

Advisory Committee on Developmental Disabilities

Meeting Minutes

January 14, 2026

I. Call to order:

Lorie Regier called to order the regular meeting of the Advisory Committee on Developmental Disabilities (DD) at 10:20 am on Wednesday, January 14, 2026. This meeting was a hybrid meeting with in-person attendance at Conference Room P, 5220 South 16th St, Lincoln, NE and virtually via Zoom.

II. Roll call:

The following persons were present:

Advisory Members Present: Dorothy Ackland, Mike Browne, Dianne DeLair, Philip Gray, Shane Hunter, Kristen Larsen, Jennifer Miller, Mark Shriver, Joe Valenti, Angela Willey, Cristal Petersen, Lorie Regier, Paige Rivard, Suzanne Wahlgren

Advisory Members Absent: Jennifer Hansen

DHHS Staff: Tony Green, Kathy Harrington, Jenn Clark, Tyla Watson

III. Approval of Agenda:

- Motion made by Joe Valenti 2nd by Mike Browne to approve agenda as presented.
 - All in Favor: Dorothy Ackland, Mike Browne, Dianne DeLair, Philip Gray, Shane Hunter, Kristen Larsen, Jennifer Miller, Mark Shriver, Joe Valenti, Angela Willey, Cristal Petersen, Paige Rivard, Suzanne Wahlgren
 - All Opposed: None

IV. Approval of September Meeting Minutes:

- Motion made by Kristen Larsen 2nd by Dianne DeLair to approve the minutes as
 - All in Favor: Dorothy Ackland, Mike Browne, Dianne DeLair, Philip Gray, Shane Hunter, Kristen Larsen, Jennifer Miller, Mark Shriver, Joe Valenti, Angela Willey, Cristal Petersen, Paige Rivard, Suzanne Wahlgren
 - All Opposed: None
 - Abstain from voting: None

V. Public Comments received at 10:30 AM

- Attachment A: Public Comments
 - Verbal Public Comments received from:
 - Susan Samuelson, Nebraska Rare, Hunters Hope Heroes
 - Heidi Sommer, Parent
 - Lisa Hobza, Parent
 - Laura Vajgt, Parent
 - Jennifer Melvin, Parent
 - Wendy Andersen, Parent & Common Coalition
 - Alana Schriver, Parent

VI. Division of Developmental Disabilities (DD) Updates:

- **Aged and Disabled and Traumatic Brain Injury Waivers – proposed changes**
 - 30-day public comment was held from December 5, 2025-January 5, 2026.
 - Summary of proposed waiver changes & copy of presentations used at the public comment sessions is posted on the public comment page.
 - Division is currently reviewing the comments received. If the department makes changes that would be considered substantial changes, we would then publish another 30-day public comment period for people. If there are no changes or minor changes, the waiver would be submitted to CMS. There is a summary of public comments we are required to submit with the application, we also have to the departments response to those public comments. Once review is complete, comments and the departments response to comments will be posted online. CMS has a 90-day window to review waiver submissions.
 - Effective date of this waiver is requested to be July 1st.
 - We had over 300 different sets of public comments. The majority of the concerns received for public comment were related to the cap of the personal care hours.
 - Committee discussion notes:
 - Would like to have a better understanding of the A&D process to determine service needs assessment. It goes through different tasks such as bathing, feeding, meal preparation, oxygen, turning/positioning. There are maximums we are looking at in the SNA, right now some people are being paid for 160 minutes for laundry, this may change to 30 minutes because hours should match the actual time staff are performing a task.
 - Sounds very similar to PAS the way it's structured. Why some would need to be on PAS vs. A&D Waiver?
 - On PAS you don't have to have a nursing home level of care. It is available to anyone on Medicaid with identified needs. PAS does not allow Supervision. A&D waivers do allow for supervision.
 - Why would the state be willing to pay more to the provider than the family over the hours?
 - Struggling to understand why we would cap on nursing level of care.
 - Having experienced this, there is a shortage of people that are willing to care for people with disabilities.
 - Regular job. This idea of a 40-hour week is not legitimate. Most need some form of 24/7. I'm concerned greatly about the budget neutrality. That does not exist as this waiver exists. I greatly hope that you remove that 40-hour cap. 70-hours is much more acceptable than 40-hours. I'm sure you have all taken some very harsh comments. Some were here today. I have always believed that you all care about our people. I still do. I hope that you are able to make changes in this waiver. I don't envy your position. I don't know what can be done here and now. We are facing a different population, than we did in the 50s. A population of individuals who are surviving that would not have survived before. We need to recognize that. Some of these system changes would be really helpful.

