CROSS-DISABILITIES ADVISORY COUNCIL

Hybrid Meeting

Thursday, APR 16, 2026

9:32 a.m. – 4:28 p.m.

Cross-Disability Advisory Council Members Present: Darcy Andahl, Kirsten Dvorak, Kyle Erickson, Andrea Hansen, Julianne Horntvedt, Kayla Johnson, Paul Kolstoe, Kevin Miiller, Katynka Morrissette, Jonathan O'Konek, Vicki Peterson, Lorena Poppe, Danielle Robbins, Kendra Vander Wal
Cross-Disability State Agency Representatives Present: Jackie Adusimilli, Kathy Barchenger, Kayla Fender, Karla Kalanek
Guests Present: Erin Leveton, Kathy Miiller, Erin Moore, Jillian Salmon

WELCOME and ADMINISTRATIVE MATTERS

- The meeting was called to order at 9:32 am.

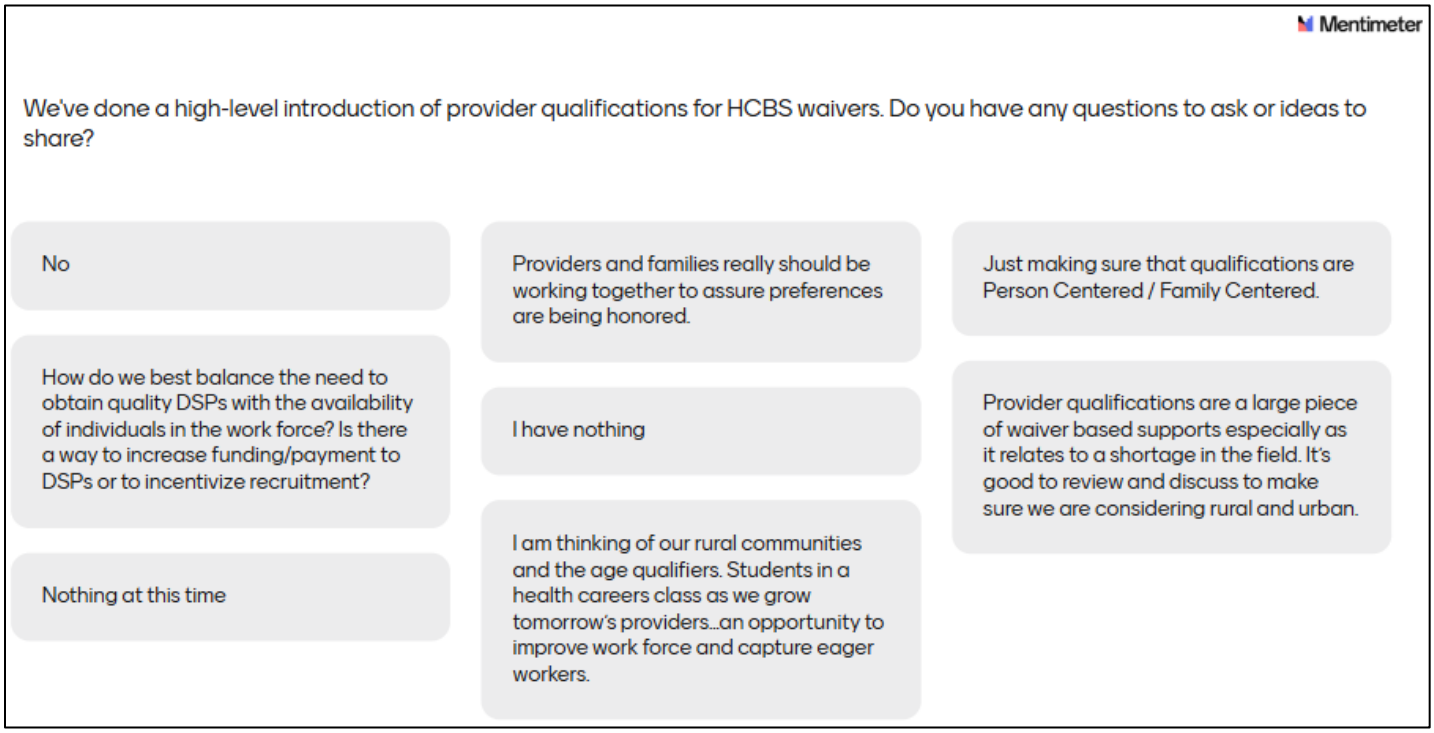
GENERAL BUSINESS

- Role Call

- APPROVAL OF CDAC March Minutes
  - Kevin Miiller opened the floor for discussion on the "ND-CDAC Minutes 26MAR26 DRAFT"
  - Motion: It was moved by Jonathan O'Konek and seconded by Lorena Poppe to approve the 26MAR26 Minutes
  - Vote (Yes): Kirsten Dvorak, Kyle Erickson, Andrea Hansen, Julianne Horntvedt, Kayla Johnson, Paul Kolstoe, Katynka Morrissette, Jonathan O'Konek, Vicki Peterson, Lorena Poppe, Kendra Vander Wal
  - Vote (No): none
  - Motion carried

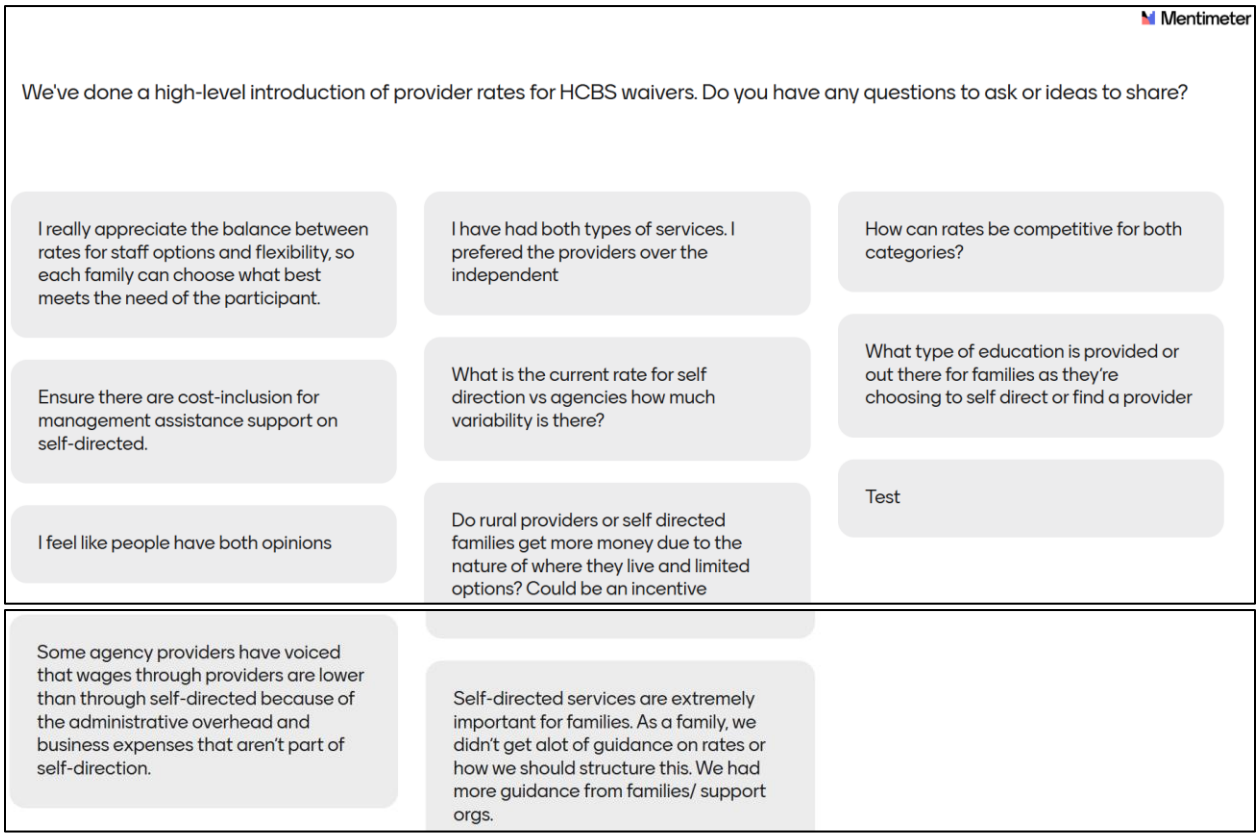
Provider Structure Introduction - Qualifications

