Cross-Disability Children's Waiver Update

ALVAREZ & MARSAL
LEADERSHIP. ACTION. RESULTS.℠

September 25, 2024

About Us

Erin Leveton
Project Leader

- 25+ years of experience working in health and human services
- Experienced government leader, past Deputy Director for DC's Department on Disability Services (I/DD and Vocational Rehabilitation)
- Specializes in Home and Community-Based Services (HCBS) transformation
- Led the North Dakota assessment of intellectual/developmental disabilities (I/DD) services
- Charting the LifeCourse certified coach
- Prosci® Change Management Certified

Jillian Salmon
Project Manager

- Partnered with multiple states to assess and redesign long-term services and supports (LTSS) programs to improve administrative and operational efficiency, as well as access to services for vulnerable populations
- Led internal and external stakeholder engagement for the North Dakota (ND) assessment of intellectual/developmental disabilities (I/DD) services
- Charting the LifeCourse Ambassador
- Prosci® Change Management Certified

How Did We Get Here? | The LMA Study

LMA Study Areas of Interest

- Explore existing pathways to services in North Dakota
- Identify gaps in access to services
- Analyze peer state service offerings and approaches used to modify services
- Estimate effects of proposed program implementation and/or expansion
- Examine the consequences of potentially eliminating the Autism Spectrum Disorder Task Force

A&M's Approach

1) A gap analysis exploring North Dakota's various pathways to existing services and outlining current gaps in access; and

2) Research and analysis of peer states to compare service offerings, a national scan of home and community-based services and waivers, and identification of promising approaches used to modify or expand programs to address service access gaps.

Deliverables

★A final report that summarizes our findings; identifies existing gaps in service access; and provides recommendations and projections for, addressing these gaps.

★Testimony to the North Dakota Legislature's Human Services Committee on our findings and recommendations.

Finding Common Language | Understanding How Medicaid Waivers Work

Medicaid funds long-term services and supports (LTSS)

- Medicaid is the primary funder of LTSS in the United States
- Medicaid provides LTSS through both:
  - Institutional care (i.e., intermediate care or nursing facilities), or
  - Home and Community - Based Services (HCBS).

HCBS waivers provide LTSS in community-based settings

- States develop Home and Community-Based Services waivers (HCBS Waivers) to meet the needs of individuals who prefer to receive long-term care services and supports in their home or community, rather than in an institutional setting.

HCBS Waivers offer medical and non-medical services

- HCBS Waivers provide both medical and non-medical services
- Examples services include:
  - Service coordination
  - In home supports
  - Respite
  - Habilitation services
  - Employment supports, and more.

HCBS programs must meet federal program guidelines

- HCBS Waiver programs must:
  - Demonstrate that providing waiver services won't cost more than providing these services in an institution;
  - Ensure the protection of people's health and welfare;
  - Provide adequate and reasonable provider standards to meet the needs of the target population;
  - Ensure that services follow an individualized and person-centered plan of care.

What Did We Find? | A Need to Streamline Access to Services

North Dakota's waivers have different eligibility requirements and varying funding support, resulting in disparate access to services. Additionally, there are also drop-off points created both by the end of the Autism Spectrum Disorder (ASD) waiver at age 15 and by changing levels of care on the DD Waiver at age 3.

Waiver	Age	Diagnostic Criteria	Waiting List	Individual Cost Limit	Max Participants/ Year	Average Waiver Spend /Year*
Intellectual / Developmental Disabilities (ID/DD)	Birth until no maximum age	Intellectual Disabilities (ID), or DD and related condition	No	No limit	6,830	$37,624
Autism Spectrum Disorder	Birth until age 17	ASD	Yes	No limit	150	$20,160
Children's Hospice	Birth until age 21	Medically Fragile in need of palliative care	No	Highest monthly nursing facility rate allowed by HHS	30	$32,165
Medically Fragile	Age 3 until age 17	Medically Fragile	Yes	$18,996	25	$6,228

Differences in age coverage, diagnostic criteria, and slot availability drive inequities between children and adults with different categories of disabilities.

**As projected in Appendix J of Waiver Application*

What Did We Recommend? | Children's Cross Disability Waiver

North Dakota can expand its strong base of supports for children from birth until age 2 and its robust IID/DD Waiver programming to create a strong foundation for all people with disabilities through Home & Community-Based Waiver services.

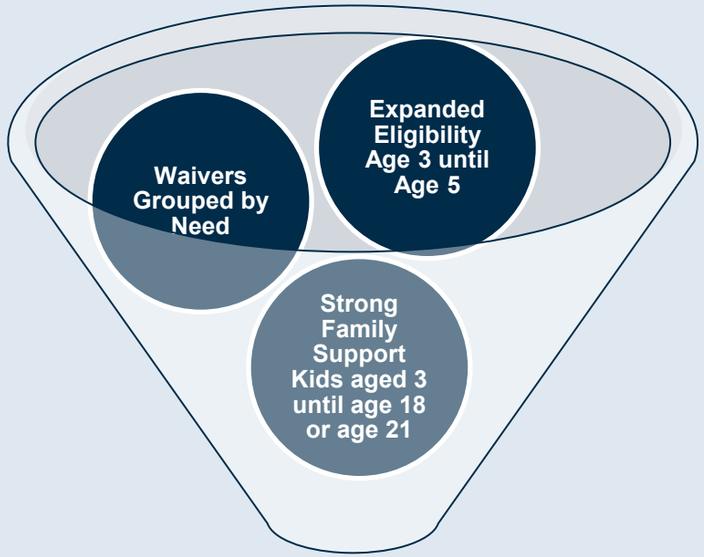
The Vision

North Dakota can build on its legacy of exceptional support for children from birth until age 3 by both modernizing and streamlining three of its existing waivers to create a system that is:

- Equitable
- Comprehensive
- Innovative

The Support: North Dakota's experienced staff and engaged advocates will form the basis for this system transformation.

The Path



A more robust HCBS waiver system, including a children's waiver that supports individuals regardless of their disability.

Creation of the Cross Disability Advisory Committee

Excerpts from Senate Bill No.2276

Duties:

The cross-disability advisory council shall participate with and **provide feedback to the department regarding the implementation, planning, and design of the cross-disability children's waiver**, level of care reform for the comprehensive developmental disabilities Medicaid home and community-based waiver, and a service option that will allow payment to a legally responsible individual who provides extraordinary care to an eligible individual through the Medicaid 1915(c) waivers.