- Is there any way we can add more respite hours to make it easier for us to get respite. I know some states have upwards of 1200 hours of respite, significantly more than Nebraska.
- Phil Gray - I believe you are doing what you can. From a systems perspective, we need to be involved we can't have these kinds of meetings if we're not involved. That doesn't seem to flow. Doing that ahead of time seems to be a much better operation than trying to fix it now, and I'm not being critical. The legislature passed legislation to form, to fund, what is now Beatrice State Developmental Center, because they thought that was the only option.
- Suzie – Have 4 children, the 2nd is disabled. Couple of comments. When you take into consideration, some of these things are just daily living. Do they take into consideration how much longer those tasks take. The additional time, more frequent time.
- Would caution sugar coating public comments. If you make them pretty. Can you leave them anonymous. Some of us, this is our life. I don't take it the best. Some of this stuff is not pretty, it's taxing.

➤ **interRAI Update**

- HANDOUT: interRAI Tracking – December 2025
- HANDOUT: interRAI Appeals 7/01/2025-12/31/2025
 - Total of 160 appeals
 - 94 are currently active
 - 66 closed
 - 27 Dismissed/Withdrawn
 - 39 Affirmed
- Division comment: If a family feels an answer is incorrect on the interRAI. Families can let us know. The answers can be updated. Just because one question is updated, it doesn't mean that the final score will change. The goal as a service system is to get people to the greatest level of independence.
- Committee Discussion notes:
 - How do we know that the algorithm that you've instituted with your actuarial has been validated? I think that is where we have some distrust. It's always the questions of those that go down.
 - Have heard concerns about the quality of the assessors.
 - The percentage of all people has not changed from when we were doing the old system. It doesn't mean people are not changing.
 - There are two separate decision-making processes. The waiver decision is independent of the case mix index decision, as is the level of care.
 - How are we preparing people currently in continuous care to go without it being a sudden transition that is upsetting and scary.
 - Could you have a person in a group home and their score indicates that they should be more independent
 - We aren't forcing people to move currently, however teams need to start having those conversations about appropriate services and steps needed to move in that direction.

➤ **DD Court Ordered Custody Act (COCA) Update:**

- HANDOUT: DD COCA Statistics
- Currently 53 people under DD COCA
 - Five (5) people do not meet DD Level of care need and are paid for via state funds only.
- How many are employed or have supported employment: Four
 - Many of the people on DD COCA do require one-to-one or two-to-one staffing which can make finding appropriate employment more difficult.
- There are six (6) people that have been on DD COCA prior to 2014
- Four (4) were known to the division/receiving services prior.
- Five (5) were charged with sexual assault of some sort. (Not found guilty of a crime.)
- Three (3) did not have guardians. This does cause a little more caution on reducing restrictions with Judges. These three have also made it known, should they get relieved of DDCOCA, they will sign themselves out of services.