- CDAC members were introduced to the structure of providers of Home and Community-Based Services (HCBS) waivers.
- Members talked about how the HCBS waiver requires states to list the qualifications providers must meet to be able to provide waivered services.
  - Members were shown specific sections of the HCBS waiver application where provider qualifications are detailed.
  - Members talked about specific examples of provider qualifications for services on North Dakota's (ND) existing children's waivers that will also be on the Cross-Disability Waiver (CDW).
- Members talked about what things are important to them when thinking about provider qualifications for the CDW.
  - Many of the things that families want choice over when selecting providers are part of the person-centered planning process.
- Members completed an anonymous Menti survey at the end of their discussion on provider qualifications to capture feedback and additional questions.



Provider Structure Introduction - Rates

- CDAC members were introduced to the structure for HCBS waiver providers' rates.
- Members discussed how rates can be different for traditional provider agency staff compared to staff of self-directing waiver participants.
    - This is because provider agencies have to incorporate more fringe benefits for staff, like insurance and paid time off, into their rates.
- Members talked about the federal rules for provider rates and how states can use rates to accomplish certain program goals.
    - Members asked for more information on ND's provider rate structures.
- Members completed an anonymous Menti survey at the end of their discussion on provider rates to capture feedback and additional questions.



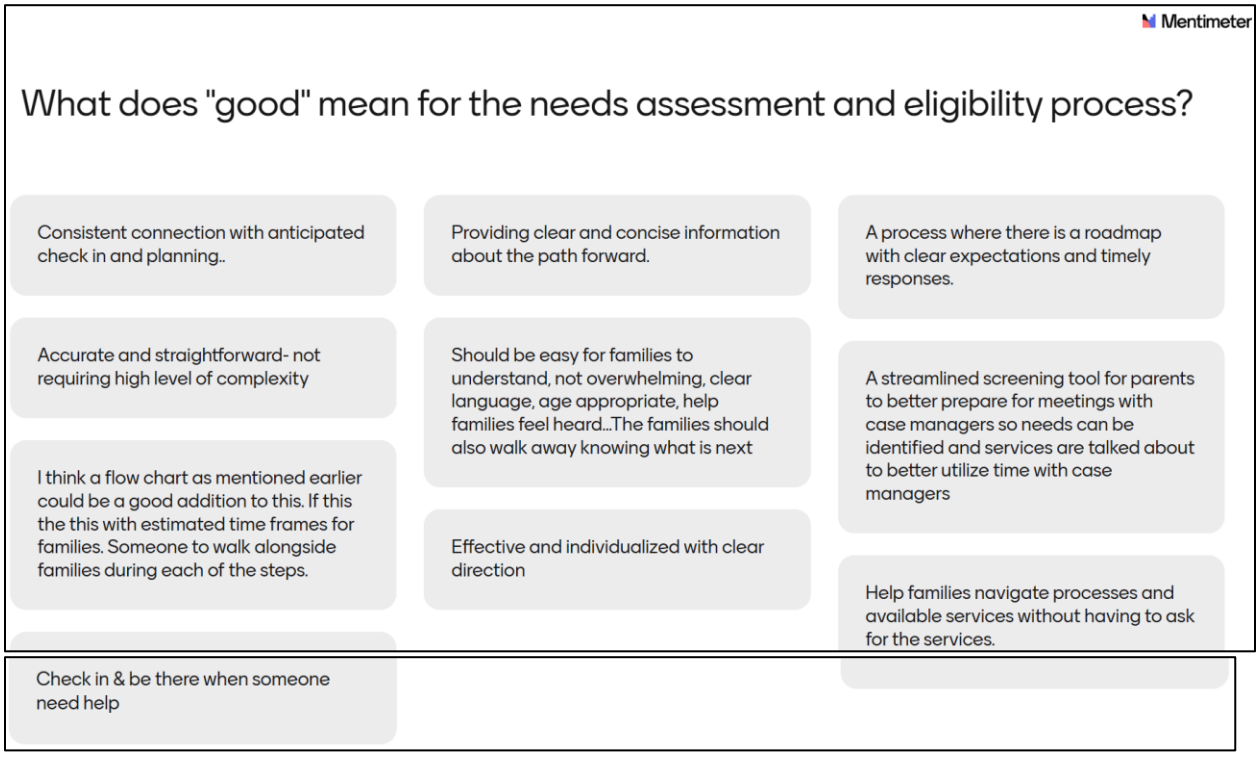
Level of Care Refresher

- Members reviewed a refresher on the work ND is doing to modernize the way eligibility is determined the level of care modernization part of ND's children's HCBS waivers work.
    - Members talked about ND's goals for this work and CDAC's role in it.
    - Members reviewed federal rules about determining eligibility for waivers.
- Members then reviewed the guiding principles they've voted on that document their guidance for HHS on how to modernize the level of care and functional eligibility assessment processes for the Individuals with Intellectual Disabilities / Developmental Disabilities (IID/DD) Waiver.
    - Members shared additional feedback about how it would be useful if families started to receive information in advance of when assessment criteria is about to change because of age, to understand timelines and next steps

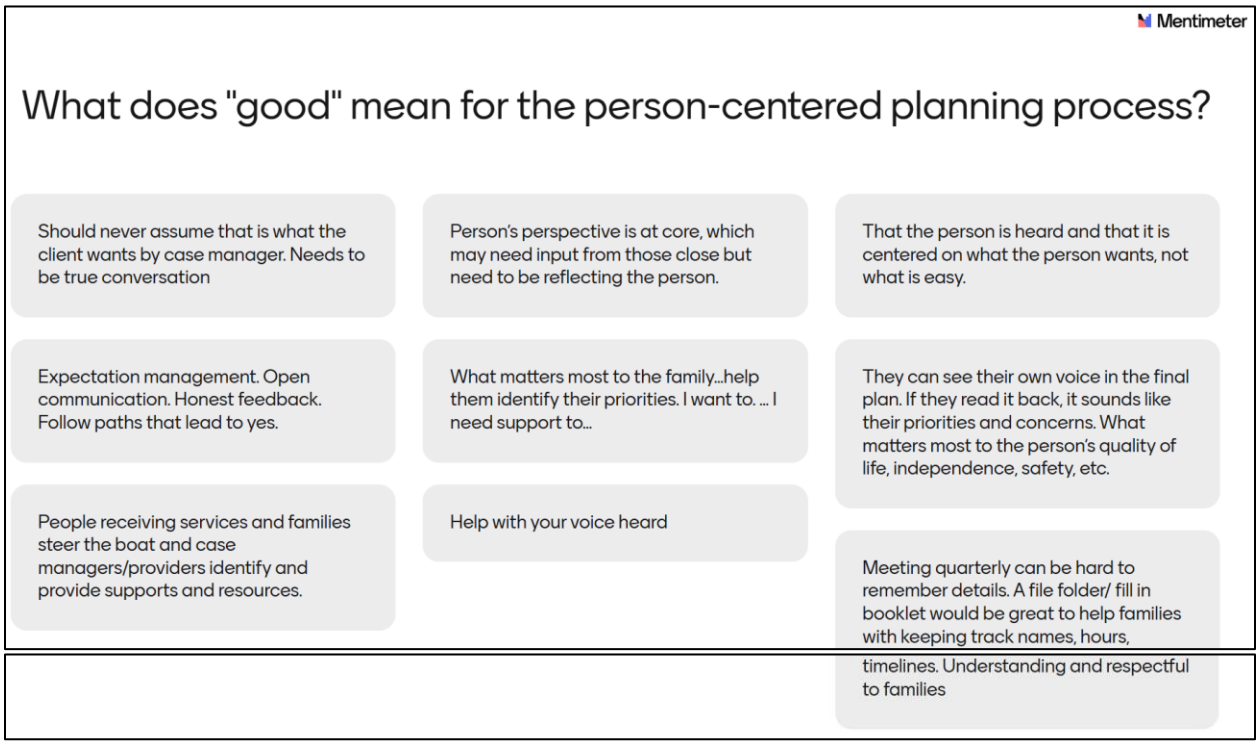
Case Management Introduction - Quality

- CDAC members were introduced to the roles of case managers in HCBS waivers.
  - Three of the main responsibilities are helping waiver applicants with the needs assessment, taking part in the person-centered planning process, and monitoring waiver participants' services.
- Members completed an anonymous Menti survey to provide feedback on what they think good quality case management looks like.

