



# Cross Disability Advisory Council Meeting



October 16, 2025





## AGENDA

- I. **Welcome Activities**
- II. **Read out from Subcommittees**
  - a. Recap of subcommittee purpose
  - b. CDW
  - c. IID/DD
- III. **Vote on CDAC's Guiding Principles for Level of Care**
- IV. **Update on Public Comment**
- V. **Discussion: CDW Service Array**
  - a. Budget
  - b. Modalities
- VI. **Closing Activities**

# Welcome Activities



# Approach to October CDAC

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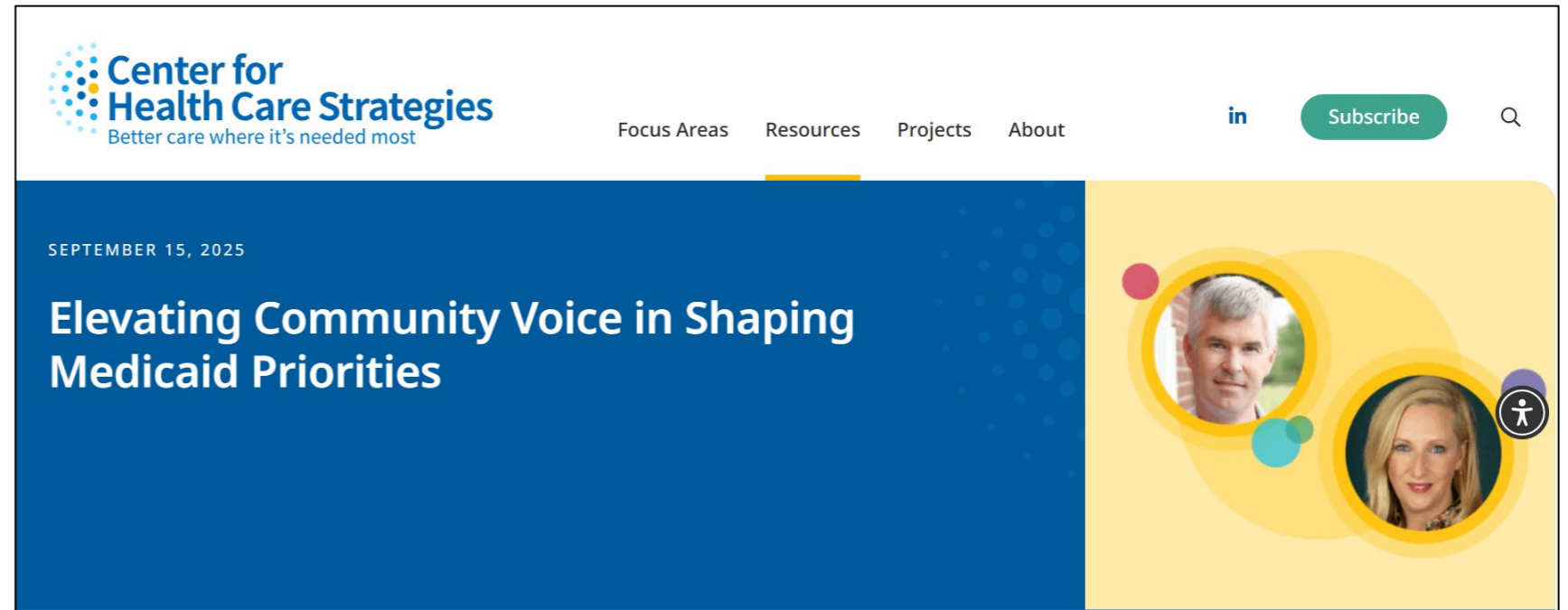
- ❖ **Content Overview:** We want CDAC members to **understand:**
  - ❑ The summary recap of each subcommittee's discussions
  - ❑ The feedback we heard from behavioral health public comment sessions
  - ❑ The key design elements for waiver services
  
- ❖ **Voting on CDAC Recommendations:** We want CDAC to **vote on:**
  - ❑ The guiding principles for ND's level of care tool modernization
  
- ❖ **Feedback:** We want CDAC's **input** on:
  - ❑ The future state of services that are carrying over from the ASD, MF, and IID/DD Waivers
  - ❑ The modalities that inform the design of services



# CDAC in the News!

*The Center for Health Care Strategies recently published an article that celebrates the great work of the CDAC.*

*“As Erin Peterson, parent advocate and member of the North Dakota Cross-Disability Advisory Council put it, “Families [are] able to provide the face and story to who the state is supporting.” That statement captures an important truth: individual and family input is not just “nice to have”— it is central to a responsive and resilient Medicaid program.”*



<https://www.chcs.org/elevating-community-voice-in-shaping-medicaid-priorities/>



# CDAC's Subcommittees



## Recap: The Main Goals of ND's Waiver Work

***The work ahead has two major goals: 1) create the new cross-disability waiver and 2) update the way people qualify for the IID/DD waiver***

**Goal #1: Create a new children's waiver  
(CDW subcommittee to lead)**

Create a new HCBS waiver for kids aged 3 until age 21. This waiver will serve kids different disabilities.

**Goal #2: Update the way people qualify for IID/DD waiver  
(IID/DD subcommittee to lead)**

Fine tune and update the process used to decide who qualifies for the IID/DD waiver.



# Why CDAC is Using Subcommittees

***CDAC will have two subcommittees. This will allow CDAC to cover a lot more ground in the time it has together.***

- There is a lot of work to get done in the next two years. CDAC has limited time together.
- Using subcommittees helps CDAC members to become more knowledgeable about some topics and makes it easier to reach decisions.
- The subcommittees will share their insight and the things they learned on their topics with the full group.
- The subcommittees will be focused on the different waivers:
  - Subcommittee #1: IID/DD Waiver
  - Subcommittee #2: CDW



# Subcommittee Schedule

***CDAC will mostly meet separately in the subcommittees. CDAC will come together as a full group once every three months***

- In some months, CDAC will split into two groups to cover different topics. These will be virtual, 1.5-hour long meetings.
- CDAC will come together as full group for an in-person, day-long meeting once every three months.
- We are meeting in subcommittees in September. We will meet as a full group again in October.
- Then, in November we will begin the quarterly cycle of meeting in subcommittees for two months then coming together as a full group in the third month.
- Sometimes the subcommittees will look at **different topics**. Other times, the subcommittees will look at **similar topics with different focuses** across the waivers.



# Read-out from CDW Subcommittee



# CDW Subcommittee

***This subcommittee is focused on tasks related to the new cross-disability waiver.***

- This subcommittee will address one of the goals of this project:
  - “Create a new HCBS waiver for kids aged 3 until age 21. This waiver will serve kids with different disabilities.”
- Reminder about the future state for the new CDW:
  - Designed to serve all qualifying children with mild to moderate support needs, aged 3 until age 21
  - Two ways for kids to qualify (LOC)
    - Easier LOC for kids 3-5 and
    - Modernized LOC for kids 6+
- This subcommittee may look at defining the service array, front door processes, and the structures for providers, case management, and quality for the CDW. Some of this work may be done in hand with the IID/DD subcommittee.



# What Was the Focus of September's CDW Meeting?

***The CDW subcommittee focused on the waiver's new target populations during the September meeting.***

- ❖ We talked about the new populations being served in the CDW.
- ❖ We explained what serious emotional disturbance (SED) is and what behavioral health services are currently available. We gathered CDAC's feedback on hosting public comment sessions for SED.
- ❖ We asked CDAC about their experiences supporting kids with SED.
- ❖ We reviewed the summary of stakeholder feedback from the assessment about the 3-5 population. We gathered CDAC 2.0's reaction to CDAC 1.0's insights.
- ❖ We talked about the members' responses to the pre-meeting survey that asked about integrated supports that exist for kids aged 3-5 with disabilities.
- ❖ We completed a survey to document the guiding principles that the subcommittee wants HHS to keep in mind as they move forward with implementing these changes for 3-5.



# What Were the Key Takeaways from September's CDW Meeting?

Subcommittee Feedback	A&M Comments
<p>Members suggested <b>clarifying language about the level of need being served on the waiver</b> moving forward. This will help reflect that some populations on the waiver, like Medically Fragile children, may have higher needs and some others may have moderate needs.</p>	<p>Agree. This will be important to keep in mind for communicating the changes to families so they can prepare for the transition.</p>
<p>Members noticed that the term for significant mental, behavioral, or emotional health challenges that create functional limitations <b>changes to "SMI" from "SED" at age 18</b>. Wants HHS to keep this in mind when designing the assessment and communicating about the waiver.</p>	<p>Agree. Many other states with 1915c waivers for serious behavioral health disorders serve kids through age 20 and use the term SED. SED / SMI are not diagnoses; they are umbrella terms to reflect the functional limitations that come from a significant behavioral health challenge.</p>
<p>Members noted that they felt like there used to be strong wraparound services, but now they think that there is a <b>gap in wraparound for BH and ID/DD needs</b>. Another <b>gap is even knowing what services are there</b>.</p>	<p>Agree. We gathered more information about people's experiences with serious behavioral health disorders during public comment sessions.</p>
<p>Members conducted an <b>Integrated Supports Star exercise for the 3-5 target population</b>. They want HHS to keep in mind that assessing this population may be challenging. They encouraged HHS to <b>focus more on the functional limitations, in addition to the diagnosis</b>.</p>	<p>Agree that it is important to understand functional limits. Diagnosis does still play an important role in helping to identify the target population.</p>

# Who Should the New Waiver Serve?

*CDAC members recommended that the new waiver should include people aged 3 until age 21 with qualifying conditions. They recommended areas where the waiver could include some people who have trouble getting services today.*

**People Already Served on Waivers** Today Who will be Part of the New Waiver

Children who qualify for the Autism Waiver

Children who qualify for the Medically Fragile Waiver

Children with developmental disabilities

**New Groups Who Do Not Already Get Services** That Will Be Part of the New Waiver

Some additional children ages 3 through 5 who fall off today

Children with behavioral health needs



When we asked CDAC members what was most important if there were limited funds, **expanding the target population for the new waiver was their top priority.**

# How do States Identify the Waiver Target Population?

Target Population

1. States start with a high-level idea of who the waiver will serve

**Age**  
*What ages of people will this waiver serve?*  
*Example: All ages*



**Condition(s):**  
*What types of diagnoses will be served?*  
*Example: People with intellectual and developmental disabilities*



2. Then, states define who is included in more detail

**Definitions:**  
*What does it mean to have an intellectual or developmental disability?*  
*Example: Areas of functional limits*



3. Not everyone in the target population qualifies for the waiver. People also need to meet level of care. This is about how high their support needs are

**Level of Care:**  
*Would the person qualify for institutional services?*  
*Example: Are the needs great enough that the individual could receive treatment in an intermediate care facility (ICF)?*



# Overview of Serious Behavioral Health Disorders

*Sometimes, youth may be facing significant functional limitations because of their qualifying behavioral health diagnosis. Sometimes these youth also have other disabilities.*

- One of the target populations for the new cross-disability is youth (aged 3-20) that have **significant functional limitations because of their serious behavioral health disorder**, who **also have other qualifying disabilities**.
- These youth **need specialized treatment at a higher level of care** beyond general mental, behavioral, or emotional health support. They **also need services for their disabilities**.
- The new cross-disability waiver will attempt to serve kids who have **struggled to access behavioral health services because of their disability**, and / or kids who have **struggled to access disability services because of their behavioral health** needs.
- Moving forward, this project will refer to this target population (3-20 with functional limitations due to their qualifying behavioral health diagnoses and other disabilities) as **“youth with serious behavioral health disorders.”**



# Why it is Important to Expand Waiver Access for Kids 3-5

***Serving children with disabilities during their earliest years yields many long terms benefits for both families and the state.***

## **Findings from the Assessment that CDAC 1.0 Concurred With**

- Diagnosing children at the youngest ages is challenging, which can make the waiver qualification process difficult.
  - It is complicated to assess young children with lifelong disabilities.
  - Assessing IQ in young children is especially hard.
  - Workforce shortages can delay completing assessments due to workforce shortages.
- Young children are the most cost-effective age group to serve on waivers.
- Very young children with disabilities respond especially well to early treatment.
  - Cheaper early treatment can help alter the course of a child's disability, reducing the need for more expensive services later.
  - Strong support during early years also sets children up to enter school in a better position to succeed.



# Sharing Guiding Principles for 3-5 with HHS

***The CDW Subcommittee shared guiding principles for serving kids aged 3-5 with disabilities with HHS as they continue to design the CDW.***

What is important for North Dakota to keep in mind as they build a new level of care for kids at age 3 on the IID/DD waiver and the CDW?

I think ND should continue to keep in mind: - focus on the process: timelines and clear explanation of different services, evaluations expectation, and information in different ways to explain.

Even though there may not be a lower IQ present, there are many developmental challenges that need to be addressed and should be considered

How will we optimally assess the child who may be nonverbal within the age 3 level.

Family voice and self direction, function not diagnosis

Also keep in mind SSI or different determination areas for eligibility that could impact families.

Every situation is unique. There are many who still require a lot of support. More family navigators.

Ongoing Trainings for BOTH families AND staff, program managers, eligibility members.



# Read-out from IID/DD Subcommittee



# Overview of the IID/DD Subcommittee

***The IID/DD subcommittee work on tasks related to the IID/DD waiver.  
We will focus on how people qualify for the waiver.***

- This subcommittee will address one of the goals of this project: “Update the way people qualify for the IID/DD waiver (through Level of Care (LOC))”
- Future state for the updated IID/DD waiver:
  - Modernized rules about who qualifies for the waiver (LOC)
  - Designed to serve people with ID/DD who have the highest needs, including both kids and adults
- This subcommittee will look at updating ID/DD definitions and criteria.



# What Was the Focus of September's IID/DD Meeting?

***The IID/DD subcommittee focused on definitions during the September meeting. We also looked at pathways for waiver eligibility.***

- ❖ We discussed the basics of what a waiver target population is. We talked about and the role definitions play in identifying the target population.
- ❖ We reviewed North Dakota's current state. This includes the definition for developmental disabilities and the paths for waiver eligibility.
- ❖ We asked members to share about the gaps they see today.
- ❖ We also looked at some national examples. This included peer states and national bodies.
- ❖ We asked members to share thoughts about possible changes.