➤ **Family Support Waiver Usage**

- HANDOUT: Where are they now?
 - Total of 2,521 offers made for the Family Support Waiver (FSW)
 - A total of 913 declined services. For some families, they have small children. The waitlist was years long, and families were encouraged to apply early. They do not need services right now. They'll come back and reapply when they need them.
 - Do have people in-process? Some are kids that are graduating this year. Some are currently determining provider. Reminder this waiver has a \$10,000 cap currently. A lot of families plan to use in the summer.
- Agency Providers are seeing that they can make some things work with the waiver. Especially during the summer with day camps or things like that. They are able to work with staffing ratios.
- Biggest gap for families? Finding provider to provide the intermittent support - one hour here or there type of help.
- Committee feedback: becoming an independent provider is too cumbersome. There are college educated people that cannot figure out how to get to the finish line. I have had people willing to provide free childcare as a friend for a night over going through the hassle of signing up to become a provider because it is too much. There are so many steps. Need tutorials and step-by-step instructions.
- Could we have a service coordinator come over to our house help sign up/help onboard new staff, writing programs?
- These people just want to help families out, and they don't want to go to 25 hours of classes. They just want to help the family out.
- People need to understand the process. This is a critical effort. Shauna – Provider Engagement manager at DHHS is great, but even if you have 10 Shauna's that might not be enough.
- Division Response: Self-direction is at the direction of the participant and the family. It is not generally the state's role to do training, oversight, and

monitoring. This is the family choosing independent providers, as they don't want an agency. The alternative for those that don't want the responsibility of self-direction would be to hire an agency. They'll do all the training, write the programs, ensure that people clock in/clock out. If you want self-direction, or the independent model, that is a responsibility that whoever's doing that self-direction, is taking on that responsibility as a family/guardian/loved one.

- Committee response: Not all families choose it because it is preferred. Sometimes there is no agency that will serve them. Location? Needs? I would be happy with an agency, haven't been able to find one.

➤ **Legislative Update**

- LB733 introduced by Reipe: Change the name of the Division of Developmental Disabilities to the Division of Disability and Aging within the Department of Health and Human Services – Hearing Next Wednesday, January 21, 2026
- LB737 introduced by Rountree: Require a joint public hearing to evaluate the progress of the Olmstead plan for individuals with disabilities
- LB898 introduced by Lonowki: Changes to Open Meeting
- LB958 introduced by Cavanaugh: Provide a requirement for the Department of Health and Human Services relating to 1915(c) waivers and define nursing facility level of care under the Medical Assistance Act
- Do expect a possible day support license bill to be introduced.

VII. New Business:

- Upcoming DD Waiver Amendment Public Comment
 - The Division intends on submitting an Amendment to the DD waivers ending Consultative assessment. It is a duplication because the MCO's can and should be paying for the Functional Behavioral Assessment (FBA).
 - Public comment to begin January 26, 2026

VIII. Adjournment: Committee meeting ended at 2:00 PM

Next Meeting:
March 11, 2026
Hybrid Meeting

Susan Samuelson, Parent, Nebraska Rare, Hunters Hope Heroes for Duchenne

Mother, Son with Complex needs. Works with Paige. Just made aware of the proposed changes December 5, 2025. I have organized a press conference to bring awareness of these changes. Feel this is inexcusable. Reducing the hours to 40 hours a week from 120, for some families this is how they survive. The families, whether they can speak or not, have a right to choose who provides services to their family. Changing these hours by such an extreme amount of time. They have got to be able to support their lives in a home-based setting. I am really, really concerned how this is taking away the rights on the individuals. There are not a lot of facilities that will take these people.

I speak on behalf of the Duchenne community. If there was a place for them to go, the amount of time and care. There is no way the facilities can support that. We are setting us up for disaster. You are pushing people to the edge with these proposals. The state has now said you can have up to 30 hour of the care with a facility coming in. Some families do not feel comfortable having people come into their homes that are not family. This is setting us up for disaster. Cutting services in the waiver is not the correct place to cut services.

Heidi Sommer, Parent

Son recently stopped walking. He has a rare disease, he is regressing. He has been on hospice for 2 years. They are choosing quality of life. His dad is his person and he is her person. Scared to die, because I care for my son 24 hours a day. I feel guilty that I have a job, that I want to spend time with my husband and daughter. Should be able to support our children and still live our lives. Son got on the waiver in 2018. So he has not cost the state a lot of money. People seem to think that families are living large. Have lived below are means.