Selection Criteria:

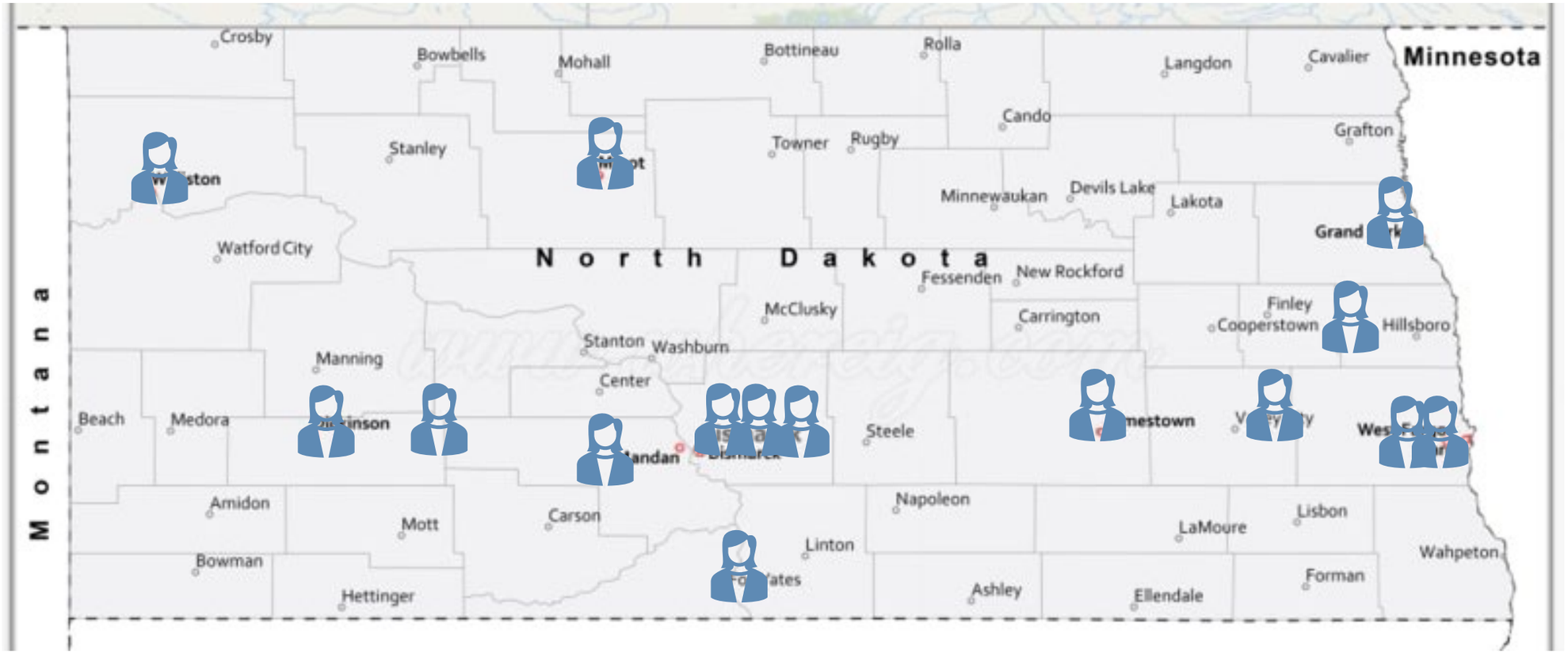
The cross - disability advisory council consists of up to fifteen voting members. **A majority of the council members must be family members of individuals with a disability or must be individuals with a disability themselves who receive Medicaid home and community-based services**. The remaining council members must be appointed based on their professional subject matter expertise or knowledge of the needs and interests of individuals with disabilities. The council's membership must represent different regions of the state and a broad range of disabilities relevant to the Medicaid home and community-based services.

Upon department’s request, state agency representatives shall participate with the cross-disability advisory council in a nonvoting role.


CDAC
North Dakota Cross Disability Advisory Council
2023-2025 Biennium
Carmen Troutman
Emily Vieweg
Jackie Adusumilli
Katynka Morrissette
Megan Sande
Toby Lunstad
Kim Hruby
Colette Fleck
Stephanie Nelson
Erin Peterson
Vicki Peterson
Heidi Wilhelm
Kayla Fender
Kathy Barchenger
Moe Swanson
Heather Larson
Mary McCarvel-O'Connor
Magan Paulson
Susan Karpyak
Kevin Miiller
Erin Leveton
Wanda Seiler
Jillian Salmon
Trevor Vannett

Geographical Distribution of CDAC Representatives

15 voting members from across North Dakota



= 1 voting member

Non-voting HHS Members: Jackie Adusumlli, HHS-Early Intervention; Kathy Barchenger, HHS-Medical Services; Kayla Fender, HHS-Developmental Disabilities; Kim Hruby, HHS-Special Health Services; Mary McCarvel-O'Connor, DPI-Early Intervention

Presiding Officer: Kevin Miiller

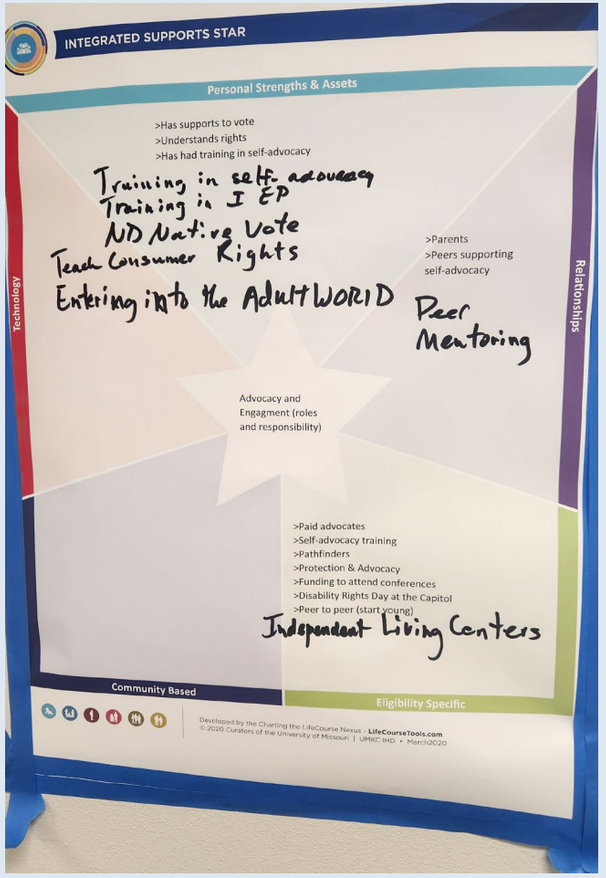
Our Work Together, with CDAC

CDAC members spent an impressive amount of time and energy to create the group's children's cross-disability waiver recommendations.

CDAC's Commitment to the Process:

- CDAC members participated in seven monthly hybrid committee meetings, often 6+ hours in length, as well as multiple additional virtual sessions when needed
- Collectively, the **15 CADC members spent over 700 hours of volunteer time working together** to define a vision for the future of children's waiver services in ND
- This extensive meeting time was in addition to optional homework / brainstorming between meetings

Thank you to the CDAC members!



