Advisory Committee on Developmental Disabilities

Meeting Minutes
March 11, 2026

I. Call to order:

Mike Browne called to order the regular meeting of the Advisory Committee on Developmental Disabilities (DD) at 10:00 am on Wednesday, March 11, 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, Phil Gray, Jennifer Hansen, Shane Hunter, Kristen Larsen, Cris Petersen, Lorie Regier, Paige Rivard, Mark Shriver, Joe Valenti, Angela Willey, Jennifer Miller
Advisory Members Absent: Suzanne Wahlgren
DHHS Staff: Tony Green, Jenn Clark, Kristen Smith, Tyla Watson

III. Approval of Agenda:

- Motion made by Chris Petersen 2nd by Dianne DeLair to approve agenda as presented. Roll call vote taken. Motion carried.
  - All in Favor: Dorothy Ackland, Mike Browne, Dianne DeLair, Jennifer Hansen, Shane Hunter, Kristen Larsen, Jennifer Miller, Cris Petersen, Lorie Regier, Paige Rivard, Mark Shriver, Joe Valenti, Angela Willey
  - All Opposed: None

IV. Approval of September Meeting Minutes:

- Motion made by Joe Valenti 2nd by Cris Petersen to approve the January minutes as presented. Roll call vote taken. Motion carried.
  - All in Favor: Dorothy Ackland, Mike Browne, Dianne DeLair, Jennifer Hansen, Shane Hunter, Kristen Larsen, Jennifer Miller, Cris Petersen, Lorie Regier, Paige Rivard, Mark Shriver, Joe Valenti, Angela Willey
  - All Opposed: None
  - Abstain from voting: None

V. Division of Developmental Disabilities (DD) Updates:

- **interRAI Update – Presented by Kristen Smith, DHHS**
  - Handout: interRAI Update – January 31, 2026
    - 643 initial & 2,342 renewal interRAI' s
  - Handout: interRAI Appeal Data – January 31, 2026
    - 237 Total appeals
      - 130 Active Appeals
      - 107 Closed Appeals
        - 61 Affirmed Appeals
        - 46 Dismissed/Withdrawn

- Question: Out of the 237 appeals - Can we get a reason for appeal? Response: The Division receives the appeal information from our appeal office. The reason for the appeal is the interRAI. Division is not currently tracking details breaking down from there.
- Question: Prior to the interRAI was the number of appeals the same? Response: No, directly prior to the implementation of the interRAI, the number of ICAP appeals was lower. However, when the ICAP was initially implemented the number of appeals was higher.
- Question: Why does the interRAI look at the last three days. Our kids don't always display all of their behaviors in the last three days. Response: The interRAI utilizes a three-day look-back window for specific items as it increases the accuracy of the recall of the interviewee(s). The behavior specific questions responses also include "present, but not in last 3 days" to capture what behaviors are currently occurring. Additionally, there are other items, such as history of violence, that have longer look-back windows to capture intensity or frequency.
- Question: How do we recruit waiver service specialists (WSS)? Response: Through regular DHHS hiring practices. WSS are required to have a Bachelor degree related to Health Services field or equivalent work experience.

➢ **Waiver Update**

- League of Human Dignity A&D Waiver transition of Service Coordination to the State of Nebraska
  - The Division is currently interviewing for the Service Coordination (SC), SC Supervisor, and Administrator positions. We hope that many people will be able to keep the services coordinator they previously had and it will be a smooth transition.
  - Change to go into effect April 1, 2026.
  - Committee Discussion/Feedback:
    - With all of the activities going in the division currently could we have waited? Response: We continue to review all our contracts and spending, as part of that review it was determined there would be tax dollar savings to transition Service Coordination to the State of Nebraska. There is no easy time to make a change. This is a budgetary change.

- A&D waiver amendment, Second 30-day public comment period closed March 9, 2026
  - Committee Discussion:
    - Concerns regarding budget neutrality. To calculate budget neutrality, the State uses the average of all nursing home individuals. Would like the division to consider comparing people with similar needs (apples to apples) not the full average. Response: There are different ways to meet budget neutrality. There are things that could be explored with CMS. The high-cost people are currently included in the average. There are always pros and cons to changing the way we calculate this.

- Question: Can you explain what the exception process will look like and how families would request? Answer: exception processes would be for those above the 150%. The request will be simple. The Service Coordinator will fill out a simple form. The clinical team will review with their nurses. We have quite a few people that have people come into their homes and wrap services around them.
- Concern is for those that really need more.
- Those that live at home with a caregiver can't go over the 150% they are working for free. This is the concern at a national level.

(NOTE: Break for public comment – see section VI)

- **Policy Manual Changes Update**
  - Handout: HCBS Provider Policy Manual Updates Presentation
  - Handout: 5.2 Funding Tiers – Update for Policy Manual
    - Question: Some of the comments we heard are about the algorithm. Does DHHS know the algorithm? Response: No, the Case Mix Index (CMI) algorithm is proprietary information owned by interRAI not the Department. The Departments algorithm (grouping of scores) for using the CMI to calculate budget tiers, is published on the public website.

VI. Public Comments received at 11:00 AM (Following waiver update)

- Public Comments attached – Attachment A
  - Public Comments received from:
    - Stacy Pfeifer, ARC of Nebraska
    - Carol Salber, Guardian
    - Tori Sorensen, Parent
    - Curt Safranek, Parent
    - Brook Fine, Parent
    - Mark Rolfsmeyer, Parent/Guardian
    - Cathy Martinez, Autism Family Network, Parent
    - Dominic Gillen, Family
    - Lehn Straub, Father/Power of Attorney
    - Molly Mailander, Family
    - Dilan Sorensen, Self Advocate
    - Shelly Jorges, Mother/Guardian
    - Savannah Baclich, Family
    - Anna Keyzer, Parent
    - Susan Brown, Mother
  - Written public comments received from:
    - Ed James, Independent Provider
    - Mr. & Mr. Stone, Family
    - Trevor Hinze, Family
    - Leila Johnson, Mother
    - Ronald Rehtus & Angela Rehtus, Parents/Legal Guardians/Conservators
    - Matt & Ame Creglow, Parents

- Committee Discussion following public comment:
  - Concerns with the quality of staffing, doing assessments. Some of these assessors are not doing a good job all the time. Example given: Assessor was supposed to be there at 11:00 and doesn't get there until 1:00 PM.
  - Question: Is it possible that a secondary person could do the interRAI and see what the result comes out to or do we have to stick with the first assessor? Answer: The family can bring corrections to the divisions. We will correct prior to the appeal if there is evidence that the answers are incorrect.
  - Comments: How do we educate people? How can we help address the situation? What are the points in the system that do need to be changed? I don't necessarily think it's the algorithm. In every situation you will have people with adverse outcomes. There are times that people are not happy. Where are the right points to make good quality outcomes. I could be wrong, but I don't think it's the interRAI. It's better than ICAP.
  - Question: Can the division re-band the interRAI results? Answer: Yes, the division can re-band them. States build those to define policy, set budgets. We took the case mix index (Which we have no control over – this is interRAI' s case mix index) and band the results to the budget tiers. This is also how the ICAP scores were done via banding of scores.
  - Feel the appeal process should be done independently outside of DHHS.
  - Concerning the funding. Developmental Disabilities continue to go up. Feels as though A&D is seeing a reduction.
  - It's not normal parental care. These people are working 24/7. I don't know how we do this. I know that number can increase.
  - Division Comment: Many states are grappling with this, paid caregivers, and what it looks like. Some states would look at Nebraska and say we are very generous. Every state does it differently.