I did the homework. There are currently no nursing homes that will take her son. The proposed changes will not work. I don't want my son to go there. This is to make the point that they would not take him. Going to the nursing home is not what our family wants.

I think you do some incredible work. Ending the waitlist is great, but not the at the expense of others. You have kids on a waitlist that have school. Our one love in the state is Munroe Meyer. He goes to programs there.

Before our caregiver got there, because they're not capable. A lot of Balance, I end up just doing things myself. So, why not pay per individual? Agency get \$30 an hour, the average pay for parents is \$15.00.

May 15th, I need to know what the plan is. I need to know which nursing homes will support my child. I don't think they exist. Cost those on the higher budgets than my son. It's just flat-out dangerous, from a safety perspective. It makes me very sad, I can't think about it. There are 168 hours a week. Why not just give them a flat rate. Feels like forced institutionalized.

Your whole department is overworked. This is no blame on the parents. We need to work together with out parents and agencies and try to tell you what my day looks like. I can't go to the bathroom because they would fall if I left their side. So I have think, do I eat or drink? Probably just not today. That is terrible.

Thank you for your time. On the outside he looks completely fine. He is a sweet pleasure.

Lisa Hobza, Parent

So I'm just gonna speak off the cuff. I have a 22-year-old daughter, with complex medical needs...So, my daughter was never supposed to survive her birth. She was diagnosed in utero. I was encouraged to terminate my pregnancy. Just because of life choices, that's not a choice for me. She's 22 years old.

They type of person, a person like my daughter didn't exist 20 years ago. My daughter would have never lived. She's trained, she's has a G-button, has a shot. She had lots of extra months. I think these changes to the program are not looking at the person. My Daughter is kind of unique. She qualified for Medicaid since birth. Since she left the hospital, received private duty though managed care, and so she turned 19 years old. She qualified for social security. I was told by Human Services that I needed to apply for to supplement her nursing care needs. In the first 19 years of life, that didn't allow us to use any extra services, it only provided for more prescriptions for nursing care.

The family is taking care of the shortage. Having people come into the home can cause stress. Not taking care of the individual who has been in constant stress.

My husband and I will continue to work. Still have 3 additional children. Not people have said really nasty comments, like, I should have never had one. You know that's very different. That all my focus should have been on Noel and her cares, but managed them all until she turned 18. This change was made on the AD waiver.

Now I'm fighting to read the waivers and manage her care. Due to her complex medical needs, she does quality for personal care. Due to the medical risks, the assessments that she needs, because she has seizures, she can not clear her own. People have to be trained, she needs to be sucked and she gets plugged, so they need to change it, she's non-verbal. She can't ask for help.

By capping the hours at 40 hours, which is unacceptable. There is no one else to do it. So I do it to show the need for her care. I have asked for more hours too.

I had my fair hearing with the state, because they have reduced hours to an all-time low. 40 hours, which wouldn't even allow me to work outside the home. Because there's travel time, there's break time. All those kinds of things are forcing me to either reduce my work hours at home and take a lower-wage job because I get paid less to provide care. That's not good for her, that's not good for me. As I continue to lose hours through

the MCO. I want to want, to provide care for my daughter, I don't want to feel like I have to. Although she is stable, they want to take my nursing hours away.

I'm not a unique situation. She may qualify for some additional hours because she has been stable. They want to take my nursing hours away and stop it with a person from a company. They will provide her personal care, but not her medical care.

By having people that are unqualified to care for her, maybe these outside caregivers that are making \$13 an hour to empty the trash, supervise a shower, make meals. I have to set her up. I have to still do everything. My daughter is a true joy, it's just too much for these people, they're not going to come back.

There needs to be some care coordination between the MCOs. What they qualify for, long-term care. During my fair hearing, they were like the state will pay for her to go to a nursing home. But like Heidi said, no one will take them. The level of care is weighing down the base. Someone living an active life in a nursing home, she can't. She needs constant care. She can't wait, even if she wanted to. She could stare at the ceiling. There is still the risk that she'll have a seizure and she can't roll. She's been aspirating.