# What Were the Key Takeaways from September's IID/DD Meeting?

Subcommittee Feedback	A&M Comments
<p>Members shared that eligibility for the IID/DD waiver can be confusing. It is <b>hard to understand the ways someone can qualify</b> for the IID/DD waiver.</p>	<p>Agree. This matches what we have heard from stakeholders in the assessment, and from CDAC 1.0. The goal is to design an easier to understand process.</p>
<p>Members confirmed that <b>sometimes people don't end up on the waiver that is best for them</b>. For example, someone with physical disabilities might be better served on another waiver.</p>	<p>Agree. People who won't be well served on the waiver should not be part of the target group. We will also need to fix legislative language to give people choice in which waiver they are served on.</p>
<p>Members liked national examples of states that included social functions when assessing DD. They <b>recommended ND look at adding social areas to their definition</b> too.</p>	<p>Agree. We have pulled some examples of how other states include this language in their definitions. We will work with the State on ways to add it in ND.</p>
<p>Members also shared that it is harder to help support social needs. Direct support professionals are skilled at supporting people with their activities of daily living, such as daily hygiene. It is more challenging to help people with social skills, such as learning how to not be gullible. <b>Someone with only social needs might find the services on the IID/DD waiver helpful.</b></p>	<p>Agree. It will be important to make sure someone with only social needs is not part of the target population. We will work with the State to make sure other areas of function besides social are required. There are examples of other states that have done this too.</p>

# How do States Identify the CDW Target Population?

Target Population

1. States start with a high-level idea of who the waiver will serve

**Age**  
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*Example: All ages*



**Condition(s):**  
*What types of diagnoses will be served?*  
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2. Then, states define who is included in more detail

**Definitions:**  
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3. Not everyone in the target population qualifies for the waiver. People also need to meet level of care. This is about how high their support needs are

**Level of Care:**  
*Would the person qualify for institutional services?*  
*Example: Are the needs great enough that the individual could receive treatment in an intermediate care facility (ICF)?*



# How Will ND Create the New Waiver Assessment Process(es)?

## Identify Population

- **Decide the target population. This includes what ages and conditions will be served by the waiver.**
- ND already knows the target population at a high-level
- The CDW subcommittee will help refine the new waiver population

## Set Definitions

- **Define what it means to be in the target population**
- This includes the definition for what it means to have certain conditions like developmental disabilities
- **The IID/DD subcommittee will help update definitions for the IID/DD waiver**

## Establish Criteria

- **Set criteria for who qualifies for the waiver**
- This starts with the definition
- Then, the state adds the functional needs someone should also have

## Pick an Assessment Tool

- **Select the tool the state will use to assess if someone qualifies**
- The tool will help the state measure needs and test the criteria
- **This is what we will talk about today.** We will come back to this again after the sub-committees have talked about the other pieces above.



# How do People in ND Qualify for the IID/DD Waiver Today?

***North Dakota's IID/DD Waiver serves individuals who have needs related to intellectual functioning. This includes either having ID, or a related condition that looks similar to ID.***

## Pathway #1

**ID and DD**  
due to ID  
(Severe ID)

## Pathway #2

**ID** (no DD),  
can benefit  
from  
services

## Pathway #3

**Related  
condition**  
with similar  
impairment  
as ID, can  
benefit from  
services



# How Does North Dakota Put This All Into Practice?

***ND looks at people's functional limitations to see if they meet the target populations.***

ND looks at functional ability using the Gollay Grid. To meet the definition for DD, someone must show 3 limits across any of the Grid's categories below. These categories are in two buckets of adaptive deficits: conceptual and practical. **Note that the language for the IID/DD waiver also requires an intellectual component.**

Gollay Grid Category	Examples	Adaptive Deficit
Receptive and Expressive Language	Understanding through listening, reading, use of oral or sign language	Conceptual
Learning	Memory, knowledge, reasoning	Conceptual
Self-Direction	Decision-making, self-awareness, cooperation	Conceptual
Self-care	Eating, toileting, dressing, taking medication	Practical
Mobility	Movement, fine motor control, coordination	Practical
Capacity for Independent Living	Using transit, housekeeping, time management	Practical
Economic Self-Sufficiency <i>Not included in federal definition for related condition as one of the three areas</i>	Job finding ability, earning capacity	Practical

# What are Peer States Doing About DD Assessment?

*Some peer states have also updated the way they look at DD. Several peer states now also look at social deficits. Below are examples of how states define social.*

- **Nebraska:** 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
- **Kansas:** Social skills, community use, leisure
- **Iowa:** Social/community skills, behavior
- **South Dakota:** Self-direction: the management of one's social and personal life; the ability to make decisions affecting and protecting one's self-interests; (this criteria may be applied in both conceptual and social)



# Level of Care Guiding Principles



# CDAC's Guiding Principles on Level of Care Assessments

Topic	CDAC Feedback / Recommendation	A&M Notes
Age	Use pediatric versions of assessment tools for kids. Young kids are harder to assess because the age norms considered are different. Consider impact of different cultural norms and traditions.	Many national tools have child and adult versions of the same tool. ND will look to use the pediatric versions where available and appropriate.
Administration	How the assessment is given matters. Some kids may struggle to answer questions due to behavioral needs. Consider ways to include parent input and / or observation of skills.	Some tests such as the ICAP have observation components. Research also shows that parent reporting is highly accurate.
Administration	Staffing will impact success of implementation. Invest heavily in training.	Training is a critical piece. Using a national tool does allow states to access additional training materials and staffing resources outside the state
Tool Options	CDAC recommends using a national tool to ensure stronger validity and reliability, and easier and more consistent / standard administration.	Validity and reliability can be built into homegrown tools. However, this process takes a significant amount of time. Many national tools are certified as valid and reliable "off the shelf".
Other	Consider impact of different cultural norms and traditions, especially for younger children where expectations may differ.	Agree. Consider options that could maintain validity while also emphasizing cultural inclusivity.
Other	Consider ways to integrate existing tests such as IEP (Part B) with the waiver testing process to reduce burden on families.	We will explore whether this is an option for ND. It may depend on the assessment tool as well.
Other	Wait time between assessment and access to services is especially difficult for families. Look for ways to reduce this where possible.	Turnaround time on scoring assessment will impact this. Parental reporting may help expedite scoring / turnaround. Workforce limitations can sometimes mean longer waits.
Other	There are kids with no ID, but a DD condition that impacts multiple areas of life function. This group is an outlier who is not served today.	Kids with no ID but DD could potentially be served on the new waiver, if they meet the functional requirements. Adults with physical disabilities are intended to be served on the HCBS waiver.

# Behavioral Health Public Comment Update



## Public Comment Themes (1 of 2)

***A&M recently held public comment about serious behavioral health disorders on the CDW. These were the themes attendees shared with us.***

### Public Comment Feedback

Access to providers is a significant challenge in the behavioral health space. There are few providers in rural areas, and there are rules about which providers can conduct the WHODAS assessment. There are also rules to prevent a conflict of interest about which agencies can conduct the assessment, be care coordinators, and provide services.

Families struggle with long wait lists to get in to providers to get behavioral health assessments and diagnoses. Diagnoses may not always be accurate or may be changed over time due to different incentives. Getting the diagnosis itself is an obstacle to access to services.

School systems have a significant impact on the child's performance. Schools may not always have sufficient resources to support children with behavioral health needs. Socialization with peers is important, but it requires a lot of support from schools that may not always be there.

Some services to address behavioral health needs could include: wraparound case management, family peer support, in home support, respite, and crisis respite / safe beds.

## Public Comment Themes (2 of 2)

***A&M recently held public comment about serious behavioral health disorders on the CDW. These were the themes attendees shared with us.***

### Public Comment Feedback

Different mental and behavioral health diagnoses get different types of services and supports. Similarly, different disabilities are treated differently in terms of what programs and services they qualify for.

Kids with serious behavioral health disorders are facing a gap in access to quality services. Consider serving kids with just serious behavioral health disorders on the CDW, not just those kids who also have disabilities.

Existing behavioral health programs have different eligibility requirements that make access challenging. Once qualified for a program, the service array may not fit the needs of the child's behavioral health needs.

Families are experiencing significant burnout from trying to secure assessments and diagnoses for their children's behavioral health needs, identifying services and figuring out what they qualify for, working with the different providers, schools, and case managements, and then making sure their children can get to their needed services.

# Approach to CDW Service Array



# Understanding Integrated Supports

***The new waiver will be focused on integrated supports. This means services wrap around what is already in the community.***

- Supports work best when they are integrated across an array of options, including both eligibility-based supports and natural supports available in the community.
- Focusing only on eligibility-based supports can unintentionally separate a person from their family and natural support system, which then can lead to segregation, loneliness, and lack of choice.
- Supports should leverage and be comprised of a mix of:
  - The person and family's strengths and assets;
  - Relationship-based supports;
  - Community supports and resources;
  - Technology;
  - Eligibility based options that are publicly or privately funded.



\*Source: *Charting the LifeCourse Nexus (UMKC IHD)*

# What Services Should the New Waiver Have? (Services 1 of 2)

***CDAC members said that no one should lose services they have today.***

- CDAC 1.0 wants to make sure that no children lose access to services they are getting today.
- They want to make things easy for families and children who are already getting help from a waiver.
- CDAC 1.0 recommends that the new waiver include all services from the existing waivers that serve kids.
- This means the new waiver would include all services from the Autism waiver and the Medically Fragile waiver, and most services from the IID/DD waiver.
- IID/DD waiver services designed for adults or people in residential settings will not carry over. This is because this waiver is focused on kids living in the community.



# What Services Should the New Waiver Have? (Services 2 of 2)

*CDAC members recommended exploring some new services to include on the waiver. These services might not be added in the beginning, but later.*

- CDAC 1.0 talked about how it was important to help children and families prepare for transitions.
- To help with this, CDAC recommended the State consider services focused on skill-building.
- Some example ideas included:
  - **Family training** to help families best support their children
  - **Skill building** for activities like self-advocacy, traveling in their community, money management, and more
  - **Discovery** to help kids explore employment and other community activities
- CDAC also talked about the need for **supports that can help families in crisis**. One example is emergency respite. This means families can get a break immediately if needed.



# CDW Service Array

***CDAC 2.0 will have an important role in providing feedback to HHS on the services to be included in the CDW.***

- Today we will talk about how to deliver the services that will likely be included on the waiver. We will talk about:
  - Budget
  - Modalities
- You will help provide ideas about what these services should look like and the options that families should have.
- We won't be talking about new services yet.
- It will be important to think about what tradeoffs will have the most benefit for participating children and their families, with a limited budget and resources.



# Budget Considerations for CDW Services



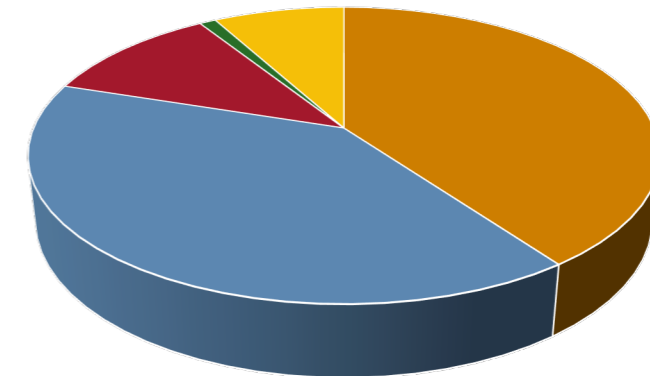
# Understanding Medicaid Waiver Spending

*Mapping major spending elements associated with waivers is important to understanding the true cost of adding / modifying waiver slots and services.*

## Medicaid Waiver Spending 101

- When someone is eligible for a Medicaid HCBS waiver, such as the Medically Fragile Waiver, they are eligible for both **waiver-specific services** (e.g., dietary supplements) **and general Medicaid State Plan services** (ex: therapies).
- To understand the impact of including someone on the waiver, states must calculate both the cost of providing waiver services to an individual and the cost of providing Medicaid State Plan services to an individual.
- States must also budget for **additional costs outside of Medicaid services**, including include case management, data servers, and fiscal management services.
- We do not expect anyone to be an expert in waiver spending! We are including this information as additional context for those who may find it helpful when thinking about prioritizing limited funds.

Total Spending, per Waiver Participant (illustrative proportionality only)



- Waiver Services
- Medicaid State Plan Services
- Case Management
- Data Platform
- Fiscal Management



# Where Should ND Prioritize Investment of Funds?

*With CDAC 1.0, we talked about how the new waiver can serve as an important investment for children with disabilities. In a world where funding may be limited, we asked members to think about what was most important to them.*

We asked: After the “status quo” of current waiver participants and services is established in the new waiver, how should we apply any additional funding? The below areas are the choices we presented to CDAC 1.0.

## **Making it Easier for People to Qualify**

*Lowering level of care requirements would result in more people on the waiver, potentially at lower levels of need.*

## **Adding New Waiver Services**

*Think about examples that may help people on the waiver address the unmet needs we've discussed.*

## **Expanding Access**

- *Lowering the barrier for kids 3-5 to qualify for the waiver*
- *Adding behavioral health to the target population for the waiver*

## **Ensuring No Waiver Waiting Lists**

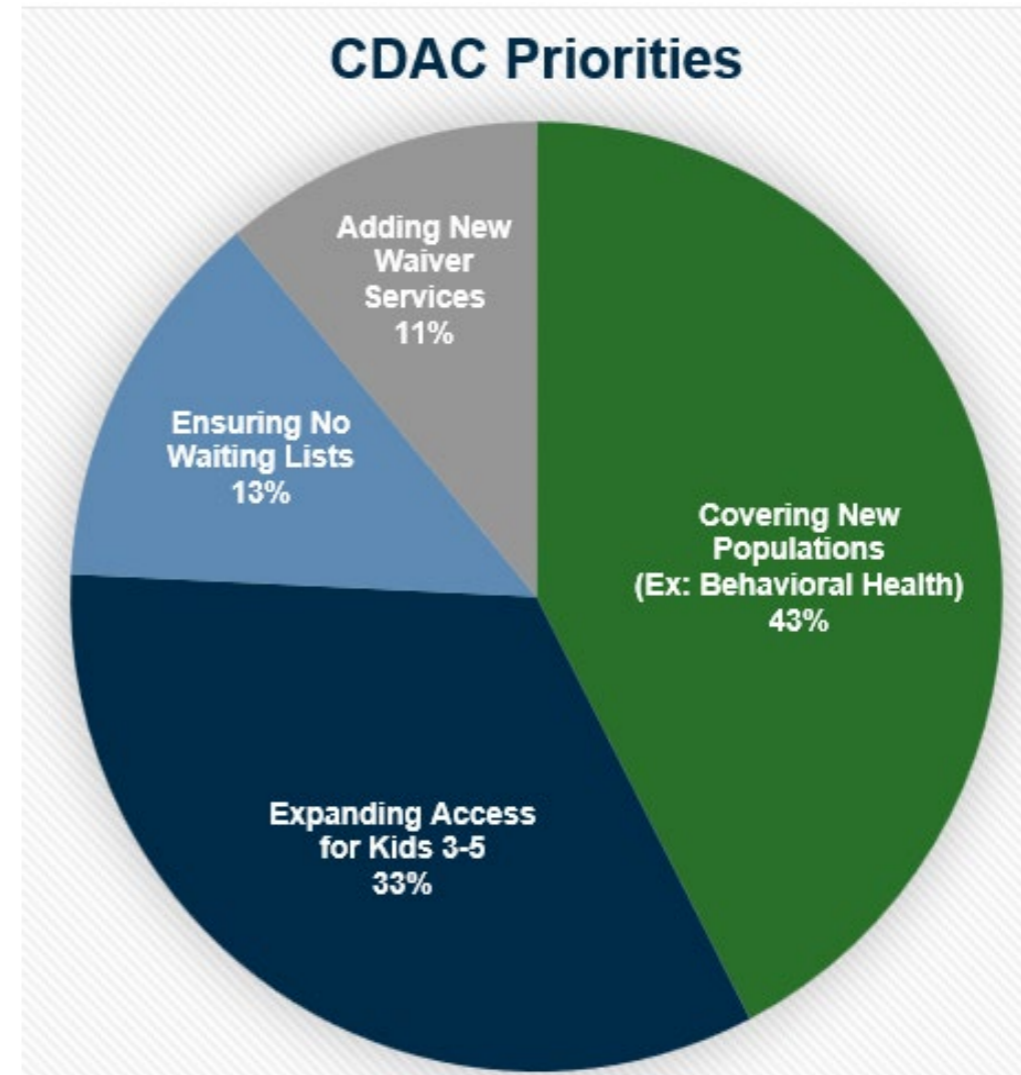
*Some states don't have enough funding to serve everyone who qualifies. North Dakota recently increased funding to address this problem in MF and ASD.*