VII. Quality Management/Liberty Update:

- Handout: Quality Team Strategic Plan 2026 – Paul Edwards, DHHS and Betty Smith, Liberty
- Four initiatives focus on the quality improvement strategy
  - National Core Indicators – working to increase participant satisfaction with services. Expand participant choice and control in daily life.
    - National Core indicator Dashboard – team managers interactive dashboard to increase accessibility of survey results. https://dhhs.ne.gov/Pages/Public-Data-Dashboards.aspx
    - Will be sending out notice to those selected to participate in the Aging and Disabled adult consumer survey this month.
    - Latest State of the Workforce 2024 Survey report has been released.
  - Critical incident management process – Reduce emergency and safety incident & Strengthen provider readiness
    - Question: How are we confirming general event reports (GER's) are correct. Just because one is marked as a medium doesn't mean it shouldn't be a high? Answer: Quality unit reviews 100% high-level GER's and does spot

check 10% Medium-level GER's. Do work with providers on report, review T-logs, and we are continuing to look at processes

- Human and Legal Rights – Reduce unnecessary human and legal rights restrictions.
- Mortality Review – screening for potential quality concerns.
  - Mortality review conducted on 100% mortality for HCBS Waivers and Beatrice State Developmental Center (BSDC)
  - Includes Mortality Review Committee - to address individual and systemic issues and analyze trends to generate recommendations to DDD for improving the quality of services
    - *Follow-up:* Committee request to have a member of the Advisory Committee (Shane Hunter) on the Mortality Review Committee if possible.

VIII. New Business:

- Olmstead Plan Goal – Lorie was asked by the Olmstead committee to bring this goal to the attention of the Advisory Committee
  - Strengthening Pathways to Access: Nebraska's Olmstead Plan found on the Olmstead Plan webpage: https://dhhs.ne.gov/Pages/Olmstead.aspx
    - **Goal 2: Enhance Data Collection and Utilization to Address Unmet Needs**: By June 2031, Nebraska will implement a comprehensive data collection system to identify the average wait time for all home and community-based services from the point of application and from the point of authorization until services begin and the percentage of authorized hours provided. Reporting will include the identification of appropriate data by 2026, and publishing an annual report on service utilization trends starting in 2027 indexed to existing participant experience assessments to assess overall system services quality.
    - The dates set in the goal are tied to the dates that are being required as part of the Centers for Medicare and Medicaid Services (CMS) Access Final Rule.

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

Next Meeting:
May 13, 2026
In-Person Meeting

STACY PFEIFER, ARC OF NEBRASKA

Communication in regards to the whole process is concerning. People did the assessment over the phone, was done in 15 minutes, which seems very concerning. The assessors remarked that questions doesn't apply and didn't ask the questions. Lots of people are afraid. They want to take care of their children and what to know how to do that.

CAROL SALBER, GUARDIAN

March 11, 2026

Dear Members of the Developmental Disabilities Advisory Committee,

My name is Carol Salber. I am the guardian of an adult with developmental disabilities. I am here to share my experience with the InterRAI ID assessment process and some concerns I believe are important for the committee to consider.

My son has severe autism and epilepsy. He also uses a communication device to get his needs met. He has been safely supported with a high level of care and supervision for the last 5 years. After my son's interRAI assessment in November, he was dropped from high to intermediate tier. His needs did not change, the assessment tool did.

In my experience, the assessment did not fully account for individuals like my son who are nonverbal or rely heavily on caregiver input. This can affect how functional abilities are scored and may not reflect the full picture of someone's support needs. Similarly, changes in behavior over time or the impact of medical conditions are sometimes not clearly captured, even though they are critical for understanding the level of support an individual truly requires.

I am particularly concerned that when assessments do not accurately reflect an individual's needs, support levels could be set too low. This creates a risk to safety and well-being, which is something we all want to prevent. The interRAI determined that my son only needs a "moderate" level of support and supervision, even though he is non-verbal and has a severe intellectual disability. This significantly impacts his ability to be aware of dangerous situations and stay safe. For example, my son will stop in the middle of a parking lot, unaware that there are moving vehicles around him. A "moderate" level of supervision will not keep him safe in a situation like this.

I am also aware that between July 1, 2025 and January 31st 2026 237 appeals have been filed. The success rate of closed appeals is currently 0%. When an appeal process results in a 0% success rate across such a large number of cases, it raises a reasonable question about whether the process is functioning as a meaningful, independent review or whether it has effectively become a confirmation of the agency's original decision.

My hope is that sharing this perspective helps inform future discussions about the assessment process for persons with disabilities in Nebraska. Assessments should be thorough, individualized, and reflective of each person's abilities and safety needs, and include a transparent and unbiased appeal process when the results are in question.

Thank you very much for your time and consideration.

Sincerely,

Carol Salber

Attachment A

TORI SORENSEN, PARENT

Basis of decision-making tree is wrong because it is looking at funding to test, not disabilities to funding. Professional opinion is to look at all of the interRAI people and review how much it will cost. It should not be viewed as a strict prescription. This is not what the State of Nebraska did.

Branch of the tree, looking at functional skills. One indicator is Full paralysis. This could mean a slight amount of help to hold a pencil or be complete help OR completely paralyzed. This Not a very valid way to review functional skills. Violence to Others is another. Bladder Continence/incontinence. Substance abuse of Mother or foster home placement. This is a guide. It was not a prescription.

THE BASIS OF THE DECISION MAKING TREE IS WRONG BECAUSE IT IS LOOKING AT FUNDING TO TEST, NOT DISABILITY TO FUNDING

BASIC IS GROUP E-Kids 8+ who have supportive family are not fully paralyzed, not violent to others in the past year, with bladder continence and no maternal substance use during pregnancy.

- This could describe a 10 year old child with cerebral palsy and autism who is not violent, but has other behaviors such as learned helplessness, who requires assistance for bathing, dressing, eating, and mobility such as walking.
- *A basic tier participant in the current DD manual requires minimal supervision and support needs; occasional support and services because they are fairly independent; can follow daily routine with limited staff assistance; may be alone for periods of time throughout the day; usually does not need support during overnight hours; some days may not need support*

INTERMEDIATE IS GROUP G AND F-Kids 8+ who have supportive family and not paralyzed, not violent to others in the past year; they were exposed to substance use during pregnancy, but are still continent OR they are incontinent and were never placed with a foster family.