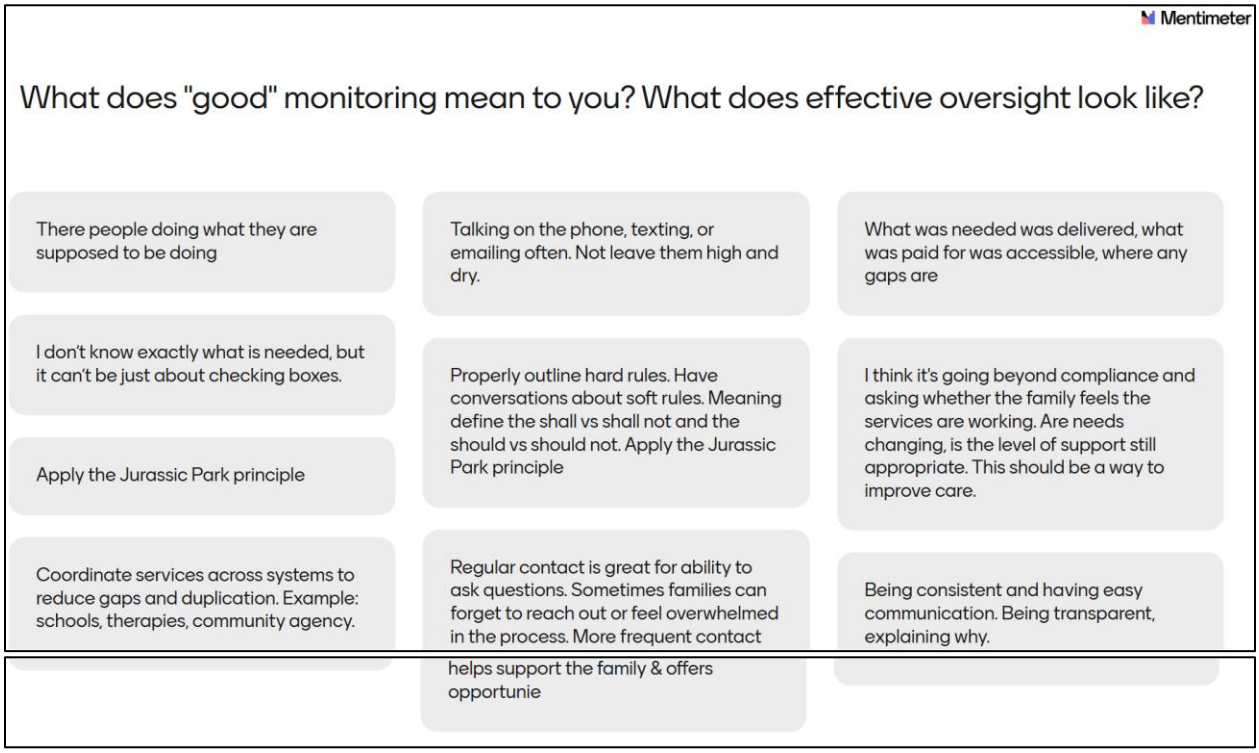
Discussion Question #1



Discussion Question #2



Discussion Question #3

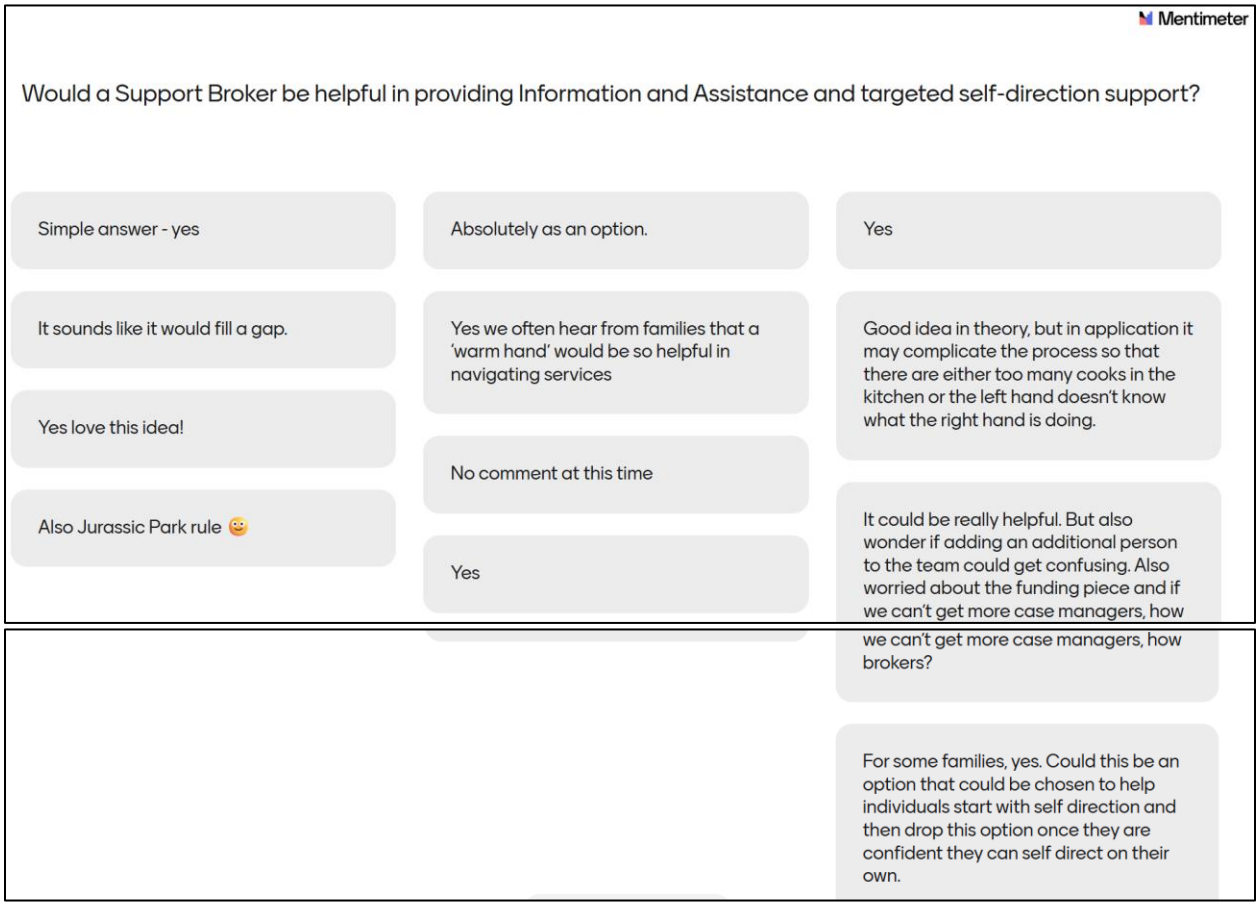


Case Management Introduction – HCBS Waiver Application

- CDAC members were introduced to how case management is talked about in the HCBS waiver application.
    - Members shared feedback about wanting to understand how provider qualifications and rates may change if case management is provided by state Case Managers on the CDW, instead of privately like it is on ND's Autism Spectrum Disorder (ASD).

