168 hours / week)

I would really like to live in my house & the community, surrounded by my interesting friends & neighbors.
Please consider allowing the necessary services for my care; as well as allowing me to choose my providers.

Thank you for your consideration
Paul D. Theiler
Omaha NE

From: Waylon Vajgrt
To: DHHS HCBS Public Comments
Subject: Waiver open comment
Date: Monday, January 5, 2026 3:19:51 PM

Public Comment on Individual Cost Limits

I respectfully submit this comment regarding the individual cost limit provisions in Appendix B-2-a, B-2-b, and B-2-c of the proposed Aged and Adults and Children with Disabilities (A&D) HCBS waiver renewal.

While I recognize the state's responsibility to demonstrate cost neutrality, I disagree with the cost limit methodology as currently structured. The individual cost limits appear to rely on average institutional cost assumptions that reflect an aged nursing facility population, rather than the actual costs associated with supporting medically complex individuals in the community.

For example, an adult with a progressive neuromuscular condition may require extended personal care hours, specialized assistive technology, and skilled supports to remain safely at home. A child with complex medical needs may require frequent caregiver assistance, monitoring, and adaptive supports that exceed typical aged-population utilization patterns. These costs are driven by medical necessity, not inefficiency, and are often still less costly than institutional placement or repeated hospitalizations.

As described in Appendix B-2-b, service planning and authorization are implemented within the individual cost limit framework. When that framework is based on population averages rather than acuity, it constrains person-centered planning and places service coordinators in the position of limiting services despite documented need.

Although Appendix B-2-c outlines safeguards when services exceed the cost limit, reliance on post-exceedance reviews does not address the underlying issue for individuals whose needs are predictably higher. For medically complex participants, this creates ongoing uncertainty, repeated reviews, and risk of service disruption.

Nebraska's A&D Waiver is intended to prevent institutionalization and support community living. Cost limits that do not account for medical complexity risk undermining this goal and may increase the likelihood of nursing facility placement, contrary to the purpose of the waiver.

Recommendation: I urge the Department to revise the cost limit methodology in Appendix B-2 to incorporate adjustments for medical complexity, acuity, or specialized support needs, ensuring that cost neutrality mechanisms do not become barriers to medically necessary, person-centered community services.

Thank you for the opportunity to comment.

Sincerely,

Waylon Vajgrt

From: Waylon Vajgrt
To: DHHS HCBS Public Comments
Subject: Waiver open comment
Date: Monday, January 5, 2026 3:19:51 PM

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Thank you for the opportunity to comment.

Sincerely,

Waylon Vajgrt

From: Beverly Hammonds
To: DHHS HCBS Public Comments
Subject: Waiver program capped hours
Date: Sunday, December 28, 2025 11:00:22 AM

> You don't often get email from [redacted] Learn why this is important

To whom it may concern:
These proposed changes are drastically affecting the care of the most vulnerable of society. Those of us who care for someone in our homes are caring for them for a reason, to provide the utmost in care and to keep them at home. This is also our income for most. So these changes are taking away not only care but income. When will the state realize that not everything is a box, exact for all. Every situation should be evaluated and be based on the needs of the person who needs care. This would never happen in other countries where the needs of the vulnerable are put first.
BH

From: GARY ANDERSON
To: DHHS HCBS Public Comments
Subject: Waiver
Date: Saturday, December 20, 2025 1:15:51 PM

You don't often get email from [redacted]. Learn why this is important

Please review carefully your future plans for funding for services for the disabled. When we became guardians for my disabled sister my husband quit his job to care for her in our home. . After strokes we could no longer physically care for her. It wa not easy to find a nursing go e that wod take her with her Medicaid funding.
More cuts would reduce even more available spots.
Please be compassionate in your decisions.
Wendy Anderson
3515 N 205
Elkhorn 68022

From: ANGELA CORNETT
To: DHHS HCBS Public Comments
Subject: Waivers
Date: Friday, December 19, 2025 8:36:58 AM

> You don't often get email from [redacted]. Learn why this is important

I am writing to request that waiver funds are not reduced. Agencies that serve people with disabilities cannot find the staff needed to adequately support needs that Nebraskans currently have. We are about to ask them to serve even more people in the community , without adequate staffing or funding. We cannot go back to just institutionalizing people with disabilities. Nursing homes are already struggling to adequately take care of residents currently in their care. Will this require them to take on more people with complex medical needs? Will it lead to neglect or abuse because a job that is already difficult and underfunded is about to get much more difficult, with less funds available to hire outside help? Who proposed these cuts and why?

Thanks
Angie Cornett

Sent from Yahoo Mail for iPhone

From: Kellie Quinlin
To: DHHS HCBS Public Comments
Subject: Ways to be more cost effective
Date: Wednesday, December 24, 2025 6:11:08 AM

You don't often get email from [redacted]. Learn why this is important

Why Family-Provided Home Care Is the Most Effective and Cost-Responsible Option

Family- and friend-provided home care is often the best possible care model for individuals with high needs. Care provided by people who know the individual's routines, communication, triggers, medical history, and preferences creates a safer, more stable, and more dignified life for the person receiving services.

Family caregivers provide care rooted in love, trust, and familiarity, which supports emotional well-being and preserves a sense of normal family life for everyone in the household. Introducing rotating outside staff can be disruptive, uncomfortable, and in some cases unsafe for the individual and family.

Health and Safety Benefits

During periods of illness, limiting the number of outside caregivers significantly reduces exposure to new germs from multiple social circles. Keeping care within a consistent, familiar group lowers infection risk and improves overall health outcomes.

Oversight Can Exist Without Agencies

Oversight does not require agency involvement. Effective accountability measures already exist or can be strengthened, including:

- Regular service coordinator home visits
- Virtual check-ins via Zoom or phone calls
- Designated out-of-home contacts for service coordinators
- Periodic photo verification (such as selfies with the client uploaded to the system)
- Existing electronic clock-in/clock-out with location verification

These safeguards provide transparency while avoiding unnecessary administrative costs.

Significant Cost Savings

Requiring families to use agencies when they are willing and capable providers adds thousands of dollars in unnecessary overhead. Paying family providers directly:

- Eliminates agency administrative fees
- Keeps costs well below nursing home placement
- Preserves agency resources for individuals who truly require them

For individuals without family support, agencies can remain the provider of

choice to ensure emergency backup. Families already have built-in backup systems and flexibility that agencies cannot match.

Impact of Hour Reductions

Many families currently provide care well below the cost of institutional care. Cutting hours places individuals at risk of losing the level of care they depend on. These reductions undermine person-centered plans that were developed based on actual needs, not arbitrary caps.

Eliminating overtime supplements already frees up funding. Additional hour cuts are unnecessary and harmful.

Rate Disparities Create Higher Costs

The state is not accounting for the cost difference between family care and agency care. For example:

- Paying 30 hours at a higher agency rate costs more than paying additional family hours at a lower rate
- Agency staff may be unable or unwilling to meet complex needs, increasing risk to both the individual and the worker
- Forcing agency hours when family care is available is both inefficient and unsafe

Economic Harm Creates Downstream Medicaid Costs

Reducing income for caregiving households creates cascading costs for the state:

- Families may lose the ability to afford housing, utilities, food, and transportation
- Caregivers may become Medicaid-eligible themselves
- Loss of car insurance or transportation increases reliance on transportation services
- Inability to pay for assistive technology, vehicle modifications, home modifications, or supplies increases reliance on state programs
- Delayed medical care due to cost leads to higher hospitalizations and more complex medical needs
- Family caregivers lose the ability to plan for retirement, increasing long-term dependency on public assistance

Conclusion

Allowing and supporting paid family caregivers:

- Preserves health, safety, and dignity
- Reduces infection risk
- Saves significant Medicaid dollars
- Prevents unnecessary institutionalization

- Protects long-term state resources

If families are willing and able to provide care at a lower cost than agencies or institutions, they should be allowed to do so. This approach is fiscally responsible, person-centered, and aligned with the goal of keeping individuals safely supported in their homes and communities.

Please do not send in the proposal as you have it now. It will COST way more!

Thanks
Kellie Quinlin

The Arc
OF NORFOLK

P.O. Box 32
Norfolk, NE 68702-0032
(402) 379-1160
arcofnorfolk@gmail.com
www.thearcofnorfolk.com

12/29/2025

Nebraska DHHS HCBS,

On behalf of The Arc of Norfolk, an advocacy agency that has served individuals with disabilities and their families since 1953, we respectfully submit this public comment to express our deep concern regarding the proposed reduction of caregiver support hours from 112 hours to 40 hours per week.

The Arc of Norfolk serves over 400 families across 23 counties in Northeast Nebraska, many of whom rely on consistent, high-quality caregiving support to maintain health, safety, and dignity in their daily lives. Through decades of direct advocacy and family support, we have witnessed firsthand that caregivers, particularly family caregivers, are the backbone of care for individuals with disabilities.

Family caregivers provide far more than basic assistance. They offer continuity of care, deep understanding of medical and behavioral needs, emotional stability, and advocacy for individuals who often live with medically complex and lifelong conditions. A reduction of this magnitude would be detrimental to quality of life, significantly increasing risks to health and safety while undermining the dignity and independence of individuals with disabilities.

For many individuals, especially those with complex medical needs, care cannot simply be transferred to unfamiliar providers without serious consequences. Family caregivers possess irreplaceable knowledge of routines, communication methods, warning signs, and emergency responses. Consistency in care is not optional, it is essential. Limiting family caregiver hours places individuals at increased risk of medical crises, hospitalization, and institutionalization.

The suggestion that families seek outside caregivers is not feasible in the current landscape. Nebraska is experiencing a severe shortage of caregivers, agencies, and support staff. Families already struggle to fill authorized hours due to workforce limitations. Reducing family caregiver hours does not alleviate this shortage; instead, it adds strain to an already overwhelmed system, pushing families closer to crisis.

Family caregivers frequently make significant personal sacrifices to keep their loved ones safe at home, including leaving the workforce, reducing income, and absorbing emotional and physical stress. Restricting their ability to provide care threatens the sustainability of

community-based living an outcome that is both cost-effective and humane when compared to institutional alternatives.

From both a fiscal and human perspective, supporting family caregivers is sound policy. Their role helps prevent emergency room visits, hospitalizations, and long-term institutional care. Weakening this support will likely lead to higher costs to the state, poorer health outcomes, and further destabilization of Nebraska's disability service system.

For more than seventy years, The Arc of Norfolk has stood alongside individuals with disabilities and their families. Based on our experience serving hundreds of families across Northeast Nebraska, we strongly urge the State of Nebraska to reconsider these proposed reductions and to collaborate with families and advocacy organizations to pursue solutions that preserve dignity, stability, and community inclusion.

Individuals with disabilities deserve to live full, supported lives with those who know them best. Family caregivers make this possible, and policies that limit their role jeopardize not only individual well-being, but the integrity of our entire system of care.

Thank you for the opportunity to submit this public comment and for considering the voices of individuals with disabilities and the families who support them.

Respectfully,

Kayla Walnofer – Executive Director

The Arc of Norfolk Board of Directors

Beth Libra
Danielle Anderson
Ruth Markhofer
Beth Sanne
Melanie Kennedy
Megan Kleensang
Kamie Woeppel
Cecilia Holland

The Arc of Nebraska Board of Directors
Executive Committee
215 Centennial Mall South
Suite #508
Lincoln, NE, 68508

Date: 12/30/2025

Dear Public Officials & DHHS Directors,

The Arc of Nebraska: Advocacy and Background

The Arc of Nebraska is a statewide nonprofit disability membership organization in Nebraska. The organization is dedicated to advocating for individuals and families with intellectual and developmental disabilities, striving for respect, dignity, and inclusion within Nebraska communities.

For 70 years, The Arc of Nebraska has been a champion for the rights and full participation of children and adults with intellectual and developmental disabilities. With a network of 13,561 supporters and eight affiliated chapters, the organization works to improve support systems, connect families, inspire communities, and influence public policy.

Request for Extension of Public Comment Period

Pursuant to 42 C.F.R. §441.304(f), The Arc of Nebraska is submitting public comments regarding the Nebraska Department of Health and Human Services (DHHS) plan to renew the 1915(c) Medicaid Home and Community Based Services (HCBS) Aged and Adult and Children with Disabilities (NE.0187) waiver and amend the Traumatic Brain Injury Waiver (NE.40199).

Before offering feedback on the proposed changes, The Arc requests an extension of the 30-day public comment period, which began on 12/05/2025 and ends on 01/05/2026. Given that the project has been developed over six months, and it does not appear the Olmstead Committee or any organizations involved with these services were notified or consulted about the proposed significant changes. The organization believes that allowing only 30 days for public comment—especially during the holiday season—is insufficient.

Historical Context & Concerns About Care

There is interest in returning Nebraska to a time when the government was not involved in the care of persons with disabilities. However, Nebraska has recognized its responsibility to support individuals with disabilities for more than a century, beginning in 1887 with the Institute for Feeble Minded Youth(the current Beatrice State Development Center) and later with the Nebraska Orthopedic Hospital for destitute crippled and deformed individuals, opened in 1905. The state has long-favored government support as a more humane approach than leaving care solely to families.

Moving individuals to large institutionalization, outside of community-based supports and family homes, would be a step backward. Nebraska has continued to evolve toward inclusive living opportunities for the safety and well-being of those who rely on individualized care. Including Nebraskans with disabilities within our communities creates stronger relationships and increases a sense of fulfillment.

Significant Changes Impacting Health and Safety

The Arc of Nebraska wishes to address several significant changes in the waiver that could affect the health and safety of its constituents.

Combined Costs and Service Reductions

The waiver application states that when the combined costs of waiver and state plan services exceed the cost limit, the Services Coordinator (SC) will work with participants to reduce services below the 175% limit, while still aiming to ensure health and safety.

There is uncertainty about what costs are being "combined." The lack of clarity leads to confusion and inconsistent interpretation.

Many individuals rely on Medicaid services not covered by the renewed HCBS or TBI waivers for their health and safety. A 40-hour cap on services will limit support for those with complex needs, such as individuals requiring 24-hour care for hospital-level needs, while few facilities exist to provide such care.

- Communication about these changes has been inadequate. Those impacted have reported that facilities either were not aware of the waiver changes or maintained waitlists, resulting in families unable to find alternate care facilities if

forced to move care for their loved ones with complex medical needs from current home based care.

- History has shown that relying on families to provide specialized care is problematic, as many lack the necessary training and capacity.
    - From a health and safety standpoint, The Arc of Nebraska requests more information regarding facility locations, associated costs, and the reasoning behind the proposed 40-hour cap.
    - The 40 hour cap will likely make it impossible for these families to continue to care for their loved ones at home and the cost of facility care will clearly exceed the cap established by the department based on the $92,438 that covers routine residential nursing home care. It is also not clear if the State has capacity to provide this advanced-level of care for the number of individuals that will be impacted by the proposed change.

Cost Limits for Nursing Facility Level of Care Waivers

The waiver application states that when the combined costs of waiver and state plan services exceeds the established cost limit, the Service Coordinator (SC) will work with participants to reduce services while still aiming to ensure health and safety.

A proposed cost limit of $92,438 is based on average per capita spending for nursing facilities.

- There is concern about the sample size and inclusion criteria for the average calculation (reported as 500 individuals). If individuals with significant disabilities were included, the average would likely be much higher. Currently, Nebraska does not institutionalize these individuals.
- Most individuals with nursing facility care needs are not in facilities, so the average cost reflects custodial or minor medical care mostly for the geriatric population, not the skilled nursing care required for individuals with significant disabilities.
- As a result, the cost base established by the State does not take into account the higher costs of institutional care in a hospital or skilled nursing facility for individuals with complex medical needs receiving appropriate at-home medical care.

Referrals to Community Services

The renewed waiver states that when health and safety cannot be met within the cost limit, the Services Coordinator will refer participants to other community services. The Arc recommends the creation of a listing or resource map of available community services throughout the state. Members report "support deserts" due to nursing facility closures, lack of critical care facilities, and shortages of direct support professionals (DSPs) and home health care workers, all of which are pressing health and safety concerns.

The HCBS Setting Rule aligns with the Olmstead ruling, requiring states to support competitive employment and community living for people with disabilities. Nebraska's Olmstead Plan aims for all individuals to live, learn, work, and enjoy life in integrated settings. Institutionalization is not considered the most integrated setting and constitutes a violation of Olmstead, if other appropriate levels of care are available.

- On 07/01/2026, Nebraska will implement the HCBS Grievance process, requiring a procedure for beneficiaries to file grievances related to person-centered planning and service plan requirements.*
- Due to health and safety concerns, The Arc is concerned that the relationship of the Grievance Process listed in the Final Settings Rule and the Due Process Appeal Procedure will be confusing to parents.
- Questions as to eligibility, evaluation of the required level of care, hours and funding are solely addressed under the Due Process Appeal procedure and the information about the new Grievance Procedure does not make that relationship clear.
- The current grievance process is inadequate given the significant changes proposed. Questions remain about how grievances against Services Coordinators or situations where providers refuse service are handled.

Recommendations for the Grievance Process

The grievance process should involve an impartial, neutral reviewer. While Liberty Health provides quality reviews, the human rights committee operates in-house. It is unclear whether families can contact Liberty Health directly. More clarification is needed regarding the distinctions between appeals, fair hearings, and due process (eligibility and entitlement issues). Beneficiaries must be made aware of their rights, which should be communicated in plain language and with reasonable assistance for completing forms. Nebraska must ensure that no punitive action is taken against individuals filing grievances, and anonymous complaints should be possible. DHHS is asked to share detailed information about existing safeguards and protections. Beneficiaries need assurance that the grievance process meets due process standards and is clearly explained. If these processes are not established before the A&D Waiver changes take effect on 07/01/2026, the public comment period should be reopened.

Conclusion

The Arc of Nebraska hopes these comments prompt further detailed examination of the proposed renewal of the 1915(c) Medicaid Home and Community Based Services (HCBS) Aged Adult and Children with Disabilities (NE.0187) waiver and the amendment of the Traumatic Brain Injury Waiver (NE.40199).

Mary Phillips
Board President

Amy Bonn
Board President Elect

Julie Stahla
Board Past-President

Angela Gleason
Board Secretary

Adam Musfeldt
Board Treasurer

Phil Gray
Second Vice President

From: [redacted]
To: DHHS HCBS Public Comments
Subject: WE NEED EACH OTHER- aged and disabled waiver changes
Date: Sunday, January 4, 2026 4:38:33 PM

You don't often get email from [redacted] Learn why this is important

EFFICIENT SPENDING
AD waiver

To Whom It May Concern:

We are a family that cares for and caregives for our sister (and aunt to the children) (and daughter to our mother).
Angie needs full care. She has cerebral palsy and has extremely limited motor control. She needs spoon fed pureed meals, uses adult diapers, needs to be bathed and needs ALL her self care done for her. She cannot walk, sit up, roll over, or speak. She needs 3 to 4 albuterol breathing treatments daily. She cannot help transfer herself to wheelchair and cannot operate a wheelchair (manual OR motorized). She cannot be left home alone. She needs 24/7 care and companionship. This is just a quick description of her situation. Most people we describe our situation to, don't really understand. If you're not the one dealing with it, it's hard to picture.

We are a family with husband, wife, and 3 children still at home. Angie's mother and stepfather has had some health issues in their home and can no longer care for Angie. The relatives suggested that she be put in a facility but WE know that in Angie's case she would not be able to get the same care and compassion and love in a facility as she would with us, her sister, brother-in-law, and niece and nephews.

AD waiver has made this possible.

We had taken a large reduction in outside of the home income and a complete lifestyle change to be able to take Angie into our home.
With AD waiver difficulty of care payments, we have been able to make this work.

Caretech Inc has informed us of possible caps to AD waiver service hours.
Please don't reduce Angie's AD waiver resources.

*40 hours per week for live in care providers
-Angie lives with us but we don't feel that this scenario would apply to Angie's situation because she is full care and cannot be left home alone, essentially requiring 24/7 care and supervision.

*70 total service hours per week
-We currently receive compensation for 78 hours, however, Angie must have constant supervision and everything done for her, and taking the kids or ourselves out for an event or even errands is something that can't be done unless Angie is brought, and even overnight we get up to check on her, and are always here with her in case of anything happening or if she needs attention for any reason we are here for her. It seems that 78 hours is not unreasonable when considering the actual limitations we accept. Being limited to 70 hours doesn't seem reasonable to us. We feel like our care commitment is more like a nursing home facility that

provides 24 hours per day at 7 days per week for a total of 168 hours per week.

*A funding limitation that would prevent AD Waiver services from exceeding 175% of the cost of nursing home care (~95,000 annually).

-I can't say that I fully understand what this means. We receive less than $61,000 for Angie's care. I'm not sure how that compares to the figures being used. I know that nursing home employees get to clock out and go home. They work together to care for their clients. We have only us, and we are glad to care for **our sister** even though we don't get days off, vacations, benefits, holidays off, holiday pay, sick days, and so on. Angie gets her needs met PLUS constant companionship and activity, inclusion and attention, family and love. Her doctor has told us many times how good it is for Angie to be with us versus a facility where patients like Angie would be put in a room and left in a bed (as described by a care facility employee)

We understand that costs are up, but costs are up for everyONE, not just every business, every governmental branch, or every program.
We agree that if the money isn't there, it isn't there.
We don't know about every person's situation. We know ours and we know of one other person's who no longer receives care. When we compare OURs with theirs we are grossly undercompensated OR they are grossly overcompensated. An acquaintance would go to their client's home to put him to bed , roll him during the night, and get him up in the morning. She did these things and **slept**. She was paid for 104 hours per week and did very little comparatively. During the day she was free to do whatever she wanted. She was free to do anything, She had her own home and another job as well. The point is, does the comparison seem realistic?

So, costs are up, yes. What to do?
Maybe putting more effort into identifying overuse and abuse would be a better response than making a blanket policy that cuts those who put in the hours and the effort.