Progress Update on CDAC's Legislative Duties

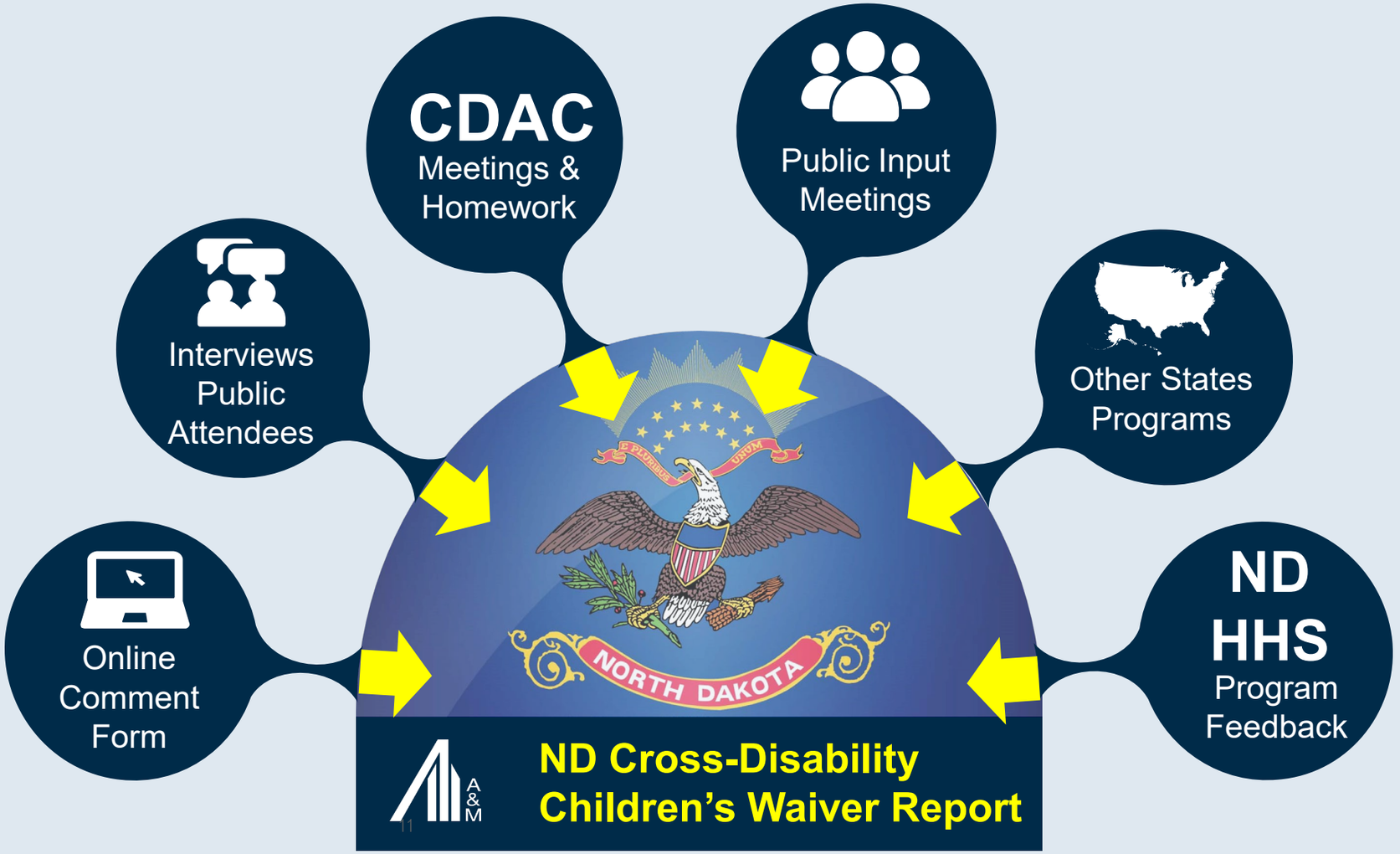
CDAC's work to date has focused on advising HHS regarding design for a new cross-disability children's waiver. Remaining areas for future input include level of care design/reform, and paid family caregiver services (currently in pilot)

Area for Input	CDAC Status Update	Anticipated Future CDAC Role
Cross-disability children's waiver	**Completed** CDAC has compiled detailed recommendations to advise the State on key principles in the design of a potential new cross-disability children's waiver.	CDAC will serve as a key input into the continued planning and implementation of the new waiver, if legislative funding to support the new program is passed.
Paid family caregiver	**Upcoming (December 11, 2024)** HHS is currently piloting paid family caregiver services and collecting further information on this potential new waiver service	CDAC will review learnings from the paid family caregiver pilot (scheduled for Dec. 11th meeting) and provide input into the design of this service, including its inclusion on the potential new cross-disability children's waiver
Level of care design / reform	**Phase 2** Level of care work was not funded as part of the first CDAC term. This complex work needs dedicated funding to support activities like testing and coordination with subject matter experts.	Level of care is anticipated to be the next focus area for CDAC, if HHS receives legislative funding for the parallel testing and subject matter expertise needed. CDAC would serve a critical role by offering perspectives on how level of care impacts families in need of support.

CDAC Recommendation: For the anticipated next phase of work that includes level of care, expand the selection criteria to specify that a majority of the council members must be family members of individuals with a disability or must be individuals with a disability themselves who **currently receive** Medicaid home and community - based services, have **previously received** Medicaid home and community - based services, **or have never received** Medicaid home and community - based services.

Our Approach Centered on CDAC Members & Included Opportunities for Public Comment

A broad range of input was gathered for this report.



CDAC Recommendations | Background

CDAC members thought broadly about what would best support children with disabilities and their families

- **Understanding Medicaid State Plan and Home and Community Based Waiver Services Access**
  - Many of the concerns we heard were from families who would not qualify for **State Plan Medicaid** due to their **family income**.
  - In North Dakota, the **home and community based services waiver** income limit is based upon the **child's income**. The family's income is waived.
  - Additionally, when a child meets the qualifications and enrolls in waiver, they also will qualify for Medicaid state plan services.

- **Need for Therapies and Other Medicaid State Plan Services**
  - A&M heard a variety of needs from CDAC members and the public. Some of what we heard, for example, was about the need for speech, occupational, and physical therapy. We also heard about the need for medical transportation.
  - These are services that are currently provided through the Medicaid state plan for children with disabilities.
  - We heard from families who need Medicaid to help with private insurance copays, or because their current insurance limits the number of visits and their children need more.

- **Children's Cross Disability Waiver Purpose**
  - Waivers are not designed to be solely a path to State Plan Medicaid. They are intended to meet children's functional needs and provide supports for family members so that children can successfully live and thrive in their homes.
  - The recommendations that follow are focused on the CDAC's legislative mission: designing the new waiver.

CDAC Recommendations | Target Population - Bridging the Gaps

Recommendations for providing broader and more equitable support for children with disabilities and their families, based upon functional need

- Today, many **children with disabilities and families face a cliff when they turn three**. They have ongoing needs for support, but no longer qualify for supports through the home and community-based services waiver for people with intellectual disabilities.

- To solve for this gap, CDAC members recommend that the new cross disability children's waiver should provide supports for the following populations, based upon each child's assessed functional needs:

Children who qualify for the Autism Waiver

Children who qualify for the Medically Fragile Waiver

Children ages 3 through 5 who qualify for Early Intervention Part B

Children with developmental disabilities

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.**

CDAC Recommendations | Service Array

Recommendations for the kinds of services that would best support children with disabilities and their families

- First, the CDAC wants to ensure that **no children lose services** because of the development of the new waiver. Therefore, they recommend that all **existing non-residential waiver services** from the Medically Fragile, Autism, and Intellectual and Developmental Disabilities waivers transition to the new waiver.

- Next, the CDAC recommended services that would help children and their families **gain independence and successfully navigate transitions**, with a focus on building skills for adulthood. Examples include services like:

    - **Family training** to equip parents to best support their children with disabilities

    - **Skill building** for activities like self-advocacy, traveling in their community, money management, and more

    - **Discovery** to put adolescents on a path to community integration and employment

- Finally, the CDAC talked about the need for emergency respite and other **crisis supports**.

Achieving Life Outcomes

Families plan for the present and future life outcomes that take into account all facets of life and have opportunities for life experiences that build self-determination, social capital, economic sufficiency, and community inclusion.