Supports for Self-Direction

- CDAC members talked about one of the responsibilities that case managers can have in waiver programs, which is helping families who choose to self-direct their services.
  - Members talked about how this responsibility can take up a lot of Case Managers' time, which sometimes might keep them from other key responsibilities.
  - Members also talked about how they have wanted more help when they're self-directing their services.
  - Members learned about other specific roles, like a Support Broker, that can provide this help to participants who self-direct, instead of Case Managers.
- Members completed an anonymous Menti survey to share their feedback about whether a Support Broker would be useful on the CDW.



CDW Service Array and Modalities Guiding Principles

- The feedback that members have shared in recent CDAC meetings about the CDW's service array and modalities was captured in draft guiding principles that will be shared with HHS.
- Members reviewed an updated draft of these guiding principles that reflected their feedback from March.
- In upcoming CDAC meetings, members will continue to review and revise these guiding principles before voting to finalize and formally share them with HHS.

PUBLIC COMMENT 1

Public Comment for the North Dakota Cross-Disability Advisory Council

April 16, 2026

I would like to offer public comment to the North Dakota Cross-Disability Council on three topics:

Public Comment

North Dakota Early Intervention System

Family Paid Caregiver Program

Public Comment

I prepared two public comment documents after attending the subcommittee meetings on November 20, 2025 and the regularly scheduled meeting on January 8, 2026. The public comment was emailed to Kevin Miller, but my understanding is that NDCDAC members did not have access to the comment. Both pieces were related to the "Birth to 2" topic and were timely when issued. I would suggest that the Council make a directive about handling written comment that comes into the website and/or through email to the coordinators in between quarterly meetings. The comments will then be timely and relevant.

I appreciate the decision to add public comment time into the agenda and hope that this continues although given the demand it appears there needs to be more time allotted.

North Dakota Early Intervention System

I pulled some information from the two public comment documents previously sent that I felt were still topics that deserved highlighting and/or I felt hadn't been considered. I noted in my January 8, 2026 public comment that I am not in favor of moving the service for our birth to 3 Early Intervention eligible infants and toddlers to the Cross-Disability Waiver at this time. Here are some reasons why:

- Service coordination is integral to the delivery of services to eligible infants and toddlers, especially through the lens of meeting the requirements of the Individuals with Disabilities Education Act (IDEA) Part C. IDEA Part C both requires and identifies as a service, service coordination, using that term specifically. Service coordination is a mandatory service for Part C eligible children and their families. North Dakota meets this Part C requirement by using the Developmental Disability Program Management system. If moved to the Cross-Disability Waiver, this issue would need to addressed and may result in needing non-Medicaid funding to meet the need if not addressed in a similar manner.

- Approximately 3000 slots would be needed to serve the infant and toddler population in the new CDW right from the start, possibly overwhelming and confusing the promotion of a new waiver.
- There are currently emergency slots built into the IID/DD waiver for additional infants and toddlers if all approved slots are filled. This would be needed in the CDW as well. There are very little state and/or federal dollars available to meet the needs of these infants and toddlers if there is not a Medicaid match. It's important to note that you cannot put these infants and toddlers on a wait list of any sort due to the protections under IDEA.
- The population that may need to transition back to the IID/DD waiver at age 3 may very well be our most medically complex and complicated children, whose parents are the most taxed with maintaining public benefits to keep their children out of institutional care. Yes, the number may be fewer, but these are who have immense burdens on their plates.
- In FFY 2023, North Dakota serves 6.2% of all North Dakota infants and toddlers under the IDEA Part C program. Historically, North Dakota has been in the top tier of states on this federal indicator. There is a strong collaborative network supported by DHHS and other partners to identify potentially eligible children. This work is intrinsically tied to the Developmental Disabilities Section and the Part C staff housed there. In addition to the Child Find work (as defined under IDEA), other work such as the Part C Technical Assistance contract, Experienced Parent project, and data management and monitoring are also within the Developmental Disabilities Section. This needs to be a consideration when discussing a change from the IID/DD Waiver because this may change administrative responsibilities within the Department. While this should be seamless, we all know that additional ripple disruptions and unintended consequences can occur when making major changes.
- Our most medically complex and complicated infants and toddlers now have the advantage of the higher service cap within the IID/DD waiver such as In-home Supports, Extended Home Health Care, equipment and supplies, etc. This may not be available in the CDW.

Eligible children and families benefit from the weaving and blending North Dakota has done with our Part C system and our IID/DD Medicaid Waiver because it is seamless for them. They only really realize appreciate the seamlessness when the braiding flies apart at age 3 and they are faced with Medicaid Waiver eligibility redetermination/determination and IDEA Part B special education eligibility. I'd ask this Council what improvements could come from the change/disruption at this time.

Family Paid Caregiver Service (FPCS) Option

It appears that the FPCS Guiding Principles were adopted, so these comments may be too late, but I'd like to remind the Council why family advocates went after funding for this option in the first place. It was because waiver-eligible families had service contracts for care for their loved ones that they were unable to staff, whether it was self-directed or through an agency. Yes, the public health emergency from COVID had impact, but many of these families' situations are so complex and unique, that the typical service delivery system do not comprehensively meet their needs.

Your FPCS Guiding Principles are generally great, but they are side by side with comments from A 'n M that make them seem unachievable. Instead of bolstering support for this approach and creating documents with solutions, we now have a laundry list of warnings to present to the public and decision-makers. While I, too, want protections for the individual, family, and the system, my hope is that the NDCDAC would have weighed in with answers for some of the issues the program has faced as they were directed to do so in SB 2305. Input was expected on the changes needed to roll into the Medicaid Waiver, upgrades to the assessment to insure we capture younger children with complex needs, and possible protections for families and the system.

The last slide of the Guiding Principles document on the FPCS is included below:

CDAC's Guiding Principles on Paid Family Caregiver (Part 3)

DRAFT

CDAC Feedback / Recommendation	A&M Notes
ND's PFCG pilot is set to expire on June 30th, 2027. This could be disruptive for families who are currently involved in the pilot. In the upcoming legislative session, CDAC recommends that the ND Legislature: • Fund the PFCG state pilot for another biennium. • Allocate funds for a PFCG waiver service modality in the Cross-Disability Waiver. • Allocate funds for a PFCG waiver service modality in the other existing children's waivers (IID/DD, ASD, MF).	Extending ND's PFCG pilot depends on the availability of state dollars. A state pilot allows for flexibility in the PFCG program but doesn't secure a federal match. The Governor's Office will release its proposed budget for the 2027-2029 biennium this year (2026). HHS must align its budget – including PFCG options – to the priorities set by the Governor's Office. The ND Legislature will then decide how to appropriate funds for the 2027-2029 biennium next year (2027). Given the well-documented examples of PFCG risks in other states (uncontrollable costs and participant isolation), we recommend starting small with PFCG as a waiver service modality with overlapping safeguards only in the capped CDW. Starting small in this way allows ND to study the impacts of PFCG and use lessons learned to potentially expand it in the CDW and possibly other waivers in more favorable budget years. Federal regulations prevent "waivers within a waiver." Adding PFCG to the IID/DD Waiver would mean it had to be an option to all families, which would not be in line with starting small to reduce risks and protect the program.