# CDAC 1.0's Recommendations on Investing Funds

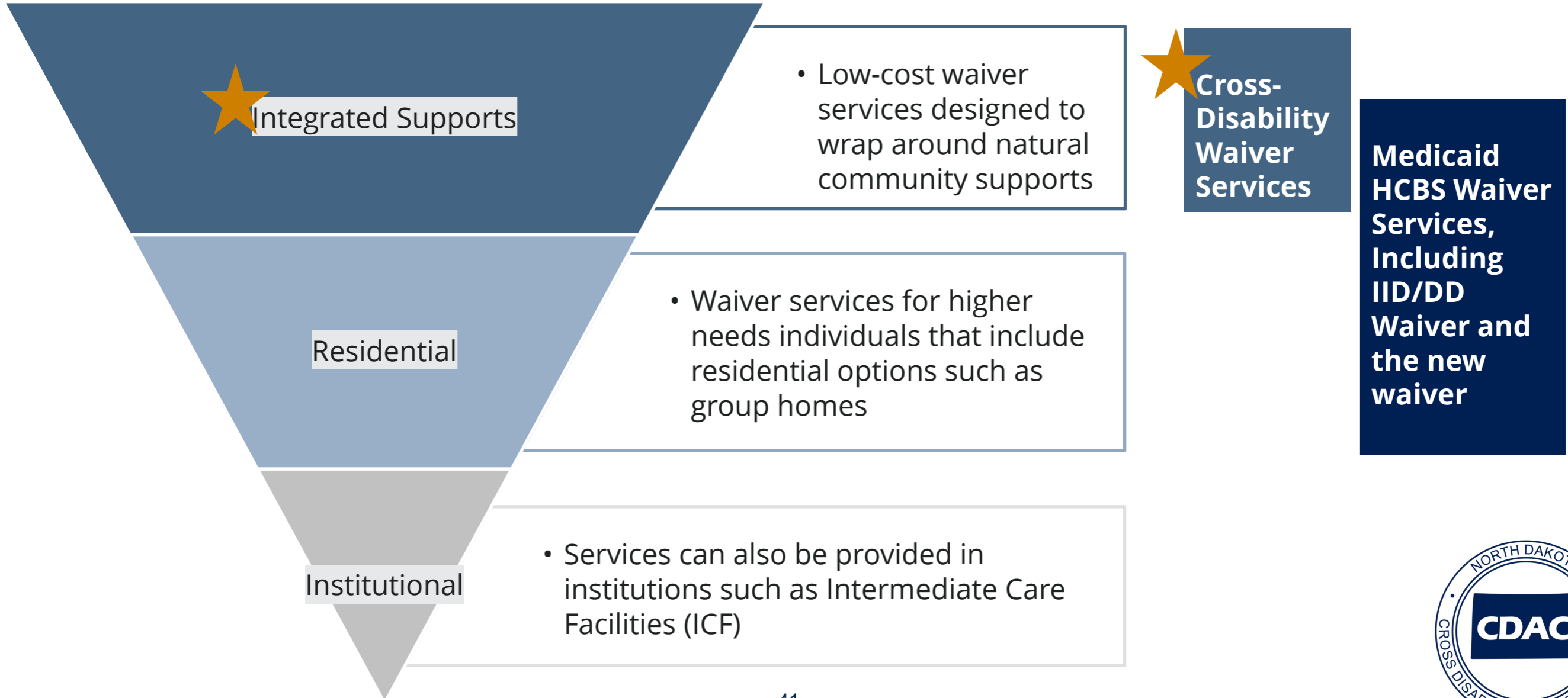
*CDAC said that it was most important to expand access and share resources equitably.*

%	Priority
42%	<b>Increasing Access for Additional Populations</b> (Behavior Health, CP, FASD, DS, MS...)
33%	<b>Expanding Access for Kids 3-5</b> (Reducing the "Cliff" for young children being re-assessed)
13%	<b>Ensuring No Waiver Waiting List</b> (Ability to access waiver as soon as you qualify)
11%	<b>Adding New Waiver Services</b> (ex: Chore/homemaker)



# Overview of Long-Term Service and Supports Delivery Models

## Types Long-Term Services and Supports (LTSS)



# Comparing State Spending on Integrated Support Programs

*Projected Spend for Supports Waivers, as reported in Appendix J of State Waivers. Note this only looks at costs on waiver service spending and does not include broader Medicaid costs,.*

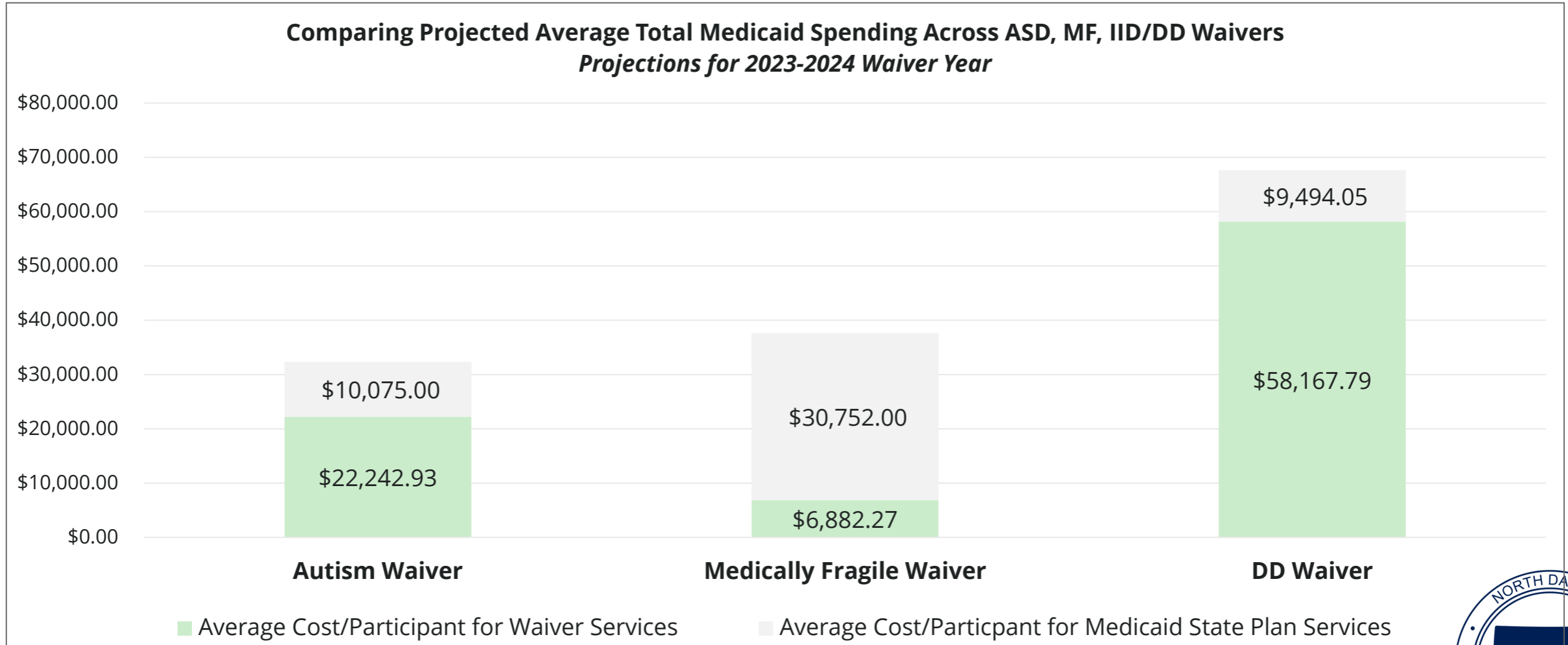
State	Population	Ages	Average Waiver Spend/Person
Illinois	Autism, DD, ID	3-21	\$16.6k
Louisiana	Autism, DD, ID	0-20	\$18.1K
Michigan	AD, DD, ID	0-17	\$21.3
Missouri	DD, ID	0-17	\$24.4k
<b>New York</b>	<b>Cross-Disability</b>	<b>0-20</b>	<b>\$3.7k</b>
North Dakota	Autism	0-17	\$22.2k
North Dakota	Medically Fragile	3-17	\$6.9k
South Dakota	DD, ID	<i>Lifespan</i>	\$4.2K
Utah	ASD, DD, ID, Brain Injury	<i>Lifespan</i>	\$24.5K
<b>Wisconsin</b>	<b>Cross-Disability</b>	<b>0-21</b>	<b>\$10.8k</b>
Wyoming	DD, ID, Brain injury	21+	\$11.3k

*There are no supports waivers for Iowa, Idaho, or Montana, so we have pulled additional examples from states beyond the immediate peer state landscape for comparison*



# Understanding How Spend Varies Across Waivers

*Spending looks significantly different across the different HCBS waivers ND operates.*



# CDW Budgeting Discussion (1 of 2)

## ***ND needs ways to help manage and predict costs for the new waiver.***

- When states start new programs, it is hard to know how much they will cost for sure. This is because people's spending varies.
- Having a waiver with more services, like the cross-disability waiver, gives people more choice. It also makes spending more difficult to predict and control.
- ND needs to make sure there is enough money to serve the people on the waiver without running out of money.
- The state also wants to make sure access to the waiver is shared equitably. The idea is everyone gets enough, but not more than they need.
- **The goal is to create a program that both expands access while being fiscally sustainable for the state.**



## CDW Budgeting Discussion (2 of 2)

***Let's talk about some options the state has to help make spending more predictable. We want to hear your thoughts.***

- To help manage costs, ND will likely need to use something called a cap. This means the state places a limit on spending.
- Caps can be for each person across all services, or for each service. Limiting amount of service usage also controls costs. There are pros and cons to each option.
- Would you rather have a total amount of money to spend for a year, or money for each service bucket?
- Would you want to see the budget across a whole year, or would it help to see it by month / quarter?
- What would help you plan for your budget?
- What could a case manager do to help you with this?



# CDW Service Modalities



# Waiver Modalities: The Details

***Modality means the way a service is delivered. Modalities are about the details of how and where people receive waiver services.***

- Today we will talk about the following modalities:
  - Technology
  - Self-direction
  - Paid family caregiving
- We will start by explaining the modality. Then, we will talk about what it looks like in ND today
- We will also share what CDAC 1.0 recommended.
- Finally, we will review ideas for the future and ask for your feedback about this.



# Technology as a Modality

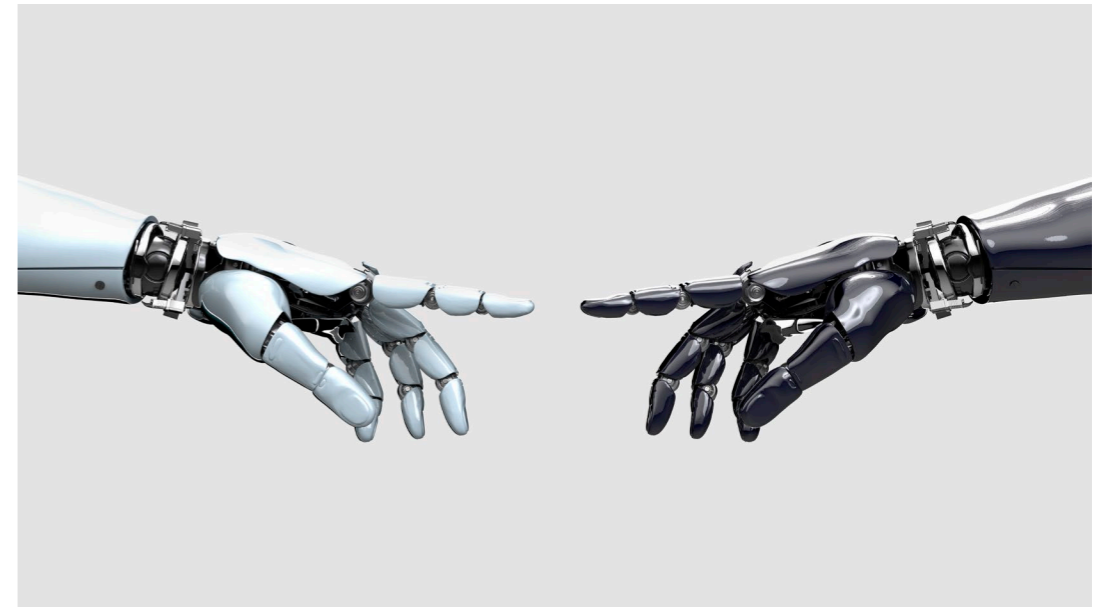


# The Benefits of Technology as a Modality

***Technology can be both a waiver service – such as assistive technology – and a modality for delivery of waiver services.***

## Technology:

- Plays a complementary role to other supports
- Can be used to supplement in-person service delivery and help bridge gaps caused by workforce challenges
- Promotes autonomy, self-direction, and engagement
- Increases service capacity in rural areas
- Gives families flexibility to safely continue services during cold and flu season by using remote supports
- Drives more efficient and effective practices, contributing to greater cost-efficiency in the waiver



# Check Our Understanding

*Let's check our understanding of technology as a waiver service modality before we learn more.*

Let's complete a Menti survey!

The question is, "What do you know about technology as a waiver service modality?"