We could put Angie in a nursing care facility. If we are cut to 40 hours, that is equivalent to a 40 hour minimum wage job. As a family, we would still be short significantly, but worse yet, is that Angie would be in a strange place with strange people, and doubtful to receive the level of care that she deserves. Would putting Angie in a nursing home really save the program any money? As a family, we get minimum wage for allotted hours given. What do nursing homes get?

Everyone's situation is different, and there are those that will take more than reasonable for very little effort or sacrifice.
We feel that what we have given up to keep Angie with us is a sacrifice the whole family has felt.
We **want** Angie with us but we need AD waiver difficulty of care payments to make it work.
So please, find an accurate realistic way to spend the resources more efficiently without cutting those whose hearts are in check and without forcing people to send their loved ones to a lonely unfamiliar nursing home where we can't protect her and care for her like she needs.

We believe Jesus has put her with us, made it all possible, and we will keep Angie with us whatever changes occur.

JAN 05 2026

To: Nebraska Department of Health and Human Services
Re: proposed changes to Medicaid waiver

Paying grandmas to be grandmas - this is the message from a state leader in regards to DHHS care for individuals that have suffered a heartbreaking change in life requiring daily/ hourly care. This mindset is so simplistic to start with no regards to actual impact. And this mindset does not take into account that the family dynamics of 50 years ago is different from the family dynamics of today.
'Grandmas' of today have their own careers. Grandmas 50 years ago worked in the home only. 'Grandmas' may live hundreds of miles away from the grandchild. 50 years ago grandmas may have been less than 5 miles away.
'Grandmas' lives and responsibilities today are so different from a generation ago. And unfortunately not all individuals in need even have 'grandmas' in their lives.
This concept of 'paying grandmas to be grandmas' not only requires grandma today to give up their career/lives but also requires the parent to give up her livelihood. The positive is that this state leader realizes that the care given to the individuals in need is greater than a parent or family member can provide in 40 hours.

Prior to us taking on home care responsibility, Justin would be bussed to a day program with caregivers available in the morning to get Justin on the bus and later in the day when the bus brought Justin home. Caregivers were not always reliable. It was not uncommon for caregivers to not be on time or not even show for the scheduled shifts requiring one of us to miss work.. Plus we had concerns about a couple of specific caregivers assigned to Justin. With no short-term memory Justin would not be able to share with us if he was in any way abused. We do not want to indicate that fear of abuse was prevalent- most caregivers were fantastic- the issue was we had no input on who was assigned to Justin. Once we had caregivers that Justin was comfortable with the caregiver was reassigned to another client. Multiple caregivers we had never met before were in our house throughout the days. Caregivers were constantly changing. When we discussed these concerns with Justin's DHHS case manger, it was mentioned that we could provide care ourselves. This was a big change for us. My wife would have to quit her career of 30 years to be his primary caregiver. Her job was also a social network with work friends and regular customers. She had to give up a major portion of her life to be a caregiver.

DHHS came to us with the hours we would be allowed as caregivers and the compensation to be received. Before we accepted this offer we had a compensation amount in mind that would make this arrangement work. DHHS would not have to pay the current caregivers, nor the cost of transportation when needed, not the cost of the day program Justin attended. Considering these expenses for care the compensation should be close to what we expected. The compensation amount required for us to consider such a drastic change a decade ago was more than what DHHS is proposing compensating after these changes. Again to make this clear - we would not have been able to accept this compensation offer 10 years ago when Linda quit her job to provide full time care. We were willing to make sacrifices to our lives to provide care. DHHS offered us hours and compensation to care for Justin. DHHS provided an option that allowed Justin a much better life while also reducing cost to DHHS if using other services.

** This section has been deleted - It referenced more about our son and family. Sure you do not find this relevant to the conversation.

Maybe this is more relevant:

- Yearly Nursing home cost last year	$92,438
- Agency caregiver cost/hr	$30/hr *this is an approximation of an assumption
- independent Caregiver (usually family)	$15/hr

Using max hr/day (16 hr/day *7 days)=112 hr/wk
Nursing home: $92,438
Agency: 112 hr/week @ 30/hr = $175,200
Independent 112* $15/hr=$87,600 for a year - with more personalized care..

How is forcing disabled individuals to nursing homes a better option than home health care provided by independent (family) caregivers?

We do not believe that the intent of DHHS care changes are to institutionalize more individuals. This would not make any sense. These facilities are already close to capacity. Facilities statewide are being closed because they are not profitable enough for out-of-state shareholders. Now include staff shortages for this care.

It appears that there is no concern for the individual requiring care or the families providing the care. To randomly change the hours of care from 105 to 40 hours/week for no regard to the needs of the individual is reckless. There are 2 groups of people being negatively impacted by this proposed change. Obviously the vulnerable individual is going to suffer. The degree of this suffering will be dependent on how many grandmas (or other individuals with free time to help) are available. And the families caring for disabled relatives. Agencies providing care are not suffering. They will provide caregivers as directed and they have no responsibility once the allocated hours for the week have run out. No matter how hard families try to adapt there will be many individuals that will suffer due to the state balancing the budget on the back of the vulnerable. And if the family caregiver is required to go back to work and use agency workers for care, the cost would be substantially more than the independent family caregivers.

It is hard to replace grandma. But maybe grandma could show you compassion for people in need. And grandma can do enough math to illustrate the benefit of family caregivers.
She would know what Pro Life actually means.

Arlen Thayn Linda Thayn

Arlen and Linda Thayn
Parents of Justin McFadden; 42 years old; anoxic brain injury; can be a functioning adult with personalized assistance;

JAN 0 5 2026

HAPPY NEW YEAR

January 1, 2026

To whom it may concern and that is everyone who works at DHHS – Division of Developmental Disabilities from Management on down and also those who work for the Centers for Medicare/ Medicaid,

I am writing in re. to the DHHS proposed change to reduce the reimbursed paid hours to caregivers in the home of their loved ones who are medically needy or physically disabled requiring round the clock care.

1. It costs more to care for these individuals in a Long-Term or Assisted Living Facility.
2. Some of these individuals are at high risk to not receive the care they need.
3. There are fewer of these facilities available to care for these individuals.
4. These facilities are not age appropriate to care for the younger individuals.
5. Some of these facilities do not provide the quality of care for anyone who lives there now.
6. There's a shortage of RN's, LPN's, and CNA's to care for these individuals.

When the employees at the Centers for Medicare and Medicaid who will consider the DHHS proposals, I pray that they have not lost their moral compass in the decision they make.

"A just society is measured NOT by how it treats its strongest most privileged members, but by its compassion and support for those who are less fortunate."

My Grandniece who required Rehabilitation following a stay in the hospital, was cared for at Madonna Rehab in Lincoln, NE. where she was given stellar care except for one RN. In the main entrance to Madonna Rehab their Mission Statement is printed on a wall at least 20" X 20". It says,

CARE OF THE SICK MUST RANK ABOVE AND BEFORE ALL ELSE SO THAT THEY MAY TRULY BE SERVED AS UNTO CHRIST!" The Rule of St. Benedict

Thank you for your consideration on this very serious matter.

Sincerely,

Lucille E. Hansen

Lucille E. Hansen, A retired RN

DEC 2 9 2025

December 23, 2025

DHHS – Division of Developmental
Disabilities
301 Centennial Mall South
P.O. Box 95026
Lincoln, NE 68509-5026

I am eventually getting to the real issue, but hear me out. I use to clean for clients of DHHS. I would submit the paperwork and then get paid. All of a sudden, the paperwork would be returned to me with yellow highlights on everything that was "wrong." DHHS will hire someone to justify his/her job, but would not pay someone to help a client at a lower cost. After this happened several times, I continued to clean for the clients but did not submit the paperwork…I wasn't going to give DHHS employees the pleasure to justify their unnecessary job. I did it for free until I could no longer do so because of health reasons. I have been helped, so doing this was a small way of paying back.

NOW, DHHS is cutting funding to recipients who need good physical and emotional care which the family is best suited to give. Cutting funding from 112 to 40 hours a week is barbaric. I do not know Brady Rohde or his family; however anyone (be it person or DHHS) knows that he needs good physical/emotional care. I commend his family to do so and I am asking that you reinstate the 112 hours/week caregiving.

Quit looking at the dollars and "justified" paperwork and start looking at the people (patient and caregivers).

Thank you.

LuAnn Meyer

LuAnn Meyer

12/21/2025

To: DHHS

Subject: Comments on the AD renewal draft

Dear DHHS –

In reference to Appendix C: Participant Services C-1/C-3: Service Specification

The limitation on the number of hours per week for Personal Care services to be provided by a live-in caregiver that are part of the draft for HCBS AD waiver services would be, quite simply, devastating.

I am the live-in caregiver to a severely handicapped adult, who is incapable of performing any activities of daily living. She requires care and supervision 24 hours per day, 7 days per week. Current DHHS guidelines prevent a caregiver being paid while she is sleeping, so that care is currently uncompensated by the state.

The participant is my adult daughter, and we live alone, in a rural community. There is (to my knowledge) no available non-in-home caregivers in the area that are certified for Personal Cares – only Companion; and my daughter requires medication 5 times daily. This precludes my being able to seek external employment, as I would have to leave work to administer medications.

If I were only paid for 40 hours of care per week, even with her SSI – we couldn't afford our home. I honestly don't know that we could afford to live anywhere. This limitation on hours would be absolutely catastrophic to her quality of life.

Please remove these hourly limitations from this draft prior to the renewal going into effect.

Sincerely,

Traci Solarz

Traci Solarz

DEC 2 9 2025

Subject: Public Comment on Proposed Aged & Disabled Waiver Changes – Live-In Care, Hour Caps, and Caregiver Pay

To Whom It May Concern,

I am submitting this public comment regarding the proposed 2026 changes to Nebraska's Aged and Disabled (AD) Waiver.

This care is for our daughter, who has multiple chronic disabilities and requires **round-the-clock care**. Her medical needs do not stop after five 8-hour days. She is sick **24 hours a day, seven days a week**, including nights and weekends. Limiting paid care to 40 hours per week does not reflect the reality of her condition and places her health and safety at risk.

Our daughter's care requires constant supervision and hands-on assistance. Because of this, it is **not possible for us to maintain outside employment**. Caregiving is not a shift we clock out of — it is continuous, medically necessary care.

Under the current system, Medicaid authorizes approximately **$36 per hour**, yet as caregivers we receive **$17 per hour** through an agency. A significant portion of the authorized funding is retained by agencies, largely to "run payroll," leaving caregivers with wages that are not livable.

Rather than reducing authorized hours or shifting the burden onto families, DHHS should closely examine:

- How many hours agencies are billing for,
- How much of the authorized Medicaid rate is being retained by agencies, and
- Whether this structure results in waste, fraud, or abuse at the administrative level.

Families providing direct care should not lose services while agencies continue to take a large percentage off the top.

DHHS should consider:

- Setting **clear, transparent limits** on how much agencies may retain from authorized hourly rates,
- Establishing **clear statewide standards** for caregiver wages under the AD Waiver,
- Ensuring caregivers are paid a **livable median income wage**, and

- Allowing individualized hour determinations based on medical necessity rather than fixed caps.

At **$17 per hour for 40 hours per week**, a caregiver cannot meet basic living expenses, afford health insurance, or sustain long-term caregiving. For many of us, this is our **only source of income**, and leaving caregiving to "get another job" is not an option when our loved one requires care at all times. If the 40 hours are enforced a livable median hourly wage should be established and paid directly to the caregiver and not be allowed to be skimmed by any agency.

The proposed hour caps risk forcing families into crisis and pushing individuals into institutional care — which is more costly to the state and directly contradicts the purpose of Home and Community-Based Services and Nebraska's obligations under the Olmstead decision.

I respectfully urge Nebraska DHHS to reconsider these proposed limits and instead focus on protecting medically necessary care, supporting family caregivers, and addressing inefficiencies at the administrative level rather than reducing services to those providing direct care.

Thank you for the opportunity to provide public comment.

Sincerely,
Shannon & Shawna Aitken
[redacted]
Parent and Caregiver of a Child with Multiple Chronic Disabilities

12/10/2025

[Heidi Sommer]
Yeah, I'm just trying to understand, when you have... think I'm with the same question with the severely disabled individual, when you have an adult child, Who needs 24-hour care and a lot of us have been... had to quit their jobs, or have very minimal jobs. And so, to support your family, You reluctantly... care for your child and be paid these hours.
I just... I think this is...This is absurd. To put a limit. I mean, your budgets for DD... kiddos and adults are higher than these most severe complex kids. I want to... I want somebody to explain that to me.

[Heidi Sommer]
And we already are. You know that we already are doing that. I'm just saying the budgets you have for DD Kids are crazy higher than what my son's is. And you guys know this. We've had this conversation a hundred times. And they have budgets that are higher. They get to go to day programs, and then they have all these hours for care that are a lot higher. Our providers get paid $16 an hour, which is an absolute joke. And so then you're gonna tell me that then I can only have help 20 or 30 hours, I mean, you want us to die trying to care for our child? Because that's what it sounds like. This is unacceptable. I guess I'll just die. Thank you. Because for the record, I was already diagnosed with cancer. And I'm sure it's due to stress

[Lisa's iPhone]
Sure, I just had a question. With the limitations in hours, uh, 40 hours or 70 hours, Does the state have a plan for the individuals when family caregivers can no longer support them in the home I have found that there are no nursing homes that are willing to take my daughter. Um, so that would leave her homeless and in limbo.

[Lisa's iPhone]
Yeah, because when you were talking about, um, when they're reaching their budget, look at community options, I've just found that there's a lack of community options. Um, that would be available. I can't say for the higher end, the elderly, but... our specific disability population that's receiving A&D services may be in that transitional young adult age. Um, that nursing homes are not willing to accept. our patients.

[hstei]
Sorry, can you hear me? I don't know why it's... the chat to everyone is disabled, so I'm not even able to see other people's questions. But my question is back to the individual cost limits and saying that you're going to get that information to us. It's unfair to have a comment period where we don't have all the facts, so we can't accurately comment on our thoughts about that, when there's no...um, clarity. In the amount that's going to be the individual cost limit, and where they're getting the comparison, nursing uh, you know, institutional rate, comparisons from. It's unfair to... close this comment period in January

without us having all of the knowledge to make accurate comments and voice our concerns.

[iPad]
is respite combined in the personal care and LRI hours?

[hstei]
So nobody answered my question? We... we want the individual cost limit and how they arriving at that, and the institutional average that they're using to make that before the end of the comment period, so we can make accurate comments.

[hstei]
Right. Will we have that before the comment period ends?

[hstei]
Okay.

[Teresa]
Well, that's a non-answer.

[Kristi]
So, I have a question, because, um, they put these, um, limits on because of cost, and I have a client that was getting more than 70 hours a week, and then these limits came up, but the cost is higher, because every time her caregiver leaves, she's averaging one to two times a week, calling 911. So the Medicaid cost to take her to the hospital just to send her home, is higher than just having a caregiver there, because that's when she has a problem, is when a caregiver is not there. So, is there a way to appeal that?

[Kristi]
Yes, ma'am.

[Kristi]
Okay, what if she doesn't have a POA or family? And I've called APS, um, several times, Um, trying to get a guardian in place for this young lady, because she doesn't have any of that. So, I'm the only advocate she has. So, I don't know which route. Yeah, I've called her case manager. I mean, I've called... I've had psychiatric involved, like, I have nobody helping me with this young lady, and she's calling 911 one to two times a week just to go to the ER and get sent home. There's nothing wrong with her.

[Kristi]
Okay, thank you.

[wv]
Yes, I have a question. Um, my daughter...qas kind of in the midst of the DD waiver, and we were told that coming to this side by Jen Clark was the appropriate way that my daughter would be taken care of, and it seems like... being over here for 2 months, this is another side where nothing's being done with her. And her safety is a concern. I think this 40 hours a week is... a lousy way to save a buck. That's what I think. I don't know how you can umbrella everyone when you have people who can function, and you have Adults who need all cares given to them. I don't understand where you're coming up with the number. I want that explained to me. How can you umbrella everybody? How does that actually work? Don't you think there should be a way that people are individualized with their care?

[Kristi]
Hmm.

[wv]
I mean, you're not putting anything in place, you're just saying, this is the number and that's it. I mean, you're not considering that some people who, for example, are ventilator-dependent, They need more cares than the average person. Who's coming up with 40? Where is this magic number coming from, and how does that relate to someone who is a very complex need oxygen, ventilator-dependent person. Can someone explain it to me? And actually, I would love Jen to explain that, because I'm kind of on this side right now because of her.

[wv]
Right, and I provide those overnight, right? I provide those, that's what you guys wanted. Is to make sure that those were provided overnight. Now you're taking more and more and more. If I was to put my child in a home, She would get 24 hours care, and you guys would be paying $1,300 a day for her. So it doesn't make sense, these numbers that you guys are coming up with, and you don't have a plan in place. If I can't take care of my daughter, And 85 other people can't take care of their complex needs. Does the state have adequate nursing facilities for these children? What is your plan? And before the next 6 months that this... are you guys ready for parents to be dropping their kids off? What's gonna happen in 6 months? What is your plan since you concocted this 40 number? I don't think you have enough facilities in the state to handle this stuff. So you are going to actually work through it? Because you guys should probably have had a plan today to actually answer my question, that if...you're not going to allow parents and treat them better, what's gonna happen to these kids? They're gonna burn out, and you don't have a plan in place. So, why even say anything until you have a plan put in place? I'm shocked that you guys just wanna... do these horrible things to this kid. to save a buck.

[Teresa]
Yeah.

[wv]

You guys get into public health for a reason. I'm shocked. Shame on you.

[Lisa's iPhone]
Okay, this is Lisa. I just wanted to bring up one thing. I think one thing in, um, coming up with this plan, That was missing, that maybe the department didn't really think of. Is there is a difference between skilled nursing care, and then, like, custodial nursing care. So I feel like the AD waiver is set up for those who need custodial Nursing home level of care, but the AD waiver is not set up or recognizing this increasing number of adults that need skilled nursing care. Um, so, and I think that bounces off my last, um...comment, or whatnot, that nursing homes are not willing to take our children. is because they are... there's not a clear, like, line in the road. Skilled care versus custodial care, because our children are not just custodial care, their skilled care. And then I think most of the people... I can't speak for everyone, but most of the outrage and most of the concern is for this population that is being served by the AD waiver is not custodial, it's skilled care. And whether it be straight Medicaid or the waiver programs, There's not really one bucket that serves this group that didn't necessarily, um, exist, you know, 15 or 20 years ago.

These individuals oftentimes passed away, and so they were served and met through federal protections, why they're a minor, living at home with these complex needs, and now they're losing those services and living into adulthood. So I really think it opens up a whole new can of worms, and whether that's a whole different waiver, A whole different pot of money. A whole different set of circumstances, but I think that's where most of the pushback is coming from, is this unique set of individuals that have more that is going on than meets the developmental disability. They actually require, like, skilled care. And if I had to just provide custodial care and sit on the couch and watch movies and provide companionship, I could probably do that for the long term, but when I'm rolling and sitting up and lifting and maneuvering and showering and wiping and all this to a child, an adult child, who is very large, Um, day in and day out, that is a totally different expectation for this specific group of family caregivers that I think needs to be looked at.

[Lisa's iPhone]
And unfortunately, just what we're finding is, um, a lack of understanding. Or maybe instruction and education that the MCOs do not believe that that level of care is their responsibility. And families are receiving a denial and pushback that those services are a duplication of waiver services and are no longer being provided. So I could use my daughter, for example. I'm going through it, I filed for a state fair hearing, I'm going... I'm jumping through all the hoops. But there is some disconnect between the fee-for-service, Medicaid, and the MCOs, is that understanding. And I know a lot, and just the outline from the MCOs of level of care, a lot of They're not gonna pay for a CNA. You know, there's just some sort of disconnect, and maybe...Just better policy and outlines needs to be written. I've...looked at some other states that have, like, real clear rules, like, and some waivers do pay for skilled care, and otherwise it's really outlined for the MCOs that that's their responsibility. Unfortunately, right now in Nebraska, the MCOs have decided that it is not

their responsibility. And that could be also the reason for the...a heightened emotions of today is because this group of parents is also suffering because we've received, you know, no services through the MCO as well. And so we're just grasping at straws now.

Um, because the MCOs have pushed it back off onto, um, waiver, so maybe there needs to be some sort of...you know, coordination of benefits, similar to what you have when you have insurance and Medicaid. You know, making sure that these needs are met in some way instead of everybody just pointing fingers at one another.

[Kristi]
I have a question. I'm sorry. I'm just trying to figure out what the repercussions are for the companies that are getting caught with fraud. Because a lot of those companies that I see on the news are not only still thriving, but they're making higher amount of money than other companies that's been around for a long time. So, is there no repercussions for that?

[ipad] 15:28:36
Hi, um, this is Abby. I just... my question comes from, you know, I... I have a daughter, For example, she's ventilator-dependent, she G-tubes, she's quadriplegic wheelchair, um, all the things that everybody knows that we live with. And I just... I think that's 100% what I... what I've found just recently, is that She obviously does require 24-7 care, and I mean, I could walk away and put her in, like, a facility like an ambassador, and you, Medicaid, would be covering it. Um, so the... the cost there is just astronomical, and I totally understand that, but then you have a willing caregiver like myself to be home with her and her siblings to keep her home as she you know, that's fair to say she's a child but then, you know, we have... I've reached out to... to our service coordinator and, you know, the MCOs. They literally say that it is not their problem, but the child, if I... if I just don't do anything, I mean, I would get I would be brought against me some charges of neglect, obviously.
So, how... he hours in the... the knowledge that... I don't know how you compile all of those to say, that I can just be home to care for her, and just... but I'm Matt, I'm just... my max is 40, and that's it. And... because, you know what? I quit my job the second she was injured. And I have been with her now for 4 years at home. in 4 years, doing the care, and, um, one income with the entire family. And... but I... what I could do is I could go to work, and I could work under the amount that the state sets as a requirement. And then I would go after SNAP, and then I would go after everything else, and I would have it, and you'd still... so the cost is just much higher for you if you...Rather than if you would just pay a caregiver to be here fill those hours and to do it. That's all I have to say.