I was fortunate enough to have the Medicaid director come to my house and meet my daughter. See all of her things, and I appreciate it. There isn't a one-size-fits all. I think it's very individualized. Kind of like the DD Waiver, there's different levels of care.

I appreciate the changes to the waiver. I don't think there is a one size fits all. I will tell you that all needs are different. I was willing to give up some of my hours. They want us to cut laundry to 30 minutes. So, when you are talking about doing laundry it was 2 hours. I don't watch the washer and dryer to do laundry. That's unfair to me, to charge 2 hours for laundry, that's not how it is. It's very much how long it takes me to walk downstairs you know. So I accept the reduction in hours. Same thing with cleaning the bathroom. I don't need to get paid. If my daughter had her own bathroom and it was gonna take additional time to clean her bathroom, it would be better for me to accept payment for cleaning that bathroom. But she shares with her sibling. I would have to clean the bathroom anyway.

Checks and Balances. There's people that have used the system. You've been taught to fight for the max, because when you turn around, they're gonna take it away. We are creating a problem that doesn't need to exist. We're trying to....create a life...to exist. I fear that there is a huge gap.

Laura Vajgt, Parent

I have a daughter, she's 21 years old. Me and my husband care for her because we're unable to get nurses into our house that are comfortable working on ventilators. She is bed dependent. She's missing a piece of her brain. And she requires all care. I originally, tried for an entire year, fought to get on the DD waiver. And when they suffer for the intra-RAI, they put her at a lower tier than I assumed she would be. Now I kind of figured out

that that was a scam as well. Doing so, Jenn told me that the AD waiver would be the best place for my daughter and her parents.

Well, Jenn, thank you. Thank you for that. So, a couple thoughts here. Um, I know that you guys have cut a lot of people since July. We've been doing cuts. With this proposal, you haven't given these cuts a good amount of time to see if anything was coming out of those financially that would benefit. I know you like to keep using the, oh, we got 300% increase. It's obvious, okay? We're not all stupid, that's obvious. Did you guys realize this when you opened that door for LRI?

It's you're doing and you're taking it off the backs of us. Okay, I find that really interesting. There is no place to send my daughter, which clearly you know, and Jenn knows, because I messaged her, and I said, "What do we do here?" Because there's a lot of parents like me...If you drop the pay, we cannot provide a safe environment. They will have to go to an institution. And I'm not talking, like, a nursing home for a grandma or grandpa. I'm talking 24-hour ventilators. Okay, and I don't... I think you guys are confused. Do you understand what that means? Did you think about that with your proposal? Did you call around? Because the ambassador said they never have had someone like her. There's nowhere for her to go.

Sorry, this is really frustrating for me.

A lot of parents are going to end up taking their kids to a hospital. And they're going to end up... I don't know how much does insurance charge, you guys are going to end up forking the bill for all this. Do you know how much an ICU would cost for a ventilator to stay till a bed open up? There isn't anything out there. You do not have a plan. Go back to the drawing board, figure it out.

Mr. Green, I think you are an absolute conflict of interest in those intra-RAI results. Shame on you. Jenn, putting us on this side, when you knew, you knew this was coming is insulting to me and all these other families.

I honestly... I don't know how you guys are leaving your house. It's very frustrating for me as a mother. There is no support outside. Mr. Green, why don't you come and suction my child through the night? Jenn, why don't you change her poopy pants? Why don't you care for her?

I don't think you guys have a clue what you're doing. Go back to the drawing board. Figure it out again. Use some education when you're thinking about stuff like this. You're creating a community problem in these hospitals.

With not having adequate places to put these individuals. Sorry for the frustration, but that's all I gotta say.

Jennifer Melvin, Parent

I will try to be as brief as I can. Thank you for having open comments today, I know this is frustrating for all of us. I am a parent of a 27-year-old disabled, completely disabled child as well.