LifeCourse Framework – LifeCourse Nexus (lifecoursetools.com)

CDAC Recommendations | Options for Services & Service Delivery

CDAC members recommend options that give families flexibility, including using technology and allowing for self-direction and paid family caregivers

Technology

The CDAC envisions a waiver that makes good use of technology:

- First, they recommend that services be able to be provided through telehealth, noting that there are workforce challenges, especially in more rural or frontier parts of the state that can make it hard to get access to services.
- Next, they recommend that the waiver include a capped, flexible assistive technology service. This would provide children with every day technology that they could use to increase, maintain, or improve functional capabilities and support increased community inclusion, including in employment settings.

Self-Direction

The CDAC values the opportunity for families to have the option to self-direct services. In self-direction, families have the responsibility to recruit, hire, and supervise the staff who provide their services. Their recommendations are as follows:

- The new waiver should include opportunities to self-direct
- Families should be able to combine self-direction and traditional provider services
- Families need support to self-direct and the CDAC recommends that this be part of a professional role (for example, a family navigator or support broker)

Paid Family Caregiver: CDAC members value the option of Paid Family Caregiver. More time and work is needed to learn from the pilot to make recommendations for the future state. This is scheduled for the next CDAC meeting.

CDAC Recommendations | Case Management

The CDAC appreciates the state-based case managers and recommends using them, along with family navigators, in the new waiver

- Members spoke highly of the work of **state case managers**. They recommend that any new positions continue to be filled by state workers, instead of private providers. There is less turnover and more continuity.
- CDAC members recommended a new position, called a **family navigator**. The family navigator would be a someone with lived experience who could help them find community-based options, make connections, and support families to self-direct their services
- The CDAC appreciates the state's investment in **person and family centered thinking** and would recommend this continue.
- As the new waiver is developed, the CDAC pointed out the need for **training for case managers**, so that they understand the new options available and can help advise families.

Supporting the Three Buckets of Need

The three strategies for supporting individuals and their families can be organized into three categories (or buckets):

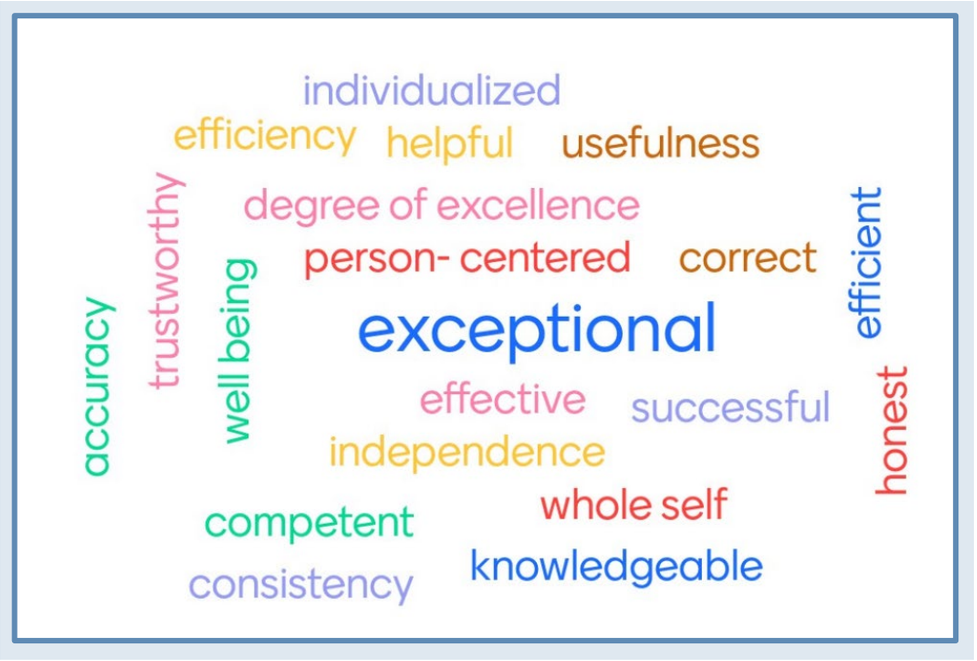
- **Discovery and Navigation:** having the information and tools you need to navigate life
- **Connecting and Networking:** making connections with peers and resources to help you navigate
- **Goods and Services:** the day-to-day tangible items you buy or use from public and private organizations in your community

LifeCourse Framework – LifeCourse Nexus (lifecoursetools.com)

CDAC Recommendations | Quality

The CDAC provided recommendations about quality, so that there will be a way to measure how well the new waiver is working for children with disabilities and their families

- CDAC members recommended using a **person and family-centered framework** for quality
- The quality management system should **focus on outcomes** for children, not just processes
- Understanding how **children with disabilities and their families experience** the waiver will be an important part of measuring quality
- Take advantage of waiver design to:
  - Achieve compliance with the new federal Access Rule
  - Align approaches to quality across the waivers
  - Have one set of provider qualifications to make it easier for providers to serve children regardless of type of disability



We Asked CDAC Members One Word the Describes Quality

LifeCourse Framework – LifeCourse Nexus (lifecoursetools.com)

Projecting the Cost of Creating a New Cross-Disability Children's Waiver

The true cost of creating a new waiver includes both ongoing service costs **and** system innovation costs to support successful systems-level change

System Innovation Costs
Time-limited, supports start-up planning

North Dakota will need to invest heavily in the process of thoughtfully redesigning their system over several years, likely seeking help from national experts along the way

Program Operation Costs
Ongoing, supports continued services

These ongoing expenses represent the anticipated cost of running the program and delivering services once the program is created and achieves steady state operations

Foundational Systems Work to Support the New Waiver:

- **Review of national LOC tools** and extensive year+ testing process to ensure no unintended consequences
- Creation of **new system definitions** and criteria for ID / DD
- Redesign of application, eligibility, and quality process flows
- Assessment / **redesign of current case management**
- Staff augmentation to guide creation of and support delivery of new program – self-advocate and community coordinator
- **Market scan of service provider rates /** adequacy review
- **Procurement of providers** for new services / populations
- Continued investment in community engagement (ex: CDAC)
- Writing of new waiver program application and oversight/management of **extensive federal negotiation process** between ND and CMS

Policy Decisions that Will Affect Final Waiver Cost:

- Approach to **waitlists**: will the new waiver include enough slots to cover anticipated growth in the ASD population?
- **Additional populations** covered by the waiver: will the new waiver include children with behavioral health needs?
- The **level of care** used at different ages: will the new waiver widen the door to serve more children 3-5?
- Services: will the new waiver include **new services?**