[Heidi Sommer]
This is Heidi with just one question. I just want to ask, um... I appreciate you guys listening. To all of us. If... if we do provide public comment, in the past, I've really felt like It's... it's out there, but, like, this document, it's really already set, nothing's gonna change. I mean, how much are you going to hear the public comment? And then my other idea... I'd like to know that, and then my other thought is...Um, I feel like there is very much a tiered...level of need

under the AD waiver, according to how you qualify, there really shouldn't be. But I can tell you, from what I see out there, and from different people I talk to, there is absolutely a tear, right? But there really should be people that need help with everything.

Um, whether or not you have an event, that's not the case, right? Um, and that doesn't mean you're more severe or less severe. I don't know if that does, but anyways...Uh, how about tiering the hours you get. I mean, for somebody that is caring for their adult child, Or they're providing...Constant care for them. And then you throw in LRIs, where you're supposed to, like... I mean, I haven't even looked at that, because I don't even have time. I'm too busy caring for my son And trying to keep a job, which I'm quitting. And so, I just think... how are we supposed to, like, oh, clock in, I just did something, oh, clock out, oh, clock in, because I'm going to do this other thing. I mean, it's, like, constant.

My son recently stopped walking. I mean, so, like, It's... I just...Again, my worry isn't about...me. I think caregivers do need, like, when, you know, to be paid when their child is an adult. I used to not think that, but I get it now. I just can't understand how...There's this expectation that everybody has these butterflies and roses families that step in and help. We do not, and I am sure there are more families out there. And if none of you have severely complex needs kids, Please bring us in so that we can have genuine conversations when you're planning this stuff, because...This plan here, especially when I see kids on other waivers that have less needs, that cost you far more money. It's just, to me, what this says is... We don't really care about your kids. That's what it says to me.

[Teresa]
It's thanks.

[Teresa]
This is ridiculous.

[Heidi Sommer]
Well, one moment. What about a tiered... I mean, I guess you're not going to answer that, because it's, like, public comment, and you're going to take all this back, but I'm just thinking...If everybody doesn't have the same level of need, Under this waiver, yet we're throwing all of the options, like, it doesn't matter what your need level is, you just get X. That doesn't make any sense to me, because that's not how it's supposed to work.

[Teresa]
Yeah.

[Heidi Sommer]
Is that due to staffing, or just capabilities? Because I just think, like, you're dealing with very vulnerable... I want this noted. You're dealing with very vulnerable...kids, and then... I will... I will live forever. Like, that's my goal. But there are parents that struggle, and I have seen struggle. And then the problem is, The state goes back to a couple other comments,

doesn't have a plan for these kids. They're just gonna, like, lay somewhere and die. I mean, so shouldn't this be a priority to figure out how to get tiered for your most vulnerable? Versus putting everything toward the DD, Because that's what we feel. Those kids, and I think I was told by somebody at the state, that the reason that those on that waiver gets more action is because they are louder in the legislature. They go up there. Well, we can't go up there, because why?

Well, what are we supposed to do? Wheel our kid in with their vent and all this other stuff? No, we can't be there. But yeah, we're being told they're heard more, and they get more, because they're louder. Well, it should be needs-based. Let's go back to the basics. Let's go back to how IEPs are done. Which is all need-based. And then when we get to be adults, it has nothing to do with needs. It's, are you loud? Do you know how to advocate? Do you know the rules? And then, you're just...in trouble. Your kiddo, you better live forever.
I've been saying that since my son turned 19.

[Heidi Sommer]
But the need assessment, I was told by a service coordinator once, They just kind of have a number they throw out there, unless a parent says something. And then they'll... they'll up it if they say something a little more. I mean, I have people... I've asked everyone what their hours are, And my son and the 5 people that I asked, is much, much, much more needy. And they have 20 to 30 more hours than my son does.

[Heidi Sommer]
Well, it's 40. I mean, because companion care? Should we even have companion care for AD waiver? To qualify, you need help with all your ADLs, so why would... then you're just gonna have somebody sit in here, but they're not gonna help with anything else, so you're gonna need another person here anyways. That doesn't make any sense! Put those dollars toward ADLs.

[Kristi]
Good answer.

[ipad]
I mean, you put everything else under an umbrella, why don't you put that together?

[Jennifer Williams]
Question. What happened when...the parent has provided the informal support, or you guys... the assumed care. They've done a 16-hour shift, wasn't paid for it. They're waiting for the care provider to come in. They don't show up. So now the parent has to do the additional 8 hours, so now they're working 24 hours. But then they have to do the next day, 16 hours. We know that there's a shortage of nurses, Which is, I know, another... area, but there's also a shortage of care providers. So, do you guys have a plan for when the parents...are worn out. And have to do something, because...We all know that lack of sleep

is...Probably even worse than being drunk. Um, I know there's times that I didn't get sleep, and I have to look at my son and say, I can't drive you because I'm impaired, because I didn't get sleep.

So I want to know what your plan is to help support the parents to support the child So that way, everybody remains healthy. Because it is a unit. It's not just the child, even though I know that's all you're looking at. But let's be realistic. If the parents aren't healthy, then no one is. And we know that as care providers, the parents are going to give their all. And everything that they can. So my question is, what do you have set up to make this successful? And not let it fail.

[Jennifer Williams]
So, and I think that's great, that's a great plan. But what do we do meanwhile? When the parent doesn't have anybody for a month or two until that gets figured out, because we all know how the employment process... goes, and how it actually works you... you... you can't just get somebody to come in... They usually quit because they realize they're not getting paid enough to do the amount of care that they're being asked to do. I have to say... I have to stay at home and work. I used to work outside of the house, now I have to stay home because I have to be here just in case the care provider can't provide certain things. Because we don't have a nurse, because technically there should be a nurse and there's things that care providers cannot do, like, administer blood pressure meds when... My son's blood pressure is 225 over 150. No, you don't call the ambulance, we have the meds here. So I have to be here in order to do that. So how are we finding these people that will feel confident in...comfortable in these positions, getting paid what they are.

[Kristi]
Okay. Can I ask my question now? I am strictly looking at Appendix C, where it's saying that the direct care provider has to have CPR, basic first aid, and abuse and neglect, exploitation training. When exactly does that go into effect? I went into all of these trainings is required, and...isn't that just, um...I don't know, y'all, you guys are asking that all these people have... this is no different to me than skilled care. The CNAs are all required to do that in a nursing home. So, you're requiring agencies to do that, and then you're saying there's no money to give us increases. So when does that go into effect?

Now, you're offering free CPR classes? Like, what... who's... so the companies have to pay for this? And... you guys don't plan on giving us a raise because we wasn't in the talk to get a raise? Like, that's... doesn't make any sense to me. Because somebody has to train them. I mean, I'm a registered nurse, and I can do that, but it takes time and money.

[Heidi Sommer]
I just wanted to make a comment, since you're taking them kind of here, too. Um, that when LRI is only for spouses or minor children, So we have all these things that are for AD waiver, but when you look at what you're providing adults, Um, like, you know, my son is still a kid, but he's 22, right? like, the... the help and stuff is just being taken away, taken

away, taken away, but...In my son's case, his needs keep rising and rising. Um, it's just, again, it... it doesn't make sense that some of this isn't considered Um, and maybe you guys did, but, like, to us, it just doesn't make sense that... you know, okay, this group of people get this. Oh, but if you're an adult, Kiddo, no. We just really don't... I mean, it just speaks that you really... Do not have a concern for adults with disabilities. That is what I am taking away from what is happening here. I feel strongly about that.

[wv]
I totally agree.

[Heidi Sommer]
It doesn't apply to all. That's the piece you're missing. I understand what you guys are doing. It's all about money. And when you have a kiddo with a high level of needs, and you're potentially staying up for 24 hours, I think it was WV, I... Please reach out to me on social media. It's Heidi Summers, S-O-M-M-E-R, I'd love to chat with you, um, and put something solid together about this. Um, anyways... I just... I think we have to consider all of this stuff, and consider how it's equitable, Among everyone on the waiver. I think that's the piece that's missing. It sure does not seem equitable.

[Kristi]
Yes, I have a question, um, because we got these new codes, and I... I don't know who's addressing the code. Once again, I come from a medical background as a registered nurse. But, like, I have a client who... the case manager told me that they just automatically put it in for shampooing somebody's hair, on a shower day. Well, everybody doesn't wash their hair when they get a shower. You have African American people that don't wash their hair every time they're showered, and it's, like, all clogged into these minutes, so I don't know who's setting up these plans. Um, or, or these codes, or anything, or it's... none of it is making any sense to me. Or if somebody needs supervision while I'm there, If I have a caregiver in the home and they need supervision, They no longer needed when the caregiver leaves, because we're maxed out at 70 hours. It's just not making sense to me with a medical background.

[Kristi]
Yeah, because the site coordinators really don't know, I promise you. They absolutely do not know, and when I discuss this with her, she said, well, that's only when she's there. Or if the client's not... needs moderate assist with walking, That... that doesn't matter anymore once the caregiver leaves?

[ipad] 15:59:43
Yes, so I guess, you know, I hear that it's person by person sometimes, and why is that, like, So, on some things, it's person-to-person, but in other things, it's not, and you're just capped at 40 hours. You know, why is a child that is under 18, minus 6, um, she's 6, but you can't count supervision, but you have a ventilator in the home 24-7, so... Supervision. If I

don't supervise her for one hour, again...something could happen, and again, I could be charged with abuse and neglect by the state, you know, and it just does not make sense, those things where you can't account for supervision on somebody that is dependent on a ventilator But you would pay a registered nurse if you had a nursing agency, because she is eligible for the overnight hours and the supervision with... with the nursing agency if I wanted to just go to work for a minimum wage job and work part-time and still have the state benefits. So, I mean, where is... how do you bridge that gap, then? Why... I mean, why is there not something that says, you, you know, this specific child, this case, like, obviously needs this and qualifies for this, because I mean, I guess I just don't clock in, and I just don't do it, and then... No repercussions can happen to me. That's it.

[ipad] 16:01:20
Well, but mom, like, that's my point, is that mom is here 24-7, and... and I asked those questions to my service coordinator, you know, I am here, and I can provide that. I mean, it's basically a thing of, you know, the client is here and needs this care, and I can provide that, like, I'm here, but as, again, as the waiver, you cap it at 40 and don't want to do any more than that, even though I will do it. So, where do you go after that? Because the cap is 40.

[ipad] 16:01:59
But, and so, and I've argued that too, you know, just because they are a child does not mean that they don't have things that need taken care of, because again, if they were institutionalized, she would have supervision. She would be... I mean, you would pay... I mean, one of her stays was $365,000 billed to a primary insurance, and then after that went to secondary, just for a week in the PICU. So, why wouldn't you? I mean, and I know there's parental obligation, But when you're talking about a ventilator in the home, yeah, I can care for her. But I'm also the only one that can care for her. I can't just leave her... I can't drop her off at the babysitter or the daycare.

And also, I want to add, nor should I bring in a nurse, because you... who's gonna take care of the child the best? But the poems. I mean...we've had nurses in this home change settings on her ventilator. We've had nurses in this home do things not on our care plan. And almost killer. But I'm not able to have more than 40 hours.

[Heidi Sommer] 16:03:07
And again, personal care is...companion care? Like, I meant companion care. There's still gonna have to do all that personal care, so if you're paying somebody to come over and just sit with them, and then... The informal supports is gonna do everything.

[ipad] 16:03:31
But you're... but you're still...

[Heidi Sommer] 16:03:31
what... like, get rid of the companion care. Like...

[ipad] 16:03:33
Yeah, you're still gonna pair.

[Heidi Sommer] 16:03:34
People on AAD waiver do not need companion care.

[ipad] 16:03:37
We need... yeah, I mean, you're gonna pay that other person.

[Heidi Sommer] 16:03:38
You need it all in personal care. You're gonna talk to the person because you're companion care, but you're doing things because these...

[Heidi Sommer] 16:03:46
If you qualify for the AD waiver, you likely need help with all ADLs. That's my understanding. So why are we even talking about companion care?

[ipad] 16:03:52
they're full quadriple

[Heidi Sommer] 16:03:54
That doesn't make any sense to me. Get rid of that. That would save you a lot of dollars right there. And then the whole clocking in, clocking out of the IR, whatever those are called. That is make any sense either. All that is is to save money. Because who's gonna... when you have to take care of somebody, that needs all their cares. Who's gonna stop clocking? Oh, I just did that. They're not going to. And I think the state knows that. So, put that in there, because no one will do it.

[ipad] 16:04:20
It just seems like you want to make it so hard to even get past, and to keep fighting, because we have to clock in, clock out, clock in, clock in, and then keep advocating, keep fighting this, that we just give up. And, I mean, there's truly kids like this, and adult children that need the care. And let me ask you this. Do any of you that are making these decisions and make these amendments, do you have, or have you lived with, is any of your children disabled? Are they on a ventilator? Are they quadriplegics? Do they have epilepsy? Do they have any of this? Where are you making... where's your background?

Questions from Chat:

From Jodi
Our child requires 24 hour care, how do you justify reducing her hours to just 40 a week? If she was institutionalized, she would have 24 hour care.

From Jodi
Will her needs assessment determine that she qualifies for more because of her intensive needs?

From Jodi
She is an adult on the AD waiver

From Kayla Jones
I apologize, did you say that Respite care is capped at 50 hrs per year?

From hstei
Chat is disabled?

From Katie Kuecker
What is the institutional cost and how was it determined?

What if the minor on the AD wavier is homeschooled? Are they still held to the hours set by the local school district?

From Bob
Please explain differentce between assisted living and supported living on the AD waiver

From Michelle
I just want to make sure I understand correctly. So for family caregivers who live with the client they can only work a maximum of 40 hours a week?

From Ann
if a child is home sick from school can services be rendered?

From Bob
Is the cost of nusing facility care you looked at for an individual who need 1:1 care 24 hours a day?

From Terra's iPad
Will provider or agency rates be impacted?

From dbarringer
The terminology of'combined' is leading providers (private and agency) to think 40 + hours of Lri in addition to the other allotted hours for care. Please mention the LRI hours are not in addition to current allotted hours.

From Teresa
I guess am not understanding. A person who needs 24hr care, quad, non-verbal, g button, trach, ventilator, bowel and urine care, on oxygen, seizure disorder is not longer allowed 24 hr care?

From Katie Kuecker
What is the cap on personal care hours a disabled adult can recieve on the AD wavier not LRI hours?

From Jennifer
Can you please specify how much the cost limit is? Please specify what “safeguards” are listed in the waiver application

From Jodi
What is happening to overtime pay? I was mentioned at the last quarterly meeting that overtime pay for independent providers on the AD waiver would be eliminated.

From Michelle
I messaged here because the other chat is disabled for me

From Teresa
I agree with Heidi Sommers statement.

From Jennifer
Can you please explain further the combination of the HCBS services AND Medicaid costs into the persons budget? Whereas before Medicaid hadn’t been previously included in the participant’s budget

From Katie Kuecker
Sorry - our adult medically fragile kids could be cut from 60 or 100 hours per week to 40 hours??!! Is that correct?

From Bob
So if a family member is currently caring for someone 16 hours per day right now and expected to care for them at no cost the other 8 hours, are you going to lower the hours even more?

From Bob
So you are going to drop individuals currently getting 16 hours per day to a total of 40 hours per week, because you are trying to save money?

From Kerin Zuger
Is the 16 hours a day still a rule

From Dana Dougherty
If a participant needs more than 70 hours per week of Personal Care and Companion, is there an exception process?

From Theresa
I have heard that AD Waiver hours will be reduced to 85 max per week?

From Kerin Zuger
Will we go through the normal review process for rates? Specifically when companion rates are much lower then personal? Looks like we are reverting back to more companion, which will have dramatic impact if the rates are normalized with personal

From Terra's iPad
Is respite combined in the personal care and LRI hours?

From there
So those clients that are more than that they will be reduced. Also for 24/7.

From Chris Stewart
what is being done for someone needing more then 70 hours

From Bob
We have all been told by your agency that agency rates are going to be updated to create a more level playing feuld for agencies. Is this not true now?

From Heather R
If I am an independant provider that cares for my son on personal care ad waiver - I can only get paid to care for my son only 40 hours a week? When he requires 24 hour care? with this update?

From Katie Kuecker
This is an enormous cut to families. What other methods of reducing costs did you consider before cutting these hours for families?

From Teresa
This person cannot be left alone at ANY time whatsoever. How do you cut so many care hours from this adult disabled person?

From Jodi
What is the institutional rate for a high needs adult requiring 24 hour care? I believe 40 hours a week of personal care on the AD waiver is far less than even 100% of the institutional amount, much less 175%. How would an individual qualify for the 175% level?

From Teresa
And why is the everyone chat turned off?

From Bob
What is the actual number for 'institutional cost' you keep referring to?

From Chelsea Jensen
What is the rate of applicants being deemed eligible after DHHS started completing the level of care compared to before?

From Paige.Chudomelka
My understanding is that when an ADL occurs for an individual on AD Waiver services, the entire shift should be authorized/billed as personal care. While some folks are getting more assistance with their IADLs but need assistance with ADLs for a small portion of the shift, would this process be changing to allow for more care to be authorized under the companion service in addition to personal care services?

From Teresa
1005% agree with Lisa.

From Heather R
Can the legal guardian still watch on the AD waiver correct?

From Bob
What is the actual number for 150% or 175%?!?

From Teresa
The drastic cut in hours is going to be financially devastating.

From Teresa
hstei is spot on.

From Bob
Agree with hotel. Please respond!

From Bob
The average cost needs to be shared before the comment period ends. We need to have all the information to be able to make effective comments

From Katie Kuecker
How can hours be capped at 70 hours combined if you aren't sure what the institutional cost is?

From Heather R
How about a life - Disabled Adult lives at home with family caregivers to give them a life, to thrive. Taking away hours from family providers and wanting to put them in nursing homes is a failure to live, failure to thrive to give these individuals with the best life. This is going to force providers that are family providers to have to go get other jobs to thrive financially forcing these individuals to nursing homes if they even accept them. Who is looking out for our disabled to give them their best life?

From Sue
Who will be reviewing public comments?

From Heather R
from the state that is

From Bob
Do you realize the stress and danger you are putting the waiver recipients and families in with these cuts? Do any of you have family of friends who will be affected?

From Teresa
why can I not comment publicly?

From Sue
When does this go into effect and how will families who have more than 70 hrs be a week see the decrease?

From Teresa
Does the cut in hours include nursing hours on top of care hours? For instance. My person gets 112 care hours and 8 hours per day nursing. How does this change?

From Heather R
Will each case be looked at on a case by case basis if over 40 hours of personal care on the AD waiver is needed for my son who needs 24 hour care? I provide care 24 hours a day and I agree this is crazy to have 40 hour cap.

From Chris Stewart
is supervision a apart of the ad waiver?

From Kerin Zuger
I do think before any decision can be made, we do need to see a public cost comparison. It's so true, that we have complex clients that if we dont support their needs and they are institutionalized, it would cost WAY more. Do we maybe have an exception process for those clients? Put it on the agency or the family to come up with a solution or a comparison to either have blended care (institutional and home care) or get additional hours they need.

From Katie Kuecker
I was under the impression that LRI was for minors or spouses. That is being broadened to guardians for adult children?

From Kerin Zuger
companion care needs to go away. It's silly. and not a 'real' thing

From Paige.Chudomelka
for AD Waiver - if the caregiver is NOT a live in caregiver, are they maxed out at 70 hours (in combination with LRI and companion)?

From Bob
Have you considered reducing some of the extremely high agency rates to help reduce overall costs? This would allow participants to keep more hours

From Terra's iPad
How are those that utilize nurses for the "childcare" portion and respite impacted by the 40 hours?

From Sue
Did I hear supervision is still included/ Or what is being cut in order to lower the hours? How will it be justified?

From Heather R
As a family independent provider do we now need to CPR, Basic first aid certifications and take a abuse/neglect/exploitation training and if so where do we get this training? Will this training be paid for?

From Bob
But rates are not actually being negotiated. For 3 years straight we have been capped at a specific number, knowing other agencies are getting much higher reimbursement rates.

From Bob
We are not asking for rate increases, we are asking you DECREASE rates for agencies getting outrageous reimbursement rates

From laura
What is the process to get these changes not adopted? Who do we lobby and press on to prevent the changes. Also why is it so easy for the state to cut funds from vulnerable individuals and not actually push forward laws passed that would fill the states coffers and allow a windfall of funds for all programs in the state?

From Sue
Thank you for clarifying.

From Jodi
It was mentioned at the last quarterly meeting on Nov. 20 that 275 participants are receiving funding over $275,000 a year. Can you not make your cuts to those people who are drawing an unreasonable amount and bring them more in line with the rest of us before cutting the hours to all the rest of us?

From Chris Stewart
I also agree that it apears theat adults with disabilities are being overlooked and their needs and safety are not more important then money. An example is the need for supervision this need does not go away just because the alotted amount of time has been met.

From Sue
Does it matter if the provider is parent/guardian or outside provider, providing care? Hours will be same

From laura
We're these changes driven by agencies that provide the service in order to get more of their employees in homes and less for the guardians and parents that provide the best care.

12-11-2025

[Dianne DeLair]
Colin? Hi, Colin, this is Diane Delair with Disability Rights Nebraska, and this might be just on my end. But the chat looks like it's disabled.

[Michelle's iPhone]
Can I ask you a question? Yeah. Um, I am a mother of a son with a TBI. He's an adult son. And this is gonna totally devastate us. I mean, it's gonna cut my income 3 quarters of my income. Now, I have recently bought a home. So, I could take care of my son. The statehas modified my home and has invested a lot of money into my home. I'm gonna have to sell that house if this goes through. I am no longer going to be able to care for my son because I can't afford to pay. Take care of him at home, because they're making these changes.
Do you guys realize the devastation that you're gonna be leading to the people that you're doing it to?