- The factors that bring a BASIC to an INTERMEDIATE are not related the functional aspects of the child's disability, but external factors that are not CAUSAL 100% in determining disability
- There is nothing in the case mix that logically relates to a change in tier that is related to the individual's FUNCTIONAL DEFICITS
- *An intermediate tier participant in the current DD manual requires moderate supervision and support needs; staff available on-site for immediate response (within moments); more than 1 participant per provider; needs staff presence and some assistance with ADLs, needs structure and routine throughout the day; usually does not need staff assistance during overnight hours.*

HIGH IS GROUP D, H, AND A-ALL KIDS 0-7; Kids 8+ who have a supportive family and are not paralyzed and have committed violence within the last year, all incontinent children who have been in foster placement for whatever reason

- The personal factors that bring an INTERMEDIATE to HIGH are age and violence towards others. The rest of the factors are external and not related to functional deficits.
- *A high tier participant in the current DD manual requires high supervision and support needs requiring 24-hour care. Staff presence throughout the day for frequent interaction an4d personal attention (reinforcement, positive behavior support, personal care, and community or social activities); may need assistance during overnight hours.*

ADVANCED IS GROUP B AND C-Kids 8+ who have no supportive relationship with family or are fully paralyzed

- It is significantly more difficult to take care of a mobile child with behaviors vs a fully paralyzed individual. Either could have trach/vent, tube feeding. A child get more funding based on the presence of supportive family and that has NOTHING to do with their functional disability level
- *An advanced tier participant in the current DD manual requires high supervision and support needs and has either high behavioral and/or medical complexity and requires 24 hour care of a sole, non-shared staff during all waking hours. They have intense physical, medical, or behavioral needs.*

THE CURRENT CASE MIX DOESN'T INCLUDE BEHAVIORAL RISK TIER OR A BUCKET FOR INDIVIDUALS NOT QUALIFYING FOR SERVICES

not a unit

First branch of the tree-**age**....

- all kids 0-7 received a high level of funding in Arkansas regardless of their needs. Some of the services provided could have been related to age appropriate needs, not just disability.

Second branch of the tree-**supportive relationship with family**

- In the study it is obvious that it would cost more money for care to be provided to children who do not have supportive families. This DOES NOT have anything to do with their level of disability or level of need. This is an external factor.

Third branch of the tree-**full paralysis vs fine motor deficits of any degree**

- It takes more support to assist an individual who does not have adequate fine motor control vs doing everything for a child who is fully paralyzed. Cognitive function and capacity to assist with tasks may be a better branch for assessing disability.

Fourth branch of the tree-**violence to others**

- This seems to be an appropriate factor, but should be higher up on the tree and should include safety risks and injury to self

Fifth branch of the tree-**bladder incontinence**

- It cost Arkansas more money to care for children who were incontinent

Sixth branch of the tree-**substance use vs history of foster placement**

- Why does maternal drug use only matter if you are continent and foster placement only matter if you are incontinent

Factors that we believe would be more appropriate in determining funding levels

BASIC-age appropriate in majority of care needs, but requires occasional support, encouragement or minimal assistance with specific tasks; no significant behavioral, medical, or communication needs that are not remediated by assistive devices

INTERMEDIATE-has medical and/or behavioral needs that do not require 24-hour care and can be left alone for periods of time and/or overnight while keeping themselves and others safe. Needs some assistance with activities of daily living or occasional support.

HIGH-has medical and/or behavioral needs that require 24-hour care of staff being available within moments; This individual has ability to complete more tasks on their own or with some assistance. They demonstrate some consistent ability to keep themselves and others safe for periods of time.

ADVANCED-has medical (respiratory, diabetic, seizures, etc) and/or behavioral needs (self harm, lack of safety awareness, impulsivity, etc) that require constant skilled supervision to keep themselves and/or others safe. This individual may not be able to consistently communicate their needs to caregivers.

Chapter 83

83-1205.

Developmental disability, defined.

Developmental disability shall mean a severe, chronic disability, including an intellectual disability, other than mental illness, which:

(1) Is attributable to a mental or physical impairment unless the impairment is solely attributable to a severe emotional disturbance or persistent mental illness;

(2) Is manifested before the age of twenty-two years;

(3) Is likely to continue indefinitely;

(4) Results in substantial functional limitations in one of each of the following areas of adaptive functioning:

(a) Conceptual skills, including language, literacy, money, time, number concepts, and self-direction;

(b) Social skills, including interpersonal skills, social responsibility, self-esteem, gullibility, wariness, social problem solving, and the ability to follow laws and rules and to avoid being victimized; and

(c) Practical skills, including activities of daily living, personal care, occupational skills, health care, mobility, and the capacity for independent living; and

(5) Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

An individual from birth through the age of nine years inclusive who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the major life activities described in subdivision (4) of this section if the individual, without services and support, has a high probability of meeting those criteria later in life.

DOES THE INTERRAI ASSESSMENT CAPTURE DISABILITY IN A WAY THAT IS CONSISTENT WITH STATE STATUTE?

Nebraska Funding Tier CMI Alignment

Nebraska Funding Tier	Child/Youth ChYRI Groups	Adult Group Number	CMI Range
Basic	E	1 to 4	.45 to .75
Intermediate	G, F	5 to 20	.76 to 1.23
High	D, H, A	21 to 29	1.24 to 1.5
Advanced	B, C	30 to 33	1.51 to 2.01

Steward et al: A Case Mix System for Children and Youth With Developmental Disabilities

- 346 children were studied who were **already receiving** Medicaid services in Arkansas
- Eligibility **was not** determined by this tool
- Funding was looked at—paid claims—that means paid services were available.

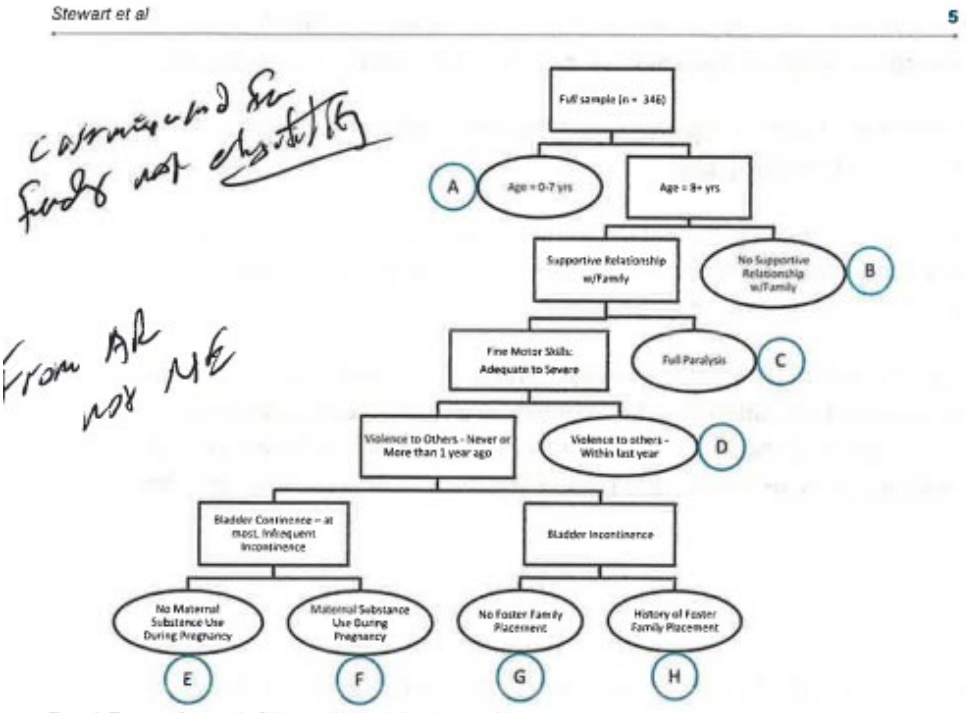

Figure 1. The case-mix groups for Children and Youth with Developmental Disabilities classification system.