Terms:
Paid Family Caregiving (PFCG)
Legally Responsible Individual (LRI)
Cross-Disability Waiver (CDW)
Fraud, Waste, and Abuse (FWA)
Centers for Medicare & Medicaid

This slide recommends another full biennium of state funding for the FPCS and then movement of it to the Cross-Disability Waiver, then maybe into the IID/DD waiver. This recommendation is not in step with the previous legislative work done on this project, nor helpful for the families that need it the most, the majority who are on the IID/DD Waiver. The ND Legislature has been clear that the Department needs to figure out how to weave the service option into our existing waivers to secure the Medicaid match. That work has

continued to be kicked down the road and entwined with the Cross-Disability Waiver, but most of us that have worked to get FPCS into place in ND, see the work as separate and urgently needed. The ND CDAC's Guiding Principles document is taking this work backwards. This program has brought serious relief to the roughly 100 ND families and the hope was that you would add to the conversation with solutions vs. making the work of families more difficult. I recommend opening this discussion back up and reconsidering your vote.

Respectfully submitted,

Roxane Romanick

701-391-7421

romanick@bis.midco.net

PUBLIC COMMENT 2

Consumer & Family Network
Mental Health America of ND
Youth Move Beyond
The Arc of Bismarck
Federation of Families for Children's Mental Health
Protection & Advocacy Project
ND Association of Community Providers
Fraser, Ltd.
Individual Consumers & Families

North Dakota Cross-Disability Advisory Council
Cross-Disability Waiver Public Comments
April 16, 2026

Good afternoon, members of the North Dakota Cross-Disability Advisory Council. I am Carlotta McCleary, Executive Director of Mental Health America of North Dakota and Executive Director of the North Dakota Federation of Families for Children's Mental Health. Today I speak on behalf of the Mental Health Advocacy Network (MHAN). MHAN advocates for a consumer/family driven mental health system of care that provides an array of service choices that are timely, responsive, and effective. Our vision is for every North Dakotan to have access to the right service—whether it be preventative, treatment, or recovery; at the right time—when the service is needed; and at the right place—as near his or her home as possible. MHAN is supporting the establishment of a cross-disability waiver and requests that it be truly inclusive of children with mental health needs. As I will detail in my comments today, North Dakota is lacking a full continuum of care for children's mental health services in both the public and private sectors and across insurance policies. Families who have a child with a mental health challenge are expected to make tremendous sacrifices to get their child access to care. Specifically including children with mental health needs into the cross-disability waiver, without requiring that they first have another disability, will go a long way to address existing service gaps.

One out of ten children in North Dakota has a serious emotional disturbance (SED). That translates to over 18,000 children. These are children with a mental health issue that significantly impacts more than one major area of life and is expected to last at least one year and are at a high risk of out-of-home placement. These are children who are often in need of

intense, ongoing services that include wraparound case management services, parent peer support, in-home supports, and respite for their families.

Many families have insurance plans that neither cover many needed services, and if they do, many of those families are faced with paying high deductibles. Some common insurance plans are not deemed in network for most North Dakota mental health providers. This places significant financial barriers to access care for their children.

Children with mental health services do not have the same opportunities to receive services as children with developmental and intellectual disabilities. The services needed by families are in extremely short supply, if available at all. The regional Behavioral Health Clinics are the primary means by which families can gain access to intensive community mental health services. During the 2023-2024 state fiscal year, roughly 1,086 children with SED received case management services through the Behavioral Health Clinics.

In the last decade, there have been tremendous strides in expanding service options for adults. Free Through Recovery provides case management, peer support, and other recovery services for people who have come out of the criminal justice system. Community Connect was established to continue that model, but for the general adult population. Both Free Through Recovery and Community Connect are state funded and are only for adults.

If families cannot receive services through the behavioral health clinics, the only real alternative is the 1915(i) Medicaid State Plan Amendment. Since 2021, the 1915(i) has provided adults and children with a wide range of behavioral health services. For children

to qualify for the 1915(i), their parents must have a qualifying income for Medicaid. Whereas since August 2024 between 500 to 900 adults a month have received 1915(i), a record number of 29 children received services in January 2026. What this means is that between the Behavioral Health Clinics and the 1915(i) there is a significant gap between the high demand for services from families and our current options for families to get those services, especially compared to populations served by North Dakota's existing waivers.

Another significant issue facing children with disabilities is ready access to evaluations. No matter the disability (including mental health diagnoses), there is a meaningful wait for families to have a suspected disability evaluated and diagnosed. Not all diagnosable conditions have similar waitlists to evaluation, however. Children who are likely to have both a mental health condition and a developmental disability like autism are more likely to first be diagnosed with a mental health condition. It is often not because the mental health condition is more apparent than autism, but rather because the wait to receive an autism diagnosis is significantly longer than the mental health condition. As such, if the cross-disability waiver were to support mental health services only for individuals with developmental disabilities like autism, the cross-disability waiver could significantly hamper the ability for families to receive timely and necessary services and supports.

Mental Health Advocacy Network has two core recommendations:

1. Include mental health conditions as one of the qualifying conditions for the cross-disability waiver, without a pre-requisite of a developmental or intellectual disability.

2. Address the lengthy waits to get a disability diagnosis by allowing *diagnosable* conditions.

The cross-disability waiver should be truly representative of children with disabilities in North Dakota by including children with mental health diagnoses, the majority of which do not necessarily have a developmental or intellectual disability. It should also be considerate to the significant challenges families have in receiving evaluations by utilizing *diagnosable* conditions to qualify for the waiver.

This concludes my comments, and I will be happy to answer any questions you may have.

Carlotta McCleary
Mental Health Advocacy Network, Spokesperson
E-Mail: cmccleary@ndffcmh.com
Phone: (701) 222-3310

PUBLIC COMMENT 3

North Dakota Behavioral Health Planning Council

Formal Written Submission to the Cross Disability Advisory Council (CDAC)
Regarding the Proposed Cross-Disability Waiver
March 9, 2026

Introduction

The North Dakota Behavioral Health Planning Council (BHPC), through direction of its Executive Committee, respectfully submits the following comments for consideration during the Cross Disability Advisory Council's (CDAC) waiver design process.

BHPC appreciates the opportunity to provide input during the planning phase of the proposed cross-disability waiver. Our comments reflect concerns raised during Council meeting held December 17, 2025, including follow-up discussion at the February 20, 2026, Executive Committee meeting, as well as ongoing themes consistently voiced by families, individuals with lived experience, and providers engaged in North Dakota's behavioral health system.

BHPC's role includes advising on system gaps, access barriers, and cross-system coordination needs. The issues identified below are offered in the spirit of collaboration and with the shared goal of strengthening services for children, youth, and families whose needs span developmental disability and behavioral health systems.

Overarching Position

BHPC supports efforts to reduce system fragmentation and improve service access for children and families with complex and co-occurring needs.

The proposed cross-disability waiver presents a meaningful opportunity to:

- Reduce administrative barriers
- Improve cross-system coordination
- Strengthen navigation supports
- Address eligibility gaps that disproportionately affect children and families
- To be inclusive of children with mental health conditions

We encourage CDAC and state partners to intentionally incorporate these priorities into waiver design.

Priority Area 1: Reduce Eligibility and Financial Barriers for Children and Families

BHPC members consistently hear concerns regarding:

- Varying eligibility criteria across programs, including age and inclusive of mental health diagnosis
- Parent income thresholds that may exclude children whose families are “barely making ends meet”
- Confusion regarding where families should begin the access process
- Disengagement after a denial from one system without awareness of alternative pathways

Families frequently describe not only financial barriers, but navigation barriers. When eligibility standards differ across systems and are not clearly explained, families often abandon the process out of frustration or exhaustion.

BHPC encourages consideration of:

- Greater alignment across eligibility standards where feasible
- Clear communication of multiple access pathways when eligibility differs
- Mitigation strategies when parental income creates unintended exclusion of children with significant needs
- Special attention to children with co-occurring developmental and behavioral health conditions

Reducing confusion and financial barriers will help ensure that children are not left without services due to technical or administrative complexity.