[Michelle's iPhone]
Um... I mean... Well, you've worked this many years. I've been caring for my son for 14 years. And they're just basically gonna rip him out of my home. And put him in a place that he's not used to, I'm not used to. I'm going to lose everything I have. I don't... what do you expect us to do, is my question, I guess.

[Michelle's iPhone]
Okay. Well, but you know, everybody doesn't have extended family that's able to come and work for free. I mean, they have families. Um, and they can't just come over and give me 4 hours. You know, if I work... 40 hours with my son, I can't go get another job to supplement, because there's no one to sit home with my child. So I'm basically at the state's mercy. And so is my son. And it's not just about money, it's about care. And where you can put all these people that can't stay home anymore throw them in a nursing home that's already overcrowded and underfunded. I mean, and they're closing down by the minute.

[Michelle's iPhone]
So, this is gonna be a disaster. And the only people that's gonna suffer or the handicapped people. And the parents of them, or their caregivers and I would hate to think of the. home health agencies that have vested time and money. In this as well, are going to go out of business because you're taking all the hours. This is going to be devastating. I know it is for my family.

[Jenn Clark]
We don't have a date of when the overtime will be changing. We are still working with our financial department regarding, um, the overtime changing from time and a half to straight time. That may happen before July 1st, because it is not in the waiver. As soon as I have that actual information for everyone, we will get that sent out in the listserv, um, for sure. Um,

but then also to answer all of the back pay, yes, that is still coming to you, that is owed to you, and that will, that will be coming to you.

[hstei]
Hi. Okay.

[Donna Sandberg]
Is it okay if I say something really quick? I'm gonna have to get off of the webinar. My name is Donna Sandberg-Goodner. I'm an independent provider for my son, who is an adult, um, on the AD waiver. His name is Eric. And I've been taking care of him for 26 years. Um, he has cerebral palsy, and I know I visited with Jen, I've talked to Stacy several times, and Karen Hausman about different things. Um, I'm highly involved in his care, so I understand where Michelle's coming from with everything. Um, because this does impact us able to have jobs outside of our homes. And, you know, our main concern is our children, too. I'm also a registered nurse. I do work a couple days outside of the home because I have been able to find some independent providers to help. But it's a struggle. It really, truly is a struggle. We have been lucky that we've had the people for several years, but they have to have other jobs, too, because we can't provide insurance and etc. For them. Um, I only work 2 days, 1 to 2 days outside of the home, just to keep my registered nurse, to keep my license going, but it is a... It is a challenge all the way around, and when hours and stuff start getting cut, that cuts into my ability to be able to help provide, because there's still other needs besides what the medical needs are as far as supplies and things that, because of the level of care that my son has, he isn't a trach, he isn't a feeding tube or anything, but there are still supplies and stuff that I have to come up with the money to provide, let alone try to find providers.

My days, my shifts for my job that I do, I have to have a job that is flexible enough with my son. And the other jobs that I do, I do an on-call thing from home part-time. It's, like, very little pay at all, but at least it allows me, it's an overnight type of thing. Um, and that is through Goodwill Industries that I work through and then I work for an in-home pediatric care that takes care of children that have special needs to medically complex kids. So all of this affects me across all across the board. But my main concern is my son, and I agree with Michelle, we've done. Different things to change and update our homes, you know, we have a house payment, we have all of these things, and we... the biggest thing is we... We care about our children, and we're trying to do the best for them. I do understand that some of this is out of your control within reason. Um, so I'm glad that we do have this open comment time. I'm just double-checking, so it'd be 40 hours per week for people that live in, like myself, is that correct? And a total of 70 hours per week, so that would be the additional care providers, correct?

[Donna Sandberg] the extra to make up to 70.

[Donna Sandberg]
Okay.

[Donna Sandberg]
Okay, because that's another thing, you know, my son needs a lot of supervision, you know, he has the ADL carers. Um, but a lot of it is because of. I wish I could figure out how to do that again. Health concerns and things that he has, he has to have that companion. Um, another quick question, since you guys are requiring now, moving forward. Um, that the providers are CPR certified, and, um, first aid, and then also the other thing was the abuse and neglect, is. Those things that are going to be offered, then, that the state's going to provide sessions, especially the abuse and neglect, because I don't know where you'd go and get a session on that.

[Donna Sandberg]
Okay, thank you. I just wanted to express just the concerns that I've had, too, just like Michelle. That, not only that, but, you know, we've talked about getting agency in here to do his care. well, if this is going to affect agency, and, you know, I really don't want to send them to a nursing home or something like that, because it is true, I have been a nurse in a nursing home, and I have been in facilities that have actually closed. Um, because they don't have the funding and stuff. So then it's, it's a concern, you know, we're trying to keep our children at home. It's not that we're getting rich doing this by any means. It's just we want the best there. So, thank you for your time.

[Michelle's iPhone]
By any means.

[Michelle's iPhone]
Can I...

[hstei]
I'd like to...

[Michelle's iPhone]
I'd like to do that, too, again.

[hstei]
I'd like... okay, so, um... can I go? Or do you want me to wait?

[hstei]
Okay, so I specifically want to know how the state plans to ensure the health and safety of our individuals while drastically cutting their services, and you're worsening the caregiver crisis. There's a clear tipping point that you... once you pass, there's no going back, and having no backup plan is simply just irresponsible. Yesterday, they couldn't give us a list of nursing homes that would take our participants, so we could go investigate these places and look and see, because at some point, as much as I don't want my individual to be in that situation, there's a tipping point where it's gonna have to happen. And I know that most

nursing homes don't like to take Medicaid-only clients, because they can't survive on that. So, the state is then going to have to further incentive To set up by the facilities with additional funding to take any of our people, why not use these resources that you would have to give them, strangers, to take care of our people to use these resources to keep people safe in their homes, where their needs... needs are actually being met, and...And dismissing and undervaluing the exceptional care that our individuals are already getting is a mistake. I want your opinion on that.

[hstei]
That is a public comment.

[hstei]
Right, but we also have a problem with the fact that public comment has already begun on the 5th of December. We yet don't have all the information. We don't have a list of nursing homes and, quote, other resources that...is pointed out in the application saying that you will give us options for our individuals. We don't have that. We don't have the cost limit, or how that's going to be implemented. And we're... I think that public comment needs to be extended till we have all the information that we need to make comments.

[hstei]
So the day before, you'll give it to us, and we'll have to... I'll make comments in one day. That is not appropriate.

[hstei]
Well, I understand that, and I appreciate it. In the application, it does say that These SCs will give us a list of nursing homes and other resources, And I think that's something we need before public comment ends as well.

[Dianne DeLair]
Hi, uh, yeah, this is Diane Delaire with Disability Rights Nebraska, and I'm a member of the Governor's Advisory Committee on Developmental Disabilities, and also the Olmsted and advisory committee, as well as several of...those, uh, the Advisory Committee Working Groups, And I'm just, um, concerned why, you know, I'm curious why this, uh, application, these changes have not been brought up to those two committees. Um, when we have had regular meetings, um, it never been an agenda item. So, could someone, um, there might be other folks who are on those committees as well on this call? Um, so could you talk a little bit about that?

[Dianne DeLair]
When did the division start discussing these changes, or the idea that you were going to submit a CMS application?

[Dianne DeLair]
And how many people, how many adults, um, are at that 150% utilization rate at this time.

for the A&D waiver.

[Dianne DeLair]
Okay.

[Dianne DeLair]
Thank you, and could you also do the same for children?

[Dianne DeLair]
Okay.

[Joe Valenti]
Hey, Colin, this is Joe. I want to go back to Diane's question a little bit, if I could, just real quickly. But first of all, I just... I want to say, uh, to Colin and Jen, and. I know... I hope everyone understands, you know, they're charged to present this information, good or bad, they're not charged with probably getting into a dialogue about how or why so much, so I just... but having said that. Colin, when you talk about renewal. I'm always curious, I think this happened, if I'm not mistaken. with the DD changes that occurred. Does the renewal have to occur right now? I mean, does it expire at the end of the year, or when...

[Joe Valenti]
Got that. But when does... when does it... let me interrupt, though. When does it end? Does it end on December 31st?

[Joe Valenti]
Okay, so my question is, and again, this, you know, won't be able to answer it probably, but. You know, I think... and I'm not... I'm not positive, but I think this happened with the last extended changes to the DD, etc, etc, but... You know, I think when you... and again, this applies to you guys, too. You and Jennifer and the rest of the crew. Does it have to always happen during the holiday season? Uh, when... I know you have to be busy also on a personal level, let alone business-wise. It just... it does seem a little bit unfair, uh, to... not only the participants, but the families and everyone affected. To have this fall right again. Christmas, New Year's, etc. So, I just... I would encourage, if you don't have an explanation, I respect that. I just... It just seems unfair.

[Joe Valenti]
Okay.

[Joe Valenti]
And in my last comment in general, is that and this goes back to other involvement I have on, I guess, whatever level you want to call it. It's just so difficult. to see these changes occurring, and I don't mean this in a bad way, Jan, when you talk about natural supports, but that's the same term I've heard before other arenas. You know, I just find it almost diabolical that.

Those natural supports are not there in most cases, if not in all cases, and secondly.

[Joe Valenti]
They... those individuals and families are older also. And I can speak to myself at being 78, it would be very difficult. I hear some of these parents talk, and I realize how fortunate we are with our son, but I mean.

[Joe Valenti]
I just... I just don't think those natural supports are there, and as you reduce funding in all these areas, and I know this is not your decision or Kyle's decision, it's a budgetary decision that's occurring, and no one wants to really talk about that openly, but that's... that's the reality of what's occurring.

[Joe Valenti]
Uh, it's gonna be really challenging on where these... again, I just give this as a general public comment, where these individuals are going to end up, and I think it's just, I think it's just unfortunate.

[Kara's]
I want to just... Yeah, I just want to touch base on that a little bit. You know, we're talking about budgets, and I know people have asked questions about nursing facilities. Now, I myself have a child... well, she's an adult now. Ventilator-dependent, uh, all cares, requires oxygen. We've, we've literally, she's been just through the hoops and loops. I've called Select Home Care. I've discussed how much, through billing, what they bill for someone like my daughter. That's $1,300 a day. If you were taking these complex children, and you're telling their parents you're taking their money away the state's gonna have a bigger budget problem, because now you're paying $1,300 a day. Do the math.

Whoever's in your finance department needs to understand the repercussions that this is going to create. You're not gonna pay us anything. We have to go out and get a job. Now you're causing a bigoter-budget crisis. And you're putting our kids in harm's way by not... by pulling them out of our house. You're literally pulling these complex kids out of our house. So don't... don't even think about the budget at this point. Because you're gonna be paying over $500,000 a year for these complex kiddos. If a 16-hour thing makes that much difference to you. You guys got serious issues coming your way. I think it's bonkers. I don't understand why you would do this to parents with complex needs. Maybe you guys need to take a hit in your pay. You don't understand what goes into taking care of kids, but I'm telling you, with what parents are hearing now, and what the chatter is in this real world here now, listening to you guys, we are going to be forced to stick these kids in these homes.

Do you have the backup plan before whatever person decided to do this? What's the backup plan? Will there be enough facilities to take all these? Well, exactly, they don't. They don't have one. I don't think you guys are ready to make this change yet, so you

shouldn't even be talking about it. What's gonna happen to the kids? I'm just letting you know, $1,300 a day, and you want to give me peanuts.

[Michelle's iPhone]
Nor do they care

[Kara's]
You want to give me peanuts, and you want me to just. Overwork myself, exhaust myself, and you keep cutting our pay. You don't understand what this is gonna do your budget crisis is gonna be a billion times worse if you don't think about the consequences of what you're doing. This is horrible. That's all I gotta say about that. So I hope you... you come up with a better way to handle these complex kids. You have a lot of complex kids, you cannot stick them underneath one 40-hour little umbrella. You guys need to figure out how to handle the complex needs kids the ones that need to be supervised and have that extra supervision.

[Michelle's iPhone]
Can I make a comment? Can I make a comment, please?

[Michelle's iPhone]
Um, my son as well has a G-tube. Oxygen, um. Non-verbal. paralyze on the left side. And, um... a lot of places won't even take them with a G-tube. So, um... Let alone my friends as children, they have traits and, uh. everything else, I mean, Were we supposed to put our babies? Do you even care? I mean, we make nothing as it is, no insurance. Nothing. We have nothing. If you want to take more away. So, you guys can... Have more is how I feel. And, um... It would be a little more understanding if they said. Okay, well, I'm sorry that we have to do this, but we have an excellent place over here that we can place your children, and they will be safe. Do you know how troubling that is for a parent that you're gonna rip our kids out of our home. And we don't even know If they're capable of taking care of them.

At least the way we would take care of them. Would love a caring. I mean, it's devastating. My son was hurt when he was 23. And he's been like this for 15 years. He has been through enough. And the state that he lives in is doing more to him. It's so unfair, you guys. That's all I have to say.

[Michelle's iPhone]
What do you do in, like, with my son. He can't even use a call light. Uh, he's non-verbal, you guys! He's... He can't do anything like that like your kids can. I worry about him. Sleepless nights! You know, I don't wish this upon you, but I wish you could understand where we're coming from. We love our kids just as much as you love yours. And could you imagine ripping your kids? Out of their home with their mom and dad Where they feel safe and secure and taken care of and do an institution. Where these people don't know him, they don't, they don't know how we take care of them, they won't feel loved, they won't be cared

for like their parents would care for them to save a couple bucks, and I really don't think you're gonna save it. I think you're gonna end up finding in 10 years. You made a very big mistake. And it's too late now. Most of our kids will probably pass, because they'll probably catch something in their facilities. I am truly frightened for my sins. Welfare. I hope you guys hear that.

[hstei]
To put this in perspective, Just a quick comment is Jen or Colin, if the state came to you and said, suddenly you're gonna have to be available outside your regular 40-hour work week, for any events at any time, any day, and Um, you're required to clock in and clock out anytime you leave your desk, or you go to a meeting, or you go to the bathroom, and despite all that, we're only going to pay you for Monday and Tuesday. How long is that sustainable for you? How long would you stay? Where is your tipping point? That's what we're trying to convey. This is a tipping point.

[Michelle's iPhone]
I mean, I'm even considering moving out of state. I mean, I don't know what to do. I'm a single parent. And I'm losing everything, everything, even my kid. This is horrible.

[Justin Tolman]
Yeah, thank you, I appreciate and share several... concerns, uh, that have already been shared. Yep, I see that there are a couple comments. There's a couple things that I want to, um, bring up and raise. I put 7 questions in the chat. There are two that I thought I'd raise here. In the interest of public comment, There's a question about the metrics in the plan for personal care plans. And, um, it looks like that... the state, or there's gonna be an audit or some quality improvement, looking at whether or not the goals of personal care plans are going to be met, and it says that the state Medicaid agency is collecting that, and my question is, how in the world is the state Medicaid agency going to identify whether or not our, um, adult children, or people we're caring for are actually meeting the goals in their personal care plans. The second question that I have is regarding a fair hearing.

The document that was shared out earlier said that we can request a notice, or a fair hearing for all those who have services reduced, And so my questions are, what is considered a notice of action for reduction in service. Does this public comment period consider... is that considered part of this notice of action? And what is the process for us to actually request a, quote, fair hearing for a reduction in service. My last comment is, uh, for all of the personal comments that have been shared so far. Um, the individuals here are I would recommend that you contact your state senators. Uh, and share your stories and concerns with them, because we're being... we're receiving the decisions of the state senators, ultimately, of what's going on. And they're the ones who can make a change to this. I'd also encourage you to contact local news agencies and share your concerns, with what's going on with you and your family. And I think if individuals are willing to share what's going on.

You will see more action than complaining... not complaining, that's because I have the same concerns, than expressing the concerns here in this meeting. And so I would encourage you to contact your state senators and local news agencies, thank you.

[Justin Tolman]
Sure, thank you for those clarifications. I want to make sure I understand what you just said. So with our service coordinator, we would document what the needs and goals of care are based on a 40-hour limit, there's no way those goals can be met. They just can't. And so what I... what I thought I heard you say is that we document what the needs and goals are with the service coordinator, in our regular contact with them, we then document why 40 hours is incapable of meeting those goals and needs, and then that will then be passed on for your quality improvement.

[Brandy]
Yeah, so my question was... Um, so how did you guys come to the conclusion of taking away hours from individuals that need them versus cutting the rates of overpaid agencies.

[Brandy]
Do you think that that should be looked at before deciding to cut hours of some of the people that need it the most. Or when, when do you... when will you look at that?

[Brandy]
I guess I just don't understand why. we would take hours from people who need them, need that care and instead continued to pay overpaid agencies. I feel like if you were to take money, put everybody on the same pay rate, then you could offer... you would save money that way and be able to offer hours to those who need it.

[Michele Zephier]
Yes, I do. I have a couple, um... questions. Actually, I have 3 things. One is if all those that have spoken out today, if you could please reach out, maybe give your name to. Diane Delair, or the Arc of Nebraska, so that we can ask and coordinate for when the legislature does call to hear us, that we can show up to be heard. Um, second is... Nebraskans provide about $2.8 billion of non... paid or unpaid, caregiving a year. Um, how do these changes with LRI affect that number? And third is, how do we ensure that parents and guardians are present? During the, um, Inter-Eye evaluations, when they are done, so that we can ensure accuracy, it seems. As some inaccuracies are leading to, um, reduction in care.

[Michele Zephier]
It's... do you know, or can you provide us with the rules and regulations on who those necessary individuals are? Those are to be in the room during the evaluation. Evaluations

[Michele Zephier]
Yes, for the NRI assessments that have been leading to the reduction in changes.As of late.

[Michele Zephier]
Our agency, um, paid staff. Um, do they... can they answer the questions? Is that an...

[Michele Zephier]
Okay, but as far as you know, there's no actual regulation? It could be a paid staff person that answers the questions. Without involving... the parent or legal guardian?

[Michele Zephier]
Yes, and I do understand that. For instance, some... Um, parents and Guardians are expressing that their individuals. Um, the assessments have been done at a day, um... at a day program or something like that, where there has... where they haven't been present.

[Michele Zephier]
Okay, I apologize, but there is... is there... Is there a way to ensure with the AD waiver, that these. you know, that... do we tell our court... our service coordinator that we absolutely want to be involved. Every time for this...

[iPhone (117)]
Um, okay, so, um. I... I am just like all the other parents who have been talking, and I have really struggled to give my son the best life he absolutely could have, and Uh, the whole AD... AD waiver is based on the fact that these adults need. 24-hour... 24-hour care. They are... nursing home level care. I do believe that. the state... limiting and putting the restriction of 40 hours because we are choosing to have our children live at home with us and take care of them at home to provide them more quality, better quality care. Is actually taking advantage of us very. I mean, very rudely, I mean. you're looking at... they're gonna end up paying, what, under $30,000 a year? To take care of a person that. like she said earlier, would be $500,000 in the facility and in that facility, they're going to be left alone, unattended, not doing anything. How many hours are us parents sitting at home getting not paid for. are 8 hours of sleep time when, let's be real, are we really sleeping at night 8 hours? No. We're awake, we're covering those hours that are not really covered anyway. So, we are all going above and beyond to give these kids the quality of life, which are not getting any really income anyway, so Those hours that we're getting paid a minimal amount anyway, it's not just compensating for the lack of us not being able to work outside the home, but it's also compensating for the fact that it's trying to give Bema income. So, to be able to have them alive. I mean, we have to be able to provide a vehicle for them for transportation. Let alone... let's go talk about the whole dental process.

You can't get these kids the dental work that they need done You can't get them in. If they have to be completely sedated okay, they'll... they'll do the regular sedation in the dental office. But if they have to be completely sedated in a hospital, oh, they'll only do that once a year because they don't have the availability. And nobody's accepting new patients and so if you have A cavity that needs fixed, oh, you're going to have to wait until the next year, or you have to wait for it to be an emergency to where you then go and just have your tooth pulled. And then, when you do that. Oh, that doesn't get covered under Medicaid. That has

to be paid out of pocket. So who's covering that? It isn't that... that kid, because they don't have the money and I say kid. He's an adult, but that's the parent. So now, that parent that would be paying for that. out of the money that they would be making in those amount of hours. That they're taking their entire lives and dedicating it to taking the. The care of that person. is now not even going to have those hours of pay, because you're taking that away all to save the buck. you're taking a huge advantage of these families, and you're. you're destroying them.

Totally destroying them. And you are making it to where You were expecting us to live off of less than what people are making at McDonald's. That's not even cool. How can... how can you guys possibly even think it's okay to live with yourselves writing that in that in that paperwork. That's not okay. And I refuse, and I will not put my kid in a home. It will not happen it's not an option. Why? Because. He will be dead, or he will be in jail because he will hurt someone because they are not equipped to handle him. You can't. So why don't you go And do a flat rate. If there are 24-7 care, okay, 24 hour, 24-7 care. You do a nursing home, right? So you give... if you're a nursing home. quality level of care, you do a flat standard rate. This parent gets this much money. If you are an assisted living quality of care person at home You give this much pay and make it be a good amount. you don't... don't make it be to where you're... you're gonna make that family struggle to survive, because every single thing that they're having to cover is... is above and beyond and they're not getting things covered and paid for.

Our... our equipment that breaks down, you don't get it covered right away, you don't get it repaired. I had to buy a second wheelchair because our wheelchair broke while we were out of town and it didn't get fixed for 4 months, because it has to go through the process 4 months to get the wheelchair fixed. So, what did we have to do in the meantime? We had to have a backup. Who pays for that? Something has to change. That... this plan...