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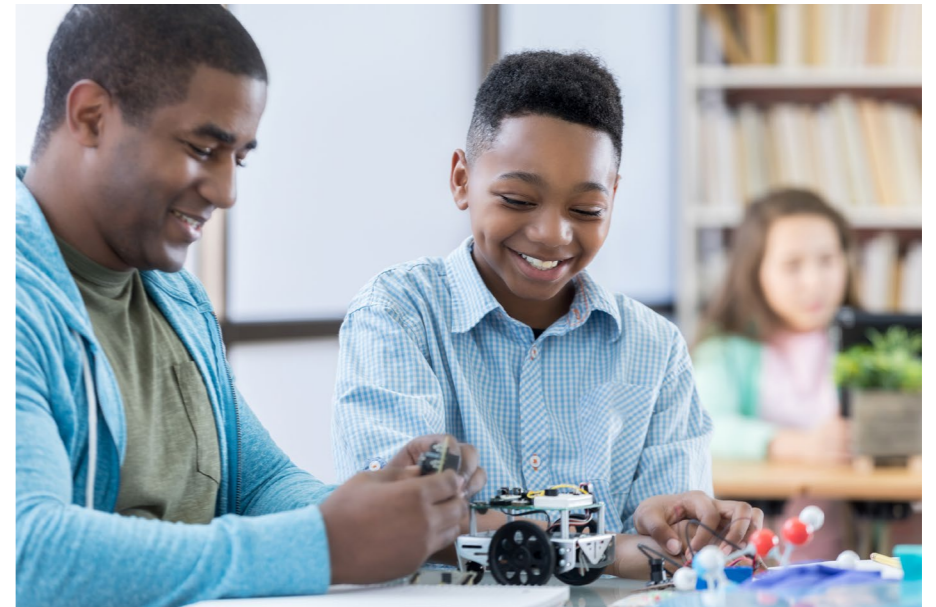
# Overview of Technology in North Dakota's Waivers

## Today (1 of 2)

DRAFT

***North Dakota allows some use of technology in service delivery. This option is included on both the IID/DD and ASD waivers.***

- The IID/DD waiver has virtual or remote support options. Services with this option include independent habilitation, individual employment support, and behavioral consultation.
- The ASD waiver allows options for some case management to be delivered via telehealth
- There are safeguards for technology in service delivery. For example, case managers must still conduct a minimum number of home visits.
- Participants always have the choice to request in-person services rather than telehealth.
- There are also multiple requirements for privacy protection.



# Overview of Technology in North Dakota's Waivers

## Today (2 of 2)

DRAFT

***The ASD Waiver includes two services where technology is the focus. These services are assistive technology and remote monitoring.***

- **Assistive technology:**
  - Provides devices and services to improve a child's abilities, such as communication tools or mobility aids.
  - Includes evaluation, customization, training, and maintenance of the technology.
  - Recommendations from professionals ensure the technology meets the child's needs.
- **Remote Monitoring:**
  - Provides GPS tracking devices to monitor participants for health and safety risks, and to ensure safety for children prone to wandering.
  - The service is tailored to individual needs and documented in the service plan, allowed for quicker responses in emergencies.
  - The service promotes independence and safety while maintaining privacy and dignity.




# CDAC 1.0 Feedback on Technology

## *CDAC members shared ideas for how technology can be used*

- **CDAC recommend that people should be able to get some services through telehealth.**
- Telehealth would help with workforce challenges. This would be especially helpful in more rural parts of the state that can make it hard to get access to services.
- CDAC also recommend that the waiver include a service for assistive technology. This would provide children with everyday technology. The goal of this tech would be to help kids increase, maintain, or improve abilities. It would also support increased community inclusion, including employment.



 **For Discussion: Is there anything you would add to this?**



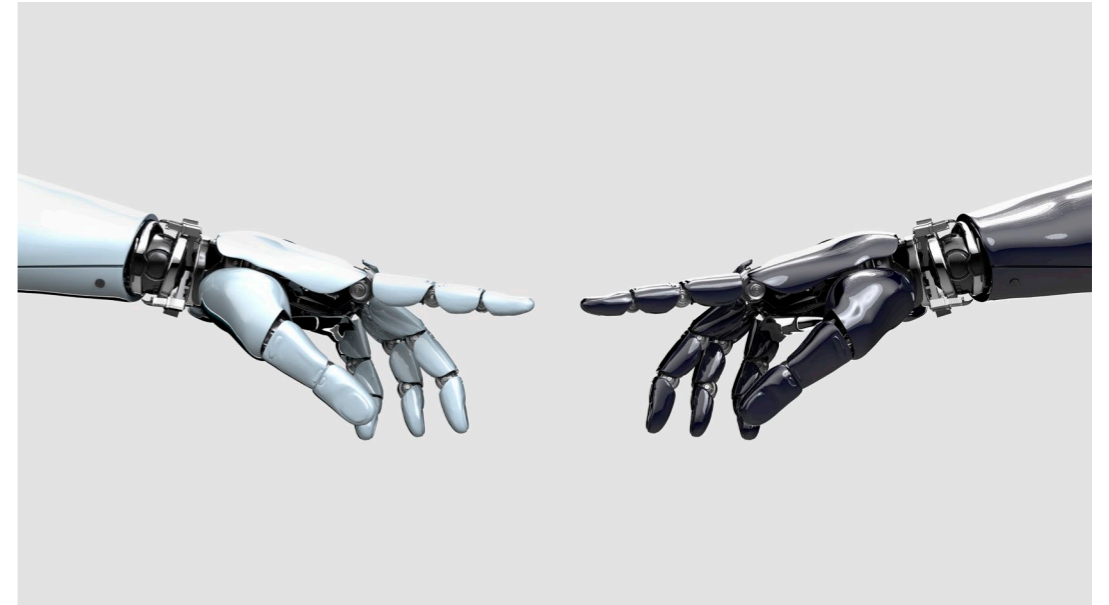
# CDAC 1.0 Recommendations on Technology in Services

#	CDAC Recommendations	A&M Response
S.6	North Dakota should continue to support the use of telehealth/remote services and include this as an option for the children's cross-disability waiver, including in new services	Agree
S.7	North Dakota should continue to build upon its use of assistive technology as an option to support children with disabilities and their families in skill building and integration.	Agree
S.8	Consider a capped, flexible Assistive Technology service that allows support team recommendations for everyday technology, documented in the person-centered plan (versus requiring a professional assessment).	Agree. <i>Note that AT is a service in the ASD waiver.</i>
S.9	Consider including training/technical assistance for the child and family on the use of the device; as well as warranties.	Agree

# Future State of Tech in the Cross-Disability Waiver

***Technology will be both a modality and service on the new waiver.***

- In the new waiver, there will likely be virtual or remote support options for Behavioral Consultation and Individual Employment Support. There may be other services that also have an option for remote / telehealth delivery.
- Protections will include:
  - A virtual support checklist during planning
  - Limit on places where cameras are allowed
  - Participant choice in virtual vs. in-person
- There will continue to be services that cover assistive technology, as well as remote monitoring, on the CDW.



**★ For Discussion: Is this the right list of services? Are there other technology-based options you know about? What other protections can you think of?**



# Self-Direction as a Modality



# What is Self-Direction, and How is it Used as a Modality?

***In self-direction, individual/legal decision-maker has the responsibility to recruit, hire, and supervise individuals who provide services.***

- When choosing to self-direct services, **you decide how to use your approved services, who works for you, their schedules, pay, and training, and where you receive services.**
- Self-direction is currently part of multiple existing ND waivers, including the IID/DD waiver, the Medically Fragile Waiver, and the ASD Waiver
- The **new cross-disability children's waiver will include self-direction as an option.**



# Check Our Understanding

*Let's check our understanding of self-direction as a waiver service modality before we learn more.*

Let's complete a Menti survey!

The question is, "What do you know about self-direction as a waiver service modality?"

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# Overview of Self-Direction in North Dakota's Waivers

## Today (1 of 2)

DRAFT

***North Dakota allows some use of self-direction in service delivery for the ASD and IID/DD Waivers. All services must be self-directed on the MF Waiver.***

- All **MF Waiver** services are self-directed. This includes case management, respite, dietary supplements, environmental modifications, equipment and supplies, in-home supports, individual and family counseling, and transportation.
- Some services that can be self-directed on the **IID/DD Waiver** include behavioral consultation, environmental modifications, equipment and supplies, in-home supports, remote monitoring, respite.
- The **ASD Waiver** allows self-direction for its respite, assistive technology, and community connector services.
- Some services that can be self-directed can be provider managed instead.



# Overview of Self-Direction in North Dakota's Waivers Today (2 of 2)

DRAFT

*There are many systems in place that help participants who chose to self-direct some of their services.*

- **Case Managers:**
  - Talk to the participant about roles, responsibilities, and risks of self-direction.
  - Oversees the Fiscal Agent's performance.
  - Helps the participant develop their budget
  - Provide general information and assistance as part of their Medicaid case management services.
- **Financial Management Services**
  - Supports participant when they are the employer of direct support workers and when they exercise budget authority.
- **Independent Advocates**
  - Disability Advocates from ND Protection & Advocacy help if participants' rights have been violated.



# How Should People Get Services?

## *CDAC members talked about the importance of self-direction*

- **CDAC values the chance for families to self-direct their services.** In self-direction, families control their services. They are responsible for recruiting, hiring, and supervising staff
- CDAC recommends that the new waiver include the options for self-direction. CDAC also wants the option for families to use both traditional providers and self-direction.
- CDAC recommends that the State build in support for people who want to self-direct. They recommend that extra support be provided by professionals. Some examples would be a family navigator or a support broker. Both of these roles are used in some other states to provide support.



# CDAC 1.0 Feedback on Self-Direction (1 of 2)

*CDAC members shared their ideas and experiences with self-direction.*

Subtopic	CDAC Member Feedback	A&M Response
<b>Challenges</b>	Members shared potential concerns with self-direction: <ul style="list-style-type: none"> <li>• Difficulty getting paid.</li> <li>• Risk of having to go back on provider waitlist if switching off self-direction.</li> <li>• Challenges hiring new staff.</li> <li>• Concerns over responsibility of W2, liability, etc.</li> </ul>	Self-direction is not for everyone! However, there are some proven best practices states can use to help make this a feasible option for more families.
<b>Opportunities</b>	Members also shared benefits of self-direction, including: <ul style="list-style-type: none"> <li>• Options for individualized training to match unique needs of families and children.</li> <li>• Increased flexibility.</li> <li>• More choice in staffing.</li> </ul>	Self-direction helps families customize staffing to meet their needs and provides increased flexibility. It is a great option that can work for many families, with the right supports in place.



# CDAC 1.0 Feedback on Self-Direction (2 of 2)

*CDAC members shared their ideas and experiences with self-direction.*

Subtopic	CDAC Member Feedback	A&M Response
<b>Staffing</b>	Several members expressed that they would like to be able to combine self-direction and provider staffing options. One member expressed that more information would be needed, including how the balance of hours would work.	This authority for a blended staffing model was proposed by North Dakota and has been recently approved by CMS for the IID/DD waiver.
<b>Support</b>	Members expressed interest in receiving more support for self-direction, including an option such as a support broker to provide assistance.	Explore adding a support broker function to the family navigator role to help encourage self-direction in the new waiver. Another option is to offer Agency with Choice.



**For Discussion: Is there anything you would add to this?**



# CDAC 1.0 Recommendations on Self-Direction in Services

#	CDAC Recommendations	A&M Response
S.10	The new children's cross-disability waiver should include options for self-direction.	Agree
S.11	Families should be able to combine self-direction and provider staffing options in the new waiver.	Agree
S.12	Families need support to self-direct services.	Agree. In addition to including a support broker role for the Family Navigator, explore Agency with Choice as an additional self-direction modality, where an agency is the co-employer alongside the family member.
S.13	Include information and assistance as part of the Family Navigator role. Family navigators serve the peer-to-peer role, can connect families to resources in the community, and, if they fill this role, there will be one less person with whom the family would have to coordinate.	Agree



# Future State of Self-Direction in the Cross-Disability Waiver

***Self-direction will continue to be an option in multiple waiver services.***

- CDAC recommended that in the new waiver, there will likely be the option for self-direction in some services, based on what aligns with the nature of this children's family supports waiver.
- There will likely still be an option to combine self-direction and provider staffing options in certain services.
- Protections will continue to include:
  - Case Managers providing information and support
  - Access to Financial Management Services
  - Access to Disability Advocates
- New protections may include:
  - Family Navigator
  - Agency with Choice



**For Discussion: Is there anything you would add to this?**



# Paid Family Caregiver as a Modality



# Check Our Understanding

*Let's check our understanding of paid family caregiving as a waiver service modality before we learn more.*

Let's complete a Menti survey!

The question is, "What do you know about paid family caregiving as a waiver service modality?"

<https://www.menti.com/ald8ymfeawhx>

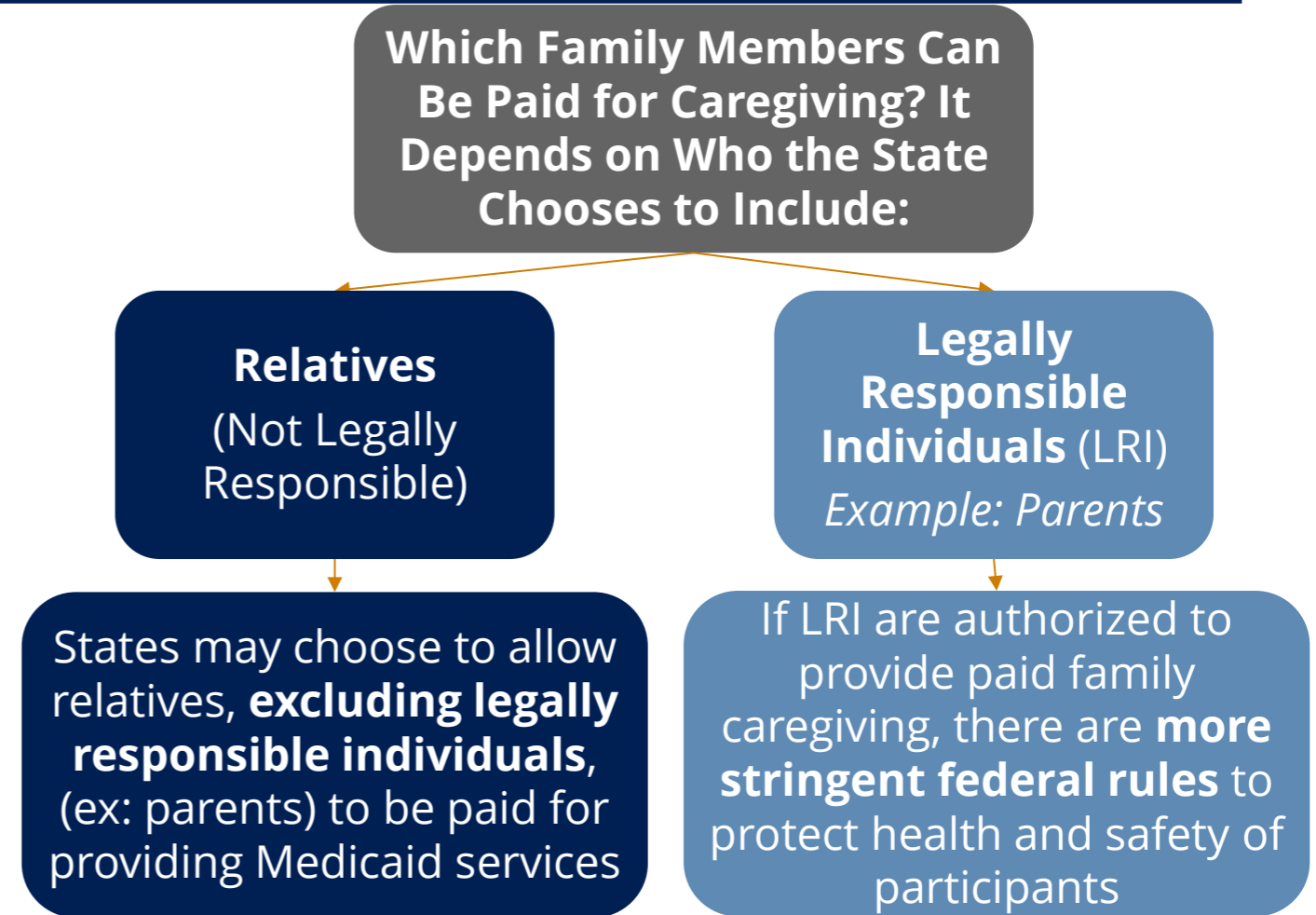


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# Key Elements of Paid Family Caregiving