FROM THE ARTICLE: "It is important to emphasize that the ChYRI is intended to be used as a guideline to aid with decision-making around allocation of resources. It should not be viewed as a strict prescription, and does not constitute the ultimate allocation cap for resources."

CURT SAFRANEK, FATHER

Hidden algorithm serves to deny a person's constitutional rights. We were not included int he assessment. There were errors, many errors in our interRAI. The state re-scored the interRAI. Guess how much it changed? ZERO change. When corrections were made nothing changed. The state's appeal process had had Zero reversed. Putting all of these cases into a class. Hold the state accountable. Class Action.

BROOK FINE, FAMILY

My son, IQ has been tested well below standardized IQ testing. He is aggressive to himself and others. When the assessment was done. The assessor admitted to not asking every question. He said he didn't need to ask the question. Only observed for one minute The assessor was in the home for maybe 40 minutes. I was part of another assessment that took 3 hours. He has always been in an advanced tier. He is now in the intermediate tier. The algorithm provided the result. I find it puzzling that no one can explain the algorithm. Common sense has been thrown out.

MARK ROLFSMEYER, PARENT

March 8,2026

I am writing as Brian Rolfsmeyer's parent and legal guardian. Brian is my 21 year old son diagnosed with

- PDD-NOS (autisim spectrum disorder),
- Epilepsy, VNS Implant
- EOE – Eosinophilic Esophagitus

The results of this diagnosis include intellectual delay, elopement, random severe and violent behaviors to include disrobing, aggression towards himself, and others, seizures, uncontrolled intermittent vomiting and incontinence just to name a few.

My wife and I were not notified when the interRai assessment took place last July (2025). We only learned that some assessment took place from his Direct Support Person at his day service site. Not by his case manager at DHHS, or anyone related to the interRai assessment team. This DSP that had worked with Brian for less than a month was the only one present and wasn't as well informed of Brians needs as much his parents and previous DSPs.

We don't know how the assessment was completed or how long it took as we were not included. We did **NOT** get a blank copy to provide our input for the interRAi assessment

In October, we were informed by Brian's DHHS case manager that Brians level of funding was being cut by two levels due to the results of the assessment which we still had not seen. She said that if we didn't agree with the results, that we could write a formal appeal and stated that she could not help us with that process. Several days later we received the interRAI assessment and were able to view it for the ***FIRST TIME***. It was competed in July and we received it in October, after being notified of significant cuts to his level of funding.

Furthermore, until questioning our case manager at DHHS, we found out that we had not received the full assessment. Section J – Independent Activities of

Daily Living was not sent to us until March, just a few days ago and we found more inaccurate information.

The number of errors in the original assessment was staggering, both in the number of errors and in magnitude of those errors. Most people that spend less than 2 min with my son, come to the conclusion that he has some significant intellectual deficits, yet the person completing the assessment documented - no intellectual delays. This leads to the question if the correct person conducted the interview. As Brian's legal guardian and parent, my wife and I are the best resources to discuss his health and development but were never questioned.

Brian has had a 1:1 since starting elementary school. This continued through middle school and only changed in high school when they increased the ratio to 2:1 after eloping from the high school. He was several blocks away when they caught them. But the level of funding determined by the interRai assessment puts him in a group of 5 or more. He is not safe without 1:1 DSP support.

Brian was on the DD waitlist for 9 years until finally getting approved for services in 2023. And now once again, the rug is being pulled out from under him due to this new assessment.

Not including parents and / guardians in the assessment process is completely unacceptable. Our input is vital for accurate assessment.

DHHS has an obligation to those with Developmental Disabilities and their families. The inteRai assessment and its scoring are flawed and needs to be fixed or hundreds of people with Developmental Disabilities will be at risk.

Mark Rolfsmeyer, Special Needs Parent/Advocate/Legal Guardian

CATHY MARTINEZ, AUTISM FAMILY NETWORK & PARENT -

I used to be member of this committee. FBA states Jake needs a 1/1 support. He was recently assessed by the interRAI, changed his level, I can guarantee my son's level has not changed. Jake has always been assessed and was found to be advanced. He's aggressive.

The behaviors are only assessed for a 3-day period for accurate recall. This will create dangerous and unsafe settings. In my opinion, the scoring algorithm is no longer assessing the true level of need. Direct violation of the Olmstead.

DOMINIC GILLEN, FAMILY

Dominic Gillen – My son has seizures. Provider supervision or caregivers. For my son there is no difference. Where is the medical supervision? There is no way he can score what he scored before. When there is no budget increase, when you change the assessment and drop everyone down. Those with the highest needs will be impacted the most. This is a failure of leadership. These people should be cherished. We are treating them like a number. It is unbelievable frustrating. That pretty much does it for me. I don't understand how there can be a change, with something snuck in. No one knew what was happening. This assessment isn't just for 100 kids, he's my kid. It's about all of them. They are a blessing to all of us, we have been given a blessing.

Lehn Staub, Father w/ Son Doug Staub

Level changed from high to intermediate. They appealed the decision. Lehn read the ISSUE section below during public comment.

DHHS Senior Team Committee on interRAI

Doug Straub, Medicaid Beneficiary; DOB: 8-26-80
Lehn Straub, Father & POA

Date of Assessment: September 26, 2025
Name of person doing Assessment: Lisa Becker, DD Service Coordinator

Date of Notice of Redetermination: September 30, 2025
Level of Changed from High to Intermediate

Date of Appeal; December 23, 2025 & January 6, 2026
Result of Appeal was no change of level of service (remain at Intermediate)

Issue:
My son, Doug, is wheelchair bound, he has a trach, he get's feed through a tube in his tummy, he is on anti-seizure medicine and he is on oxygen at night. He in non-verbal and uses a DynaVox to communicate with very limited success. He is incontinent and he is totally immobile. Clearly, he is in the High level of care & services.

Through the appeal process we provided documentation from Doug's neurologist. He documented his severe limitations and I am sharing this with you today.

The doctor said, "Given all of Doug's documented impairments and inability to safely perform daily activities without substantial assistance, a high level of disability care is medically necessary to ensure patient safety and prevent further deterioration."