[Michelle's iPhone]
They don't even care, they're

[iPhone (117)]
And I'm sorry, but I know you... I know you guys have said you've taken care, and you guys have... some of you have said in the past, you've been a care provider before, not the same. Not the same at all. Because until you have lived the situation, it is not the same. going day in and day out, and when you go and you have a surgery, and you wake up and you say, I don't want pain medicine because I have to go home and go right back to taking care of your child and that you'll deal with the pain because there's nobody else that can handle him. When you had a job, because they were in school and the school couldn't take care of them and the school tried to get rid of them.

[iPhone (117)]
When you had care providers, and you tried, and nobody could take care of him, so then you were having the care providers here and they weren't doing the work so you were doing

the work. How does that... how is that even fair? I had somebody come into my house, I was still doing the work. So I still wasn't actually getting to work.

[mmh]
Jen Clark, are you even listening? Because I'm watching your eyes, and I can see you're multitasking, typing, I saw you roll your eyes. Are you listening? Because you're not even replying to these questions.

[mmh]
Why can't we see these comments, questions, and messages? Why are they hidden?

[iPhone (117)]
I couldn't even send anything in. Well, it says chat is disabled, it wouldn't let me...

[mmh]
I can't either.

[Brandy]
But why can't we all see the comments and the questions? These are comments and questions that could save a lot of people time. We could all see them. We could all know the answers, and it could help a lot of us. It just seems like there's so much hush-hush, and it's so secretive on the other end.

[Michelle's iPhone]
No, no, Ray. Take care.

[mmh]
I need... I need to throw something out here.

[iPhone (117)]
So, can I ask? Can I ask you...

[bw]
There's several questions that I've asked. There's several questions.

[mmh]
I typed in multiple questions yesterday, and you guys chose to only read.

[Michelle's iPhone]
Hmm.

[mmh]
part of my questions. That is not being... Open. That is hush-hush. That is being gray. Why are you guys doing this?

[bw]
Please... Alright, well... Right, these need to be longer.

[Michelle’s iPhone]
It almost seems... I'm sorry, I didn't mean to interrupt.

[Michelle’s iPhone]
It almost seems like, um, you guys have already made up your mind. You're just telling us the way it's gonna be, and we have to deal with it. It doesn't really seem like an comment, because the comments that you reply with are like, well, this is what we're gonna do. Well, I mean, that's not fair, you guys.

[bw]
Yes, I'd like to know, um... On these... on these comments, I'm curious, why don't you put them out and answer them in a timely manner to where.

[Dianne DeLair]
Hi. Oh, go ahead, Brett.

[bw]
possibly the next meeting that you have, these same questions may not be asked, and we won't be spending a lot of wasteful time on the same questions. Also, I'd like to know what additional cuts you're, like, you're wanting to make. Of proponents. That we currently don't know about.

[bw]
Well, I mean, if you're answering them, they should be able to be on... a website, or this website, even, to where we can all see the answers that you're putting out to where maybe we can ask additional questions about it, or That may have been an answer that we... totally agree with, and move on to the next question.

[bw]
So you're saying every question that's asked will be answered. Every question.

[bw]
Yes or no? Yes or no? All questions will be answered. Yes or no?

[bw]
That's all I need to know.

[Dianne DeLair]

Yeah, I... uh, this is Diane Delaire with Disability Rights Nebraska, and I might have missed this earlier, but I'd like to, um, try to understand why, um, you're making this change now with respect to the 175% ceiling or cap. And then how you came to, uh, that determination, how did you come to the figure of 175% of nursing home level of care, and just, um, just a comment, um, you know, Olmsted and the Americans with Disabilities Act is about community-based services, it's about keeping people, families in the community and, you know, in the application language, it says, Uh, you know, you might be going to a nursing home or another institution, and so I'm just really disappointed that this had not been brought up, um, at the Olmsted committee. I think it's disingenuous for you to say that it has no bearing on the work, the hard work of that committee. Um, so I just wanted to make that statement.

[Brandy] 10:00:53
Okay, I just wanted to chime in quick. I feel like this was really rushed into public comment, because we didn't really have a lot of this information before this, some of this stuff is new that I'm hearing. So it just feels like... you guys may not have had time to look at the bigger picture when you're looking at budgeting and cuts and there are other places you could have cut to ensure that you know, people out there still got care. Um, I just don't think that this was well thought through, or maybe you didn't have a board or a committee to talk to to bounce ideas off of, because when you're cutting the people... the people who have the most hours are the ones that need that care the most. They're not the people that are cheating the system or stealing from the state. Those are the people that need it the most. So we're taking that care from them, rather than looking other places We're not looking at, you know, people who only have a few hours here or there. Do they really need it? Assessing them. We're not looking at other agencies that are making $38 an hour. I mean, there's, there's so many more places that you could save money for your budget And, you know, redo this, this... waiver the system, other than taking hours from the ones who really critically need it and then it was rushed into public comment, so we can just push this on through.

[Brandy]
If that's true, and I don't mean to be rude, you came here to public comment with so many things that you don't, you cannot answer. You didn't look at the budget in order to cut cuts from other places and save money on different agencies, and you also don't have a number like, a budget of care per year. with a... if you were to send someone to, you know, um, to a home. You don't even have that number. So, I feel that you guys came so unprepared to these meetings and this isn't the first one. This is the second public hearing, and you guys were not prepared.

[Brandy]
No, ma'am, you don't have the answers, because I don't think you guys had enough time to really decide on this and to look at the budget and go through everything and come to us

with an entire you know, with all the answers that we could possibly need you guys came here just shooting us and... hiding the comments and hiding the chat.
Thank you.

Questions from Chat on 12/11/2025

From Brette
What is the cost that the state is using as the figure for the insitutional cost?

From Brenda Hoffman
is personal care the same or different the chore

From Heather R
For a disabled adult Can a Legal Guardian be the provider for Personal Care, LRI Personal Care and Companion care?

From Jodi
Please explain how $31,200 a year for a parent caregiver of an adult child with disabilities matches the institutional cost for care. $31,200 is 40 hours a week at $15/hr that your are limiting us to as independent providers. In the last quarterly meeting, Tony Green mentioned the average institutional cost is $85,000 per year. And with the waiver stating the cap is 175% of that institutional cost, how is $31,200 (40 hours a week) a reasonable or comparable amount!? Parents should be allowed at LEAST the $85,000 average institutional cost amount to care for their child at home and not be restricted to 40 hours a week. Please explain how this issue will be fixed so parents receive the same amount that institutional care costs.

From Kara's
So you said something I didn't hear you say yesterday. The 40 hours personal care there can be exceptions for more hours if need be with a complex individual?

From Katie Kuecker
What is the current cap for companion serivces? Can companion care be cut and/or combined with personal care to be able to provide families with more hours?

In a similar manner, should chore be combined in personal care hours for live in providers because we are doing all of those things for our adults at home anyways?

From Jodi
Please explain the process and steps we need to take for getting exceptions to the 40 or 70 hours a week for Personal Care. Our adult daughter requires 24 hour care and we will need that exception made for her.

From Heather R
Are providers still able to work over the capped limits to July 1st 2026? Will they still get overtime payments through time worked through July 1st? Also since overtime payments are not up to date will the providers still receive all overtime due to them so far for the time they already worked?

From Brette
For children are legal guardians not able to provide LRI services? It lists parents and adoptive parents but not legal guardians

From Kierstin Reed, LeadingAge Nebraska
what is the total dollar amount that is considered Institutional LOC that the 175% limit will be applied to.

From Teresa
Will we see others chat questions?

From Dianne DeLair
How many adults are currently on the A&D Waiver that are at the 150% utilization level? How many children are at the 150% utilization level?

From Chelsea Jensen
With the division of personal care and companion, will providers need to anticipate scheduling multiple EVV visits during the same shift with the two different codes?

From Kierstin Reed, LeadingAge Nebraska t
There are many nursing facility rates based on complexity-- is it the average nursing home rate? This needs to be made public ASAP

From Dianne DeLair
Why was the A&D Waiver application not an agenda item at the Governor's Advisory Committee on Developmental Disabilities or the Olmstead Advisory Committee meetings?

From Brette
What if a minor child only has legal guardians?

From bw
Its very appeaent

From Kierstin Reed, LeadingAge Nebraska
Is there a consideration for putting measures in place to streamline the rates for these services so they are not different for each provider, but instead based on the complexity of need of the individuals supported. It seems this would be a better cost saving measure than what is in this plan.

From Jennifer Meints-Hands of Heartland
Now that AD waiver participants will have an annual budget, how is that determined and will it be shared with the families?

From Michele Zephier
Are service hours increased when school is not in session? How do we get the additional hours added to reflect that?

From Kierstin Reed, LeadingAge Nebraska
These services should be in tiers similar to DD services and based on the needs of the individual.

From Dianne DeLair
How did the Division determine 175% would be the ceiling for the A&D Waiver?

From Jodi
40 hours a week at $15/hr is not equivalent to a full-time job. That's only $31,200 a year.

From Dianne DeLair
When did the Division start to discuss making an application to CMS for changes to the A&D Waiver?

From Haley
Is there any way to get the questions put into the chat in case we miss it when it's read out while it's being answered? Some questions that are multi-part are hard to follow. Thank you!

From Kierstin Reed, LeadingAge Nebraska
How many people exceed the 175% in the state currently?

From Teresa
My family too.

From Brenda Hoffman
we understand cant raise our rates without funding but the reduction of hours is drastic drop. Most of us quit jobs and some of us good paying jobs. we gave up jobs, and 401 k, we give up our lifes to care for our children. If we had extended family help we wouldn't have needed to quit our jobs. Our other children have jobs and children and unable to help or UNWILLING t o help. when our children are older which my son is we no longer have parents to help. WHO is going to give us the UNPAID help

From iPhone

What was the previous cap on these hours that are now being decreased to 70 per individual?

From Brenda Hoffman
We are also unable to keep a job that will pay us to work so little hours that we would be available to work if someone would help.

From iPhone
What is the process for "Exceptions to both limits may be approved by DDD Central Office to meet the immediate health and safety needs of a participant."?

From SH
Just to confirm - Does the proposal state the max amount of hours a client would be capped at is 40 hrs or 70 hrs? IF only receiving personal care

From bw
Its very apperent that you can not find or hire qualified medical profesional to perfom the necessary assessments to determine the needs of the disabled people that should quaiify for in this program. Also would like to know what your wages are ??? Look like we need to also make some cuts at the top ADMINISTRATIVE level. Not just us providers

From Teresa
How do I raise my hand?

From Kierstin Reed, LeadingAge Nebraska
What happens when someone is exceeding this level of care, but they are unable to find placement in a nursing home or other care facility?

From Justin Tolman
I am happy to unmute to pose these questions (1 of 3 messages).
Questions regarding Appendix D: Service Plan Development (p. 132-138)
1. What limitations are placed on the Service Coordinator (SC) when developing a Personal Care Plan (PCP)?
2. What type of oversight and approval does the Medicaid agency place over PCPs?
3. Given that PCPs must address "needs, goals, and preferences" of the participant and also address "how those needs, goals, and preferences will be addressed"... What is the process to address the discrepencies between the PCP and limtations on care these revisions are mandating?

From Justin Tolman
I am happy to unmute to pose these questions (2 of 3 messages).
Questions regarding Appendix D: Quality Improvement: Service Plan (p. 141-158)
4. How is the State Medicaid Agency going to collect the specified metrics for PCPs:

- Number and percent of participants reviewed for whom all assessed needs have been addressed
- Number and percent of participants reviewed for whom all assessed personal goals have been addressed

From Justin Tolman
I am happy to unmute to pose these questions (3 of 3 messages).
Questions regarding Appendix F-1: Opportunity to Request a Fair Hearing
We have a right to request a "fair hearing" for those whose services are reduced.
5. What is considered a "notice of action"?
6. When does the state provide a "notice of action"?
7. Is this public notice for comment considered a "notice of action"?

From Brenda Hoffman
I think we feel that to get a nursing home for Medicaid only clients our children will be placed in far away locations to have any availability. and then as family we are not able to check in as often as we should because to be honest CARE is very sad at these locations. I wouldn't want my dog to go.

From Brenda Hoffman
I think we also feel that with the ok to have LRI for minor children that the funding for adults is a cost of that. Not that minor children are to be dismissed but us older parents have been giving care for over yrs

From Chelsea Jensen
Have you submitted the proposed changes to the Olmstead Advisory Committee for their input? I am concerned about telling people their option is institutionalization if service needs exceed the cap.

From kgould
Will SC's receive a list of nursing homes/ALF to be able to provide that to our consumer's?

From Cheri Albin
Isn't the nursing home option which we are being forced into are higher rate of pay and going to cost the State more dollars? And originally these waivers were created to get our individuals our of these facilities and into the community?

From SH
Previous questions is in reference to adult clients only. So they would not be receiving LRI.

From Brenda Hoffman
why not just stop the over percent . so instead everyone suffers

From Kayla Jones

Do you know if this is also available in other languages?

From Heather R
I feel that the state of Nebraska is taking advantage of Families of disabled children and adults. You are stating that families need to step up and take care of their disabled, but you are capping their pay at 40 to 70 hours depending on their level of care. This equals someone that needs 24hour a day care you are only compensating them less than 2 days a week, 8 days a month and that equals less than one month a year of pay and you are stating families need to step up and care all of the other 11 months out of the year? How can you justify this? This seems to take advantage of family, causing them to lose everything they have. There is already a shortage of providers and you are taking away their compensation and taking away hours from the disabled that needs that care.. This #1 is taking advantage of the disabled seems like you are trying to save a buck at the expense of those that are unable to take care of themselves.

From Brenda Hoffman
required to make changes within 5 years. the AD terms end terms 8/1/2026 i understand the need for review but again this is such a drastic cut that DEFINATELY will cause harm to all providers Natural supports as not there. and feel that our adult children are going to feel this. our son requires complex care and a nursing home years ago for my mother (whom i couldn't care for because of my son was 8000 a month)

From Angie
You won't find NF to take people under the age of 50

From Kierstin Reed, LeadingAge Nebraska
The cap on hours alone will likely cause people under the 175% cap to need to enter intuitional care because their family is unable to continue to care for them at home. If others with significantly high needs need to enter intuitional care, the nursing home rate will likely be MUCH larger than the way their services are set up now.

From Brenda Hoffman
no back up care for these adults, i know we sound angry but we are tired, Tired of the fight we have to fight for our children. unless you have walked our walk not just know someone you do not know. we seldom sleep and some of never get to go to dinner alone let alone vacation. so please forgive us when we are frustrated.

From Kierstin Reed, LeadingAge Nebraska
The people they are discussing on here would not qualify for assisted living, which is the bottom two rates for nursing home care, so those rates should be excluded from the calculation when determining the intuitional rate.

From Kayla Jones

Also, as far as I understand, that 40 hr cap for Personal care, that will likely not be given, is only for LRI correct? I think that people are thinking that all personal care hrs will be cut to 40 hrs. Might be worth reiterating? Also, I hope that that didn't sound rude, I absolutely do not mean it that way!

From Brenda Hoffman
Michelle's voice is ringing in our ears. yes in 10 yrs the cost is going to be high because nursing homes will not be cheaper but our children will die in them.

From Brenda Hoffman
a average nursing home stay is years.

From Kayla Jones
Also, I could be misunderstanding as well..

From Brenda Hoffman
average nursing home is 5 yr stay

From Teresa
With this administrations recent rules changes for nursing homes, making care even less efficient, if we could even find a facility that would take Medicaid, most have long waiting lists already.

From Brette
Why the change to guardians needing be family related going forward? What if we have lived with the person we are guardian of and acted as parent for years but are not family related?

From iPhone
Why was LRI for minors just introduced this summer just to then cut personal care hours for adults?

From Steve
I would appreciate some clarity - is the reduction of hours a budget decision or a policy decision?

From Sarah Murcek
Do you have a link for those InterRAI updates?

From Teresa
Why will the pay not qualify for overtime? Isn't that a federal rule?

From thomaskellogg
This issue should definitely have a face to face public meeting with State Legislature and Governor

From Brette
We were told when taking guardianship of these kids from foster care that we would be able to care for them through the AD waiver as guardians and this change makes that not possible

From Ron Riggle
Is seems like much of the public comment is focused on budgetary issues, will the transcript or recording of the public comment meetings be shared with the NE Legislature?

From Brenda Hoffman
WHO actually makes the decision to lower the hours ?eon

From Heather Kozak
Come care for our kids..for an hour, for a day, for a week. Our kids require 24/7 care...and this is more care than your typical child. They will always require 24/7 care. My child will never be a burden to me, but to others she certainly is seen as such. Our families can't afford to live without getting paid. We can't ask ppl to care for our children for free. That doesn't work. That's not realistic. A nursing home is going to cost way more...you are paying multiple staff 24/7 and not just one, plus the cost of the facility. A nursing home is going to cost the state $540,000 a year

12-16-2025

[Lori]
Yes, I have a quick question for Jen, but it looks like you're on mute, it looks like, from my end. Um, the question is for the high utilization review. Can you kind of explain that to me? I know that the timeline seems pretty crunched here If this was to go through, where are you looking at letting parents know, perhaps they can benefit from the high utilization review. What does that look like? How long is that going to take? I know there's been problems with that intra-RAI. Um, and I know that, you know, obviously the state's got a lot of lawsuits going on with that. How are we gonna know that we're... where we need to be, just what does that look like on your end? When would that process start?--Okay, thank you.

[Teresa]
Okay, hi. Hi, this is Teresa. I have 2 questions. Um... I guess just one, you just answered one of them. Pardon me, I digress. Um, my question is, is that, so... You're cutting... you're cutting all these for... for especially high needs, uh, participants. Um, like my son, whose trach, ventilator, quadriplegic, nonverbal, G button, cerebral palsy, back to pump. Vagal nerve stimulator, et cetera, et cetera, needs help with all and every care. So, why is it then that. If my son were to be placed in an extended family home, those people would make $693 per day. According to a high-risk person like my child. Yeah, you're cutting us. I mean, this makes no sense to me. It makes no sense. Can you explain that one to me, please? So, extended family homes are on our DD waiver, so it's not really something that I can answer because it's not apples to apples. Well, that answers nothing, but thank you.

[Jordan]
Yes, thank you. Oh, let me mute, hold on here. So, I am curious, it's been brought up a couple of times that you're capping. Um, relatives now at... Relative caregivers at 40 hours a week. However, you'll bring in a stranger from an agency. For up to 70 hours a week, which is going to cost you more. Can you explain that to me? And can you also explain why relative caregivers are now being penalized or basically used for free to take care of. These... you know, most of them are basically adult children. Um, where we've been getting 112 hours, and now you're saying, oh, well. You're only worth paying 40 hours, and you're just gonna work for free the rest of it. I have a 24-7 CARES need child. Can you explain that to me? And everybody else, we're all very... interested in this. Oh, and one other question before I forget. You're making all of these cuts because you said DHHS didn't get any more funding. However, in some of my research that we've been doing, I did find that some individuals on this call actually got, um... A 7% pay increase last year. So, where are those funds coming from? Thank you. Just throwing it out there because, you know, this is all about a budget. All this money's in a bucket. Just trying to figure out... you know, how some people are getting these increases, while the parents who are literally working. 24-7, 365 days a year with no breaks, no vacations, no sick leave, no health insurance are being penalized. Thank you.

[Jeanine Amaro]
Okay, thank you. Um, I guess my question is, I understand we have to be fiscally responsible, right? And make sure these programs last for years and years and years. Um, my concern, though, is that not everyone has extra. Family support, um. Anyone that would work with us with our kids, um, I, and I don't even have a child that's receiving this care yet, because he's too young and they don't consider it, like, extraordinary care yet. Um, but... I wouldn't have this village that is gonna come and help me, but to make something like, you know, 40 hours. Even if you're making $20 an hour, that's like $40,000 a year. I mean, we can't live on that. So, when it's... so then I would have, right, like, so then I would have to work, and then we'd have to bring someone else in. But then it's still... I'm constantly on my toes and never get a break, like, you know, they're saying, so. What if we don't have that support? What happens? Well, if... yes, I... Yes, and I do, and I was able to find someone to help with some of that care. The problem is, too, like, as he ages, we're gonna lose some of the respite care, but also the, um. What is that? Like, the agency couldn't help me find anybody. I have to go out and find it myself. Like, none of the agencies that I've contacted have resources. They put ads out. No one wants to work with a level 3 autistic child, like, who, you know, is severely disabled, so I'm... I'm at a loss when it comes to that. Because agencies haven't been able to help me.

[Catherine Jensen]
Can you hear me? Okay, um... I guess just in regards to following up those questions. Um... It's trying... in trying to find people to care for your child. Um, you can make more at Target, and that's a little frustrating, um. You know, who is going to want to... come and care for your medically fragile child, and. Um, and even as a parent. Um... caring... getting... having it cut to 40 hours a week is just. It's laughable, I just... Nothing has changed in our life, no needs have changed. If anything, they've gotten more so. And to think that. It’s going to be cut. And then in other, you know, we're already just scraping by, but then looking ahead at the age I am. This factors into our Social Security. you know, the amount of money I make. Um, if that drastically decreases, then that. greatly affects what I'll be paid for Social Security. And... I'm 62 years old. That's huge! And... We don't have family that they don't want to take care of our child. I'm sorry, that's just... how it is, and... It's terrifying. And... I don't... I don't understand why parents have been penalized. over and over again. I mean, just being able to attend this meeting is a hardship. And the EVV situation is a huge hardship. I have. Anyway, I'm rambling, I'm sorry, but... we cannot be limited to 40 hours, I just... I don't understand that.