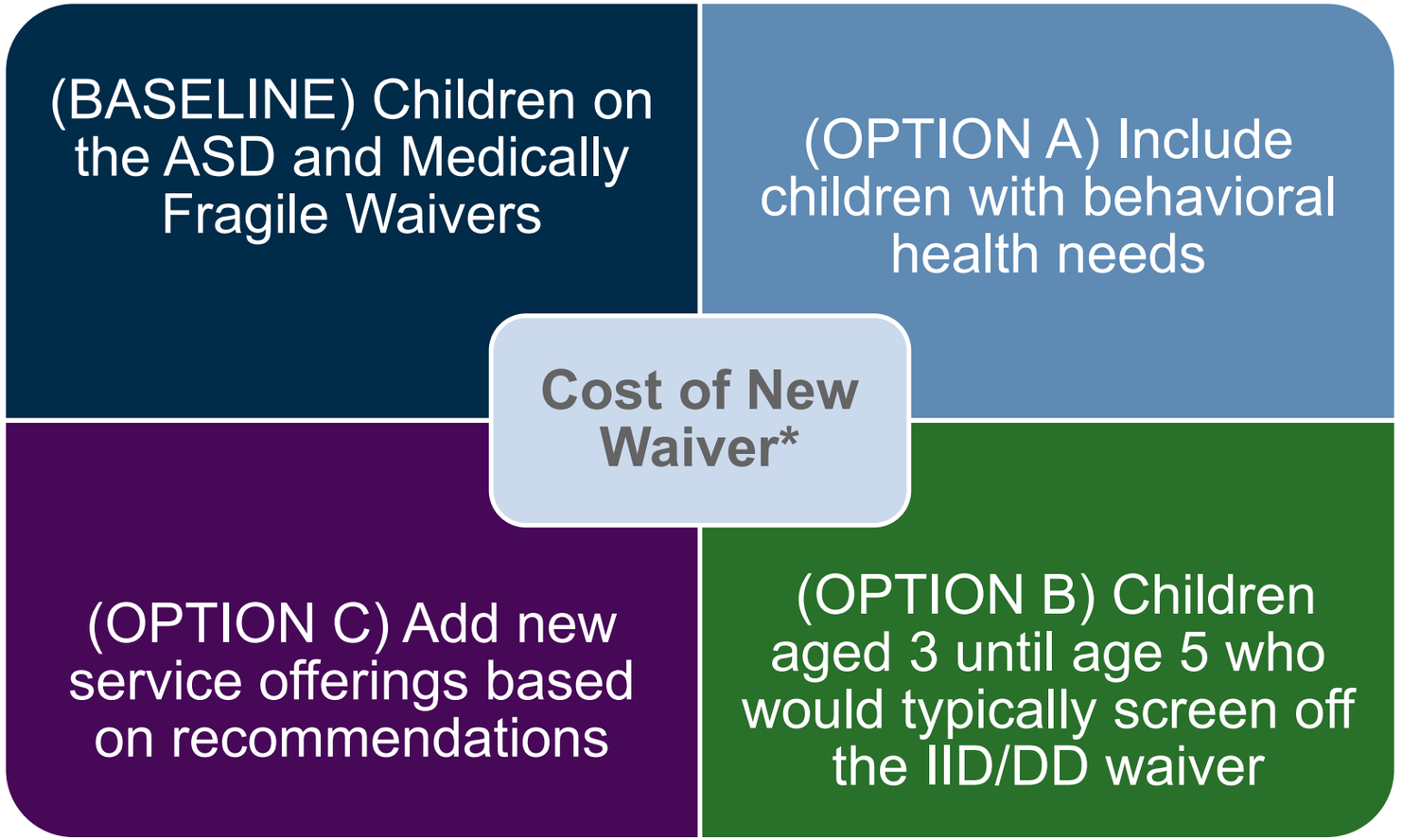
Core Elements Included in Cost Projections:

- **Historical expenditures from existing ND waivers** serve as an input to understand how existing populations utilize services
- **National waiver program information** provides an insight into the potential costs associated with adding populations or services not yet included on North Dakota children's waivers

Understanding the Elements of Program Operation Costs for the New Waiver

Estimating the cost for the new waiver requires both understanding existing costs for the ASD and MF waivers, and predicting costs for new elements, including expanded services and populations.

Part 1: Baseline Costs for Existing ASD+MF Slots, **Part 2:** Projected Additional Cost for Expanding ASD Slots to Avoid Waitlist



Optional add-on costs / enhancements

New cost, optional expanded service offerings

Note: Total cost projection estimates include the following core expenditures: waiver services, Medicaid State Plan services, case management services, and additional costs such as slot management and fiscal management vendors.

(BASELINE, Part 1 and 2) Projected Cost to Meet the Growing Need for ASD Services

The below costs illustrate the projected total expense of serving the ASD/MF population, **assuming the creation of additional slots** to address the growing need for ASD waiver services already seen today.

Population	Slots	Waiver Services (Current Costs + 25%)	State Plan Services	Case Management (DDPM Ratio: 1/40)	Additional Costs (Slot management, FMS)	Total Projected Costs
Existing MF + ASD Slots	395	$2,338,051	$5,013,475	$942,628	$636,763	**$8,930,917**
New Slots	126	$701,324	$1,269,450	$300,686	$203,119	**$2,474,579**
Total	521	$3,039,375	$1,243,314	$6,282,925	$747,645	**$11,405,497**

Baseline Estimate for Serving ASD/MF Populations on New Waiver, Adding Slots to Avoid Waitlists

- **Total Costs:** ~$11.5 million
- **Participants:** ~500 participants
- **Average:** Approximately $22k/participant

Note: The Federal Government pays for 51.55% percent of North Dakota's Medicaid costs, including waiver expenses

(OPTION A) Projected Cost of Serving Children with Behavioral Health Needs on CDCW

The below costs illustrate the projected total expense of serving children with behavioral health needs on the new waiver

Population	Projected Slots	Waiver Services (Based on national scan)	State Plan (Based on national scan)	Case Management (DDPM Ratio: 1/40)	Additional Costs (Slot management, FMS)	Total Projected Costs
Behavioral Health	155	$1,281,382	$2,925,688	$369,892	$249,869	**$4,826,831**

- Both CDAC members and public commenters described a gap for children with behavioral health needs, and voiced that a true cross-disability waiver should include behavioral health, especially given the common co-occurrence of behavioral health needs with other disabilities such as DD
- A&M agrees with the CDAC recommendation to add behavioral health to the children's cross-disability waiver and worked with the State to estimate projected number of slots and costs associated with slots
- We conducted a national scan of states serving children with behavioral health needs and utilized data from a group of five model states

Estimated Cost of Serving Children with Behavioral Health Needs on the New Cross Waiver, Based on National Scan of State Waivers Serving Children with Behavioral Health Needs

- **Total Costs:** ~$4.8 million
- **Participants:** ~150 participants
- **Average Spend:** Approximately $31k/participant

Note: The Federal Government pays for 51.55% percent of North Dakota's Medicaid costs, including waiver expenses

(OPTION B) Projected Cost of Increasing Medicaid Waiver Access for Kids Ages 3 Until 5

Given the large number of children who screen off the waiver at age 3, the State will need to make decisions about how widely to open this door.

Population	Potential Slots	Waiver Services	State Plan	Case Management	Additional Costs	Total Costs
Ages 3-5 Expansion	840	$5,841,063	$4,457,054	$2,003,956	$1,368,948	**$13,671,022**

Explanation of the Above Cost Elements – Understanding Projections to Expand Access for Kids 3-5

- **Potential slots:** This number represents the universe of possible additional children who might be served on the new cross-disability children's waiver, if a lower eligibility threshold is established for children from ages 3 until 5
  - This figure is calculated using Part B breakout numbers by disability type to identify target populations (ASD, TBI, DD, Other). 840 is the difference between children ages 3-5 served on the IID/DD waiver and those served on Part B.
  - **It is likely the actual number of additional children served would be smaller, depending on the functional level of care established for this age. This number represents the upper limit of possible individuals in the target population.**
- Waiver Services and State Plan Service Costs: These figures are based on a blended estimate of Medicaid claims data for children ages birth until 3 and age 3 until 5, to reflect the fact that new children continuing on the waiver would represent a lower acuity.
- Case Management and Additional Costs: Numbers are calculated consistent with previous figures (assuming 1:40 DDPM ratio)

Note: Any additional costs from 3-5 expansion would be phased in across three years as increased access out for children ages 3+. Costs reflect total expenditures; North Dakota receives federal match of 51.55% towards all Medicaid waiver costs.