InterRAI is not designed to accurately evaluate a person like Doug with severe disability. For example: page 20, question 4, FATIGUE, it was scored "Moderate – due to diminished energy, Unable to finish normal day to day activities". Doug cannot perform any normal day to day activities but it is due to his severe disability, not fatigue. Page 37, question 4, BEHAVORIAL SYMPTOMS, wandering, verbal abuse, physical abuse, socially inappropriate behavior, outbursts of anger all rated Not Present. They are not present because Doug cannot perform any of those activities because he cannot speak, walk or control his movements. So the score of not present for these activities totally disregard the level of disability for someone who cannot perform any activities for themself.

InterRAI does not accurately assess severely disabled people like my son Doug. It should be discarded as an assessment tool to determine the level of care for these individuals.

Bryan PHYSICIAN NETWORK

Neurology Associates
2631 S. 70th
Lincoln, NE 68506

October 27, 2025

Patient: **Douglas L Straub III**

Date of Birth: **8/26/1980**

To whom it may concern:

I am writing to formally request a higher level of disability care for Douglas Straub whose medical and functional status necessitates comprehensive support. I have been following Doug since 2017 for his neurologic care. However, I would note he has been under neurologic care since approximately 6 years of age when he developed encephalitis. He has neurologic diagnoses of static encephalopathy, spastic quadriparesis, and epilepsy. At baseline, he is a full care patient. He is nonverbal. He has a tracheostomy and feeding tube for which he gets all his nutrition and medications and requires daily maintenance care. He requires oxygen at night. Patient is wheelchair-bound and needs aid for all transfers. He requires help to perform essential daily activities such as feeding, toileting, and personal hygiene. In addition, patient requires multiple daily medications which he needs administered through his feeding tube.

Given all of Doug's documented impairments and inability to safely perform daily activities without substantial assistance, a high level of disability care is medically necessary to ensure patient safety, optimize quality of life, and prevent further deterioration.

If you have questions, please do not hesitate to contact me.

Sincerely,

Matthew S Kniss, MD

MOLLY MAILANDER, FAMILY

Was at Nephew's assessment. The assessor repeatedly referenced Down Syndrome, kept correcting her that was not his diagnosis. The assessor did not review his treatment plans and was not able to review this during the assessment because she couldn't get into the system. Some of the questions were skipped and minimized. Assessment stated he met mobility, self-care, this is not correct. He has a safety plan. Level of support should reflect what is truly needed. My nephew is not just a name on a form. When assessments are inaccurate, they affect his quality of life. Shame on you guys.

DILAN SORENSON, SELF-ADVOCATE

The assessment said I would jump off a roof. I did jump off a roof but it wasn't like that. The ladder fell. I wouldn't just jump off a roof. They also put down I was non-verbal. Which I'm obviously not. I don't know why I am still qualifying for services. I have 120 merit badges in boys scouts. I'm wondering how I'm still able to be on this assessment. (COMMENT FROM TORI SORENSEN) Being on the waiver is preventing his availability to be able to work with someone, he cannot do so because he is on waiver.

SHELLY JORGES, MOTHER/GUARDIAN

March 11,2026

Contact: Shelly Jorges, Mother & Guardian of Ty, sjorges@charter.net, 308-440-1288

Situation: Sharing a brief snapshot of a day in the life of Ty Jorges, our experience of the InterRai Assessment and potential impact this can have on people with Developmental Disabilities in our State. Following his recent InterRai assessment his funding level dropped from advanced to high.

Background:

- Ty is a 26 year male who was born with Down Syndrome. In addition to Down Syndrome he is also significantly challenged by obsessive compulsive behavior, attention deficit disorder, oppositional behavior and autism.

- He is essential non verbal, will repeat a few words, requires hands on assistance with all activities of daily living, is incontinent of bowel and bladder, mobile, very strong and very quick. He functions cognitively at a 12-15 month old level that is 4 feet 10 inches weighing 140 pounds. This is a very dangerous combination.

- We are from central Nebraska near Lexington. Ty has lived with my husband and I since birth. After careful planning and consideration we made the difficult decision to move forward with residential services for him when he became eligible for the comprehensive waiver. We are in our 60's and it was time for us to make some life planning decisions for what happens to Ty when something happens to us and we wanted to ensure he had a safe, fulfilled and solid life plan like our other two adult children.

- For the past year Ty resides in Kearney Nebraska in a residential setting with 24 hour support and attends the same day services program he has participated in since aging out of school services at 21.

- I work in Kearney and I am able to see him several times a week where I have lunch with him at his day site, walk with him after work and he is able to come home for visits periodically.

- Routine behaviors exhibited by Ty (which have not changed in the last year) are:
    - Throwing objects
    - Hitting anything-walls, table, furniture, people; (he has broken two car windshields and a radio screen from the inside when with a 1-1 caregiver and 2 TV's) in the past year. He has broken another vehicle windshield and other windows prior to that.
    - Grabbing at your clothes, hair or random things and then throwing them.
    - Constantly checking doors to see if they are locked or he has an escape route
    - Constant noise making through vocalizations and yelling and thinking spitting is quite funny.
    - He has an exceptionally short attention span(less than a minute) and moves at 150 miles per hour all day.
    - Ty can be pleasant and engaged with normalized daily routines however this is short lived as his behavior can change in a flash and is not predictable.
    - Not all of Ty's behavior is malicious, but he can find it very funny at times like a toddler with the game of pick up.
    - Ty needs line of sight supervision at all times.

- How are these behaviors mitigated? Very carefully with structured and supportive programming, BSP's, safety plans, right restrictions, and his ISP team.

- We have seen multiple mental health providers, behavior specialists and psychiatrists for med management. To address the above issues. We have attended all the parent behavior courses offered. He has been on some type of behavior management medications since 2nd grade. The challenge is also present in balancing the benefit of medications and side effects that bring on additional issues.

- Bottom line--Ty's journey has been very complex to get to where we are today and everyday continues to be a challenge. We have a great team working with him and the level of advanced funding support he has received has met his needs and allowed him to be safe and function at the highest capacity possible.

Assessment:

- The InterRai assessment data collection was a collaborative effort between Ty's service providers and myself. Ty was present (distracted watching a movie on an electronic device). I did not have a copy of the tool or answer options.

- The reviewer completed it on her computer as we went through the questions.

- I did not understand how the outcome of our discussion would impact her interpretation of what she selected for answers.

- The 3 day look back is challenging when you are talking about ongoing chronic issues vs a new acute episode of care. Even the MDS that is used in a nursing facility has a 7 day look back.

- With high anxiety I asked what happens if his funding level changes, knowing that would change his programming? We have worked so hard to get to this point and it is still challenging daily. I was assured you will have options: you can appeal the decision, you can ask for emergency exception funding. Don't worry the tool will capture Ty's care needs. We all know how that story ends. No funding and no chance at overturning the appeal.

- A month later I was notified by Ty's service coordinator of the funding level drop. My presuffering with the process became a reality. Ty's functional behavior and needs are unchanged. We met and I shared with her my 30+ items of concern. She did take that information back and had a couple of questions updated which did not change his funding level.