[stevemorris]
I'm sure that I probably echo many of the other comments already made, particularly Teresa who commented about her, her child who has CP, and um... requires 24-7 care, and I think is ventilator-dependent, too. I think she mentioned. Um... I guess, you know, when you're looking at the average, the average cost of a nursing home uh, it seems to me that that's not the correct number you should be looking at when it comes to people like... like Teresa's child, and our son, uh, who are ventilator-dependent, because the only place we can send our kids. Are to places like Madonna and a couple others. And last time I checked it at Madonna, the cost there... And their ventilator-dependent unit was, like, $30,000 a month. So that's $240,000 a year. Uh, I think, is that right? There are $360,000 a year. And that was 10 years ago. So, that's the cost that we're compared to... being compared to. In other words, institutional care for our son and Teresa's child would... if they had to go that route, would be at least $360,000 a year. So, the numbers we're talking about here... are totally unrealistic, and... And, um, the 110 hours that you're talking about, I don't know where that came from either, But there's 168 hours in a week, and that's what they would be getting if they were in an institutional setting. Which, as I understand it, is the primary goal of the waiver program, which is to allow people to be in a non-institutional setting. So... those are... those are our main points, and I guess question there. Um... I don't know if this is strictly a budgetary thing, that you just have to make arbitrary cuts and let the chips fall where they may. But, um... it seems to me like, uh, people need to... work a little harder on figuring out the...correct parameters for this, because some of these things just seem highly unrealistic. --Well, you know, actually, actually, Jenna, that sounds like you're making the argument for the other...For the other approach that I just mentioned, because if you can get one-on-one care at home...Which is vastly better for the child. Than group care at an institutional setting and that setting costs dramatically more than what you're getting in the home setting, that seems like a win-win all the way around. So, I'm suggesting the group care is I guess you were suggesting it's less expensive, or something like that, where in fact, we know the numbers are not that way. 10 years ago, like I said, there were, I think, 30,000 a month. I don't know what they are now.

[Kim Naverson]
Yes, I have a couple questions. The first question is, uh, so the 40 hours is for relatives. Is that any relative up to 4th degree? Or just live-in relatives. Okay, so then, uh, like, a relative caring for someone, they could get. They could get 40, and then... you would have to give, if someone required more. Um, then someone else would get 30 through an agency. So, it'd be 70 total. So, my question is, why would we pay someone... if we're paying the money. For someone, why does it matter if we're paying the relative? Or someone else. the money is the money, it's go... you're paying it regardless. So why does it matter who you're paying it to? Yes, that's true. They are, but to a degree. And not everybody has that additional support. That we just assume that they do. And so, even when you... when you mention respite care. When you're still paying someone else to come in, and you're... you're still paying that money for someone else to come in. So, if we notice that this person, this particular client that is high needs and needs a lot of care. What does it matter when you send somebody in to assess them, and they assess them, and they say, this person needs 90 hours. This person needs 100 hours. Why does it matter who we're paying it to? It really doesn't matter at the end of the day, and 112 hours or 90 hours. It's not 24-7 care. Because that's... you still have 160 hours in a week. So, that ratio and what you're thinking there, you're just assuming that people, And listen, if it's your kid, I assume you're probably going to take care of them no matter what, and that's what you're banking on, is there... someone's gonna step in and take care of them no matter what, out of the love of their hearts. And I get that, because I would do that. I would figure it out. But then you're also taking money away from people that the state doesn't cover all of their medical needs, and they have, they have certain houses with an extra room and an extra this. And an extra wheelchair, and an accessible, and they've made improvements on their houses so that they can be accessible for this child. So now, all those things cost them more money. They're... that's just more money out of their pocket. So, you can't just say, well, we're gonna give you 40 hours. And then, if you need to get an additional job, that's fine. You can go get an additional job. We'll give ours to someone else. To cover that, so you can go work. That's just... that's just asinine to think. Um, and then my last question is, if our goal is to be under... at or under the nursing home rate. Then why are we knocking providers down to 40 instead of capping them at that nursing home rate? So... and that's on a case-by-case basis, because some people are going to cost more in a nursing home than another. So why are we not looking at that individual's needs? Putting a cap on their care and saying, this is what we're willing to pay, because essentially, that's what you're going to pay. You're gonna pay it at home, or you're gonna pay it in a nursing home, but you're gonna have to pay it. So, why don't we cap them and say, this is what we're willing to pay for this person's care at this time for these particular needs? In this moment, maybe not in a year, whenever when those needs change, but in this moment, and then pay that caregiver, whether it's a relative or somebody else. That's that cap. That makes a lot more sense than cutting everybody down and making it uniform. Because if you were considering making it uniform, you would need to look at the agencies that are making far more than the independent providers, and some agencies making more than other agencies. If you were to cap that and cap all the agencies

at a certain amount, and all caregivers go through an agency. Then their care would be different, and you could pretty much say, yeah, everyone's cares that needs this much care is going to get this much money. That's what they're going to cost regardless where they go through.

[Edna's S23]
Am I unmuted yet? Okay. I had listened to all other comments, and I agree with what they were saying about how that, especially the last lady, um, speaking about the cap, you know, everybody's care is different. And I just disagree with how that... you guys didn't come to that standpoint where to cap it at 40 hours when there's different levels of care for each individual. Everybody is not the same, and I just disagree with how y'all come up with that to put 40 hours on each person, especially home care, like my grandson. My grandson is non-verbal. Um, he has issues like no other. I can't hardly take him to the grocery store without him having a tantrum. Without him falling out or fighting or want to get a hold of things, it's hard to deal with that type of, uh, with my grandson that way, you know. Um, he may not be on a ventilator, but I look at the fact that. All of us have kids and loved ones. I got a daughter that have pain 24-7, could barely walk. And yet, y'all capping it at 40. You know, I disagree very strongly, because. It's not even out the care, it's not even. You're trying to make it all in one. It's not that way. Please take a good look at it, because if it were your kid, like the young lady said, you'll do whatever you... can to take care of your child, to take care of your loved one. You do whatever you can, but at the same time, y'all need to look at the fact, too, that the caregivers, they're stressed out, too, behind a lot of this. And then you're bringing in all... you want to bring in sometimes strangers and everything. Um... Sometimes people is uncomfortable with other people coming in, you know? They would like to have that, you know, where they do their care themselves, and then putting them in the nursing home. They're not gonna get the same care if they got it at home, either. Because I worked in the nursing home. I worked there, and I saw many things that happened to different ones when it shouldn't have never happened, but it did. So, everybody ain't gonna be treated together to put them in a nursing home, to put them in some other area. These people love their kids, just like I love mine. I disagree very strongly how y'all managing this, and you're looking at a money level. Please learn to look at it at love level. Feelings and emotions is in this thing. Stress. People are already stressed out. I mean, it's enough stress just taking care of your loved one. It's enough stress. But to bring in this also? If that was your mom, your sister, your brother. Please, it ain't about money. It's about taking care of your loved ones.

[Jennifer Melvin]
There we go, okay, sorry. Um, I have to hide in a room because of my daughter. Um, I just... I echo all the other families. Um, with the issues. And I'm going to put my caseworker hat on. Because I gave up a job. to stay home with my daughter, and I started out at $9 an hour, because I was a parent. So, I did not get the minimum wage. Until it got bumped up. And when I say this isn't about money, it isn't about money. If you drop us. We will have to give up our house. That we have made out of our own pocket accommodations with the money that we make. My daughter has daily seizures, 15 to 30 a day. Um, she has all types of seizures. She's had brain surgery, very rare genetic disorder. And I know you had talked about the day programs, and we tried to get her into a day program. When she aged out of high school. They wouldn't take her because of her seizures. And I know she's not on a trach. And... and I... we've spent the first 2 years of her life at the hospital. My daughter does require 24-7 care. I have to watch her every minute and pray after every seizure that she wakes up and breathes. And to call us parents who are doing this. Who have taken the CNA courses are basically a nurse in our own right. Um... basically, we're just... inappropriate caregivers is kind of how it comes across. Because, um... My daughter has two bedrooms, her own bathroom, a living room. A huge yard with a swing. She's got her own little ATV that we take rides in. We go to McDonald's for her Happy Meals twice, two, three times a week. No nursing home, one, won't take her. We called. Just for respite when she qualified, we don't get respite. I have older parents with cancer and back issues. Um, a brother with heart issues. And a sister who is raising her own children. We have nobody. So, to say that we can access supports, we're in rural Nebraska. Our town's 600 people. There are no groups here for support. There is no family for support. And we... I do utilize an in-home person twice a week. But I've had to set up a video camera, because my daughter has had bruises. She's non-verbal and can't tell me if somebody's hurt her. Um, over my dead body, will she ever be put in an institution? Because as a caseworker. I had a young lady who had been thrown down a flight of stairs. At 22, because she was impregnated, by a faculty worker. So, when I say us parents do this out of the love of our hearts, and 90% of our income goes back towards our children. That's what we do. The state does not supply the lotion she needs for the blood clots that she gets in her legs. I give her injections every day. She has a list of medications. My daughter has, like, 6 different specialists that I have to travel to. I do not get paid for that. She has to have a special vehicle to haul her wheelchair and everything else. State don't pay me for my vehicle or my mileage, or any of that. I don't charge that, even if I could. Because she's my daughter, she's my responsibility. But when I say no nursing home will take her. They won't. And I want you to sit down and think about if you were having 15 to 30 seizures a day. Would you want to be strapped down to a bed, waiting for someone to come check on you? She is incontinent. Right now, she's on her period, so we have that lovely fun thing. Autism, shreds diapers, smears poo. You know, nobody's gonna do that. And us parents do that, and you've already. hit our hours once, which was fine. We made that adjustment. And we cut back on certain things. She has an iPad. State didn't pay for that. She's connected to the internet, state doesn't pay for that. All of her special roly-poly-oli and Sesame Street and all of that clothes and stuff.

Another gal prints out stuff for her son. State don't pay for that. We use the money that we get for taking care of our children. To take care of our children. Because an institution will not take them. And I will not let her be strapped to a bed and doped up or taken advantage of. I was in the Health and Human Service field and family advocate. For decades, and I've seen it. And what you guys are proposing is inhumane to these children. These adult children are special, and their families have taken the time to give them the best quality life. And now we're looking at having to move. Because we can't afford the place that we modified for her. With her wheelchair setup and her playroom. And her back. Sorry, I don't want to ramble, because there's other families. But, like the other gal said, it's a matter of heart. And... if I put her in a nursing home, you'd be paying. Probably 5 times more than what I get right now. And Merry Christmas! This comes at a perfect time. Our family just lost a loved one. Tragically, and like Steve said, the situation is stressful enough, and the lady before me. And you guys are talking about ripping. Our children's... lifestyle from them. So, as you're sitting around your tables unwrapping your gifts this year, think about the children whose parents sacrifice and give up their lives. We don't do cruises. We don't do vacations. I have a... had... we don't do any of that. My life is 24-7, my daughter. And the money I make goes to her. I don't... I don't do my hair, I don't have nails, I don't have purses. It goes to her. And I can tell you, every other family on here. The money goes to our children, and giving them the best lifestyle, because they know nothing but pain. And struggle every day. But they wake up and they smile. And it makes our lives. Worth it. Thank you. Sorry.

[Kim Naverson]
Hi, I'm sorry to interrupt, but I can't stay longer, and I just wanted to make one more comment. That being willing to pay. an institution a certain rate, or being willing to pay 70 hours to someone who's not related to the person is discrimination of a family caregiver.

[k]
So, my brother is severely disabled. And... I grew up with that. I missed birthday parties. I missed so much because my mom couldn't just. Get him in the car and drive me there, because it is such a hassle to get him out. We have finally got what we needed. And she's able to support that. We finally got a vehicle that we can put him in being a modified van. Not cheap, nonetheless. But we're actually able to go out in public now. And now she's gonna be losing the money to pay for that. When we had caregivers in our house. They would come to me, the younger sister who's trying to do homework, and ask. I don't know what he's saying. Can you just do that for me? That... that... they were getting paid. But as a younger sister, I was still having to do that, because we are the ones who knows him best. So now you're saying that my mom's only going to get paid 40 hours, and then she's gonna have to go find another job to be able to keep her and my brother afloat. And have somebody else come in. Who doesn't know anything about him and is just going to trigger him. That makes no sense. And it's frustrating, because you guys are supposed to be advocating for us, you guys are the program. And you're just stabbing us all in the back. I don't understand.

[Kara Nitz]
Hi, I just didn't hear you answer the question as to why we're not reviewing everybody. And setting their cap at the nursing home rate instead of 40 hours, was that ever even considered when making these decisions? Okay, and then another thing we need clarification on is once you do the review, and they're determined that they meet that 150% the family can only do 40 hours of that. Is that correct? Or now the family can do all of that? And where... how did that decision come about? I think that would help us understand what... what made you guys decide that.

[Tobis phone]
Yeah, I'm here. I just don't see where this is... this is okay for somebody that requires 24-7 care. You know, I'm-I'm speaking for myself, but everybody else that has talked. My son is in a vegetative state, has a feeding tube, has a baclofen pump. He cannot do anything on his own. Nothing. If he was in an institution, which he'll never go to. He would have bed sores. The first four days he was in Madonna, and he was there for 4 months. The first 4 days, he had bedsores. He can't move. He had cuts on his nose. Explain that. I asked them, how did he get cuts on his nose? Oh, I think he's crushed himself. He can't even move his arms! He can't talk, he can't walk, he can't do anything. I gave up my career for my adult son because. He needs 24-7 care, and now you're gonna cut 40- down to 40 hours. But you'll hire somebody else to come in 30 hours? You can't even trust him in a facility, let alone in your home. I mean, this doesn't make sense. I mean, what if this was your child? That required 24-7 care. Your child couldn't talk, your child couldn't move. Is this what you would want? And I'm just like the other ones. I have put so much money into getting him outside. Getting him down two different ramps. Modifying and spending the money on a $60,000 vehicle, because that's how much they are, and I know others are higher. To lose everything? I can't even get him into a neurologist! Nobody wants to see him because he's in a vegetative state. Make two appointments, they cancel. We can't help your son. But you think an institution or a caregiver of 30 hours can help take care of it? No! I think the state needs to make other cuts, or possibly check into fraud charges with other Medicaid cuts. And leave the parents and the family that are giving the best care to their loved ones. That's all.

[Robin Quarles]
Did you say Robin? Hi. Well, I'm... I'm in a different situation than a lot of the people on the call, as in, um. I haven't even gotten my hours assigned to me yet. I just had my assessments done, and the league is sending down my paperwork to Lincoln. And, um, another reason why I'm a little bit different than some of the other callers is. I'm taking care of a parent. Um... and when I first saw the news breaking on TV. About, um... the auditor and his audit. Um... I knew then that... that the hammer was gonna come down, because this is what... conservative leaders do in conservative states, right? They talk about... uh, safety net programs that help people. And the first thing they start talking about is waste and fraud, waste and fraud. Um... and it was just... It's, um... Curious to me how. At the same time, they've decided to cut these- these benefits for families. That they magically found all this fraud. I would... I'm curious to know as to the percentage of actual. Uh, participants. Uh, what the fraud percentage is, because I guarantee you, like, most of the things, when they're. Talking about voter, uh, uh, fraud and all that stuff, that it's probably less than 1% of the participants in the program. And why aren't they just going after those people the way they should be going after those people, instead of using these small incidents. Um, as an opportunity. To take the hammer to other parents and to family members who are taking care of their-their family. My mother was diagnosed with dementia. And I am highly. Um... offended when I hear comments like, we don't think people are sitting with their relatives 24 hours a day, or looking in the face. My mother's sitting right next to me as we speak. I do the cooking, the cleaning. Um, I go to her doctor's appointments. We literally... are together 24 hours a day. Sometimes my mother wakes up in the middle of the night, she has, she's starting to do the sundowners. I get up in the middle of the night with my mother. It's offensive to tell family members on this call that you don't think. Um, yeah, we sleep, but our family members also sleep too. But guess what? Just like when you have a newborn in your house for the first time, and you... that little bit of noise you hear, and then you jump up like a lightning rod, once you've been taking care of a loved one that needs that care. You're not sleeping through-anything-every little sound you jump up. It's offensive to tell people, well, you know, you're an informal caregiver. I have a background in healthcare. I was a whole medic in the United States uh, National Guard... the Nebraska National Guard and the, uh, Nebraska Reserves. I had my EMTB. I put that aside because I really didn't have the stomach for that, and so I didn't want to do it. But the amount of experience that people have taking care of their families. Throughout the years, especially the folks on this call that I'm listening to, if they've had to clean out a trach, or they've had to do. Um, you know, change a catheter, or all of that. You get experienced in doing that. And just because you don't have an LPN behind your name, or an RN behind your name, or an MD behind your name, doesn't mean you have any less experience than anyone else. You guys are gonna tell folks, um, from what I'm reading, it's either take these hours or institutionalize your people. I have a lot of family members, nieces, nephews, even some of my kids have their CNAs, CMAs, all of that. The horror stories that I hear. Coming out of these places. They're understaffed. Number one. So... either the caregivers that are there take their charges, even though they know they're out of

ratio, and then something happens, and then you guys want to hang that around their heads for taking the charges. Well, you knew you were out of ratio, or there's nobody there to take care of folks. So, you want people to either put their folks in a home where they're understaffed, underpaid, overworked. No one there to really... supervise and help, or for people to cut their hours because, you know, we're informal. Um, it's just... It's sad, because it's taken me literally a year to even get to the point where you guys are even looking at us, because it's. The whole process is already. Um, very hard to get through. And very hard to, um, understand, and there's a whole lot of jargon that we don't understand when we're just getting through this, so... Um, my hat's off to all of you guys who are already in the program, um... And have your stuff going, because this is the second time in two years that I've even tried this, because it was so confusing, uh, for me. But... I'm just... so irritated that the governor and his administration are taking... these small cases that they can make. And blowing it up, and going to the press and going, see? See, these people don't care about their family. These people are working jobs outside of here, and why should we pay any of them then? If we can find these 2 or 3 that are doing something wrong, we should just screw everybody else. And it's wrong, and to... to... piggyback on what another, uh, caller said, and it's very wrong to do it at the holidays. I mean, has this administration no shame? There's no empathy here, no... no humanity, no... No sympathy to do this around the holidays, I mean, but I guess we're also hoping that people are so busy. Trying to get those last-minute doctor's appointments and. Health, uh, insurance their family's gonna be on the next year and get through the holidays, that they would be too distracted to pay attention to what. What, uh, Pillen and his ilk and DHHS are trying to do with this program, so that you wouldn't get a whole lot of comments, but. That's all I wanted to say is. you know, um, there are also people who are also taking care of parents and other relatives, and we're not informal. And we don't... this isn't, um, uh, uh... a payday for us. Most people aren't living in $600,000 homes and buying yachts and stuff with this money, um, just like a lot of these parents are saying, when I... I already have a list of the things that I need to do and get for my mother out of a paycheck that I haven't even been. Uh, uh, approved for yet. No one's living the life of Riley with this money. They're taking care of their family and trying to give a family member dignity. That's what I want to do for my mom. My mom was a single mom, and she started sacrificed a lot for me, and she doesn't deserve to be in a home. Just like she doesn't deserve to have dementia. But these are the cards that we've been dealing. And I'm gonna do my level best to make sure that my mom spends the rest of her days living in dignity, and not in somebody's home.

[Susan Samuelson]
Yes. Okay, so I have a number of questions. I'll try to make them fairly quick. Um, number one is, do you... Does the department actually run all of these changes through a, um, through your attorneys to make sure that you're not violating disability rights, etc, before you propose these? Okay, and the next question is, I am aware I've been in contact with Dr. Fisher... I'm sorry, with Senator Fisher's office, and I know that there's an exorbitant amount of new Medicaid money coming to Nebraska for the next 3 years. Where is all of that money going? When you're proposing changes like this? No, this is new money coming in, um, over the next 3 years. According to Senator Fisher's office, specifically for Medicaid, it's, um... more than the state has ever received before. Yeah. Okay, well, provider payments is one thing, but also this nursing home and the, uh, more care that a lot of our Uh, people need beyond nursing home level, and how is that going to be managed for people on vents and trachs, etc. That's a huge amount of money, and I guess I'm really shocked. That, um... who maybe have not been, uh, fighting for the... or that I could tell here. I, you know, for our people who, um, you know, you're talking to the least of these right now. You're talking to the people who they... many of our disabled and rare disease families, they absolutely have nobody to fight for them except the families, because guess what? I can't afford an attorney. Most of the people are on here can't, and so you're coming after the most vulnerable. And I think that's the part that really, um... really just is... unfathomable that you would come after these people who are caring, that are saving money, that are caring for their loved ones, and there's really just-- just doesn't seem to be a way. Um, to... compensate them fairly to have safe places for their loved ones to go, and now you're going to make it even worse. So, I really am disappointed in where this is coming and where this is going. Um, and so, I guess my next question is. With the comments that we're making, what is the reality that any of this can really shift or make a difference? And how does that happen? Because making a comment is one thing. But having change is something else, so can you... Can you talk a little bit about that? And who evaluates them? Who's going to look at these comments and potentially say, wow, maybe we've made a mistake here. This really is not going to work for families. So yes, I would appreciate that. Thank you. So, the comments really go back to the people who have made this proposal and are thinking that this is something that--That should be done, and then, obviously, the administration, who I believe is on board with this also. So, the likelihood of change is probably very slim. Am I correct in that? Okay, thank you.

Questions from Chat 12/16/2025

From katie
Can you explain to the relation between the hours being capped at 70 but the nursing facilities are avg. $92k. Shouldn't it then depend on how much your agency is being paid or if you are an independent provider through the state?

From katie
Because if you are a provider through the state, 70 hours would come in a lot less than that nursing home cost. I'm confused about that.

From katie
Ambassador has told parents that their contract with DHHS charges $1,000 per DAY. Can you explain that to us because a lot of us have adults that can not go into a regular nusing home. Ambassador and Madonna are the choices.

From Jodi
Many parent independent providers are confused and wondering... What is the purpose of the 150% limit of nursing home cost if we are limited to 40 hours per week at only $15 an hour? That's only $30,000 a year!

From Jodi
Please answer publicly so all can know.

From k
So, if we have an adult child who is 16 hour a day current care in home care independent in home providers and no where near the max amount will our hours be cut or do we get to stay the same?