I do appreciate you guys taking the time to listen to us parents. I reiterate everything that every other mom has said here with the hours. And the math, is not mathing. I just wanted to make you aware I had a meeting with my daughter's service coordinator this week. We live in the Hastings area. And in past Zooms, Jen had said to... utilize respite and a few other things, day programs. My daughter has had a slew of medical emergencies over the years, and has had brain surgery. She has to take injections every day for blood clots. I have sent in this letter to Mr. Green and other people, so you guys have this in the public comments, my daughter's history.

She has 15 to 30 seizures a day, and to reiterate another Mom's comments. Sorry, I'm trying not to cry right here. We got about 2 hours of sleep last night, and it wasn't all at once, because my daughter does not sleep. Because of 15 to 30 seizures on average a day.

We will go maybe one or two days a month without a seizure. When we have in-home care. All they will do is stand and watch. They cannot put her on their side, they cannot clear her airway, make sure she doesn't aspirate. We were told very early on that Tabitha would need in-home care. And our caseworkers told us to buck up. There was a gap in the system. We did what we could. We were told to...train ourselves to take care of her, because there was nowhere for her to go. Nursing homes will not take anybody under the age of 55. In our area. There is no respite in the Hastings, Kearney, Grand Island area of 100-some people, there is not one respite provider signed up.

We currently... they are currently paying someone to come into my home twice a week, so that way I can either take a nap, get laundry done, whatever. But I'm here in case there's a seizure, because they can't take care of her. They pay them \$48 an hour. I started out at \$9, and I only got bumped up because the cost-of-living increase with the minimum wage. So, at \$15 an hour ... if you guys pay somebody \$30... 30 hours a week...at the 48, that's \$14.40 a week. For 112, it's \$16.80. And that pays for my daughter to have two rooms. She's got an exercise playroom, her own bathroom, her own bedroom, handicap accessible house everything that we need.

I'm trying to keep this very short, and I apologize. But my frustration right now, I guess...These changes started in October. And it kept getting pushed back off of the calendar, and you guys knew about this stuff. being proposed, months ago, and waited until Christmas time to tell us for the open comments.

The only good thing that's come out of this is I've met other moms like us. But my daughter has a rare genetic disorder that was not diagnosed until 2008. And there are less than, like, a thousand in the entire world that have this very rare genetic disorder. You guys are putting the lives of the very most vulnerable in jeopardy. And I fear that if

this goes through, there will be death and injury. And, quite frankly, sadness is already here.

This is a very, very real concern for us families. We are now looking at having to move, because we can't afford the house that we modified for our daughter. That she loves. She has blood clot in her leg, can't walk, has wheelchairs, needs oxygen that Medicaid and our insurance won't cover.

So please, please visit some of these families when they ask you to and take a hard look at us parents that are sacrificing everything. Everything to fill the gap that we were told by HHS that we had to fill, because you guys don't have the resources for our children.

Thank you.

Wendy Anderson, Common Coalition & Parent

Hi, my name is Wendy Anderson. Professionally, I represent the Common Coalition, where we're here to protect the rights for individuals with disabilities. I appreciate all of your time. Not a day goes by that I don't receive a phone call of a family member in tears, worried about the care for their loved ones, worried about having to lose their job to care for them, or what are they going to do about their house with life problems when they can't afford it anymore?

Professionally, I ask you to consider your daily lives. And then if you don't have an individual with a disability living in your house, to consider all of the stress that's on top of that.

Personally, I have 3 children. My youngest is here with me, learning about the process of this. My older children had disabilities. My son, Dexter, is 16 years old. He was 6 months old, he was diagnosed with a rare genetic disorder tuberous sclerosis.

So he has non-cancerous tumors throughout his body, seizures, epilepsy, autism, intellectual disabilities, we can come up with a list here. Suddenly, in September, he had to have emergency brain surgery.

We live in Iowa. My parents are from Lexington, Nebraska. They're elderly, they're coming down with dementia. I live 4 hours away from my parents. All of my son's care is in Omaha, therapist, his doctor's visits, we have an open enrollment in the Madame School. So we spend at least an hour and a half. Every day, driving him to and from school, and his therapies, and all of that.