Priority Area 2: Reduce System Fragmentation and Administrative Burden

Families report repeatedly retelling their story across agencies and completing duplicative intake processes. For families already navigating crisis or chronic stress, intake itself can become a barrier.

BHPC members described the experience of interacting with siloed systems that do not share information or coordinate effectively. Families experience the system as fragmented rather than integrated.

BHPC encourages waiver design elements that:

- Minimize duplicative intake processes

- Promote appropriate cross-system information sharing (with necessary privacy safeguards)
- Reduce administrative burden on families
- Strengthen coordination between developmental disability and behavioral health systems

Intentional design to reduce fragmentation will improve follow-through, continuity of care, and overall system trust.

Priority Area 3: Ensure Developmentally Appropriate Screening and Assessment

Concerns were raised regarding screening and assessment tools that may not adequately reflect developmental differences across age groups or the complexity of co-occurring conditions.

Particular attention should be given to:

- Age-appropriate assessment tools across early childhood, school-age, and adolescent populations
- Clear guidance on evaluating co-occurring developmental and behavioral health conditions
- Identification of potential "service gaps" that arise when eligibility categories do not align with developmental stages

BHPC also emphasizes the importance of addressing high-risk transition periods, including:

- Early childhood transitions
- Transitions between school-based and community services
- Transition from child to adult systems

These points of transition are consistently identified as times when families are most vulnerable to falling between systems.

Priority Area 4: Strengthen Navigation Supports and "No Wrong Door" Access

BHPC members highlighted the period immediately following diagnosis as particularly overwhelming for families. Families may receive a diagnosis but lack clear, coordinated next steps.

Navigation models in other health systems (such as nurse navigators) provide structured follow-up and coordination. North Dakota's Aging and Disability Resource

Link (ADRL) was referenced as a successful “no wrong door” model that assists individuals in navigating complex systems.

BHPC encourages exploration of:

- Formalized navigation or care coordination supports within waiver design
- Strengthened “no wrong door” entry points
- Structured follow-up after diagnosis
- Clear guidance during major transition periods

Improved navigation will reduce family frustration, improve system engagement, and increase service utilization where appropriate.

Commitment to Ongoing Collaboration

BHPC understands that CDAC is currently in the design phase and that formal legislative action is anticipated as part of the 2027–2029 biennium planning process.

We offer this input proactively and respectfully. BHPC stands ready to:

- Participate in public comment opportunities
- Provide additional written feedback
- Engage in cross-council collaboration where missions intersect
- Assist in identifying behavioral health implications within waiver design

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Conclusion

The proposed cross-disability waiver presents a significant opportunity to improve system alignment and reduce barriers for children and families with complex needs.

BHPC encourages thoughtful incorporation of the following guiding principles:

1. Reduce eligibility and financial barriers
2. Minimize fragmentation and administrative burden
3. Ensure developmentally appropriate assessment
4. Strengthen navigation and “no wrong door” access

We appreciate the opportunity to provide input and look forward to continued collaboration in service of North Dakota’s children and families.

Submitted by: Tania Zerr, Chair

On behalf of the ND Behavioral Health Planning Council

PUBLIC COMMENT 4

Protection & Advocacy Project
400 E. Broadway, Suite 409
Bismarck, ND 58501
701-328-2950
1-800-472-2670
TTY: 711
www.ndpanda.org

November 6, 2025

Cross Disability Advisory Council
Attn: Kevin Miiller, Facilitator
kevin@itcbconsulting.com

Dear Mr. Miiller,

The North Dakota Protection & Advocacy Project (ND P&A) is the leading civil rights organization for North Dakotans with disabilities of all ages, including children with developmental disabilities and serious emotional disturbance. P&A is committed to equality and inclusion for individuals with disabilities in all aspects of life and provides an array of services to ensure this becomes a reality.

The study from Kids Count North Dakota reveals that mental health conditions for youth have worsened in the past five years, with 23% of children and adolescents in the state experiencing one or more mental health conditions. More than 35% of high school youth reported feeling sad or hopeless almost every day for two weeks or more in the last year, and 18% of high school students seriously considered suicide in 2023. These statistics highlight the urgent need for accessible, affordable, and supportive treatment options and crisis services for youth in North Dakota.

North Dakota currently has a significant gap in services for children with serious emotional disturbance (SED), and those who may have a co-occurring diagnosis of a developmental disability (DD). The details of this need were comprehensively captured in the June 2022 Alvarez and Marsal study. Additionally, an April 2018 report from Human Services Research Institute (HRSI) identified the presence of a significant mental health crisis in North Dakota. The final report published identified 13 major recommendations for improvement that the state needs to address. These include:

These recommendations identified a need to expand community-based and outpatient care within the state and did not recommend expanding institutional services for youth. Despite these recommendations, the solution that the state of North Dakota took during the 2025 legislative session was to redefine the population of eligible individuals who could be admitted to the Life Skills Transition Center (LSTC), the state-owned and operated institution for individuals with developmental disabilities. SB 2112 in the 69th Legislative Assembly expanded the definition of "individual served" to include an individual who has not been deemed eligible for developmental disability services and is under eighteen years old.

P&A is very concerned about the current gap in services for children, especially those with already existing DD and SED challenges. Using institutional settings is not the answer. The delays in important developmental areas of physical, hormonal, cognitive, and emotional development are compounded when placed in institutional settings. (Children in Institutional Care: Delayed Development and Resilience, 2014).

Further, as a member of the ND Children's Cabinet, P&A has been participating in a subcommittee working to identify solutions for children with dual diagnosis and complex needs, specifically for those children with SED. Through this, P&A has identified issues that include a siloed system, lack of providers/services, and lack of funding streams as key problems when serving these youth. P&A believes it's in the state's best interest to ensure a full continuum of services exist for youth; this must include access for youth with SED to the Cross Disability Waiver which should contain a full array of services that meet their needs, including access to safe/crisis beds, respite, and a second set of hands.

Recognizing these challenges, we urge the Cross Disability Advisory Council to include children with SED as an eligible population in the new Cross Disability Medicaid Waiver and ensure that a comprehensive menu of services is included in the waiver that will meet the needs of children with SED, thereby preventing institutional placements.

We appreciate the opportunity to provide input on the Cross Disability Advisory Council's important work. Thank you for your consideration, and please contact us with any questions.

Sincerely,

Veronica Zietz
Executive Director

Pamela Mack
Program Director

PUBLIC COMMENT 5

CDAC Public Comment 04/16/26

My name is Patricia Camisa and I am a parent of a Five and half year old son with Fetal Alcohol Spectrum Disorder and ADHD.

The Cross Disability Waiver is greatly needed in North Dakota. My child has had to abruptly stop Occupational therapy services because of lack of funds to pay for it solely because our insurance deductible reset at the beginning of the year. This upsets our entire everyday lives and routines and we see a regression of progress because of this. We have Sanford PERS and before our deductible and out of pocket are met we pay $168.40 per 45 minute appointment once a week for OT. He has also been assessed for Physical Therapy and is in need of that as well, but because we can't afford to send him we haven't started that therapy. We make too much money to qualify for Medicaid and his diagnosis doesn't make him eligible for reasons I will mention next.

My son was assessed twice by the Mandan Public Schools Special Education preschool and both times was deemed “Too smart with too high of an IQ to qualify.” At his second assessment he actually ran away from the assessor upon her trying to bring him back to me, which is a behavior that will not be tolerated when he goes to school in August. We see very high IQ’s in children and adults with Autism and accept that they still should be able to access services regardless of IQ and family financial status.

I am privileged enough to know many people in advocacy, the medical field and school systems that I have had a less difficult time finding support for my son. But this waiver can NOT be contingent on the financial status of parents nor the child's IQ for the above reasons and because not everyone is as privileged as I am in my knowledge.