From katie
Would it be possible to seperate the general ederly from the disabled even more then so that the adults who are trach and vent dependent or having mutiple daily seizures can recieve the care that they need?

From emannschreck
When is the interRAI going to match the NFLOC assessments? People qualify for waiver who would not meet by NFLOC assessment standards.

From dominicgillen
My son receives 116 per week and we are listed as chore. How will the changes influence our situation?

From mmh
Why would you only allow a relative to care for someone for 40 hours, but let a stranger come into the home for 70 hours? nobody wants a stranger taking care of their loved ones

From Hom Rai
Hi

From Michelle
I was told that on the AD Waiver side that we would have to make sure our caregivers are CPR and first aide certified by July as well. Is that another thing you guys will be implementing? OK thank you!

From Stephanie.Hoyt
Who will be responsible for monitoring the 40 hour cap whether individual or agency being authorized. This is not monitored currently until someone over bills and has no units left for the year.

From Stephanie.Hoyt
What efforts are being made to hold mco's responsible for providing the hours they are obligated to provide for the medical needs that seem to be of high focus during these calls?

From Lori
What plan is in place- if us parents have these hours cut- we will have to put our kids into institutions- there is only 2 in Omaha area with no room- I. Called a skilled care and they didn't even know this was happening. Why are you purposing this without a safety plan in place. What will happen with influx into these skilled care. Where do we put our kids when there is no beds available?

From Chelsea Jensen
Public comment sessions were originally scheduled for Oct. 20, 22, 27 and 30. What caused the delay that moved public comment period to the holiday season, which multiple people have mentioned is causing additional stress?

From Nina Burkey Graceful In Home Healthcare
Thank you!

12-17-2025

[Teresa]

Hi, can you hear me? Okay, great, thank you. My first question is about the no longer mandatory RNs for assessment of cares, so who's going to do those assessment of cares, then? If it's not an RN or a doctor, who will it be? Will they be a professional? Will they know what's going on? They said it really fast. They said there will no longer be a mandatory... it will no longer be mandatory for an RN to do assessment of cares for the care plan. For these people via the doctors and. etc, right? Okay. All right, and my next, uh... If comments were, you know, when will we be advised what the final accepts-acceptance of policy changes will be, and what those changes will be. How soon will we get that information? Okay. When will that happen? You don't have a... you don't have a date for that? That would be very helpful when our financial status is going to change considerably. Don't you think? I understand that it will not go live until July 1st, but we don't know exactly what's going to go live July 1st, correct? Okay. I see. Okay. Well, I just want to add that this is not a family-forward proposal. Where's the moral character of this administration? A family caregiver going from 112 hours to 40 hours per week is absolutely not sustainable. It's not only financially devastating and unsustainable. But providing the best option for care is abolished. Families will lose or will forfeit handicap modified homes and vehicles due to not being able to afford the payments. And wouldn't most of these families then qualify for Medicaid, health insurance, SNAP, and Therapy? Are you going to provide them housing, too? For disabled, essentially putting them at least right at poverty level or less. Essentially, if you're okay for extra hours over 40 for complex patients to be performed by others. This will not only disrupt the consistency, continuity, and compassion of care, exposing the most vulnerable of this population to additional illnesses and viruses by adding and introducing more potential characters into the home. Expect more hospital stays. And this is if I can even... if even staff is considering the risk care of needs. Furthermore, my son's level of needs finding staff to cover him would be damn near non-existent. Agencies can't provide staff to do medical cares on my son. This includes suctioning trach, drawing up and administering medications, administering life-saving medical interventions. Such as respiratory rescue inhalers, rescue nasal spray for seizures, maintaining and troubleshooting ventilator issues, and providing urinary catheterization, and the list goes on. They are not... They are not legally able to do that. So, in essence, in essence, if by some miracle I find staffing, I would still have to be available at all of these hours. To provide those cares for my son, which is around the clock. Uh... the... Me, at the age of 61, finding additional employment would be difficult. I've been out of the workforce for over a decade now, and with the unemployment rate at a 4-year high of 4.6. How employable do you think

at 61. With physical limitations. How employable do you think I would be to get a... to even get part-time job? And that's all I have to say, thank you.

[Michelle]

Yes, can you hear me? Okay, so I have two different questions. So, the 70 hours part of it. Um, and along with that 150%, that $137,000. Does that 137, if I make... less than, like, the highest amount. I... my clients would actually qualify for just a little bit more than that 70 hours. It would be more like 77. So, is it actually capped at 77, or is it that $137,000? Okay, and then I just have one other question. I know nobody else has mentioned it, but we did see in there that CPR and first aid certification that you guys are wanting, like, the agencies to have their caregivers have. I was wondering. If that gets approved, would that actually be... implemented July 1st. Or would it be one of those things where it gets implemented July 1st, and we have a little bit of time after that to be able to get that certification? Okay, that's all I needed.

[thomaskellogg]

Yes, can you hear me? Um, so I... I learned in these public meetings that the agency hourly rates are up to twice what the rates are of independent providers. So, if the... if the rates are double, an independent provider could work twice the number of hours as the agency caregiver for the same amount of money. For example, assuming the agency's charging $32 an hour for their caregiver and the independent provider is making $16 an hour. If it's determined that the adult child should receive an extra 30 hours of care per week. The agency would be billing. DHHS, $32 an hour, times 30 or $960 for these extra 30 hours. Whereas the independent provider would only be billing $16 an hour times 30 hours, or $480 total. In this example, the independent provider could actually be working the extra 60 hours per week for the same amount of money that the agency working 30 hours 60 hours times 16 bucks an hour would be 960. The same as what the agency would be charging for those, for 30 hours. Now, I have a comment about nursing home rates. Anyone that requires 24-7, 365 care is certainly eligible for a nursing home. It was mentioned yesterday that the average cost for a nursing home is $93,000. Per special needs individual per year. It was also mentioned that in a nursing home, a caregiver will be required to take care of 2, 3, or even 4 individuals. At the same time. Obviously, those individuals with limited speaking availability could receive the least amount of care. To look at the money, if the nursing home is caring for 2 individuals, they will receive 2 times 93,000, or 186,000 per year. And if they're caring for 3 individuals, the nursing home would receive $279,000 per year, and so on. So, to compare apples to apples let's assume the nursing home rate is based on getting

paid for 70 hours max per week. The same maximum being considered for in-home care. For someone with 24-7, 365 care needs. At 70 hours per week, there are 3,640 hours in a year. The nursing home that is receiving $186,000 for the 2 kids. Based on being paid 70 hours a week, or actually making $51 per hour. Compared to the two independent providers in separate homes. Caring for two individuals. Making a total of $32 per hour, that's $16 for each of them. And if you assume a nursing home caregiver is watching 3 kids. The hour rate... hourly rate goes up to $77 per hour for the nursing home. Uh, as compared to $48 per hour for the 3 independent providers at home, to try to compare apples to apples. So DHHS would be paying $77 per hour for the nursing home. For this one caregiver. Compares with $48 per hour for the 3 independent providers. And total would be be making. Obviously, a nursing home spends more than 70 hours per week caring for the special needs adult. But the parents at home spend the same amount of hours at the nursing home. Not only is the in-home care a lot less expensive. But the quality of care would be much greater. In conclusion, I'd like to say. DHHS and providers should all be on the same team trying to provide the best care. For our special needs adult children. After all, adults having special needs should be the primary focus. For not only the caregiver, but for each of the 4,800 employees at Nebraska DHHS. Parents and relatives of the special needs adult are without a doubt the ones that will be most passionate in the care of their child. But DHHS seems to be more focused on trying to limit the number of hours. Parents can work caring for their own child. It is a little ironic how. in the last Nebraska state legislative session. They were actually having public meetings. Considering significant raises for the hourly rates the family caregivers. Now the focus is how to cut their annual income by 100%. When I had shoulder surgery last year, I was limited on what I could do. We called 4 of the best agencies in Omaha for help. Only one came out to meet us. And all of them said they did not have anyone available. About 5 years ago, I attended a meeting at DHHS at the conclusion. I met with the person in charge of the meeting. I described my son's condition and asked if something happened to both parents, where would my son end up? She said in a nursing home. Based on this, we met with 5 nursing homes to determine a good place for our son. All 5 either said they had no beds for Medicaid patients. Or they only had one, and it was always taken. We took our son with us to each of these meetings so they could see him. At the time, he was 38 years old. One lady asked us, why would we consider putting our 38-year-old son in a nursing home. Where the average age was over 85. I said that was our only choice. All of them said that their staff are not trained to care for our son, and their rooms would not accommodate his needs. The mistake we made was going to 4- and 5-star nursing homes, instead of one-star nursing homes. In my family, I have 7 siblings and about 85 relatives. Most of these relatives do not live close, and all of them are either in school, have their own career path, or are retired. None of them are available to help us. And I remember reminding you, we're both 70 years

old. So, in conclusion, again, in my opinion, DHHS and the parents should meet to agree on the number of hours needed to care for their special needs adult. DHHS should then be asking parents. How many of these hours a week can they work? The least expensive alternative is not to use nursing homes and agencies. But to allow the parents to work as many hours they can. Having the parents be the primary caregiver is also the best addition option for the special needs adult. Why is it so hard for DHHS to see this? I'm done.

[Lee Palmer]

I've got a question, because I don't understand the 70 hours. So, can you ex... can you explain the 70 hours to me? And... Okay, so... My daughter is autistic and nonverbal and completely unavailable to take care of herself. 10 hours a day would leave her. 14 hours to... probably hurt herself or harm others, or... do danger... have danger to herself. We have no care facility here that can take care of her. And I live so far... we live out in the country by Sioux City. And there isn't extra caregivers to come this way. I am the primary caregiver for her. So, by cutting me down to 40 hours, you guys are taking all of her- all the available, that I have to take care of the house. I think this is a mis... misguided and completely unthought through plan by people that don't understand people that take care of people. I'm so disgusted in the... in the way you guys are just nonchalantly saying these things. It's... it's gut-wrenching to the fact that you think that. Oh, we're just gonna cut this out, and it's not a big deal you're... you're taking away the ability for people that can't... the weakest among us. You're taking away their ability to live a comfortable and a sustainable lifestyle, outside of an institution. But the institutions get 175%. Wait a minute, somebody padded something somewhere. Because you can take it away from the families, but you're gonna add 175% to care facilities? I think we need to have some questions asked on who's paying who for what. I think Ms. Clark here understands that there's money getting flown... floated around somewhere. And I think it needs to go to the people that need the care first. Instead of going to big corporations that are. buying up, uh, small mom-and-pop nursing homes. That's all I got.

[Melanie Davis]

Thank you. Um, again, my name's Melanie, and um... I've made some notes about what I want to say, because I'll forget them. Um, first of all, I received the A&D waiver. After close to 9 years of fighting and navigating a system that didn't want to give to me. And now you're about to change it. And I really worked hard to navigate this really complex system. Um, I think that there is a huge lack of understanding of the overall social and connection abilities of people with disabilities and families. We are consumed with what it takes to live. And when you force us to rely on informal supports that maybe are not there. You are changing our life completely. I'm not going back to relying on neighbors to just do things for me. Don't send me back there. I'm 40 years old and I'd like to continue moving forward. You are also changing the lives of my friends who need that waiver to survive. If I can't see my friends because they don't have services. You're changing two people's lives. I strongly suggest you look at that. Because I don't think you see it. Um, second to that, my second comment would be. Overall, listening to this presentation. I don't have a single friend that could come here and make a comment because it was too complex to follow. And there are plain language guidelines out there by the federal government that I don't think that you even looked at before making these slides. If you want to hear from people with disabilities, you need to change the way you presented this. I hope DHHS is working to educate everyone.

[Shelley Gillen]

Hi, so I have several questions. My first question is... Who is making these changes? Is it people at the DHHS? Is it people that work with the governor? Is... I just would really like to know who thought of these grand ideas, and if they spent any-- --re-quote unquote, revising this. Okay, so... the... So, my brother is severely disabled, has seizures every single day, nonverbal, um, relies on us for quite literally everything. So, what I'm hearing is that with this waiver, they would prefer people to... be in homes, rather than be with their families. I just... when I first heard that this was a possibility. I literally laughed it off, because I was like, no, there's absolutely no way. It's unconstitutional. It's completely unethical. It literally makes zero sense whatsoever. So... And I guess I would like a list of all of these religious communities and organizations and people that are gonna come in and do these services, since we can no longer be doing them. So, is there going to be a list of those things that the DHHS compiles and sends out? Or are we just gonna be told, quote-unquote, as Mr.

Governor Pillen said. That we need to just talk with our local charities. No, they can't, because we talked to our service coordinator, and she didn't know any of this was going on.

[HS]

I was trying to unmute, can you hear me? Yes? Okay, so I... I have a question about that as well, which we was just talking about. I have two questions. The first regards. Um, federal regulation that says natural supports must be provided to someone voluntarily. Now, you want us to provide 128 hours of natural supports and be paid for 40/hrs in a week, and that ratio is just unsustainable and ridiculous. And there is no mandate that we are obligated to provide unpaid ongoing personal care or support. That significantly impacts our life or finances. Forcing us to choose between providing this unpaid support 128 hours and institutionalizing our individual is insane. That's my first statement. I want everyone to know their rights, there is no mandate that we have to provide that. Secondly, my question is about the NRI. As a parent and guardian I have legal standing to get a copy of the NRI that was done on my child, my individual. When I asked for it, the service coordinator told me I couldn't get it. I have no way to know if the answers that I gave or they, you know, filled out for us even reflect his real level of care. How can I get that copy of that NRI document? Wonderful, thank you.

[Catherine Jensen]

Oh, there we go. Okay, um, I listened in yesterday. And I was... this is just... gut-wrenching to all of us. First of all, the fact that any of this is fiscally responsible. I don't... it doesn't make any sense. I don't know how... paying an agency for 30 extra hours instead of a parent is fiscally responsible. And also, how... if there are exceptions made. Um, how do we go about... getting that. I mean, how... who do we contact first? What is the process in getting an exception made? And what does SNA stand for? Okay, okay. Sorry, misunderstood you, okay. And... That's what our service coordinator did to get us on the waiver, correct? Okay. Okay. Okay, is there any, um... well, I guess that answers my question on that. All right, thank you.

[LV]

Yeah, I have a quick question about a plan. Um, my daughter is completely ventilator-dependent. With your decrease in funds and your hours, you are now making my home a risk. I won't have the money to provide an adequate care environment for her. I've talked to at least 12 to 13 other parents who are in the same boat as me, with a very complex ventilator-dependent child. We have nursing shortages that you guys are well aware of, and I know, Jen, you are putting pressure on us to lean on family members whom do not want to have the responsibility of handling our ventilator-dependent individuals. We are feeling forced to put our individuals in skilled living. I want to let you know, because I did the work for you. There's only two places in the Omaha area who would take a ventilator 24-hour care child like mine. Madonna, which has no beds, and the ambassador, which has a waiting list. When I called both of those places, they knew none of this was happening. You guys are proposing a risk, no plan in place. The lady at Ambassador told me that if come July, and you cut these hours, and now our homes are unsafe for these individuals, because again, you're not paying us, that we are supposed to take our children to the hospital. If the hospital takes my ventilator child, you will be paying an ICU stay. Which, again, is pretty expensive. Also, if I was to stick my child in the ambassador. You would be paying $1,000 a day for her care. There are 12 other parents in my position who feel forced to stick our children into skilled facilities. I want to know how soon you're going to tell us this is going to take place. And what plan and action do you have if there is an influx of people who need to go to these skilled places, and there are no beds. That's what I want to know. What is your plan? Because come July without this money, my home now is no longer safe. I can't pay my bills. I won't be able to do what I need for her to have adequate care. And now, like I said, 12 other parents are in my boat. That's over $300,000 a year just for my child, and you have 12 other people who are ready to put their kid in a home if this happens. So, if this is budget-related, you guys are in trouble. And I want to know what your plan is, because if you're going to tell me in May and there's no beds available, what happens to my daughter? That's what I want to know. You're forcing us. You're making our homes unsafe. There is no outside help. Nobody wants to take care of a ventilator child. No family wants the responsibility. What are we supposed to do? Tell me what your plan is, since you're proposing this. Where do I take my child. No, my child... no, no, no, no, my child doesn't need a nursing home. They need 24-hour skilled care. Okay? They don't need a place that has a CNA. They need someone who can operate a ventilator. A nursing home is not... these numbers that you're saying, these are skewed. My daughter needs a skilled care

facility with licensed people to take care of a ventilator. Not a nursing home. So, and you're not even contacting the two places that would take my child. They haven't even been contacted by you. This is sickening to me. This is horrible. I'm really hoping there's a lot of lawyers on here today, because I feel like this is an Olmstead violation and just a side note, and then I will be done. This is all about taxable income for the state. This is why you don't want to pay me, but you want to pay an outside person to come in and care for my kid. Because you know I'm tax-exempt. And you want to make revenue for the state, that's what Pillen wants. That's what this is all about, is money, and you're willing to sacrifice our kids for the money. I hope you guys sleep good tonight.

[Lisa's iPad]

Yes, um... Like everybody else has said, uh, it's extremely gut-wrenching. And... first of all, um... I kind of feel for you to... DHHS people. Because you're the ones having to be the front people on this. And if you have hearts at all. They should be breaking also, for these people, and these children. Who are going to be affected by this. And, you know, truly. I feel for you, because I wouldn't want to be in your position at all. And, um... That being said. I do have some questions. And I know it was asked before. Um... And obviously, it must be budgetary. Um... of who decided this, when they decided this. Who was the actual person that decided this at DHHS? Um, what... Are other states doing? What's the average number of hours other states are paying their care providers? Is Nebraska now the outlier? Because I have been actually really happy, by and large. So far, with what Nebraska has provided, until now. So, what... what are the averages, with other states. Can you answer that? Uh, well, I think you better find out. That's a good question, because... We all know that the feds provide the money that you're spending for these children and these people. That's where the money comes from. The money doesn't come from the state, it comes from the feds. And you are given the responsibility to apply it. Am I incorrect on that? Correct me if you need to. Well, there's still a 45%. So, I mean, fiscally, like, everybody else has been saying. I mean, my goodness. that's gonna eat you alive. It's our, you know, the stuff with EVV. Um, you know. Uh, that's probably eating you alive already. just with the... Um, let's say... you know, I built something wrong, and somebody has to approve it, and I have to send in reports, and somebody has to approve it. That's got to be eating you guys alive just in a, um, staffing. Situation there. Um, you know, there's probably... waste all over the place. And... Your task... Your task, what all of these people are saying, and. We represent all of the special needs people in this state. I would say however many of us are on here. This is your job to take care of these people and these families. This is your job. This should be all that you do. It should be your primary focus. And supporting the people that need it the most.

So, like I said, I don't want to say shame on you two, because you're the front man and women. But whoever decided this higher up. Shame on them. And yes, I agree with anybody else listening. My name is Lisa Larson, I live in Arthur, Nebraska. I'm easy to find. If you want to come, um, hire some attorneys, sign me up, and let me know. That's all I have to say, thank you.

[Mark Kuecker]

Jen, thank you for letting me have the opportunity to speak. As president of Dad's Appreciating Down Syndrome in Omaha, which is a non-profit that supports fathers and fathers' figures of individuals with Down syndrome, and as a long-time professional in the care industry, I'm deeply concerned about the proposed 40-hour cap on paid live-in caregivers. Consistency in care is critical. Medically complex individuals who rely on caregivers who know their routines, medications, communication cues, Uh, early warning signs, uh, like seizures. Uh, apparent or long-term live-in caregiver has this deep, intuitive understanding. Allowing the full 70 hours to be provided by a single live-in caregiver preserves the continuity of care. Which leads to safer, more stable outcomes. Caregivers are not interchangeable. When hours are divided among multiple people, it creates gaps in communication, increases anxiety for the individual receiving care, and raises the risks of preventable medical emergencies. For many families, especially those caring for medically fragile children, including my two granddaughters, introducing additional caregivers is not just disruptive, it can be dangerous. The only restriction the state is looking at is who can provide those hours. Limiting the living caregiver to 40 doesn't save money, it simply forces additional caregivers into the home, creating unnecessary disruption and significant safety risks. This is a quality of care and safety issue. I urge DHHS to reconsider the 40-hour cap for live-in caregivers and allow for up to 70 hours for the primary caregiver. This approach ensures consistency, safe care for support for those individuals with disabilities to remain healthy, stable, and dignified in their own homes. In summary, consistency of care is critical. Caregivers are not interchangeable.

[Lisa’s iPad]

Somebody's found me.

[Mark Kuecker]

This is a quality of care and safety issue, and thank you, Jen, and others, for listening to my concerns and taking this into serious consideration.