- Paid family caregiving is **an optional service delivery method**; states may choose whether or not to authorize this modality
- If a State decides to pursue paid family caregiving, they can include this option for:
  - Medicaid State Plan Services; and / or
  - In some or all the State's 1915(c) waivers (most common method)
- See the appendix for more information about paid family caregiving specifics



## ★ **KEY TERM: Legally Responsible Individual / Relative (LRI)**

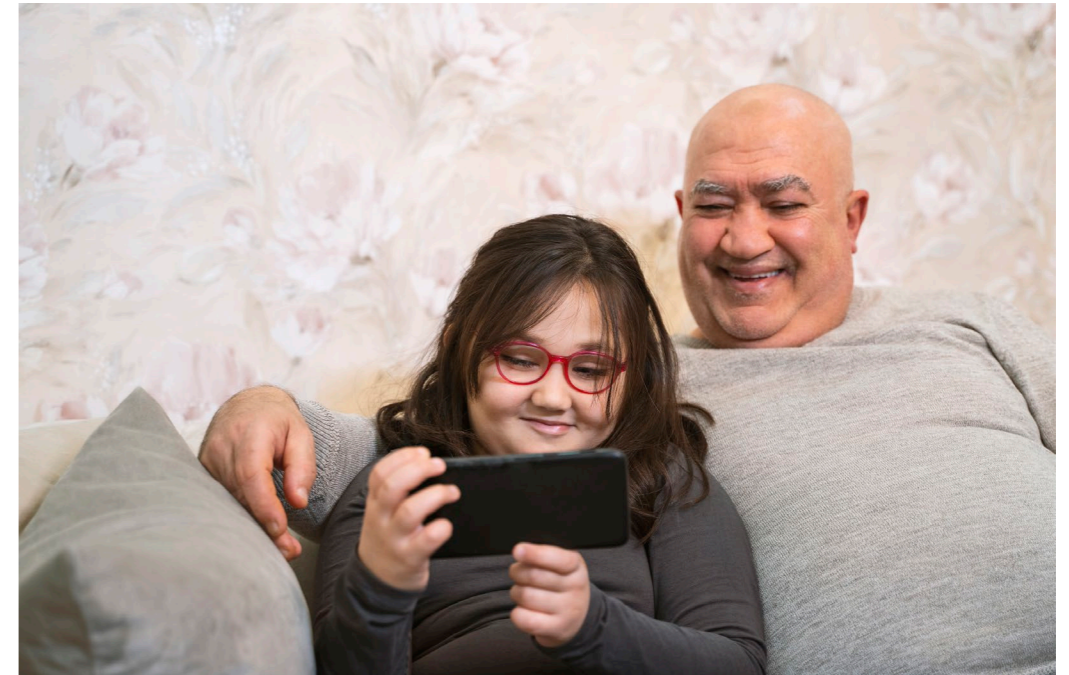
This term typically refers to parents or spouses. In North Dakota, LRI means an individual who has a duty under law to care for the participant, including a biological or adoptive parent, nonentity custodian, guardian, or a spouse.



# Federal Requirements Around Paid Family Caregiving (1 of 2)

*There are federal rules about paid family caregiving.*

- **Service Type:** Personal care, or related service (ex: home health aide, homemaker, chore, and companion services)
- **Provider Qualifications:** Providers of paid family caregiving must meet the same standards as other providers of similar waiver services
- **Extraordinary Care:** Payments may only be made to **legally responsible individuals when services are deemed extraordinary care**, and not for tasks falling under ordinary care. States use various assessment forms to measure an individual's need for extraordinary care.



# Federal Requirements Around Paid Family Caregiving (2 of 2)

***States must show that a parent is providing extraordinary care to qualify for paid family caregiving.***

- CMS requires states to assess whether individuals demonstrate need for extraordinary care when screening for paid family caregiving provided by LRIs (ex: parents).
- CMS defines extraordinary care broadly, but leaves flexibility for states to further define this term (see next slide).
- It is the responsibility of states to assess and measure extraordinary care vs ordinary care.

## **Defining Extraordinary Care: An Excerpt from CMS Guidance ([Source](#))**

"A state may elect to make payment for personal care or similar services that are rendered by legally responsible individuals when such services are deemed extraordinary care so long as the state specifies satisfactory criteria for authorizing such payments. **The criteria must include how the state will distinguish extraordinary from ordinary care.** By extraordinary, CMS means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant and avoid institutionalization"



# CDAC 1.0 Feedback on Paid Family Caregiving

## *CDAC members value the option for paid family caregiving*

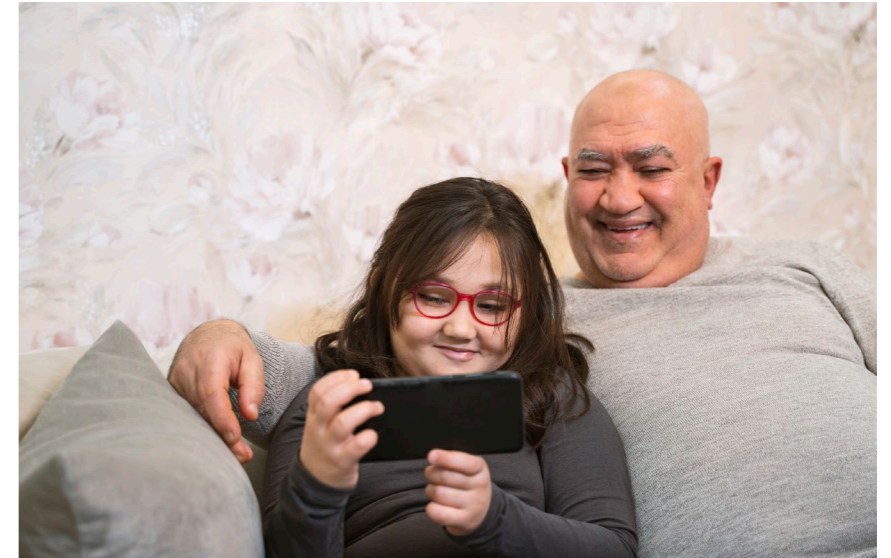
- CDAC members were very supportive of including the option for paid family caregiving.
- The State is currently testing out this option as a pilot.
- CDAC talked about the opportunities paid family caregiving gives families, including flexibility and control. It also helps increase access to providers in more rural areas.
- CDAC also talked about needing protections for safety, and to make sure the service is the right fit for the child.



# Overview of Paid Family Caregiving in ND Today

***North Dakota is currently running a pilot on paid family caregiving.***

- Under the pilot program, family members who provide extraordinary care to either a child or adult enrolled in one of the following Medicaid 1915(c) waivers may receive payments from the state:
  - Autism Spectrum Disorder Birth Through 17 Waiver.
  - Children with Medically Fragile Needs Home and Community-Based Services Waiver.
  - Children's Hospice Home and Community-Based Services Waiver.
  - Traditional Individual with Intellectual Disabilities and Developmental Disabilities Home and Community-Based Services Waiver.



**State funding for the pilot program was approved with the passage of Senate Bill 2276 during the 2023 legislative session.**

## **How is “Extraordinary Care” Defined?**

When a family member provides care for someone with medical or behavioral needs that is beyond what a legally responsible individual would typically perform.



# Future State of Paid-Family Caregiving in the CDW

***CDAC recommended that Paid Family Caregiving will be an option on the new waiver. There will be extra protections.***

- Paid family caregiver will no longer be a standalone service like it is in the pilot program, but a way to receive certain waiver services.
- Under federal law, this is option is only allowed for what is deemed extraordinary care
- ND will need to show people meet this definition to qualify for this service delivery option
- There will also be protections in place:
  - Making sure it is in the best interest of the participant
  - Health and welfare – home visit requirements



**★ For Discussion: What would you add to the protections? Any other comments?**



# Appendix – Subcommittee Reference Slides

# Discussion

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- What do you think about adding a social component to how ND looks at functional needs to define DD? Would adding social help address some of the gaps you see today? (ex: FASD)
- Which of the national ideas on social areas do you like? Do you have any other ideas about types of social needs you think should be considered?
- What do you think about the idea of requiring deficits across multiple categories?
- Do you think adding category requirements would help make sure people with physical needs are served on the right waiver for them? (ex: CP)
- What else do you think ND should keep in mind? Areas for further research?



## Pathway #1: People with ID and DD

*People with severe intellectual disabilities are part of the target population. They qualify through pathway #1.*

Formal ND century code definition:

“...the individual has a **diagnosis of intellectual disability which is severe enough to constitute a developmental disability.**”

Source: 75-04-06-02.1



## Pathway #2: People with ID and Need for Services

*People have an intellectual disability and show a need for services are part of the target population. They qualify through pathway #2.*

Formal ND century code definition:

“...the individual has a **condition of intellectual disability**, diagnosed by an appropriately licensed professional using diagnostic criteria accepted by the American psychiatric association, which is not severe enough to constitute a developmental disability, and the individual **must be able to benefit from treatment and services** purchased through the developmental disability division on behalf of an individual who meets the criteria of subsection 1.”

Source: 75-04-06-02.1



## Pathway #3: People with Related Conditions

*People who have a related condition that affects them in ways similar to an intellectual disability are part of the target population. They qualify through pathway #3.*

Formal ND century code definition:

“...individual has a **condition, other than mental illness, severe enough to constitute a developmental disability**, which results in impairment of general intellectual functioning or adaptive behavior **similar to that of an individual with the condition of intellectual disability**, and the individual must be able to benefit from services and intervention techniques which are so closely related to those applied to an individual with the condition of intellectual disability that provision is appropriate.”

Source: 75-04-06-02.1



# How do National Groups Define Social Areas of Function?

***Many national groups have added social to their definition of DD. Below are some examples of how they measure this area.***

Group	Definition
AAIDD	Social skills—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
DSM-5	The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
ICD-11	Social skills are those related to managing interpersonal interactions, relationships, social responsibility, following rules, obeying laws as well as avoiding victimization.



# What Does it Mean to Have an Intellectual Disability?

***Intellectual Disabilities (ID) include limitations in both intellectual functioning and adaptive behavior***

- The American Association on Intellectual and Developmental Disabilities (AAIDD) is a widely respected group of experts in this area. We will use their definitions.
- **Intellectual disability:** A condition characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 22
  - **Intellectual functioning (aka intelligence):** Refers to general mental capacity, such as learning, reasoning, problem solving, and so on.
  - **Adaptive behavior:** The collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives.



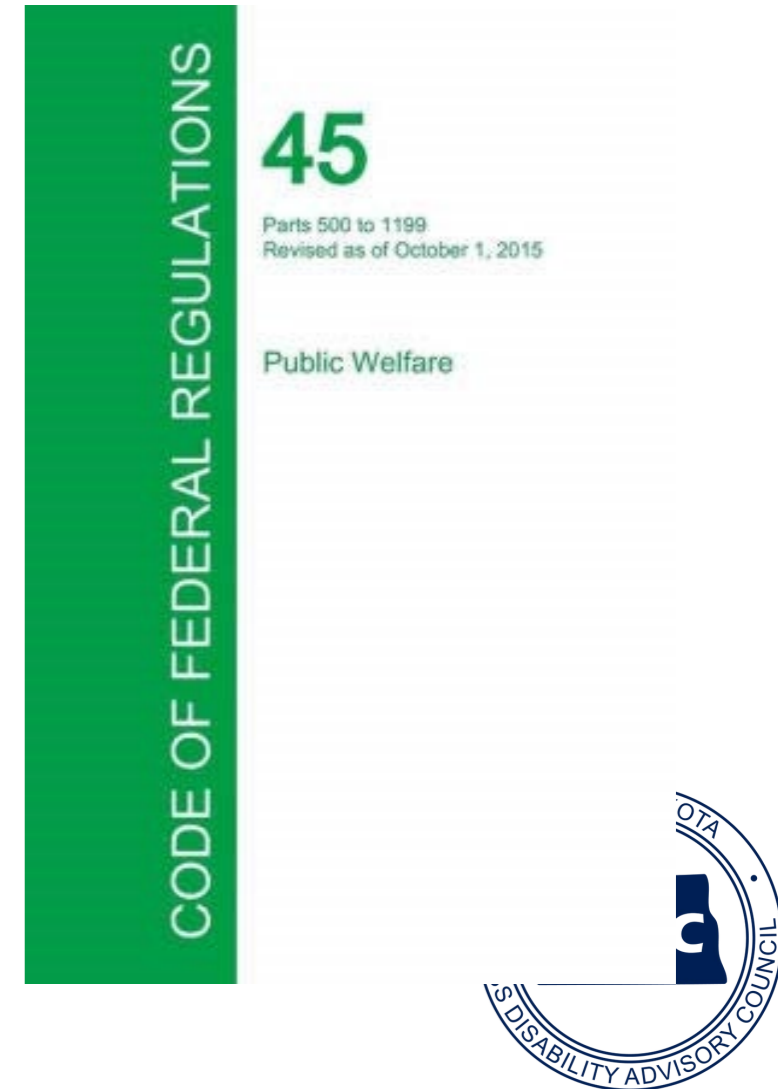
# What Does it Mean to Have a Developmental Disability?

***Developmental Disability (DD) includes both mental and / or physical impairment that began before the age of 22.***

The below is an excerpt from 45 CFR § 1325.3

The term “developmental disability” means a **severe, chronic disability** of an individual that:

- (1) Is attributable to a **mental or physical impairment** or combination of mental and physical impairments;
- (2) Is manifested **before the individual attains age 22**;
- (3) Is likely to continue indefinitely;
- (4) Results in substantial **functional limitations in three or more areas of major life activity**;
- (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.