(OPTION C) Example of Variable Cost Projections for New Services: Homemaker / Chore

A&M estimated the potential cost of adding homemaker services, using existing services in other children's waivers as an example

- As a minimum, the new cross-disability children's waiver will include the services currently offered on the MF and ASD waivers
- CDAC also explored whether there were additional services that should be included on the new waiver
- The cost of adding new services to the waiver is highly variable and depends on several factors, including how many slots are added and whether new services have individual budget limits
    - Policy decisions on waiver size must first be made in order to understand cost of potential new services – see example
- A&M conducted national research to identify estimated utilization and cost for potential new services based on other states who already offer a similar version of said service

Potential Waiver Populations	Slots	Total Projected Cost
Lowest Cost – Only Foundational Populations Included (Existing MF/ASD already served, additional ASD slots)	521	$180,191
Medium Cost – Foundational Populations + Behavioral Health	676	$233,799
Highest Cost – Foundational Populations + Behavioral Health + Complete Expansion for Ages 3-5	1516	$524,228

There are currently wide variations in potential slot numbers for the new waiver. Thus, there is a significant range for how much it would cost to add a new service. The above example* highlights how different waiver slot totals the affect ultimate cost for adding a new service. **Consider how the factors of slots and services operate as connected levelers, impacting total waiver cost.**

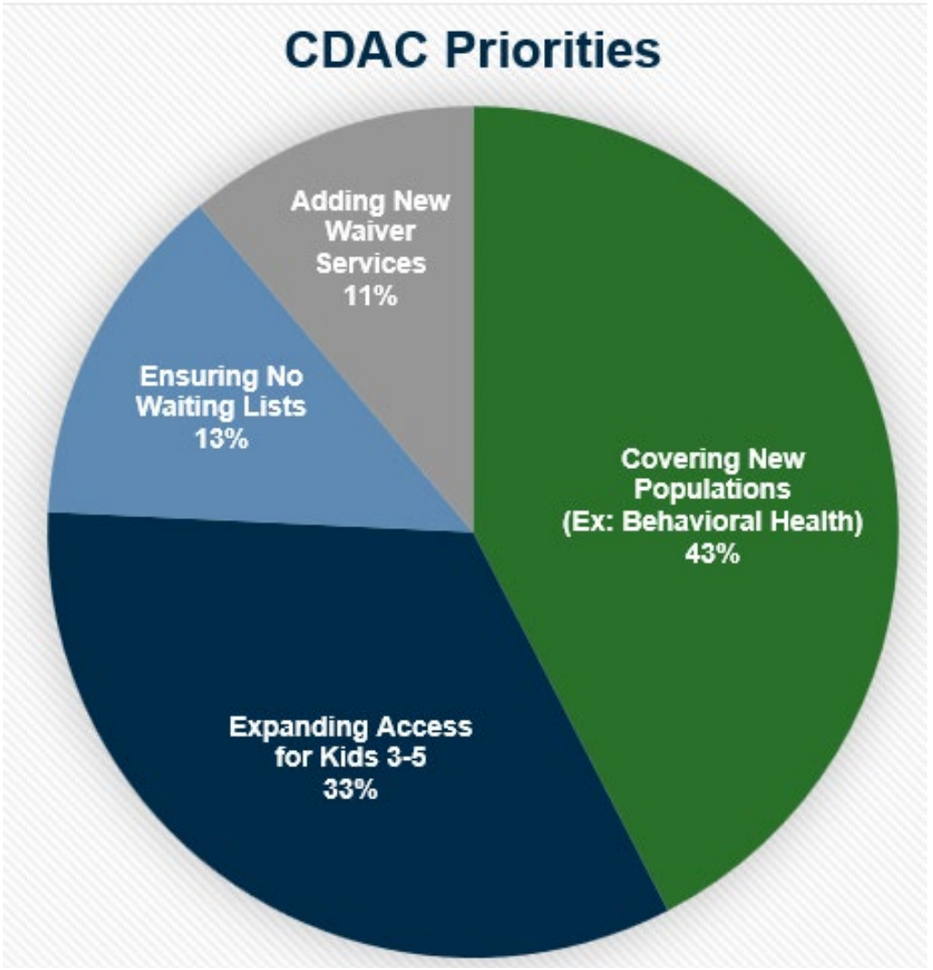
**Note: A&M has included additional data on other potential new services in the full report*

Asking CDAC to Prioritize: How Would You Invest Funds in the New Waiver?

Voting	%	Potential New Service
19	42%	**Increasing Access for Additional Populations** (Behavior Health, CP, FASD, DS, MS…)
15	33%	**Expanding Access for Kids 3-5** (Reducing the "Cliff" for young children being re-assessed)
6	13%	**Ensuring No Waiver Waiting List** (Ability to access wavier as soon as you qualify)
5	11%	**Adding New Wavier Services** (ex: Chore/homemaker)

Each member received **three votes (3) and could split votes as desired:**

3 2/1 1/1/1



Roadmap | What is the Path Forward

The three phases cross biennium and include milestones needed to support the launch and sustainability of a cross-disability children's waiver. We roughly estimate that each phase spans two years.

Phase 1:
Laying the Foundation for Sustainable Change

- Improving the front door to services
- Supporting people and families with navigation and person-centered case management
- Level of care tool selection & testing
- Launching new services
- Expanding self-direction
- Find opportunities for alignment and efficiencies across programs
- Build a sustainable infrastructure to stay on track and report progress
- Deep stakeholder engagement to build the future state together

Phase 2:
Launching the Children's Cross -Disability Waiver

- Plan for the new target populations
- Plan for potential waiting list
- Update level of care for the IID/DD waiver
- Build provider capacity, especially for new populations and new services
- Write and submit waiver for approval
- Continue project and change management
- Continue deep stakeholder engagement to build the future state together

Phase 3:
Stabilizing & Improving

- Test and implement level of care tools for each group
- Review case manager and family navigator caseloads and function allocation
- Pending fund availability, consider adding additional services
- Continue project and change management
- Seek feedback from waiver participants and their families to understand what's working well and where there are opportunities for improvement

Appendix

CDAC Composition Recommendation

The CDAC recommends a broader composition of members for the next phase of work on Level of Care

#	CDAC Recommendation	A&M Response
C.1	For the anticipated next phase of work that includes level of care, expand the selection criteria to specify that a majority of the council members must be family members of individuals with a disability or must be individuals with a disability themselves who **currently receive** Medicaid home and community - based services, have **previously received** Medicaid home and community - based services, **or have never received** Medicaid home and community - based services.	Agree

CDAC Access Recommendations | General

Below are the key recommendations to make it easier for people and families to access services

#	CDAC Recommendations	A&M Response
A.1	Include clear language information about the new waiver on the HHS website. Partner with community resources to spread awareness.	Agree
A.2	Provide families with a clear understanding of the application process, including who is likely to qualify for services, before they decide to apply.	Agree
A.3	Use a family-friendly application process that is easy to understand, and trauma informed. Provide families with a simple way to ask questions and check their status.	Agree
A.4	Create an expedited version of the application process for families with children who are already receiving services under a different waiver.	Agree
A.5	Share plain language information about appeals options during the application process.	Agree