- I still have many questions and am requesting the opportunity for those to be reviewed for correction prior to Ty's appeal and am still waiting for direction on how to get those reviewed although I have been emailing my service coordinator since February 23 weekly. Her response is she is waiting for direction from her supervisor.

- I have asked for a policy on the workflow from a parent/guardians perspective to have the results reviewed for correction and was told to look on the website. Which I have and I am not able to figure out the procedure on this process.

- I am terrified as to what this means for Ty's future. The residential and day service agency will need to adjust ratios, change his ISP to balance out programming and funding or ultimately could serve notice to discontinue services altogether.

- In rural Ne services are already VERY limited. This outcome could mean Ty needing to receive services far away from his home and support.

- I have worked in healthcare for 40 years and I have seen this happen in the nursing home industry. Funding levels are cut, residents are placed hours from their homes as no one wants to serve a highly complex behavioral individual that they are not accurately funded to care for. 39 nursing homes have closed in NE since 2017, mostly in rural NE.

- The InterRai tool is not designed to capture the true burden of care for someone that is cognitively impaired and highly mobile.

- As I said before I work in healthcare and I complete a very similar tool for people receiving acute rehab services and the same issues exist with that tool so that is why clinical judgement needs to be a part of the process and not just a number of algorithms that is not the true burden of care of an individual .

- If the tool works and is reflective of his needs, I want Ty to be at a lower funding level. If that is true I want Ty to be the one that makes the basket in the basketball game with everyone cheering, but that is not reality and that is not our story.

Recommendation:

- It is evident that this tool is not going away as it is a standard in many other states. This transition year is a difficult year for everyone. However, we are not just a line item on a spreadsheet trying to get numbers to balance. These decisions are impacting real lives. And as I have recently learned Ne has created its own funding tiers based upon the algorithm to determine levels of care.

- Agencies need proper funding or they will deny applicants. Rural Ne is VERY limited on resources and the outcome of the InterRai and funding drops and reimbursement will make them even more limited.

- Learn from other Healthcare industries such as the nursing homes in Ne and closure of many facilities related to funding and staffing issues. This WILL happen with the DD resources as well.

- I urge you to stop now, reflect on our feedback and real patient stories and get the InterRai and funding for this special population of Nebraskan's right for today and future planning 3 years, 5 years and 10 years from now.

- You would be devastated and terrified if this was your family member experiencing this significant support change and decrease to their lives. Please do not do this to our family members. They matter too! Thank you!

SAVANNAH BACLISH, FAMILY

Son has oppositional defiance disorder. He was dropped from high to basic tier. Like he could just go on with his day with minimal care. He's non-verbal. If we are in the parking lot, he will just stand there oblivious to the cars around him. He needs constant reminders of ADL's. Asked Service coordinator acceptation. We are told we need to work towards the tier they are supposed to be at. The support doesn't disappear; it is shifted to the families. How is the system going to support families that cannot shoulder that change?

ANNA KEYZER, PARENT

Son on AD Waiver – 112 hours of caregiving. Have a sister-in-law that helps. It has been a hard few months. In the middle of December we found out we were going to be lowered to 40 hours a week. Then we went through public comment. Now it's capped at 150%. My son is not average. He cannot take care of himself. I understand that this is an optional program. Every time I hear that they could take the entire thing (waiver services) away. I am so thankful that my son is on the waiver and that I'm able to be paid to be his provider. If we get our van modified, that is also going to come out of that $138,000. As would Day services, if I did that. I believe that if I apply to be an independent provider, I will lose money. No one cares about my budget or my son. I feel like you should. My son's evaluation was in October and everything stayed the same. Was approved for 112 hours. Because we are fighting this fight together. If you only wanted to pay for all of those things, what happens if I'm only being paid for 8 hours a day. My son is too disabled to live by himself. Why in the world those disabled not be able to apply for an exception because they live with their family. I'm the person that knows it all. If he went to an institution, I don't know how long I can do that. I have to pay my mortgage. I stupidly built my home for my family based on my income. No one cares about my mortgage. He has a life with me. He goes to concerts; he goes to church every week; he travels.

SUSAN BROWN, MOTHER

To DHHS AND THE PRESS:

I am Susan Browne a 72-year-old Nebraska mother undergoing cancer surveillance every three months. For my entire adult life, I have also been fighting to keep my profoundly disabled sons safe.

They have been abused by caregivers repeatedly over the years. Each time, the systems meant to protect them failed to intervene in any meaningful way. Recently, a licensed PhD-level psychologist conducted a comprehensive evaluation of my son. Across multiple standardized assessments, they both scored in the lowest percentiles in every domain. Her professional conclusion was unequivocal: my sons require continuous one-on-one care, 24 hours a day, to remain safe and to meet even their most basic daily needs.

Despite this, the Nebraska Department of Health and Human Services abruptly implemented a new assessment system that—without warning—reclassified my son's to an "intermediate" level of care. This decision directly contradicts the psychologist's findings, our sons' documented medical and safety history, and decades of lived reality. Even more troubling, the state assessor recorded numerous answers that were simply false.

This reduction in care is not a paper change—it is a life-threatening one. Under intermediate-level funding, my sons will not be safe. They will not receive adequate care. And the responsibility will fall on two aging parents, one of whom is battling cancer.

Gov Pillen, has spoken publicly about being pro-life. This is the same. It's about the moral responsibility we hold toward the most vulnerable. I ask you plainly: Is this the integrity and compassion you all want Nebraska to demonstrate in how it treats its most defenseless citizens?

My greatest fear is not my illness. It is dying before my sons and leaving them unprotected in a system that has already failed him. There is no compassion in what is happening—not for my son, and not for families like ours who have given everything for decades.

Institutionalization is not an option. As grim as that sounds, Nebraska does not even have a facility willing or able to take him. We are trapped in a system that removes care without providing any alternative—and does so at the very stage of life when parents can no longer physically carry the burden alone.

I am asking you: what would you do if this were your child? What is the answer for families who have done everything right and are now being abandoned at the end of their strength?

I am asking for your intervention—not just for my son, but for every profoundly disabled Nebraskan whose life depends on decisions made far from their voice.

Respectfully,
Susan Browne

Susan Browne
Mar 11, 26

Watson, Tyla

From: Dwayne <[redacted]@gmail.com>
Sent: Wednesday, March 11, 2026 1:32 PM
To: Watson, Tyla
Subject: DD advisory committee comment

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

Hello,
I did have some comments for the board that I'd like for them to take in consideration.
My comments are for the AD waiver.
It was brought up about the SNA and the changes in hours that are already happening. One thing that these proposals has done has connected a lot of families and they are seeing the discrepancy across the board. There are individuals whose supervision hours are being reduced based on a number that has been arbitrarily chosen. Also supervision hours are being cut for high risk individuals with the response of family members should provide informal support, ie free help. That these are normal tasks that should be provided by the family. Unfortunately, these people that are being affected are not normal and the cares are far beyond from what an individual would provide for a non disabled individual. Even with proper documentation the hours are objectively adjusted by arbitrary factors.
Second, the use of an average cost to determine individuals budgets based on a extremely large population that is obviously skewed toward the lower end is absurd and seems reckless and purposeful to reduce budget numbers for someone else's agenda. Here's is a comment for Tony Green to counter his repeated planned answer. In regards to his salary and Steve Corsi and Jenn Clark's, what if we base their salary on a bell curve budget. Take all the state employees and average their salaries, which is roughly $58,746 and then implement the 150% cap which is $88,119. Now apply this new salary cap to them and see how they feel about this new determination. This here is a solid point of cost neutrality and should be implemented for them.