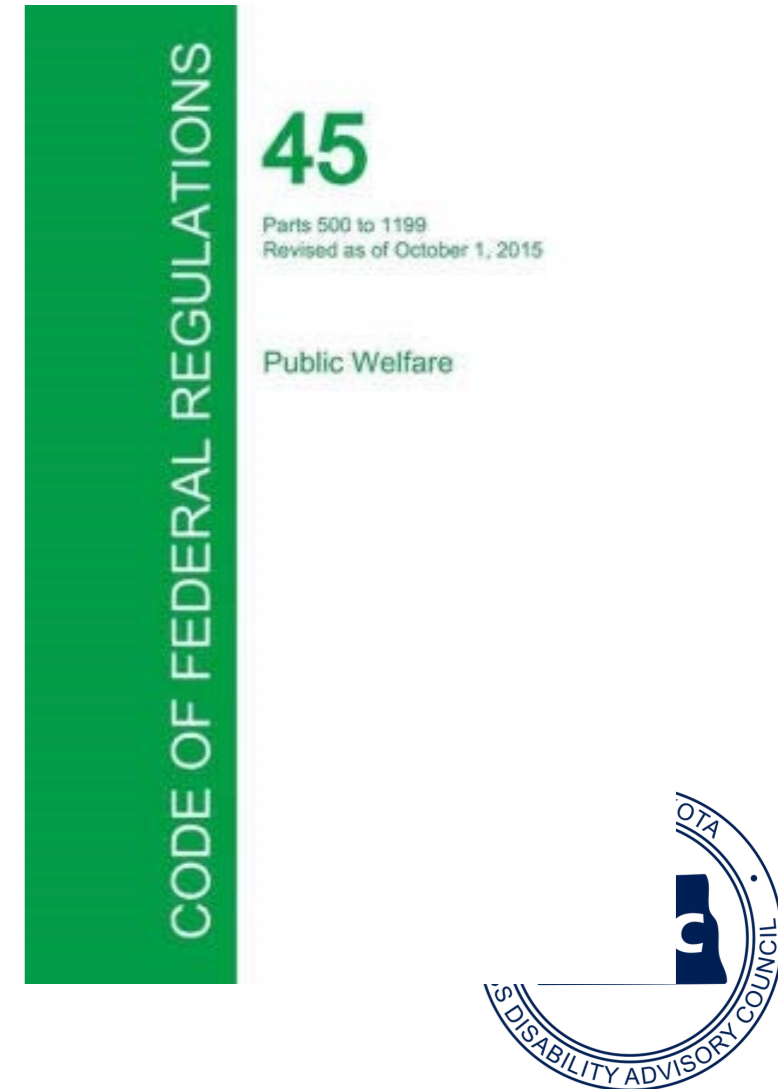


# What is Meant by Areas of Major Life Activity?

***Developmental Disability (DD) includes both mental and / or physical impairment that began before the age of 22.***

*The below is an excerpt from 45 CFR § 1325.3*

- (i) Self-care;
- (ii) Receptive and expressive language;
- (iii) Learning;
- (iv) Mobility;
- (v) Self-direction;
- (vi) Capacity for independent living; and
- (vii) Economic self-sufficiency.



# Recapping What We've Heard About the Gaps

***We've collected lots of feedback from people, including CDAC 1.0, about ideas for modernizing how North Dakota looks at developmental disabilities***

## Core Feedback Themes from Stakeholders:

- Some people who have more social needs, such as people with Fetal Alcohol Spectrum Disorder, do not qualify today
  - Takeaway: Consider adding a social category of needs. See section on national best practices
- Adults who have more practical-based needs, such as mobility, would be better served on the HCBS waiver.
  - Takeaway: Consider tweaking the practical category. The goal is to help make sure that people who would be better served on the HCBS waiver end up there.
- Kids who have developmental disabilities with no intellectual component are not part of the target population for the IID/DD waiver and need support.
  - Takeaway: Look to add kids



# What are National Bodies Recommending About DD Assessment?

***Many national groups have updated the way they look at DD. This update means many groups now also look at social deficits. ND does not do this today.***

Adaptive Deficit	Gollay Grid Categories (ND Today – Any 3, no Area limit)	Included in ND?
Conceptual	<p>I like this, I think it's important to have different assessments for children so they can be completed/conducted correctly based on their age and ability.</p> <p>Receptive and Expressive Language, Learning, Self-Direction</p>	Yes
Practical	Self-care, Mobility, Capacity for Independent Living, Economic Self-Sufficiency	Yes
Social	N/A	No; however AAIDD, the DSM-5, and ICD-11 all include social in the definition

# Appendix – Level of Care Research

# Example Homegrown, Cross-Disability Tool: MnCHOICES (1 of 3)

## *Minnesota created its own assessment called MnCHOICES.*

- Minnesota worked with a vendor to build an online assessment tool called MnCHOICES.
- MnCHOICES is used to assess all people who need long term services and supports.
- MnCHOICES is used for both eligibility and service planning.
- The assessment includes many populations such as older adults, people with I/DD, and those with physical disabilities.



# Example Homegrown, Cross-Disability Tool: MnCHOICES (2 of 3)

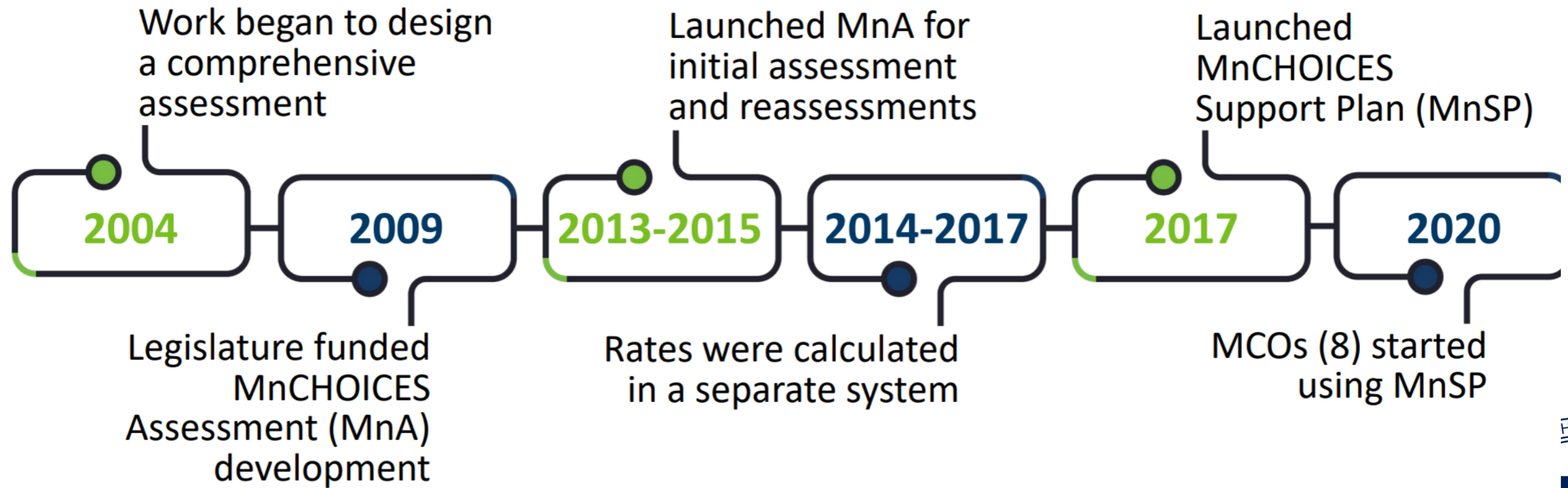
## *Minnesota is continuously updating and improving MnCHOICES*

- MnCHOICES was launched as a “minimum viable product”.
- The first counties piloted MnCHOICES in 2013.
- Minnesota recently updated the assessment. This took four years to do, from 2020-2024.
- MnCHOICES was certified by CMS in April 2025. This makes the state eligible for enhanced match on maintenance (75% versus 50%).
- Minnesota uses a system governance group to help prioritize upgrades and projects related to MnCHOICES.
- Future updates include a personal portal.



# Example Homegrown, Cross-Disability Tool: MnCHOICES (3 of 3)

***The below timeline shows MN's path to create and update MnCHOICES 1.0. This version is now retired.***



Source: Excerpt from MN's presentation at the HCBS Conference.



# Example National, Cross-Disability Tool: The FASI (1 of 2)

***The FASI is a national, cross-disability set of measures created by the Centers for Medicare and Medicaid Services.***

- FASI stands for Functional Assessment Standardized Items.
- The FASI is a set of measures for people receiving HCBS.
- It is designed for a wide array of populations. This includes older adults, people with brain injuries, and people with I/DD.
- The FASI is a person-centered tool. It focuses mostly on functional status and need for assistance.
- States can choose to use all or part of the FASI.



## Example National, Cross-Disability Tool: The FASI (2 of 2)

***The FASI includes both standard measures of function and consideration of personal goals.***

- The FASI includes a standardized rating scale for self-care, mobility, and IADLs
- Ratings range from independent to dependent and closely mirror other functional assessments
- There are also open ended responses that ask about an individual's top priorities in the next 6 months.
- Currently both OR and CO are using some items from FASI
- The FASI was also tested by 6 states as part of the Testing Experience and Functional Tools (TEFT) demonstration.



# FASI Excerpt: Self-Care (Section B, Functional Abilities)

## Rating Items:

Performance Level Enter Codes in Boxes		
A Usual	B Most Dependent	
<input type="text"/>	<input type="text"/>	<b>6a. Eating:</b> The ability to use suitable utensils to bring food to the mouth and swallow food once the meal is presented on a table/tray. Includes modified food consistency.
<input type="text"/>	<input type="text"/>	<b>6b. Oral hygiene:</b> The ability to use suitable items to clean teeth. [Dentures (if applicable): The ability to remove and replace dentures from and to the mouth, and manage equipment for soaking and rinsing them.]
<input type="text"/>	<input type="text"/>	<b>6c. Toileting hygiene:</b> The ability to maintain perineal/feminine hygiene, adjust clothes before and after using the toilet, commode, bedpan or urinal. If managing an ostomy, include wiping the opening but not managing equipment.
<input type="text"/>	<input type="text"/>	<b>6d. Wash upper body:</b> The ability to wash, rinse, and dry the face, hands, chest, and arms while sitting in a chair or bed.
<input type="text"/>	<input type="text"/>	<b>6e. Shower/bathe self:</b> The ability to bathe self in shower or tub, including washing, rinsing, and drying self. Does not include transferring in/out of tub/shower.
<input type="text"/>	<input type="text"/>	<b>6f. Upper body dressing:</b> The ability to put on and remove shirt or pajama top; includes buttoning, if applicable.
<input type="text"/>	<input type="text"/>	<b>6g. Lower body dressing:</b> The ability to dress and undress below the waist, including fasteners; does not include footwear.
<input type="text"/>	<input type="text"/>	<b>6h. Putting on/taking off footwear:</b> The ability to put on and take off socks and shoes or other footwear that is appropriate for safe mobility.

## Coding Instructions:

**Safety and Quality of Performance** - If helper assistance is required because person's performance is unsafe or of poor quality score according to amount of assistance provided.

*Activities may be completed with or without assistive device*

- 06. **Independent** - Person completes the activity by him/herself with no assistance from a helper.
- 05. **Setup or cleanup assistance** - Helper SETS UP or CLEANS UP; person completes activity. Helper assists only prior to or following the activity.
- 04. **Supervision or touching assistance** - Helper provides VERBAL CUES or TOUCHING/STEADYING assistance as person completes activity. Assistance may be provided throughout the activity or intermittently.
- 03. **Partial/moderate assistance** - Helper does LESS THAN HALF the effort. Helper lifts, holds or supports trunk or limbs, but provides less than half the effort.
- 02. **Substantial/maximal assistance** - Helper does MORE THAN HALF the effort. Helper lifts or holds trunk or limbs and provides more than half the effort.
- 01. **Dependent** - Helper does ALL of the effort. Person does none of the effort to complete the activity. Or, the assistance of 2 or more helpers is required for the person to complete the activity.

**If activity was not attempted, code reason:**

- 07. **Person refused.**
- 09. **Not applicable** - Person does not usually do this activity.
- 88. Not attempted due to **short-term medical condition or safety concerns.**



# Example National, Cross-Disability Tool: The interRAI (1 of 3)

***The interRAI is a national tool that looks at people's unique needs.***

- The interRAI is a set of tools that help measure someone's needs, strengths, and preferences.
- Lots of researchers helped develop these tools. The tools have high inter-rater reliability. The questions are also standard across the different tools.
- InterRAI tools look at the whole person. This includes health needs, quality of life, services, and preferences.
- The tools are updated and supported by a team of over 100 fellows across the world. This tool is used in 35 countries.



## Example National, Cross-Disability Tool: The interRAI (2 of 3)

***The interRAI can be used with many different populations.***

- interRAI has many tools for lots of populations and needs. This includes both adults and kids.
- States can use data from the assessment in other areas. For example, to help support care planning.
- InterRAI data can help identify risks, like caregiver burnout. It can also help states see trends for planning.
- The assessment can be added to existing software.



# Example National, Cross-Disability Tool: The interRAI (3 of 3)

## *A&M has had an initial meeting with interRAI to discuss tools.*

- Confirmed tools of interest:
  - InterRAI-ID and ChYMH-DD (DD and ASD)
  - ChYMH (kids behavioral health needs)
  - interRAI-HC Ped (medically fragile)
- Several states currently use at least one subset of interrail.
- Nebraska and Iowa both recently transitioned to using the interRAI-ID. NY and OK also use. AK and IN are in discussions.
- Recommend sticking to sub-tools even for cross-disability waiver, as tools are strictly normed.
- One option other states have looked at is a screener to identify the right tool to use.



# Example National, Narrow Tool: The SIS

***The SIS looks at the frequency and levels of support needed.***

- The SIS was developed by the American Association of Intellectual and Developmental Disabilities (AIDD).
- The tool is only for people with intellectual and developmental disabilities.
- It is focused on acuity levels.
- The SIS needs its own software and training.
- The SIS is used by many states.



# Example National, Narrow Tool: The ICAP

***The ICAP is another national tool for the IDD population.***

- The ICAP is only used for people with IDD.
- The tool can be used with both children and adults.
- The ICAP looks at skills like motor, personal living, social and communication. It also looks at behavior.
- The ICAP has a score of 0-100 that shows level of service needed.
- Usually, the ICAP is used in combination with other tools.



# Example Homegrown, Narrow Tool: Oregon Needs Assessment

***Oregon created its own tool called the Oregon Needs Assessment (ONA). The ONA is used for people with ID/DD.***

- The Oregon legislature required OR to move to one tool
- Oregon created the ONA to achieve this. The ONA looks at level of care, support needs, and risks.
- OR has trained assessors deliver the ONA. Case managers only do the ONA when nothing has changed.
- The ONA helps determine the service group someone is in. This is related to how many service hours they get.