We would like to move to Nebraska. I have elderly parents that someday, I might have to look into a care home for them. We can't move to Nebraska. We have a business. We would like to move to Nebraska. We can't move any of... Because we aren't able to get the care and the support that we need in the next person. And I know there's other families like mine that would like to move to Nebraska.

Because of the changes in the blocks and the systems and things that are happening, we aren't able to. And it's really sad, because. I don't know how I'm going to be able to help care for my parents, unless I leave my family here, and we don't have any support here.

In Iowa, it's just us, so we'd like to move closer to my family. My sisters. We just aren't able to because of my son. So, thank you again, um, for all that you're doing, and everyone's perspectives that you're taking into consideration.

Alana Schriver, Parent

Hey, everyone. I'm gonna speak as a parent who's service coordinator has only reached out once in the last 6 months. I'm not on the A&D waiver, it's a different waiver. Based on what all these parents are saying, and how impossible it is to find alternative care, that should be a responsibility of service coordination, and that if service coordination does not have a real viable alternative solution to capping these parent-caregiver hours, we shouldn't do this.

I think everyone has shared how difficult it is to find an actual nursing home placement, even if you want that option. From what I'm hearing, Ambassador is the only place accepting individuals like this right now, and that's \$1,000 a day. I don't think the state should be able to cap someone's hours from a health and safety perspective, unless there is actually a real viable alternative with an open bed, willing to take that specific individual and their needs on Medicaid in real time. Otherwise, I don't think it is safe to cap that person's hours.

Secondly, it is incredibly difficult to find a provider to come to your house, because the wages are so low for this challenging work. Our rate methodology for the A&D waiver had a study done a couple of years ago that recommended increasing the rates and then tying those to inflation.

I understand that there is a budget deficit in Nebraska, and rates are stagnant, but...that is not a revenue issue, that is 100% a policy problem. And this administration is choosing policies that value tax cuts for corporations. And the wealthiest Nebraskans on the back of the aging and disabled. I know the other parents here have expressed frustrations that maybe people on the DD waiver are getting more money, or should be getting cut.

This is not a competition between other types of disabilities ...aging or disabled persons or other waiver programs. This is a competition between wealthy corporations getting their taxes capped at 3.99%, which costs the state \$720 million in revenue per year. They're putting that on the backs of the aging and disabled. It's not a state revenue issue. It's a policy problem. And this shows the values of our administration, and I was surprised. I shouldn't have been surprised, but I was appalled at Governor Pellen's comments in the Nebraska Examiner article. I spoke with that reporter right after Governor Pellen did.

And he told me even some additional things Governor Pellen had said. So, this is Governor Pellen's DD Advisory Committee. He refuses to meet with any of us face-to-face, so if you

can pass the message on to him. He wants to go back to this utopia in his mind of neighbors helping neighbors or not paying grandmas to do a grandma's job.

Back in the day, these individuals, to Lisa's point, didn't survive a lot of times to adulthood. We've had medical advances, so we have more people with disabilities living longer. It's a pro-life stance, to walk the walk and support them through that life.

Also...I don't know any grandma whose grandma role involves changing the diaper of a 45-year-old man. My son's only 13, and his grandparents are in their 80s. They're going to need caregivers soon. Not that we live anywhere near each other, they're on a farm in the middle of nowhere, there are no services. In the area where my parents live, so I can't live next to them. To say we should be relying on local charities, or neighbors, or churches is, I hope, willfully obtuse. I would hope. He's not that ignorant, but if he is, he needs to actually meet with these parents face-to-face, and visit their homes, and see for himself. The results of his decisions.

If you want more reliable care, you need to increase the rates and pay for quality workforce, so that a workforce is available, and you need to have real alternatives that service coordinators can actually give families when their hours are cut.

Thanks.