Thank you,

Patricia Camisa

PUBLIC COMMENT 6

Protection & Advocacy Project
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To: North Dakota Cross Disability Advisory Council
From: Protection & Advocacy for Individuals with Mental Illness Advisory Council
Date: April 16, 2026
Re: Cross Disability Children's Waiver Public Comment

Dear Members of the North Dakota Cross Disability Advisory Council:

The Protection & Advocacy for Individuals with Mental Illness Advisory Council (PAC) is a federally authorized advisory body that represents individuals with serious mental health conditions. Sixty percent of our membership is made up of people with lived mental health experience and parents of children with lived mental health experience; the remainder of our members are made up of professionals that work in the mental health field.

We advocate for services and protections for North Dakotans with mental health conditions. We believe in equal access to community-based services for children with disabilities, including children whose primary disability is a serious mental health condition.

Mental health care is health care, and it needs to be treated equitably. Individuals must have access to adequate mental health care without fear of stigma and consequences. North Dakota's mental health care system is in crisis. Services and treatment are unaffordable and inaccessible, especially for children with mental health disabilities. This lack of community-based care and treatment results in children struggling in all aspects of life. For example, we have seen that many children are forced to withdraw from public school and rely on their families to meet their educational needs. Similarly, lack of community services makes it difficult for children with mental health conditions and their families to be successful in the community resulting in increased referrals for residential placement.

Having a child with a serious mental health condition can put emotional and financial strain not only on the child, but on the whole family. Programs and treatments can be so costly that families are forced to choose between affording mental health treatment and feeding their families. Employment disruption can also be a significant issue for families who are forced to take time off work to travel to access care,

to attend appointments, or to provide care when other support systems fail. This creates yet another financial strain and barrier to accessing services.

Families across ND frequently report travelling long distances or out of state to access diagnostic assessments and specialty behavioral health services. North Dakota families are even choosing to permanently move out of state to access services. There isn't enough help for people with mental health needs in our state. For those who chose to stay here, when community supports are unavailable or unaffordable, families are left with the only option of accessing care through emergency services. We are using these high-cost services inappropriately because families are desperate.

To illustrate this point we would like to share two personal experiences from families involved with our Council.

Jocelyn is a 16 year-old freshman in high school with a heart of gold. She is empathetic and caring; the kind of person who would stop and help her enemy. Jocelyn was born to young parents in rural North Dakota. At age two her parents went through a contentious divorce. It was found that her mother used substances while pregnant and Jocelyn's father gained custody. From a young age Jocelyn was described as aggressive with uncontrollable emotions, which lead to her being kicked out of daycares repeatedly. These challenges bled into her school years with fits, agitation, and aggression starting in kindergarten. Jocelyn's single father was called at work nearly every day to pick up his daughter from school early. By first grade, Jocelyn's father was even called into school and told his daughter's challenges were due to his poor parenting.

With no support from the systems put in place to help children like Jocelynn, her dad sold personal property and real estate to come up with $80,000 to get medical help. They went to Fargo, Minneapolis, and even Chicago to find a specialist to help Jocelyn. Jocelyn was diagnosed with Fetal Alcohol Spectrum Disorder, Bipolar, and emotional control issues. Jocelyn immediately started medication and twice weekly therapy treatments. Even though the family had good private insurance, it covered just 12 treatments per year. This required the family to pay out of pocket for 110 treatments for the remainder of the year at a cost of $280/session for a total of $30,800/year; this was on top of the insurance premium. Another challenge they faced was that many mental health medications used to treat Jocelyn's condition weren't covered by insurance costing the family an additional $200/month out of pocket for just one medication. Jocelyn's father is blessed with a great job and salary, had it not been for these personal resources Jocelyn likely would have pursued suicide without the treatment she needed.

Due to the frayed relationship with Jocelynn's school her father moved her to a new school in fourth grade. She got on an IEP and Jocelynn was happy and getting good grades. Unfortunately, by seventh grade the school had put unqualified professionals in place, was dealing with staffing shortages, had no in-school therapists or counselors, and failed to implement her IEP appropriately.

After dealing with North Dakota's broken system for thirteen years, this family has had enough. They have decided to move to another state that provides services and holds their systems accountable. They will find another state who values their children and wants them to succeed.

Tommy is a sweet child with a big heart; he loves to advocate for others. In first grade he was diagnosed with anxiety. The school didn't know how to handle symptoms of his mental health disability and called his family to pick him up from school nearly every day. As a result, mom was forced to quit her job, which led to the family losing their home and being forced to move in with relatives just to manage. Even with private insurance the cost of Tommy's care was $250 per visit; this added up to over $1,000 per month. The family had to make the hard choice to give up occupational therapy for Tommy just to sustain his mental health care.

After a long wait Tommy got a referral to go to Fargo for an assessment, where he was diagnosed with Autism 1, ADHD, and Anxiety. Tommy was finally eligible for the Autism Waiver; however, he sat on the waitlist for a year. Once Tommy got on the waiver there was no respite or additional help available due to staff shortages. Finally, Tommy was getting waivered services but was making too much functional progress and was dropped from the Autism Waiver. Since Tommy has been dropped from the Waiver, he has had increased incident reports in school and is also experiencing suicidal ideation. The family has been forced to make an impossible choice - to cut back on treatment due to the cost of care. They've gone into debt and had to be on a payment plan with Tommy's therapist, because there is no other option. Tommy is a fighter and so is his family, but individuals with mental health disabilities and their families shouldn't have to fight to show they have value and to access care. North Dakota can do better.

We are formally recommending that the Cross Disability Advisory Council include children with mental health disabilities as eligible participants in the Cross Disability Children's Waiver. In addition, the CDAC should:

- Offer educational support as a service within this wavier. This could be modeled after the 1915(i) and would allow students with serious mental health conditions to be integrated and successful in the general education classroom.
- Adjust income eligibility limits and make the qualifying income level based on the child's income rather than the family's income. Families often make too much money to access services, but not enough to pay for services on their own.
- Concurrently assess services available at the Human Service Centers and adjust the sliding fee scale to ensure those in need can access help.
- Ensure that there are an adequate number of slots on the cross disability waiver to eliminate potential waitlists.
- Ensure the cross disability children's waiver covers early intervention, assessment, and related services. Before children get their diagnosis from a neuropsychologist, many first see their primary care provider and get an anxiety or depression diagnosis. A formal diagnosis can often take years. Families must be able to gain access to services before they get their final diagnosis as they are missing out on a key early intervention opportunity.

It is vital that children with mental health conditions be included in the cross disability children's waiver. This will result in earlier intervention, improved family stability, reduced reliance on emergency and institutional care, and more equitable access to services for low-income families across North Dakota. It will also align with the state's commitment to serving children in the least restrictive and most appropriate community-based settings.

This is important for children with mental health conditions because these conditions can significantly impair major life activities such as learning, emotional regulation, social interaction, and daily functioning. Without access to intensive community-based supports, children are at greater risk of crisis intervention, school exclusion, hospitalization, and out-of-home placement.

Children with mental health conditions have value, they deserve services, and they will one day be leaders in facing our society's challenges. It is our responsibility to ensure they have the best opportunity possible for a meaningful life through access to affordable and appropriate home and community-based services via the cross disability children's waiver.

Thank you for the opportunity to provide input on the Cross Disability Advisory Council's work. Your consideration is appreciated.

Sincerely,

Protection & Advocacy for Individuals with Mental Illness Advisory Council

PUBLIC COMMENT 7

North Dakota Cross-Disability Advisory Committee
April 16, 2026
Cross-Disability Waiver Public Comment

In 1993 La Vonne Daniels, of Crow Mountain Mental Health Consulting in Connecticut, submitted a report to Sam Ismir, the then Director of Mental Health services in North Dakota's Department of Human Services. The intention of the report was to serve as a blueprint for developing a children's mental health system in North Dakota. Prior to this moment, for all intents and purposes, there was no children's mental health system. The report, in part answered questions as to how many children require publicly funded services.