CDAC Access Recommendations | Target Population (1 of 2)

Below are the key recommendations around who the waiver should support

#	CDAC Recommendations	A&M Response
A.6	Eligible children with disabilities should be supported for the same age range in the new waiver, regardless of diagnosis.	Agree
A.7	There is an ongoing need for more services for children with behavioral health needs, and this population should be served on the new waiver.	Agree. Consider adding behavioral health to the list of target populations in the cross - disability waiver to address both the common co-occurrence with other disabilities, and the gap in services for this population.
A.8	There is a need for a new level of care for children with developmental disabilities. This extension is necessary to provide ongoing supported for children with disabilities such as muscular dystrophy, fetal alcohol syndrome, Down syndrome, and cerebral palsy.	Agree
A.9	The hospice population should potentially be included in the new cross-disability waiver to minimize need for any transfers between waivers.	The initial target population should be focused on children with ASD and MF, as well as children with ID/DD who have lower functional support needs, and the SED population. Hospice should be kept as a separate waiver population, which has its own unique services and dedicated funding. Ensure there is a pathway for families to switch waivers if needed.
A.10	The waiver should include children with any conditions on the Social Security Compassionate Allowances list.	A&M's research shows this practice is not used in any other states because it does not include an assessment of functional impairment. Keep the target population for the new waiver focused on specific populations including ID/DD, ASD, MF, and potentially behavior health (BH) needs. Utilize functional eligibility measures to determine who qualifies for waiver services, in compliance with existing federal policies around waiver eligibility. Medicaid may consider exploring broader, general Medicaid eligibility questions for children with disabilities outside of the waiver.

CDAC Access Recommendations | Target Population (2 of 2)

Below are the key recommendations around who the waiver should support

#	CDAC Recommendations	A&M Response
A.11	More support is needed for children aged 3 until age 5 who do not qualify for the traditional DD waiver and who are not yet in school.	Agree. Use a lower barrier to qualifying for kids from age 3 until age 5 to reduce the cliff families are experiencing and to allow for more school services to be in place prior to potentially screening off the waiver when the eligibility criteria changes. The waiver should continue through age 21, aligning with EPSDT and school transitions.
A.12	The waiver should continue until age 26 to align with health insurance policies.	A&M recommends that the waiver continue until age 21 to align with national standards for children's waivers.
A.13	The right people aren't qualifying for the right waivers. There are groups of people who should get waiver services, or be on different waivers, but are not screening correctly.	Agree. Consistent with the original recommendations, A&M suggests North Dakota revise the level of care process for all children's waivers to better align with newer guidance around screening.
A.14	Developing the right level of care to screen people for the waiver is critical to the waiver achieving its intended impact. Given the importance of this process, CDAC should be involved in LOC.	Agree
A.15	Currently ND Century Code 75-03-23-04 holds that if a person is found eligible for the DD waiver, adults are not able to receive services through a different waiver. This section would need to be amended to allow the person to select the waiver that best fit their assessed needs.	Agree

CDAC Services Recommendations | Service Array

Below are the key recommendations around what services children with disabilities and their families need

#	CDAC Recommendations	A&M Response
S.1	CDAC members have expressed a need for more complex care coordination resources. Families are looking for a central resource who can help with tasks such as scheduling, communications, teaming, and care coordination between multiple providers. CDAC members recommend that this be part of the role of the family navigator rather than adding a new service. This is an area where peer support would be valuable without adding a new person with whom the family would need to coordinate.	Although waiver service coordination will occur through case management, there is an additional need for some children and families for medical care coordination that is not well met today. This support should be developed outside of the waiver; however, it should be designed to complement and coordinate with waiver services and supports. Work with stakeholders to launch a health model that addresses complex care needs outside of the waiver. Additionally, explore how family navigators could help support waiver participants in navigating the system.
S.2	Offer all existing services from the MF, DD, and ASD waiver, except for residential services targeted to higher-needs populations in the DD waiver.	Agree
S.3	Pending funds availability, use contracting to add services that support transition and peer supports (ex: family training, discovery, self-advocacy skill building).	Agree
S.4	Use a family navigator to provide information and assistance for self-direction.	Agree. Another option is to add an Agency with Choice option to support families to self-direct.
S.5	Consider additional services to add based on CDAC recommendations.	Agree, please see details on the service array options within

CDAC Services Recommendations | Technology

Below are the key recommendations around how children with disabilities and their families could benefit from the use of technology

#	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. **Sample excerpt of an AT service definition:** Assistive technology means an item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities and can also support increased community inclusion, including in employment settings. *Source: DC Individual and Family Support (IFS) Waiver (1766.R00.00) | Medicaid
S.9	Consider including training/technical assistance for the child and family on the use of the device; as well as warranties.	Agree

CDAC Services Recommendations | Self-Direction

Below are the key recommendations around how self-direction should work in the new waiver

#	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

CDAC Services Recommendations | Paid Family Caregiver

The CDAC looks forward to learning from the Paid Family Caregiver pilot program and will make additional recommendations about how this should work in the new waiver at that time

#	CDAC Recommendations	A&M Response
S.14	The new children's cross disability waiver should include options for paid family caregiver.	Agree
S.15	Use learnings from the pilot to define the parameters of Paid Family Caregiver for the Cross-Disability Children's Waiver. Consider parity between self-directed, and paid family caregiver rates.	Agree. This topic is on the agenda for the next CDAC meeting, scheduled for December 11, 2025. There will time available for public comments.
S.16	Work with the CDAC to inform the Paid Family Caregiver option for the Cross Disability Children's Waiver.	Agree

CDAC Case Management Recommendations

The CDAC appreciates the state-based case managers and recommends using them, along with family navigators, in the new waiver

#	CDAC Recommendations	A&M Response
CM.1	**Family Navigator:** • Examine the current tasks of case managers. Identify areas where a new family navigator position, with lived experience, can supplement the existing case manger role and help fill gaps. • Hire and train family navigators, using lived experience to substitute for formal education. • Consider whether the family navigators can assist with support for self-direction and with complex care coordination. • CDAC members noted that the introduction of a new team member role, the family navigator, will require training for individuals and families, case managers, and providers.	Agree
CM.2	Explore caseloads to identify if more staffing needed to support the new waiver.	Agree
CM.3	Consider hiring more **state-based case managers** to support the new waiver population, based on CDAC and public feedback regarding the value of having case managers housed in the state offices.	Agree
CM.4	CDAC members suggested that the Charting the LifeCourse tools be used as an input for the person-centered plan for the CDAC, given their focus on planning for people in the context of their families. A&M agrees, and notes that there are many different types of person-centered planning tools that may be good inputs into the plan.	Agree
CM.5	Train all case management staff in the new policies and procedures regarding the cross-disability waiver.	Agree

CDAC Quality Recommendations

The CDAC recommends a quality approach that focuses on person and family centered thinking and outcomes for the new waiver