# Example Homegrown, Narrow Tool: ND's PAR

## *North Dakota created its own single-disability tool called the PAR.*

- North Dakota created the Progress Assessment Review (PAR).
- This tool helps decide if people are eligible for the IID/DD waiver. This includes if they meet level of care for the waiver. It also includes if they have a need for waiver services.
- There is a child version of the PAR for kids 0-3.
- People 3+ are assessed using the adult PAR.
- The PAR looks at levels of functioning and support needs.



# Appendix – CDW Service Array

# Caregiver Support Services on the CDW



# Service Category Overview – Caregiver Support

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*Caregiver Supports are services that attempt to help family caregivers navigate the stress and challenges associated with caring for a child with disabilities.*

- Respite is the most commonly covered benefit for family caregivers.
  - Respite provides short-term relief for caregivers. This allows them to travel and rest.
  - Respite can be provided for a few hours during a day to several weeks at a time.
  - Respite can be daily, weekly, or institutional. Daily respite is the most common care offered on waivers, weekly respite is the least common care offered.
- Other kinds of caregiver supports in waivers can include caregiver training, counseling, or support groups.



ASD

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IID/DD

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# Caregiver Support Services (1 of 1)

**Service Title**      **Respite**

## Simple Definition

Provides temporary relief to primary caregivers through short-term care for participating children. Can be provided in the child’s home, a facility, or the caregiver’s home. Respite is flexible and is tailored to the family’s needs. It ensures a child’s unique medical and functional needs are met while maintaining their health and welfare. It helps prevent caregiver burnout, supports family stability, and delays institutionalization.

## Existing Modalities

- **Self-Direction:** Can be self-directed (all waivers).
- **Tele-services:** N/A.
- **PFCG:** Can be provided by relative (ASD, IID/DD Waiver). Cannot be provided by relative nor LRI\* (MF Waiver).

## Existing Limits

Institutional respite is limited to 14 consecutive days (MF Waiver).  
Limited to 600 hours per State Fiscal Year (IID/DD Waiver). Limited to 40 hours / month (ASD Waiver).  
Cannot be used as day/childcare. Cannot be used when Part B services could be used.

\*LRI = Legally Responsible Individual



# Case Management Services on the CDW



# Service Category Overview – Case Management

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*Case management is an essential component of HBCS waivers. The purpose of case management is to help individuals identify, access, and coordinate the supports that they need.*

- Case management can either be provided as a waiver service or as an administrative service.
  - States receive different reimbursement rates depending on whether it is a waiver or administrative service.
  - **Waiver service case management** is focused on direct client support, providing information to support informed choices, and ensuring the individual receives quality care.
  - **Administrative case management** is focused on overseeing the operational aspects of the waiver program and making sure the waiver services are effective.
  - North Dakota's ASD and MF Waivers use case management as a waiver service. Case Management is administrative on the IID/DD Waiver. HHS is still considering whether case management will be a waiver service or administrative on the CDW.
- Case management is provided by state staff or by private agencies.
- Case managers play important roles in helping individuals and families navigate the services system. They also promote participants' health and well-being.



ASD

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# Case Management Services (1 of 1)

**Service Title** Case Management

## Simple Definition

Helps families by providing information, referrals, and support to coordinate services and ensure needs are met. Case managers assist with planning, monitoring, and reviewing services to promote quality outcomes and address barriers. They meet with families regularly to review progress, provide emotional support, and help with crisis intervention or paperwork.

## Existing Modalities

- **Self-Direction:** Cannot be self-directed (both waivers).
- **Tele-services:** Meetings can take place via telehealth (both waivers).
- **PFCG:** Cannot be provided by a relative nor a legally responsible individual (both waivers).

## Existing Limits

Limited to 16 hours / month. Must meet face-to-face at least twice a year and must engage with participant and family at least every 90 days (ASD Waiver).



# Equipment, Technology, Modifications, and Supplies Services on the CDW



# Service Category Overview – Equipment, Technology, Modifications, and Supplies (ETMS)

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*These services are material goods to help a person improve or maintain function.*

- Most states cover equipment, technology, and modifications in any HCBS waiver program.
- More states cover these kinds of services in waivers for individuals with ID/DD, but many also cover them in waivers for people ages 65+ or with physical disabilities.
- **Equipment:** Devices, controls, or appliances that enable a person to perform ADLs or to interact with their environment.
- **Technology:** can include assistive technology and IT infrastructure to support independence and improve functional capabilities.
- **Modifications:** Structural or physical adaptations made to a person's home or environment to create an accessible / safe living environment.
- **Supplies:** Consumable items necessary for a person's health and daily living to support proper functioning and needs not met by other services.



ASD

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# ETMS Services (1 of 5)

**Service Title** Assistive Technology

## Simple Definition

Provides devices and services to improve a child’s abilities, such as communication tools or mobility aids. It includes evaluation, customization, training, and maintenance of the technology. Recommendations from professionals ensure the technology meets the child’s needs.

## Existing Modalities

- **Self-Direction:** Can be self-directed.
- **Tele-services:** By nature, can include technology-based services.
- **PFCG:** Cannot be provided by a relative nor a legally responsible individual.

## Existing Limits

Limited to \$5,000 per participant for the duration of the waiver, unless an exception is granted ot prevent imminent institutionalization.



MF

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# ETMS Services (2 of 5)

**Service Title** Dietary Supplements

## Simple Definition

Provides nutritional products for children who rely on supplements for over half of their intake or have disease-specific needs. These supplements are prescribed based on medical evaluations and can include those administered through feeding tubes. Products like herbs or botanicals without scientific basis are excluded.

## Existing Modalities

- **Self-Direction:** Can be self-directed.
- **Tele-services:** N/A.
- **PFCG:** Cannot be provided by a relative nor a legally responsible individual.

## Existing Limits

Does not cover products where little or no scientific basis has been established.



MF

IID/DD

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# ETMS Services (3 of 5)

**Service Title** Environmental Modifications

## Simple Definition

Provides funds to modify a family home or vehicle to improve accessibility and independence for children with disabilities. Modifications include ramps, lifts, bathroom adaptations, and vehicle adjustments to ensure safety and functionality. Professional recommendations are required to ensure the modifications meet the child’s needs.

## Existing Modalities

- **Self-Direction:** Can be self-directed (both waivers).
- **Tele-services:** By nature, can include technology-based services (both waivers).
- **PFCG:** Cannot be provided by a relative nor a legally responsible individual (both waivers).

## Existing Limits

Limited to \$18,966 per participant (MF Waiver). Limited to \$40,000 per participant in the five-year waiver period (IID/DD Waiver). Cannot duplicate modifications that could be covered under EPSDT or the Medicaid State Plan.



MF

IID/DD

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# ETMS Services (4 of 5)

**Service Title**      **Equipment and Supplies**

## **Simple Definition**

Covers specialized equipment, supplies, or safety devices to help children with disabilities perform daily activities and communicate effectively. This includes items like generators, clothing modifications, and assistive technology not covered by other programs. Maintenance and training for equipment use are also included.

## **Existing Modalities**

- **Self-Direction:** Can be self-directed (both waivers).
- **Tele-services:** By nature, can include technology-based services (both waivers).
- **PFCG:** Cannot be provided by a relative nor a legally responsible individual (both waivers).

## **Existing Limits**

Does not cover generic items that are not specialized for a disability. Cannot duplicate equipment and supplies that are part of the EPSDT benefit.



ASD

IID/DD

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# ETMS Services (5 of 5)

**Service Title** Remote Monitoring

## Simple Definition

Provides GPS tracking devices to monitor participants for health and safety risks, and to ensure safety for children prone to wandering. The service is tailored to individual needs and documented in the service plan, allowed for quicker responses in emergencies. The service promotes independence and safety while maintaining privacy and dignity.

## Existing Modalities

- **Self-Direction:** Cannot be self-directed (ASD Waiver). Can be self-directed (IID/DD Waiver).
- **Tele-services:** By nature, a technology-based service (both waivers).
- **PFCG:** Cannot be provided by a relative nor a legally responsible individual (both waivers).

## Existing Limits

Does not allow for experimental treatments or generic items (e.g., air tags) that are not specialized for a disability. Remote monitoring devices are limited to \$5,000 per participant per waiver year, with a maximum of \$25,000 per waiver period (year 1 through year 5 of the current approved waiver), unless an exception is approved by the DHHS/DD to prevent imminent institutionalization.



# Community Integration Services on the CDW



# Service Category Overview – Community Integration

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*Community integration is demonstrated when people with disabilities are fully participating and equally valued members of their communities.*

- Community integration supports help achieve the goal of full and equal participation in a community, instead of living separately in an institution.
- The goals of community integration are to reduce institutionalization, promote inclusion, enhance autonomy, and foster connections with others.



# Community Integration Services (1 of 2)

**Service Title**      **Transportation**

**Simple Definition**

Provides reimbursement for non-medical transportation to help families access essential community resources or services. This includes mileage, per diem, and specialty vehicle costs when necessary. Drivers must meet licensing and insurance requirements.

**Existing Modalities**

- **Self-Direction:** Can be self-directed.
- **Tele-services:** N/A.
- **PFCG:** Can be provided by a legally responsible individual.

**Existing Limits**

Covers in and out of state travel only for services that are non-medical in nature.



# Community Integration Services (2 of 2)

ASD

**Service Title** Community Connector

**Simple Definition**

Helps children access community activities and build relationships in inclusive settings. Services include socialization, adaptive skills, and support for participation in community events. Activities are tailored to the child’s goals and needs.

**Existing Modalities**

- **Self-Direction:** Can be self-directed.
- **Tele-services:** N/A.
- **PFCG:** Cannot be provided by a relative nor a legally responsible individual.

**Existing Limits**

Does not cover anything that is entertainment in nature.



# Nursing Services on the CDW



# Service Category Overview – Nursing Services

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*Nursing services provide professional medical care in a person's home or community.*

- Nursing services are crucial for enabling people to maintain independence in their chosen setting. People choosing to live in their community would otherwise be served in a nursing facility.
- Nursing services go beyond personal or home health aide assistance.
- Tasks can include wound dressing, administering medication, managing IVs, and monitoring health.



MF

IID/DD

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# Nursing Services (1 of 1)

**Service Title** In-Home Supports

## Simple Definition

Provides trained caregivers to assist children with disabilities in their homes, supporting daily living activities, mobility, and safety. It helps prevent institutionalization and can be provided while the primary caregiver is present or away. The service is tailored to meet the child’s unique needs and integrates support into family routines.

## Existing Modalities

- **Self-Direction:** Can be self-directed (both waivers).
- **Tele-services:** N/A (both waivers).
- **PFCG:** Can be provided by a relative (both waivers).

## Existing Limits

Limited to 300 hours / month (IID/DD Waiver). Cannot be used when Part B services can be used instead.



# Other Mental Health and Behavioral Services on the CDW



# Service Category Overview – Other Mental and Behavioral Health Services

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*These waiver services reflect the fact that individuals with disabilities are likely to also face mental and behavioral health challenges and would benefit from supports that help address those.*

- This service category tends to vary the most across states and across different waivers, according to waiver target populations and functional needs.
- These services largely consist of different kinds of therapies or counseling.
  - Can be targeted towards the waiver participant, towards the participant and the family, or just to the family.
- Services can sometimes include different behavioral supports and crisis interventions as well.
- Other mental and behavioral health services can be accessed in a state through a behavioral health system continuum of care.



# Other Mental and Behavioral Health Services (1 of 2)

Service is currently in these waivers:

IID/DD

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## Service Title

Behavioral Consultation

## Simple Definition

Helps families develop intervention plans to address behavioral challenges. Services include training and technical assistance for caregivers. Plans are tailored to the child's needs and monitored for effectiveness.

## Existing Modalities

- **Self-Direction:** Can be self-directed.
- **Tele-services:** May be provided remotely through virtual supports for non-hands-on tasks.
- **PFCG:** Cannot be provided by a relative nor a legally responsible individual.

## Existing Limits

Limited to \$5,200 per participant per State Fiscal Year. Cannot be used by participants who receive Residential or Independent Habilitation. Virtual supports cannot be used for surveillance or staff convenience. Cannot be provided in a clinical setting or a school. Cannot be billed at the same time as other services.



# Other Mental and Behavioral Health Services (2 of 2)

Service is currently in these waivers:

MF

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**Service Title** Individual and Family Counseling

## Simple Definition

Offers counseling to address stress related to a child's extraordinary medical needs, supporting their integration into home and community life. Sessions may include family-focused or individual counseling tailored to the child's situation. This service complements but does not duplicate counseling available under the State Plan.

## Existing Modalities

- **Self-Direction:** Can be self-directed.
- **Tele-services:** N/A.
- **PFCG:** Cannot be provided by a relative nor a legally responsible individual

## Existing Limits

Cannot duplicate what is available under the Medicaid State Plan.



# Employment Services on the CDW



# Service Category Overview – Employment Support

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*Employment support services facilitate integrated, competitive employment for people with disabilities by providing tailored support to help them find, secure, and maintain jobs in their community.*

- Supports can include career planning, job coaching, training, transportation, and other accommodations.
- These aim to support long-term success in the workplace and in community participation.
- IDEA Part B and Vocational Rehabilitation (VR) programs also provide these services. HCBS waivers have to be careful to not duplicate services for its participants that are likely receiving them elsewhere.
- Key aspects of the support include creating integrated settings, conducting person-centered planning, providing individualized support, and providing ongoing support to ensure sustained employment.
- Because the CDW is a children’s waiver, some employment services on the IID/DD waiver may not be the best fit for this waiver, especially if they are routinely provided through other programs like Part B or VR.



IID/DD

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# Employment Support Services (1 of 1)

**Service Title** Individual Employment Support

## Simple Definition

Provides one-on-one support to help participants maintain paid employment or self-employment in integrated settings. Services include job-related interventions and transportation assistance when necessary. Participants are paid at or above minimum wage, and supports are tailored to individual needs.

## Existing Modalities

- **Self-Direction:** Cannot be self-directed.
- **Tele-services:** May be provided remotely through virtual supports as needed.
- **PFCG:** Can be provided by a relative, cannot be provided by a legally responsible individual.

## Existing Limits

Total hours in Day Habilitation, Individual Employment Support, Prevocational Services, and Small Group Employment may not exceed 40 hours per week. This service does not include facility-based support.