[anna]

Thank you so much. Um... Just have a couple quick questions, because I'll email you my comments. Do you happen to know when... there's, like, a DD waiver that allows live-in caregivers. When does that have a 5-year review? Do you know? Okay. Okay, um, and you might not have any idea, do you think a similar thing might happen? Like, I'm being advised that maybe for the sake of my son, I should move over to the DD waiver, which doesn't help you guys' situation, but might help mine. But I don't know that I want to go through all those hoops. I mean, maybe for... I don't know. Anyway, uh, do you foresee those types of cuts to happen as well in the DD waiver, or can you say? Okay. And then, um, so I have never been able to keep a caregiver other than myself. Um, I train them, and... It's too much, like, they can't handle my son, and they leave. Um, sometimes they no call, no show. Sometimes they leave him in the middle of a shift. Um, and it makes it really hard to depend on someone other than myself. Um, so I guess my biggest concern is I've never been able to hire someone, um. And if I can prove that I can't hire someone for those 30 hours, do you guys have plans, or maybe would it be possible to then revert those hours back to the parent caregiver, since no other suitable caregiver could be found. Okay, and then, um, I guess I just, um, my last thing is just, like. My life has been sort of built around being my son's caregiver and.I... I'm sorry that I became dependent on that income. But I did, and I don't know what I'm gonna do, and if I need to go get a job. Then maybe he does have to move into a place. But I don't know of any places that will take him, and so I guess I and I really didn't want him to end up in a place, because I feel like with his needs, not to mention everything that Mark said and others about, like. If you don't know to watch for, you're not gonna know. I mean, my son had a bleeding ulcer and ended up in the hospital for over a week because nobody knew he had a bleeding ulcer and. Anyway, um, if... If no one can see or understand him. Then he just starts hitting himself and bashing his head against stuff. And I can fast forward, I can push fast forward on the button. And he's gonna end up drugged. And tied to a bed. And that will be his life! If a place will take him. If a place doesn't take him, then I don't... I don't know. How am I supposed to hold down a job? With my son along with me for the ride. I don't know how that's gonna work, um... And so, I guess those are just some of my... concerns, and I think... Um, and I mean, I'll try to share this in my public comment, but... My life is really hard, like. After I waited all these years to get him on a waiver that did something. I mean, thank you for the child waiver, and that was nice, but I didn't really have anyone to do my respite. Nobody was paid enough to do it outside the family, and- Anyway, I got to this time. When he turned 18, I was super excited, because

I thought, oh, someone's gonna come to my house and help me for 40 hours a week, but I... Get anyone to do it, and then I was like, oh, when I could be his caregiver, it was like... I live at, like, this amount of stress all the time, you know, there's something like nails on a chalkboard when your kid is beating the crap out of himself. It's just... a lot, and um. It helped to have an income. It helped. To be able to own a home, it helped. Um, it helps. It helps so much. And I didn't know... No, that you might take it away because, you know, like. When he was a little kid and in school, all the counselors and everybody along the way were like, you just gotta make it until he's 19! And then, you know. The state helps take care of them, and it's great, you know, and like, I got to do it for a year and a half, and... He's gonna graduate, and I don't know of a day program that's gonna take him, and even when he is at school, they call me and make me come get him, like, because the nursing home gonna call me and make me come get him, or are they just gonna drug him and tie him to the bed? Okay, thank you.

[Courtney Berg]

Hi, can you hear me? Okay. Um, I just had a couple of questions, uh, or comments. If you are already receiving exception that is already approved. Will you have to redo that entire process again? Ah, okay. Like, the exception, no. No, I mean, I... if you already are receiving an... hourly exception due to high needs. Will you then have to redo that exception process, or will that be honored? My friend, it felt like a process, I'm not gonna lie, when I did it. Um, like, it was a real process, and, like, somebody told me how to do it. And then I had to do it, and it was this huge, detailed... list of cares and letters from doctors and blah blah blah blah, so... so what you're saying is that. The same doctor who still sees the same patient that nothing has changed with, we'll then have to do something. Similarly difficult, again, to get their exception. Well, somebody in Lincoln, because we were asking for additional hours, above and beyond what was currently available. So, I was just curious how that was gonna work. Yeah, that would be fine. And then, just... I would like to just make the same statement that other people are making, that. A. It's not a good place for people to be in nursing homes, particularly people who can't make their needs known. B. We don't have any nursing homes that take Medicaid... that aren't... that Medicaid beds aren't already full in. Um, Medicaid pays their nursing homes poorly, which is why we go over the nursing home cap, because we don't pay what other people pay nursing homes from our Medicaid program. So, they have, like, one bed or two beds, or... It's the worst nursing you can come by in town. Um, we all know it, you know it, I mean. We can pretend like it's not true, but it is true. It's also the same nursing homes that take veterans. Because they're the cheapest. Um... And... I'm a nurse, I'm a Medicaid waiver provider. I provide respite care. I'm also a

mental health nurse and a hospice care in Nebraska, even financially, because we're not only going to be cutting income to people, home providers, we're cutting hours to. To come- - --thought about, I think... Um, and it just... it comes out at a really unfortunate time, stand-up on television and talk about how the men... Oh, okay. Thank you. If you want to involve... Fraud, waste, and abuse. No. Oh... I feel like...

[jamie jansa]

Hi, um, okay. So, I have a couple questions, and then just kind of something to say. Um, so... first, just because I'm... this is my first one attending. But, um, you said for... for the exception, like, to file for the exception is... So, anything over 40 hours, then we apply for the exception, or is that over 70 hours? We can apply for an exception. I guess I just need more clarification on that. So, regardless, the 70 hours is maxed out, even with an exception. Okay, so I guess that kind of answers that. Um, so then what I want to say is... so I provide round-the-clock 24-hour cares for my son. He was in a car accident 6 years ago. When we originally placed him into a nursing home facility. We... there was only one place in Omaha that would take him. Only one place. They checked surrounding states, and other states way beyond our surrounding states. Nobody would take him due to his injuries, the complexity of his cares, and everything else. We did that, constantly, in and out of hospital, due to the, you know, not getting the proper cares that he needed, people not being trained, not knowing what to do. 3 years ago, they almost killed him twice because of lack of cares. I had to quit my jobs. I was working two to three jobs just to maintain my bills, my home, my other kids, and still provide stuff for him that was not covered. So now, having him at home, this... this income that we get getting cut down to 40 hours, I have no family. I have a 13-year-old son. That's who I have. I have a 13-year-old. So, if I go and I have to go try and get another job to supplement the income that I already have. And then also to be able to pay for any of the extra things that he needs. That's not covered by insurance. He only gets a limited amount from Social Security. What am I supposed to do? Leave him home alone with my 13-year-old? Leave him home by himself. If something happens to them, who's at fault? I'm gonna be at fault. I'm gonna get in trouble. But I have to pay my bills. I can't send them back to another facility. And I definitely won't send them back to the facility that caused him harm that allowed... that. Made me bring him home to begin with. So, what am I supposed to do with him? What am I supposed to do for income? Are you guys going to provide me with a new home? I can't take them to... I can't go and get an apartment. Because why? I can't even get them to a doctor's appointment. There's no transportation available for us. He has to get stretcher services. Do you have any idea how hard that is to do? So, what are we supposed to do? You guys are thinking one-minded. If you guys would

come into people's homes. Look at these... look at these clients, all these people and make a determination at that point but stop judging everybody and trying to make a decision as a whole. Because it doesn't apply that same way for everybody. And it's not fair. It's not fair to the person, and it's not fair to the family. Especially if there's no village. It's me and my 13-year-old. I have no friends, I have no family, and I know I'm not the only other person in this situation. I don't know, that's all, because I can go on for days.

[Paul Dodson]

Yes, Paul, can you hear me? Yes, this is Paul, can you hear me? Oh, yeah, thank you, uh, Jen. So, I have a 26-year-old son, um, he suffered a severe brain injury in 2021, an anoxic brain injury. Um, my wife and I are his full-time caregivers. Um, I work from home and, uh, she had to walk away from her, uh, 25-year career as a schoolteacher um, to become his full-time caregiver. He was. Uh, suffered a severe anoxic brain injury, um loss of oxygen for over 30 minutes. Um, when we got him out of the hospital, or when... in the hospital, they originally told us that he would be bedridden the rest of his life, be ventilated the rest of his life, on a feeding tube the rest of his life. We made the tough decision to say that was... that was bullshit. Um... We moved forward, we got him into Madonna Rehab, um, about 5 weeks later he and miraculously began to, uh... uh, stand. Um, he was, uh, able to begin walking. We were able to get him to, um... Actually, after a feeding tube was out, he was able to, uh... Uh, start to feed himself. Uh, but the next stage we were at to try to find him in to a care facility. We got him into what we thought looked like a very nice, skilled facility to keep rehabbing him. In a matter of 3 short months, they managed to, um... due to the fact that the food was atrocious. Um, we told him that he was very mobile, they decided to, uh... he decided to get in the middle of the night and go try to find food on his own in the kitchen. That terrified them, so their solution was to lock him in his chair, lock him in his bed, and tranquilize him. They tranquilized him, and after they tranquilized him it essentially caused him further brain damage. He lost the ability to... all ability to speak. He lost ability to use his hands. He was- when we finally, after 3 months, we said, we're bringing him home, we're done with this bullshit, before you kill my son. We brought him home, and we have dedicated our life the last 3 years to try to help rehab him. And miraculously, he is doing better. So, I'll flip the table here a little bit and say the money that the dollars the state is investing does make a difference in some of these people. I know there's a lot of different cases here. But with extreme care through families, people are working. They want the best for their children. Or for their family members. And the ultimate goal should always be to help these people progress, not just care, but to progress, and have a life, and to begin. And we have done that, and he is making some... he is making some miraculous progress in

many ways. Um, but it takes extreme care. It's just last night, you know, my wife was up in the middle of the night with him, and so this whole 40 hours, it's just, it's ridiculous. To, uh, think that that's a... and the state is looking at it, thinking, well, the family member... additional family members will step up. I'm hearing the exact same thing here, and it's exactly right. You can't expect outside family members to just give up their life and, you know, drive across town to help you in the middle, and especially a situation. My son is, he's 6'5", you know, he's 170 pounds. We use same case. Any care facility we've tried to bring in to help, you know, a little old lady at, you know, 95 pounds is gonna volunteer and help they turn around right away. Oh, I can't help your son. You know, it's ridiculous, so... You know, so trying to, you know, say, the state needs to understand investing in people to help... investing in these people to try to help them gain abilities. Is the direction that we should be looking. That should be the benefits. The benefits, and I keep hearing... the. With this proposal, there should have been a cost-benefit proposal put together. I have seen none of that here. I see some dollars, but I see no cost-benefit. The only benefit I see here that potentially is the dollars, as people we're talking to, is to go into big facilities. Um... That is not a benefit. That's a benefit. That's not a benefit to the people that need this. So, uh, that be said, I... again, I realize you two are on the front end of this, and they're taking a lot of heat on this, but I just want to try to re... re-evaluate the message, or do... state the message. The best we should be looking to try to invest in these people to help them gain better abilities, and uh... not looking at them, just, oh, what's the minimum care we can get away with? Thank you.

Questions from Chat 12/17/2025

From wv
In regards to the institution's limits its my understanding these numbers were determined based on averages of previous billed individuals. How were the individuals that would require high utilization that are not currently in an institution accounted for. If the individuals that are on the high end of needs were to be institutionalized their rates would not be anywhere near the 175% cap. I keep hearing references to the bell curve. But the bell curve is apparently missing much needed data that would account for the individuals that require the highest need.

From Brenda Hoffman
There is NO-ONE who will be more vested in the care of our adult children the the parents.! Sounds more like they want to put priority in reducing Live in parent hour? WHY? Will there be any exceptions to the 70 hours?

From Sue
Can an individual Adult on AD waiver receive Personal care AND Chore if identified as a need?

From Mark Kuecker
Will there be time for comment on the 40 hours still? I will raise my hand when appropriate, but want to make sure my voice is heard in the public comment. Thank you

From Mark Kuecker
I will simply raise my hand and get in cue. Thank you

From Heather R
Is the 40 hour Cap on the disabled person on how many hours they are allowed on the AD waiver or is it per provider? The live in legal guardian can have the 40 horus and someone not related has to work the other 30 if the service needs assessment shows that 70 is needed.

From Heather R
So if someone is not the legal guardian they can still be a provider for over the 40/70 hours? Or is it capped on every provider?

From Courtney Berg
Your audio broke up- if you would like to submit your comments here or you can email them to us at DHHS.HCBSPublicComments@nebraska.gov

From Natasha Livingston
Is the Medicaid rate across the board or is that for special needs low needs etc? Can you explain what 150%/175% means? What is the goal of AD Waiver? I want to make sure im

understanding correctly, is it to keep people in their homes as much as possible and in order to do that care cannot exceep nursing home rates? Thank you for your help.

From Teresa
Will we see other public comments? And if so, where can that be access at? When will be know what the final acceptance proposal is implemented and what adjustments may have been made?

From Teresa
Like Sheely, We would like the names of who is on the advisory decision making panel

From Teresa
LV is spot on. My concern as well. This proposal is a death sentence for many of us. Frankly deplorable.

Natasha Livingston
Is anyone there? Is anyone responding to chats?

Kuecker
How was the decision made that if someone qualifies for 70 hours that the live in family can only provide 40 of that? If another family member who does not live in the home can provide the other 30 hours, why specifically limit live-in family members? Are we allowed to see copies of our service needs assessment for our adult daughter? I have guardianship so I feel that should be public to us.

Recently the Co-Chairs of the Olmstead Advisory Committee which was created by statutory authority under Neb. Rev. Stat. §81-6,122, serves as a primary stakeholder voice to review and advise other stakeholders regarding the State of Nebraska's Olmstead Plan development and implementation. Recently, the advisory membership was contacted about proposed changes in the Aged & Disabled Waiver. The Co-Chairs felt it violated the Olmstead Plan Core Principles established earlier by the Advisory Committee. Nebraska's Olmstead Plan was developed utilizing these Core Principles in order that it reflect certain fundamental beliefs in supporting individuals with disabilities. Included in these principles:

The State of Nebraska is committed to

- Person- and family-centered approaches.
- Ensuring the safety of, and an improved quality of life for people with disabilities.
- Provide needed services that are readily available at locations accessible to individuals in need and their families, and
- Support individuals with disabilities so that they can live a meaningful life in the community they choose.

In addition, the Co-Chairs felt it violated the basic concept of the Olmstead vs. LC decision which is "In Olmstead v. L.C., the Supreme Court ruled that people with disabilities have a right to lives of inclusion and integration. Disability is a normal part of life, and we all benefit from communities made up of diverse people, life experiences, and abilities."

Regarding these concerns, the Co-Chairs worked with the Department of Health & Human Services staff to call for an Emergency Meeting of the Olmstead Advisory Committee. The meeting was scheduled for December 19. 2025 and the public notice was distributed. There were approximately 120 members of the public present.

The purpose of the meeting was to have the Department address the concerns that the Olmstead Advisory Committee had. The meeting began with a Power Point Presentation by Health and Human Services Department Staff. Unfortunately, the format of the PowerPoint was inaccessible for persons with disabilities. There were too many words per page, the font was overly small, and it was not written utilizing Plain Language requirements. In addition, the Department either substantially limited or failed to respond to some of the questions from the Advisory Committee and public.

Based on the subsequent input we received from the public and the members of the committee it was decided that a document would be developed incorporating concerns about the proposed changes and that this would be submitted to the Department as public comment for the Aged & Disabled Waiver Renewal Application. To this end, the Co-chairs will develop and provide a letter incorporating the concerns raised in the emergency meeting to the Department representatives prior to January 5th, 2026. To wit:

- Concern that the Olmstead Committee hadn't been informed
- Upset about the way recipient family caregivers are being treated
- Using $94,423 as the average cost of a nursing home is not equitable. It does not level the playing field
- It isn't clear what age would overlap with school hours
- There are lot of people with disabilities who couldn't be able to be independent within 40 to 70 hours/week
- There seems to be a high rate of turnover of the number of service coordinators
- Many of the service coordinators aren't trained in Person Directed Planning
  1915(c) isn't peer-directed, 1915(k) is and that one allows more flexibility and doesn't limit the number of people using it. That doesn't allow a wait list either
- If you want to have to make significant changes to the application, you shouldn't have made it so problematic
- Some service coordinators have already changed the maximum hours and have not waited for the application to be approved.
- I understand renewals of waivers. You didn't have to change from the last one (2021)
- You've changed the definitions of various services. General housekeeping is now "light housekeeping. This does not clarify service definitions.
- What you've written makes no sense whatsoever to the average person. You can't get relevant comments.
- The percentages of recipients who are below 150% or over 175% don't help us with this application. 255 being over 175% should not be limited to an approval process to get more services. Would they end up in nursing homes. How do we know that the process will be successful?
- We could consider grandfathering those families that are over the limit now.
- You can't project the amount of money the legislature will provide in the long run.
- This process is onerous. It's not easy for parents and guardians.
    - They don't have the expertise

    - The resources are overwhelmed
- In the past, the DOJ has said that budget constraints are no an excuse to fail to comply with Olmstead
- You need to “flag” the numbers of members or you won’t know if have too many hours.
- If a person or family member is working directly under Medicaid, they are not using the A-D waiver. I assume they are not subject to these maximums
- Some families are being told their hours are being limited to 2 hours of day as of January
- Limiting public comment to the meetings you’ve scheduled would be an inadequate with only 35 (as stated in the application)
- The very complex needs adults that live with parents are probably the highly affected by these changes
- There are no nursing homes that will take my son
- This is discrimination. Iowa had a case that was found to be discrimination under civil rights
- If the parents die, who’s going to take care of the offspring
- Limiting families to 40 hours and 30 additional hours is unreasonable
- A contract with Ambassador is $1,000 a day for complex needs. More hours outside of the would be over the budget you’re talking about
- The Olmstead Committee has been written into state statute
- There’s a lot spoken about here. We will have to institutionalize our children. The shift in cost doesn’t make sense
- $300,000 per year if you’re worried about the budget
- Shame on you. Your math ain’t nothing. Show us how you got the solution. I’m telling you like a teacher
- Governor Pillen is taxing HHS 10%. Couldn’t that be used?
    - The waiver uses Person Centered Planning. I helped train PCP in NE. Tony Green was excited about the PCP in 2000. There is no *Person-directed care*. I read the whole 238 page dang thing.
    - PCP is a huge empowerment piece. States use it. States who don’t , don’t like to give people with disabilities the ability to control their services and their

budgets. You can find this on page 132, so you can find it. The application is inadequate.

- This meeting was designed to be accessible, including ASL. The state's presentation was not accessible: too many words on a page, too little space between sentences. Not plain language
    - The sound was inadequate due to the ceiling mics in the HHS building not being turned on. They used one of the computers for sound!
- Do the "risk factors" mean that if the participant exhibit any of these, they will be institutionalized?
- The changes are being made to make the waiver "sustainable"
- Participants that are vent-dependent, there are only a few places that can provide those services
- We didn't hear about this until we had only 30 days to comment
- My daughter has 15 to 30 seizures a day. There are wait list to get Medicaid beds in nursing homes.
- My daughter uses a trach. I was with someone who also used a trach. It took over 3 minutes to come clear her trach. My daughter has stopped breathing 6 times. She can't wait 3 minutes. One time she stopped breathing for 2 hours and 30 minutes. Two of us spent all that time bagging her
- You haven't even discussed this with nursing homes.
- You haven't included participants or families in the design of this application
- Several doctors within our community don't know how to treat her. We've had to take her out of state. How do you expect an institution to care for her.
- You're taking away our livelihood. You're taking away the quality of care my daughter deserves
- If it truly, truly, truly comes down to budget, then why would they be really willing to pay somebody more to come into my house, and put my kid into a horrible situation for another 30 hours instead of paying me less for 30 hours.
  And they can't say that it's, you know, to have another set of eyes for protection, because That's not… that's not gonna fly, because guess what? We aren't gonna do it, because that's gonna jeopardize my son's… my son's safety. It's not gonna happen, so they're not gonna have another set of eyes.

- We just would go without those 30. They're just banking on it, and then… and then they're sacrificing the children, or the adults, and that… that situation, hang on, Bubba!
- There are more “other” eyes in the community than in an institution
- I personally brought my son all of his equipment for his shower. I paid for all the modifications there. I paid for our van. I did that out of the income that I was paid. If you take that away, now I will have to revert to going and getting all of that through those funding, so then the sources that I didn't use, now I am going to have to use those sources.

- Really, you're not going to be saving any money, so is it really about budget, or what's the deal here?

- My name's Phil Gray, I'm a member of the Executives Committee of the ARC, and I was here today to basically learn about the process and understand the waivers paying and not be able to help formulate a physician for the art as things go forward.

    - The thing that stands out to me today, um, by the articles that we, largest advocate agency, nonprofit, volunteer advocate agency for IDD people in the state. We have a large list of email addresses, a large staff of people taking part with other programs, which go across the state.
    - So, we are very concerned, and the thing that strikes me here today that I will carry back to the executive committee, the description of these changes Um, sound reasonable, quite frankly, and we understand the need to have an organized way to manage these programs, because if not, the chaos will be unmanageable.
    - But what I'm hearing is the difference between The organizational program coming from the state, which seemed reasonable and doable, and the reality on the ground are two different things that do not fit and do not match and are not going to work.
    - We get the stories from parents that we listen to these kinds of catastrophes that are happening. And we can't match that with what we're hearing from the state in how this is a positive a reasonable and positive process and if I’m not convinced that ending the waitlist, which… I'm a former parent, my son was on for a while, is worth this catastrophe for what I'm hearing from parents.
    - We just… we don't get it. We frankly don't understand, I think, where this is going, and I… and I'm really concerned that this waiver is going to be implemented And the chaos I'm hearing from parents?
    - These are not made-up things. I don't know how you're going to deal with that. And you're going… and unfortunately, you've got that responsibility, and it's not what I want, but it's one that you've got, and I'm not convinced that this process is going forward in any kind of manner that we can manage, that

you can manage in a reasonable way without having the catastrophes we're hearing about here.
    - Um, I don't think anybody wants to fight with you about making a process that works. I just don't see, I don't hear from what I'm hearing today, that is working. And I don't understand how it's going to be managed to make it work, and you're not going to have the catastrophes you've heard today.

- Tony Green was condescending to participants.
    - I'm not sure I understand you (this makes people feel they are dumb)
    - You're talking to the Olmstead Committee. This is not public comment
    - Inadequate sound, horrible feedback, & not able to see most of the people in the room
    - He keeps saying that people are under the caps now. However the limits have to change due to increased costs. This is misleading.

The Olmstead Advisory Committee welcome the opportunity to discuss the concerns listed as well as any feedback the Department may have regarding these comments (and how the Department intends to provide feedback.) The renewal application did not consider health/safety issues for those using the waiver that would allow them to stay in the community and could severely limit the number of people that could get out of institutions.

Thank you for your attention to this matter.

Kathy Hoell, Mark A. Smith

Co-Chairpersons, Nebraska Olmstead Plan Advisory Committee