These are just a few things I would have liked to state to the board so that they could see how Dhhs would react/consider this.

Thanks

Ed James

Open Letter for Public Statement regarding the InteRAI Assessment for the DD Waiver

A developmentally disabled individual has been hit by a car, has drowned, has eloped and is yet to be found. These are the headlines that Nebraska will be facing if they move forward with the InteRAI assessment which has been known to inaccurately determine the supervision and care levels of disabled individuals. As reported by DHHS, 18% of the individuals assessed so far have had a drop in their tier funding. This can mean a deduction of over a $100K dollars annually for the disabled individual. Our son went from Advanced tier and dropped to the High tier which has a budget difference of $112,415. We have been informed that his supervisory parameters will change based upon this, however his needs have not changed. Our son still has the same diagnosis, the same safety concerns, the same cognitive deficits and lack of skills and abilities he has always had. The only thing that has changed is the methods by which he is being assessed by DHHS.

The methods by which the InteRAI assessment has been executed has varied widely. First, upon scheduling I asked our Service Coordinator whether school staff could be present at the meeting since they are with our son almost as much as we are, and we were told "it is not necessary". We also asked about any documentation that we could provide and we were also told that "it wouldn't be necessary". We prepared some documentation for the assessor to take with them, such as our son's previous Notice of Redetermination dated 7/17/25, school information including IEP and doctor notes. This did not include all documentation indicating his functional needs that we would have provided had we known that it would be considered. Director Green indicated in front of the HHS Committee on 2/26/25, that documentation and record review is a big component of the determination on the InterRAI. This is not being communicated nor is it being followed. Our son's clinical care team was never contacted for supporting documentation nor were they consulted for their input. Had these things been done it would be apparent that our son's needs have not changed in scope of diagnoses, safety concerns, skills, abilities or the need for 24/7 supervision. In essence, DHHS would realize that nothing has changed with our son's required level of care. The only thing that has changed is the InteRAI, a stricter test that DHHS implemented by which to assess these individuals to lessen budgets to save money.

Previously DHHS was using a third party to conduct the InteRAI assessments until they realized there were problems with that. Now they are using internal DHHS employees and there are also problems with that. The assessors have no medical experience or credentials, yet by Director Green's admission, the DHHS assessors are supposed to observe these individuals to

assist in deciding their level of care. They are not qualified to make such determinations. In our case, they observed our son for less than ten minutes. There has been a wide range of time reportedly spent with families and individuals ranging from 30 minutes to 3 hours for the InteRAI assessment. Ours was 73 pages in length and even if the assessor witnessed my son for the full two and a half hours during the entire assessment, that would be inadequate to provide an educated analysis of my son's disability.

Next, the lack of transparency with the line of questioning felt very deceptive and manipulated. It was not until halfway through the assessment that I was told there was a comment area for additional information. The multiple-choice questions were not fully shared, and I was unable to read the InteRAI questions myself for clarity. The assessor's screen was hidden from me. Now we are being told to re-review the results for accuracy. We have been told that we are able to change responses and re-submit them however it may not make a difference in the tier determination. This is likely because not all of the 73 pages of answers are used. We have not been told which answers are inserted into the system for determination. That seems manipulated as well.

The algorithm used is being passed off as InteRAI's however DHHS knows exactly how this is being used to score the individual assessments. Director Green indicated they are using a "Case Mix Index" which appears to be a "Cost Measuring Index". By his own admission "It categorizes folks and spits out a score. Let's say it spits out a score of 1.0, that means you are the *average cost to serve* and it will spit out scores above and below that. The scores that InteRAI sets out fall into the budget tiers." They haven't explained how they get to the 1.0 score and upon a public records request, we were provided with a redacted internal DHHS document that blocked out the scoring methods. It came with an explanation of Neb. Rev. Stat. § 84-712.05(3) indicating that this is proprietary information. ""Trade secrets, academic and scientific research work which is in progress and unpublished, and other proprietary or commercial information which if released would give advantage to business competitors and serve no public purpose." Neb. Rev. Stat. § 84-712.05(3). Our families are not business competitors. This information does serve a public purpose because the budgeting outcomes from the InteRAI assessment's algorithm directly and adversely impacts the individual's rights to person centered planning.

Person Centered Planning is at the root of the waiver system. According to Director Green via his testimony on 2/26/25, there are questions on the InteRAI tool to determine caregiver capacity. Based on those answers it is undetermined whether at home support will deduct from the scoring and drop the individual's budget tier. Person Centered Planning is the whole premise of Nebraska offering waivers to this population. It also is protected Federally by Code of Federal Regulations Title 42. Based on the requirements outlined in 42 CFR §441.301,

funding cuts to Home and Community-Based Services (HCBS) that occur without documented, individualized assessment and evidence of improvement or reduced need likely violate federal regulations, specifically regarding the person-centered service planning process. From the initiation of the InteRAI to present day, DHHS has failed to inform the waiver participants to provide the proper documentation regarding their level of care needs to be examined prior to a determination. DHHS has failed to consult the participant's care team members to determine any changes in functional needs. DHHS has failed to relinquish any scoring methods, input criteria being used or the algorithms that are calculating these tiers. There has not been any specific explanations as to why an individual has dropped in tier funding.

At this point we urge DHHS to come forth with additional information for waiver participants and families and not hide behind confidentiality or proprietary statute. We request full transparency with the individuals assessed to provide a clear explanation of which answers from the InteRAI are being used, how these affected their scoring and why it has dropped their tier budgets. We are requesting a comparison of the ICAP assessment to the InteRAI assessment to determine whether DHHS implemented the InteRAI, as a stricter assessment tool, to reduce fiscal spending. Finally, we ask that DHHS point to documented proof of the participant's functional improvements or need changes that were used to make the determination to drop their tier funding.

We appreciate the time to provide our experience with the InteRAI assessment through this public statement.

Sincerely,

Mr. and Mrs. Stone

Omaha

Dear Advisory Committee Members and DHHS Employees,

Thank you for allowing me a few moments to speak on the impact of this assessment change, and, most importantly, the lack of transparency and consistency surrounding the interRai and the subsequent impact on the individuals assessed.

Our experience with this assessment began with a request to schedule the interRai a month before our daughter's annual meeting. We were told it must be completed before her annual meeting. We requested information about this tool, as this was not a change we had been made aware of. We were directed, by link, to the DHHS website.

We had only one date available in the time frame requested, so we scheduled the assessment for that day. Quite unfortunately, this directly followed the first vacation my wife and I had taken together in years. During that time, my mother in law drove 500 miles to care for our daughter.