# Appendix – Technology as a Modality

# Understanding the Current State of Tech: IID/DD Waiver

Waiver	Services with Virtual or Remote Support Option	Context, Limitations, Safeguards
IID/DD	<ul style="list-style-type: none"> <li>• Independent Habilitation</li> <li>• Individual Employment Support</li> <li>• Behavior Consultation</li> <li>• Parenting Support</li> <li>• Infant Development</li> </ul>	<ul style="list-style-type: none"> <li>• A Virtual Support Checklist is completed by the DD Program Manager and the team during the person-centered planning process. Safeguards to ensure virtual supports can help meet the needs of the participant in a way that protects their right to privacy, dignity, respect, and freedom from coercion.</li> <li>• The use of cameras in bathrooms or bedrooms, which impacts the participant's dignity and privacy, is not permitted.</li> <li>• Virtual supports reinforce community integration by encouraging the participant to engage in community life as independently as possible and to be able to safely engage in activities in his or her home or in the community without relying on the physical presence of staff to accomplish those activities.</li> <li>• The participant's services may not be delivered via virtual support 100% of the time.</li> <li>• The participant must always have the option to request in-person services. The amount of time chosen shall be determined during the person-centered planning process and outlined in the Individual Service Plan.</li> <li>• Provider must use a HIPAA-compliant service delivery method (e.g., Microsoft Teams, Zoom for Healthcare).</li> <li>• Virtual supports are not a system to provide surveillance or for staff convenience.</li> </ul>

# Understanding the Current State of Tech: ASD Waiver

Waiver	Services with Virtual or Remote Support Option	Context, Limitations, Safeguards
ASD	<ul style="list-style-type: none"> <li>Remote Monitoring</li> <li>Case Management</li> </ul>	<ul style="list-style-type: none"> <li>Privacy of the individual must be respected at all times, such as in the bathroom or while bathing.</li> <li>Remote Monitor Service is not covered through Assistive Technology Service.</li> <li>Telehealth will be allowed for Service Management, but waiver will continue to require 2 home visit to meet health, safety, and welfare.</li> <li>Telehealth must follow and meet all criteria of the Medicaid telehealth policy found in the provider manual, meeting HIPAA requirements and ensuring that service is not permitted within the bathroom or bedrooms of the household.</li> <li>Telehealth supports reinforce community integration by encouraging the participant to engage in community life as independently as possible and to safely engage in activities in their home or community without relying on the physical presence of staff to accomplish those activities.</li> </ul>



# Appendix – Self-Direction as a Modality

# What is Self-Direction & How is it Used as a Service Modality?

*Self-direction is an alternative to provider managed services where the individual/legal decision-maker has the responsibility to recruit, hire, and supervise individuals who provide services. Self-directed services promote personal choice and control over the delivery of waiver services, including who provides services and how they are delivered.\**

## The Basics of Using Self-Direction as a Modality in the Waivers:

- When choosing to self-direct services, **you decide how to use your approved services, who works for you, their schedules, pay, and training, and where you receive services.**
- Self-direction is currently part of multiple existing ND waivers
  - IID/DD waiver: includes options for self-directing services,
  - Medically Fragile Waiver: self-direction waiver,
  - ASD Waiver: includes options for self-directing services.
- The **new cross-disability children's waiver will include self-direction as an option.** CDAC helps by:
  - Sharing your experiences using self-direction, if applicable,
  - Providing feedback on what would be helpful to include for people who choose to self-direct.

\*Source: ND DD Manual

# What are the Participant and Family Responsibilities Under Self-Direction?

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*Self-direction means you are the boss; this flexibility and choice comes with added responsibility.*

## **Key responsibilities for people who self-direct include:**

- Managing your self-directed budget.
- Recruiting, hiring, and training your workers.
- Supervising and evaluating performance of your workers.



# Understanding the Current State of Self-Direction: ASD Waiver

Waiver	Services with Self-Direction Option	Context, Limitations, Safeguards
ASD	<ul style="list-style-type: none"> <li>• Respite</li> <li>• Assistive Technology</li> <li>• Community Connector</li> </ul>	<ul style="list-style-type: none"> <li>• Assistive Technology and Community Connector is solely participant directed.</li> <li>• Respite can be participant or provider directed.</li> <li>• Financial management services (FMS) are furnished through governmental and private entities.</li> <li>• FMS helps when the participant is the employer of direct support workers and when the participant exercises budget authority.</li> <li>• Case Managers meet with the participant to explain the roles, risks, and responsibilities of self-directing supports.</li> <li>• Self-directing participants have access to Disability Advocates from the ND Protection and Advocacy Project.</li> <li>• Case Managers help develop the budget for the participant's staff and services.</li> </ul>



# Understanding the Current State of Self-Direction: MF Waiver

Waiver	Services with Self-Direction Option	Context, Limitations, Safeguards
MF	<ul style="list-style-type: none"> <li>All Services</li> </ul>	<ul style="list-style-type: none"> <li>No provider-manager option is available on this waiver; families must self-direct.</li> <li>Families elect self-direction upon enrollment as a condition of waiver participation and may adjust service arrangements during annual reassessment.</li> <li>Support is available from state staff and service coordinators to help families manage employer responsibilities.</li> <li>Participants have employer and budget authority.</li> <li>Private agencies provide FMS.</li> <li>Information and assistance is provided in support of case management and in-home supports services.</li> </ul>



# Understanding the Current State of Self-Direction: IID/DD Waiver

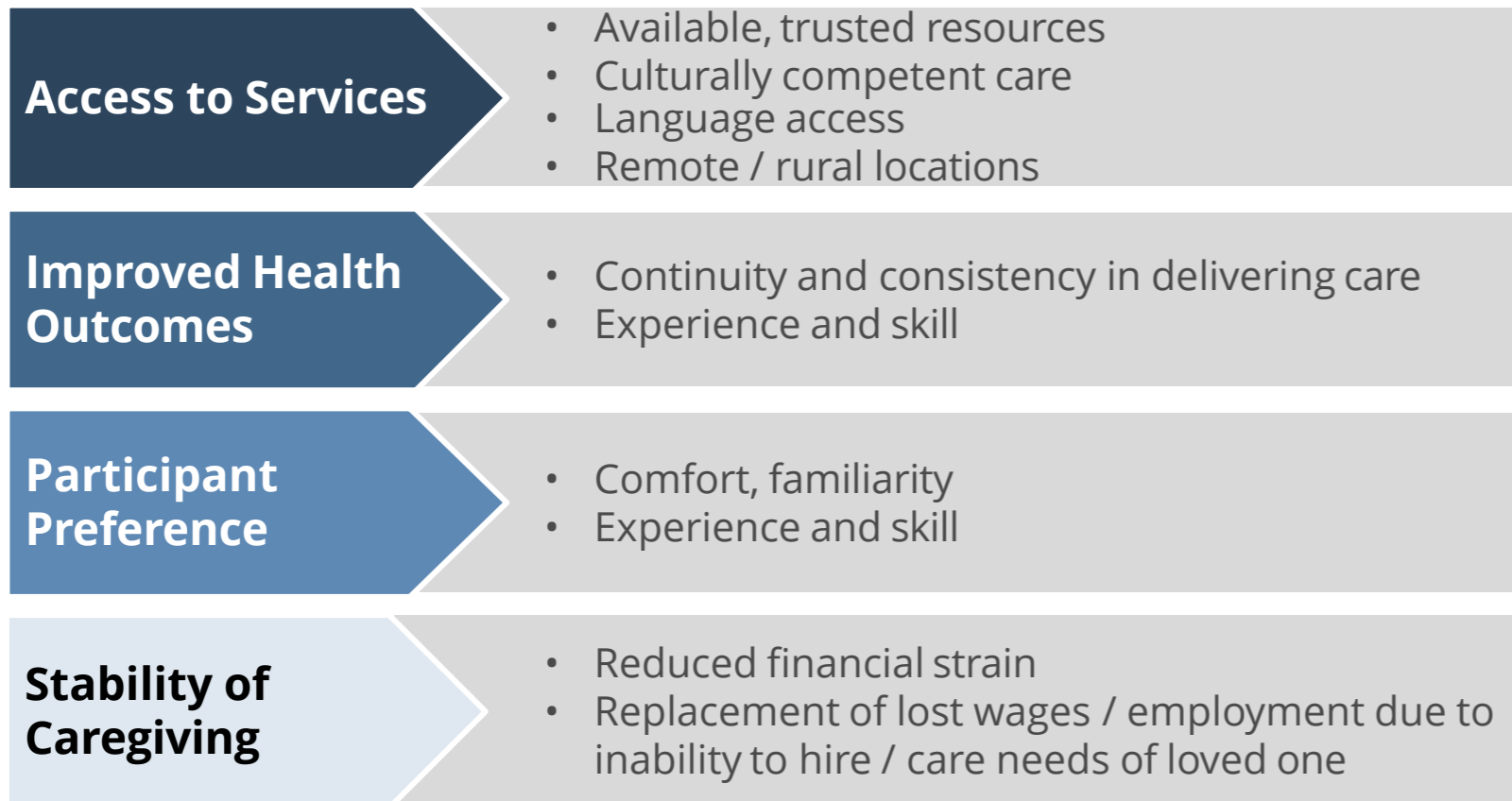
Waiver	Services with Self-Direction Option	Context, Limitations, Safeguards
IID/DD	<ul style="list-style-type: none"> <li>Behavioral Consultation</li> <li>Environmental Modifications</li> <li>Equipment and Supplies</li> <li>In-Home Supports</li> <li>Remote Monitoring</li> <li>Respite</li> </ul>	<ul style="list-style-type: none"> <li>Participants have employer and budget authority.</li> <li>Private agencies provide FMS. The state oversees the Fiscal Agents.</li> <li>DDPMs can provide information and assistance to self-directing participants.</li> <li>DDPMs meet with the participant to explain the roles, risks, and responsibilities of self-directing supports.</li> <li>Self-directing participants have access to Disability Advocates from the ND Protection and Advocacy Project.</li> <li>Changes in the self-direction budget are aligned with service plan changes.</li> </ul>



# Appendix – Paid Family Caregiver as a Modality

# Paid Family Caregiver | Opportunities

*Family caregivers fill an important role in home and community-based services.*



**During COVID-19, use of paid family caregiving increased.** According to a Kaiser Family Foundation survey, 37 of 50 responding states reported allowing spouses and parents of minor children or other legally responsible relatives to be paid providers. 70% of these states (26/37) have (or plan) to sustain this policy as permanent.

*Source: [KFF State Survey](#)*



# Paid Family Caregiver | Policy Considerations/Safeguards

*States must carefully define who they consider a family caregiver, the type/scope of services available, participant choice in using family caregivers, and how they will provide monitoring/oversight to ensure safety, well being and choice.*

## Definitions / Criteria

- Extraordinary vs. ordinary care
- Legally responsible individuals (state laws)

## Scope / Limit

- Waiver services
- Type of family caregivers
- Service limits / requirements

## Choice / Best Interests

- Integration
- Supported decision making
- Conflict of interest / financial dependency

## Oversight / Monitoring

- Qualifications
- Program integrity
- Administration / costs
- Health, welfare and safety

Following COVID-19, some states opted to end previously authorized policies, including workforce flexibilities. According to the Kaiser survey, 11 states reported that they intended to stop allowing legally responsible relatives such as parents to be paid providers. States who have opted to keep provisions for paid family caregiving must ensure careful program safeguards, and meet federal requirements.

*Source: KFF State Survey*



# The Importance of Balancing Opportunity with Risk

*To fully benefit from the opportunities of paid family caregiving, North Dakota needs to establish safeguards that will limit risk and help set this option up for long term success.*

- North Dakota should embrace the opportunity to work with stakeholders to think proactively about program decisions that will allow the State to **protect against known risks and help ensure program sustainability moving forward**



## The case for caution:

- We know there are some states that used paid family caregiving but stopped using this method due to challenges
- There are legitimate concerns about issues like health and welfare, participant choice, isolation, state budgetary limits, and potential misuse of the program



## The case for optimism:

- Groups like CDAC are passionate about helping the State design paid family caregiving in a way that works long-term
- Technology such as EVV can provide a lower-effort way to help protect against potential risks such as fraud/waste
- North Dakota can learn from other states across the country



# Appendix – Medicaid 101 Refreshers

# Medicaid 101: What is a **Medicaid Waiver**? (Recap)

***Waivers are a type of custom Medicaid program. Waivers let states support specific groups of people and better meet their needs.***

- States can choose to create Medicaid waivers. Waivers allow states to “waive” certain Medicaid rules. This means to not follow specific rules to do something different for their Medicaid program.
- Waivers help states create customized programs that better support specific populations. One example is a waiver for people with ID/DD.
- Waivers typically have higher participant income limits than the Medicaid State Plan. Kids qualify for Medicaid waivers based on their own eligibility and income. This is separate from any family eligibility.
- People who qualify for waivers automatically qualify for Medicaid State Plan services too.



# Medicaid 101: What is a Medicaid **HCBS** Waiver? (Recap)

***HCBS waivers allow people to receive Medicaid services in their homes and communities instead of institutions***

- HCBS waivers are a type of Medicaid waiver. HCBS waivers let states provide services in people's homes. **This helps people stay in their communities.**
- HCBS waivers are the most common type of Medicaid waiver that states use.
- Almost every state has at least one HCBS waiver.
- Waivers cannot cost more than the services would cost in an institution. This is called "budget neutrality"
- Sometimes you will see HCBS waivers called 1915c waivers. 1915c is just the part of the Social Security Act that describes these waivers.



# Medicaid 101: What is a **Target Population**?

*Each HCBS waiver is designed to serve specific people, with specific types of needs. This is called the target population.*

- Waivers provide services that support people with **specific conditions**. For example, people with autism.
- Each waiver has its own target population. The waiver services and supports are **designed specially** for this group.
- Some examples of people who can be covered by waivers include: older adults, people with disabilities, medically fragile individuals, people with autism, and individuals with developmental disabilities.
- States must describe the target population in their waiver application to CMS. States also have to say **how they will identify** that someone is in the target population.
- Some waivers have a narrow population. Other waivers include several types of people.



# What target populations does North Dakota include today?

***North Dakota has five HCBS waivers today. The Target Populations served by each waiver are highlighted in orange below.***

**Medically Fragile Children**

*Medically needy children 3-17*

**Traditional IID/DD**

*Children or adults with ID and DD*

**Autism Spectrum Disorder**

*Children with ASD under 18*

**Children's Hospice**

*Children with a life limiting medical diagnosis under 22*

**HCBS Waiver**

*Older adults and adults with physical disabilities*



# Medicaid 101: How Do People Qualify for HCBS Waivers? (Recap)

*The federal government requires states to set rules about who can access waivers. These rules include income, conditions, and need.*

- 1. States must set an income limit for the waiver.**  
Typically, this amount is higher than Medicaid State Plan. This means it is usually “easier” to meet waiver income requirements.
- 2. States must list which conditions the waiver will serve.** For example, Autism. If someone does not have the types of conditions covered, they do not qualify for the waiver. There is another step after condition. **Condition alone cannot qualify someone for a waiver.**
- 3. States must also measure someone’s functional support needs.** This is done to show that someone qualifies for the waiver based on need. This process is sometimes called level of care, or LOC. We will talk more about this on the next slide.