The assumptions La Vonne Daniels and her team made were just as important as their ultimate recommendation. They argued that research indicated about 12-15% of children have a diagnosable mental health condition, and between 5-6% of children have a serious emotional disturbance (SED). Today, the research indicates that while earlier research of children who have any mental health condition remains fairly accurate (at 16%), we had significantly underestimated the number of children with SED, with the correct figure at about 10%. Whereas Daniels and her team believed that 8,769 children in North Dakota had SED, today's figures put that at well over 18,000. They made a two-part argument stating that not all children with SED need public services. First, families could seek services in the private sector. Second, other may seek no services at all. In retrospect, the former suggestion sounds plausible, the latter a bit preposterous as a rationale to design for the capacity of a system of care for serious and chronic health conditions. With these rationalizations, the North Dakota public system only needed the capacity to serve 2 to 2.5% of the state's children's population on an annual basis. At the time, that translated to roughly 3,507 children— "if the system of care is fully developed and balanced."

This was a time before the *Olmstead* decision, which specified that *all* individuals with a disability had the right to community-based services, whether through the public or private sector. This was also a time during which North Dakota was experiencing continual population decline for multiple generations in the aftermath of the Great Depression. Now, North Dakota has had multiple years of reaching an all-time high population.

Within a couple of years of the publication of this report, all members of my family were among the first to receive a full array of mental health services through the Human Service Centers and contracted providers. These services were designed to keep the three of us children in the home, rather than face the very real prospect of having our family split up and/or my brother send to an out-of-state institution for the rest of his life. In addition to special education services, we had wraparound case management, mental health therapies (including occupational and physical therapies), in-home support staff Monday through Friday (mornings and the afternoons to early evening), my parents had parent peer support, I had a mentor, and my parents had respite services. We needed these services throughout our childhood, until we became adults. My brother, on the other hand, would continue to need services and support well into his 30s. Services were not designed as they are today, with the assumption that we will just magically get better within less than a year, perhaps "cured." When I was in high school, North Dakota hit its zenith in providing services to children with mental health issues. We never got to that 3,507 figure in our state's history, instead getting to 2,307 in 2002.

From the time I entered college, the state of North Dakota would slowly begin serving fewer children like me and my family. The state submitted records which explicitly set goals to serve fewer children, and they delivered on that promise nearly to the exact child. According to the records, this wasn't a force beyond our control, so much as an intentional choice. By the time

I was in graduate school, we were serving roughly a third of the figure recommended by La Vonne Daniels and her team. By 2018, that number dwindled to between 404 and 810. Meanwhile, the number of children in the juvenile justice system (most of whom are male) who had an SED rose from an already alarming 49% in 2011 to over 79% in 2017.

At the same time, the Department of Public Instruction began prioritizing kids like me who had a primary disability category of Emotional Disturbance to graduate. The history of kids like us was never pretty, with upwards of a 50/50 shot that we would ever graduate high school. We were among the least likely in the state to graduate, go to college (national data from my near-same age peers indicated that only 12% of us would do a community college, 4% of us would do university), or have a job. The goal the state has to this day is to increase the percentage of us who would graduate one or more years after our same aged peers would. More often than not, we've failed. Occasionally, the results suggested that we were worse off now than before we tried to make things better.

As I've entered this field, it's only become more readily apparent that my siblings and I were lucky, because since the time I left high school, kids like me and their families haven't been given the same opportunities I have had. My nephew is entering middle school with autism, and he hasn't been given the same opportunities we had. We're helping perhaps half the number of kids we did when I was a teenager, and it's been that way for over 13 years; over twenty years if you think about the depreciation of services.

I'm going to be a father in five months, raising a little boy. We all know that my child has a significant chance of having mental health challenges, perhaps even significant ones. We also know the data about young boys and men with serious mental health struggles and their outcomes, what dangers lurk beyond the horizon for those parents. We interact with their "cases"

every day. I would be lying if I said I didn't think about what I may be facing in five or six short years, comparing the intense struggle my parents had just over 30 years ago to our own potential future. How confident can I be that what families are facing now won't happen to me? Frankly, I don't know. Among my happiness, hopes, and dreams also comes lurking anxiety over our future; my son's future. The families I do and don't have the privilege of knowing deserve the same opportunities I had. My nephew deserves the opportunities that I had. My son deserves the opportunities I had. It grows tiring knowing that for over 20 years, fewer children and families do get the opportunities I had.

Records indicated that the state of North Dakota intentionally decommissioned its children's mental health system. That was an active policy choice. Inaction is also a public policy decision. If an opportunity arises to address a public policy problem and policymakers elect to not act, that is also an action. This seems to be another moment to address a glaring public policy problem. What will the choice be?

Thank you.

Matthew McCleary

PUBLIC COMMENT 8

My name is Carl Young. I'm a parent of a 25-year-old with Fetal Alcohol Spectrum Disorder, and I've spent over 20 years working with individuals and families across this state.

I speak nationally and internationally on FASD, contribute to research and policy work, and I also bring **living experience**—not only as a parent, but as someone diagnosed with FASD myself later in life.

And it's from that perspective that I want to speak about what families are experiencing here in North Dakota.

North Dakota's eligibility criteria for Developmental Disabilities services are written in a way that makes sense. They state that eligibility should be based on multiple factors—including adaptive functioning and substantial functional limitations—not just IQ.

This is also reflected in North Dakota Administrative Code, which outlines a multi-factor, professional judgment-based approach to eligibility.

However, what families are experiencing does not reflect that standard.

In my work with individuals and families affected by FASD, I am seeing a consistent pattern of denials where individuals with clear, lifelong functional impairments are not qualifying for services—often in cases where IQ does not fall below a specific threshold.

So the issue is not the written criteria.

The issue is how those criteria are being applied in practice.

[Pause]

If IQ were truly just one part of the determination, we would not be seeing individuals with documented adaptive deficits and significant needs denied eligibility at the rates we are seeing.

FASD is a condition that exposes this gap very clearly.

Individuals with FASD often do not have a low IQ. But they do experience significant impairments in executive functioning, judgment, memory, and the ability to live independently.

These are exactly the kinds of limitations the system says it is designed to recognize.

And yet, these individuals are falling outside of eligibility.

It is also important to recognize that in 2023, North Dakota took an important step by formally recognizing Fetal Alcohol Spectrum Disorder as a developmental disability in North Dakota Century Code, under section 25-01.2-01

That recognition matters.

But recognition without access does not change outcomes.

We are not denying disability.

We are denying eligibility.

[Pause]

And when that happens, the need does not go away. It simply shows up somewhere else.

And too often, it shows up in the juvenile justice system.

My own son has been involved in the criminal justice system since he was 8 years old. He will be 25 this year.

At the time, we believed we were dealing with behaviors.

What we were actually seeing were symptoms.

Without the right supports, those misunderstandings compound over time—and the consequences can last a lifetime.

FASD alone is significantly underdiagnosed, and as awareness increases, so does demand for appropriate services.

Current CDC estimates suggest that as many as 1 in 20 individuals may be affected by FASD. For insight, in North Dakota, this can be represented by as few as one child per classroom, however the number could be much higher.

This is not a rare condition—and the demand is already here.

We cannot fix access by tightening eligibility in practice while also underfunding the workforce needed to provide care.

I understand that CDAC's role is advisory—but that role is critical.

So I would offer three specific recommendations:

First, review and revise how eligibility criteria are applied so IQ is not functioning as a gatekeeper.

Second, ensure individuals with documented FASD are eligible based on functional need without reliance on the Goulet Grid.

Third, improve Paid Family Caregiver implementation so it works as intended.

If families cannot access eligibility, they cannot access support—and no downstream policy can fix that.

When practice does not match policy, the policy is not the protection it is meant to be.

Thank you for your time.

ADJOURNMENT

- The meeting was adjourned at 4:28 p.m.