The day of the assessment, the assessor was pleasant, but had never met our daughter previously. Many of the questions began, " In the previous three days". We explained that we had been gone and it had been a weekend without day services, so there was no data gathered for two of the three days. It was reiterated that the information gathered was needed from the last three days.

When we received the results of the assessment, we noted that 15 areas were marked incorrectly, or were missing information. Including diagnoses. We reached out to the interim service coordinator assigned to us as well as Kristen Smith to correct those areas and address concerns related to transparency, process and impact on our daughter's level of supervision and support. After a week of no corrections made or concerns addressed, we then reached out once again to the service coordinator, Kristen Smith, Tony Green and Jenn Clarke. At this time, we are still waiting on a reply.

While three minutes is not nearly enough time to share the full impact on our daughter, I would like to offer a brief overview. Our daughter is fully reliant on the supervision and assistance of others for all of her basic needs and her safety. This lowered tier places her in a higher ratio supervision situation, which does not give us confidence that her caregivers are placed in a situation to successfully ensure safety while eating, going into the community, bathrooming and interacting with her peers. Understanding that she is not the only one who has had her level of supervision and support changed adds to our concern. It seems that caregivers and individuals alike are being placed in a situation that reduces outcomes for success.

I believe that it is incredibly important to remember that, when observing our individual's data, for each day that certain behaviors are not present or certain programs have been run with success an incredible amount of supports have been in place to help them achieve those outcomes. Those outcomes are not permanent, but fully rely on the amount of support provided.

Thank you for your willingness to hear and contemplate our concerns. Your time is greatly appreciated.

Sincerely,
Trevor Hinze

My son, Jim Plate, was in a car accident at age 16. He suffered a severe TBI. His health has declined as he has aged and PT was cut. He cannot eat, use the restroom, or walk without assistance. He has been with MNIS for 20 + years.

5 years ago, his funding was cut. I protested. Someone came to Kearney and actually spent some time with him. Not only was the funding restored but the decision was that Jim belonged in the highest level of care. MNIS and we felt he would not do well with someone beside him 24 hours and we agreed to 1 step down. I do not know the exact amount. We never see the money. The protest hearing was cancelled. The interview this year lasted 1 1/2 hours. We participated by phone. Staff from MNIS were present. All the questions were based on the 3 previous days and there had been no falls, etc. on those days. Last year his support was $107,000. They are cutting it by $6,000 a month. They said he is at the intermediate level. We challenged many of the evaluator's placements when we sent in the protest. Our protests consisted of 18 pages. The hearing is scheduled for March 19. It will be held on the phone, which is how it would be even if we were in NE. I am preparing a statement, so I don't leave anything out. It sounds like this will be a yearly battle. He pays rent, food, electricity, and they have raised his rent!

Leila Johnson

Jim's mother

Kearney

March 9, 2026

Governor Jim Pillen DD Advisory Committee

RE: DHHS DDD InterRAI Intellectual Disability Assessment for HCBS Waiver

Dear Committee Members,

We are Ron and Angela Rehtus, the parents, legal guardians, and conservators for our son, Benjamin Rehtus, who is an adult male with intellectual disabilities. Ben is both Down Syndrome and severely autistic with the latter being his primary disability. Ben had his DHHS required interRAI intellectual disabilities assessment performed on 2/9/2026 by Jeff Rudy, a Waiver Services Specialist with DHHS. We met Jeff at Ben's day services provider's office in one of their conference rooms. Ben was present for the assessment interview, but since he is non-verbal, all of the questions were directed to us or to his day services coordinator and caregiver that were also in attendance at our request. The assessment interview lasted for approximately 60 minutes. Jeff was very professional and courteous. His knowledge and background with intellectual disabilities seemed adequate for him to ask the assessment questions. Several times he even prepared us for what might be some very sensitive questions about Ben's behaviors, to make certain we would not be offended by the questions and to make us aware that they were purely for intellectual disability assessment purposes. Our biggest concerns with the assessment were that there was not a good way for Jeff to share his laptop screen with us, as he was completing the assessment questions, so we had no ability to see if we agreed with the information he was inputting into the system or we thought corrections should have been made, which leads to our other concern, which was after getting the assessment back, not the full document, but the abbreviated version, we found what we thought to be seven errors made with the biggest one, in our opinions, being that Down Syndrome was indicated as his primary disability, when it should have been incredibly obvious to Jeff that severe autism is his primary disability and we even said that to him in the interview. Our other concern was that very little time was spent actually observing Ben, who was sitting in the room with us and we specifically had him come to the meeting, because we thought this would be the most important part of the assessment, actually witnessing some of his behaviors, especially being in a room he had never been in before and having to sit patiently while the

assessment questions were answered by his guardians. Since the age of six years old, our son has been repetitively diagnosed by multiple psychologists as being severely autistic and yet his assessment came back as indicating him primarily Down Syndrome and at an intermediate level of intellectual disability, which seems to directly contradict ALL of the previous psychologists who evaluated him and used various nationally recognized processes to do so. Something seems VERY WRONG with the interRAI process, and it needs to be investigated by a non-partial investigation committee. We have appealed Ben's assessment and are awaiting a hearing date to discuss it with the Hearing Officer.

Thank you for your time.

Sincerely,

Ronald Rehtus / Angela R. Rehtus

Ronald Rehtus and Angela Rehtus

Parents, Guardians, and Conservators for Benjamin Rehtus

[redacted]

Lincoln, NE 68510

[redacted]

March 11, 2026

DD Advisory Committee Members:

Our son is 21 years old and has Down syndrome, autism, and epilepsy. He is also nonverbal. Our experience with the interRAI assessment process has been very concerning.

During the hour-and-a-half interview, the assessor asked numerous questions about our son that we simply cannot answer because he is unable to communicate verbally. These included questions such as whether he is depressed, or has thoughts of suicide..

When we later received a copy of the results, we discovered that every question for which we responded, "There is no way for us to know because he cannot communicate," h*ad* been recorded as "not present." This makes it appear as though those issues do not exist rather than acknowledging that they cannot be assessed.

We were also concerned that the assessor declined multiple offers to observe our son. He was sitting in the next room during the interview so that we could monitor him for safety, yet the assessor chose not to interact with or observe him at all.

Most concerning is that none of our son's medical records were included in the assessment process. We cannot attend today because he is currently undergoing his 10th extended EEG monitoring at Nebraska Medicine. His epilepsy is extremely complex and has not been controlled by medication. He experiences frequent falls and must be constantly monitored for his safety. He wears a helmet and requires a gait belt.

Despite the seriousness of his medical condition, the assessment did not include information from his EEG studies, his neurologist, or his primary care provider. The extensive list of medications he takes was also not considered.

We are deeply discouraged that such a significant portion of our son's care needs were not considered in this process. We respectfully ask the committee to suspend the current process until it can be improved to ensure that the full needs of Nebraska's most vulnerable individuals are properly assessed and addressed.

Thank you for your consideration.

Sincerely,

Matt and Ame Creglow

Lincoln NE