Advisory Committee on Developmental Disabilities

Order of Business

Hybrid Meeting

Virtual: <https://us06web.zoom.us/j/81882479790?pwd=j96SwCxKth6QBjkVM5uB5aRcAre5Qu.1>

Meeting ID: 818 8247 9790 Passcode: 459198

In-Person: Conference Room P, 5220 South 16th St, Lincoln, NE

Wednesday, January 14, 2026

10:00 AM – 2:00 PM CT

- I. Call Meeting to Order
- II. Roll Call
- III. Order of Business:
Committee action: Motion to approve the Order of Business
- IV. November Meeting Minutes:
Committee action: Motion to approve the November meeting minutes.
- V. Public Comments: Committee to hear Public Comments at 10:30 AM
- VI. Developmental Disabilities (DD) Division Updates:
 - a) Renewal Aged and Disabled and amend Trauma Brain Injury Waiver – Proposed Changes. The 30-day public comment period was from December 5, 2025, through January 5, 2026.
 - b) interRAI Update
 - (1) Oversight of the interRAI results, changes in the Tier Levels, and the services which are being offered
 - c) DD Court Ordered Custody Act (COCA)– November meeting Follow-up: Committee requested additional information on the individuals that the division has requested be removed from commitment but continue to be served under DD COCA
 - (1) Tracking and Understanding Court Ordered Custody Individuals
 - d) Family Support Waiver (FSW) Usage – November meeting follow-up: The committee requested an update on the usage of services on the FSW and FSW Budget usage
 - e) Legislative Update
- VII. Old Business:
 - a) Discuss interest in Committee holding a 2026 Spring meeting at Beatrice State Developmental Center (Agenda items tabled during the November meeting to a later date for discussion/consideration.)
 - b) Oversight of the SLP versus Group Home settings
- VIII. New Business:
 - a) Committee Goals for 2026
 - b) DD Waiver Amendment – Notifying committee of upcoming public comment to begin January 26, 2026



**Division of Developmental Disabilities
DD Advisory Committee
interRAI Appeals
July 1, 2025 – December 31, 2025**

Total InterRAI Appeals:	160
Active Appeals:	94
Closed Appeals:	66

Closed Appeals Outcomes	
Affirmed	39
Dismissed/Withdrawn	27
Revered	0



Division of Developmental Disabilities
DD Advisory Committee
End of the Waitlist

Where are they now?

	DD WAIVER			Total
	CDD	DDAD	FSW	
Declined Offer		275	913	1188
In Process		80	382	462
Receiving Active Services	71	195	265	531
Accepted Alternative DHHS Services		190	608	798
No Longer Using Services	6	115	353	474
Grand Total	77	855	2521	3453

DD ADVISORY COMMITTEE

DD Court-Ordered Custody Act Statistics

GENDER

Female	10
Male	43
	<u>53</u>

CURRENT AGE

19-24 yrs	10
25-39 yrs	32
40-59 yrs	11
60+ yrs	0
	<u>53</u>

FUNDING

CDD	48
DDAID	5
	<u>53</u>

COUNTY OF COMMITMENT

Buffalo	2
Butler	1
Cass	3
Cheyenne	1
Colfax	2
Dodge	1
Douglas	10
Gage	1
Holt	1
Jefferson	0
Johnson	1
Lancaster	8
Madison	5
Otoe	1
Phelps	1
Platte	1
Thurston	1
Sarpy	8
Saunders	2
Scottsbluff	1
Wayne	1
Washington	1
	<u>53</u>

YEAR OF COMMITMENT

2009	1
2010	0
2011	3
2012	0
2013	0
2014	2
2015	1
2016	4
2017	2
2018	1
2019	6
2020	5
2021	5
2022	7
2023	4
2024	4
2025	8
	<u>53</u>

CURRENT RESIDENTIAL

Shared Living	29
Continuous Residential	18
Independent Living	2
ICF	2
NRC	1
LRC	1
	<u>53</u>

SERVICES BEFORE DDCOCA

None	28
SC Only	7
Day Services	2
CDD	15
LRC	1
	<u>53</u>