#	CDAC Recommendations	A&M Response
Q.1	Consider using the Charting the LifeCourse framework for quality management to keep a focus on outcome measures that are person and family - centered.	Agree
Q.2	Develop a case management monitoring tool that includes a focus on personal outcomes and that can be entered into an electronic system for tracking and trending.	Agree
Q.3	Moving to a new framework for quality management will require training at all levels (from individuals and their families, to providers, case managers, and others).	Agree
Q.4	The development of a new waiver and the upcoming Access Rule, provide ND with an opportunity to review and revisit its quality management strategy to determine opportunities for alignment and to add additional person and family-centered performance measures.	Agree
Q.5	Align approaches to customer satisfaction across the IID/DD, ASD, and MF waivers.	Agree
Q.6	Continue to participate in survey opportunities like NCI Child & Family survey. Seek opportunities to include children and families currently in the ASD and MF waivers.	Agree. Note that MF does not fit with the current NCI survey framework.
Q.7	Leverage requirements in the IID/DD waiver and include them in the Cross Disability Children's waiver, thereby extending these requirements to providers for all other populations.	Agree

Cross-Disability Children's Waiver Report

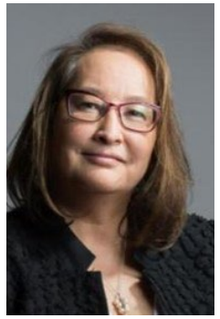
ALVAREZ & MARSAL
LEADERSHIP. ACTION. RESULTS.℠

September 25, 2024

AGENDA

I. Introductions
II. Overview of the Cross Disability Children's Waiver
III. Understanding the Role of the Cross-Disability Advisory Council (CDAC)
IV. Recommendations for Waiver Design
    a. Access
    b. Services
    c. Case Management
    d. Quality
V. Fiscal Implications
VI. Road Map: Outlining Next Steps
VII. Appendix

Introductions: Alvarez & Marsal (A&M)'s Team

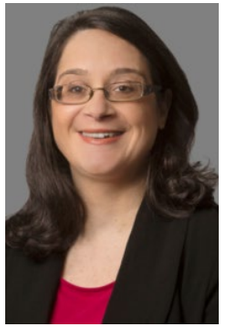


Wanda Seiler
Project Executive

- 30+ years of experience working in health and human services
- Experienced government leader, past director of South Dakota's Division of Developmental Disabilities
- Leads A&M's Public Health and Human Services practice
- Prosci® Change Management Certified

Jillian Salmon
Project Manager

- Partnered with multiple states to assess and redesign long-term services and supports (LTSS) programs to improve administrative and operational efficiency, as well as access to services for vulnerable populations
- Led internal and external stakeholder engagement for the North Dakota (ND) assessment of intellectual/developmental disabilities (I/DD) services
- Charting the LifeCourse Ambassador
- Prosci® Change Management Certified



Erin Leveton
Project Leader

- 25+ years of experience working in health and human services
- Experienced government leader, past Deputy Director for DC's Department on Disability Services (I/DD and Vocational Rehabilitation)
- Specializes in Home and Community-Based Services (HCBS) transformation
- Charting the LifeCourse certified coach
- Prosci® Change Management Certified

Overview of the Cross-Disability Children's Waiver

Understanding How Medicaid Waivers Work

Medicaid funds long-term services and supports (LTSS)

- Medicaid is the primary funder of LTSS in the United States
- Medicaid provides LTSS through both:
  - Institutional care (i.e., intermediate care or nursing facilities), or
  - Home and Community - Based Services (HCBS).

HCBS waivers provide LTSS in community-based settings

- States develop Home and Community-Based Services waivers (HCBS Waivers) to meet the needs of individuals who prefer to receive long-term care services and supports in their home or community, rather than in an institutional setting.

HCBS Waivers offer medical and non-medical services

- HCBS Waivers provide both medical and non-medical services
- Examples services include:
  - Service coordination
  - In home supports
  - Respite
  - Habilitation services
  - Employment supports, and more.

HCBS programs must meet federal program guidelines

- HCBS Waiver programs must:
  - Demonstrate that providing waiver services won't cost more than providing these services in an institution;
  - Ensure the protection of people's health and welfare;
  - Provide adequate and reasonable provider standards to meet the needs of the target population;
  - Ensure that services follow an individualized and person-centered plan of care.

Background: A&M's Original Intellectual and Developmental Disabilities (IID/DD) Assessment

LMA Study Areas of Interest

- Explore existing pathways to services in North Dakota
- Identify gaps in access to services
- Analyze peer state service offerings and approaches used to modify services
- Estimate effects of proposed program implementation and/or expansion
- Examine the consequences of potentially eliminating the Autism Spectrum Disorder Task Force

A&M's Approach

1) A gap analysis exploring North Dakota's various pathways to existing services and outlining current gaps in access; and

2) Research and analysis of peer states to compare service offerings, a national scan of home and community-based services and waivers, and identification of promising approaches used to modify or expand programs to address service access gaps.

Deliverables

★A final report that summarizes our findings; identifies existing gaps in service access; and provides recommendations and projections for, addressing these gaps.

★Testimony to the North Dakota Legislature's Human Services Committee on our findings and recommendations.

North Dakota's Strengths: What's Working Well Today?

North Dakota's strong IID/DD Waiver services, skilled Health and Human Services (HHS) staff, and passionate advocate groups are all assets to the State.

The IID/DD Waiver Programming

- The IID/DD Waiver provides comprehensive supports to individuals throughout their lifespan.
- Services are provided cost-effectively to the youngest children with great success.
- Self-advocates spoke positively about their experiences in the IID/DD Waiver and described flexible and supportive day programming where they had freedom of choice to volunteer, work, or pursue activities like learning to cook.

State Staff

- State staff, from executive leaders to division managers to case workers, clearly have a demonstrated commitment to caring for individuals with disabilities. When faced with resource constraints, such as limited case workers, staff work hard to maximize available resources and continue to provide quality services.
- Many senior leadership staff have been with the department for over a decade and bring valuable knowledge and expertise.
- Staff are also committed to engaging with the community and skillfully facilitate these interactions through the Autism Task Force.

Community Advocates

- There is a strong network of advocates who are passionate about providing the best services for individuals with disabilities.
- Groups and individuals were extremely generous with their time, often meeting with us more than once to share feedback.

The Opportunity: A Need to Streamline Access to Services

North Dakota's waivers have different eligibility requirements and varying funding support, resulting in disparate access to services. Additionally, there are also drop-off points created both by the end of the Autism Spectrum Disorder (ASD) waiver at age 15 and by changing levels of care on the DD Waiver at age 3.

Waiver	Age	Diagnostic Criteria	Waiting List	Individual Cost Limit	Max Participants/ Year	Average Waiver Spend /Year*
Intellectual / Developmental Disabilities (ID/DD)	Birth until no maximum age	Intellectual Disabilities (ID), or DD and related condition	No	No limit	6,830	$37,624
Autism Spectrum Disorder	Birth until age 17	ASD	Yes	No limit	150	$20,160
Children's Hospice	Birth until age 21	Medically Fragile in need of palliative care	No	Highest monthly nursing facility rate allowed by HHS	30	$32,165
Medically Fragile	Age 3 until age 17	Medically Fragile	Yes	$18,996	25	$6,228

Differences in age coverage, diagnostic criteria, and slot availability drive inequities between children and adults with different categories of disabilities.

**As projected in Appendix J of Waiver Application*

Growing the Foundation: A Vision for the Future of North Dakota's HCBS Waivers

North Dakota can expand its strong base of supports for children from birth until age 2 and its robust IID/DD Waiver programming to create a strong foundation for all people with disabilities through Home & Community-Based Waiver services.

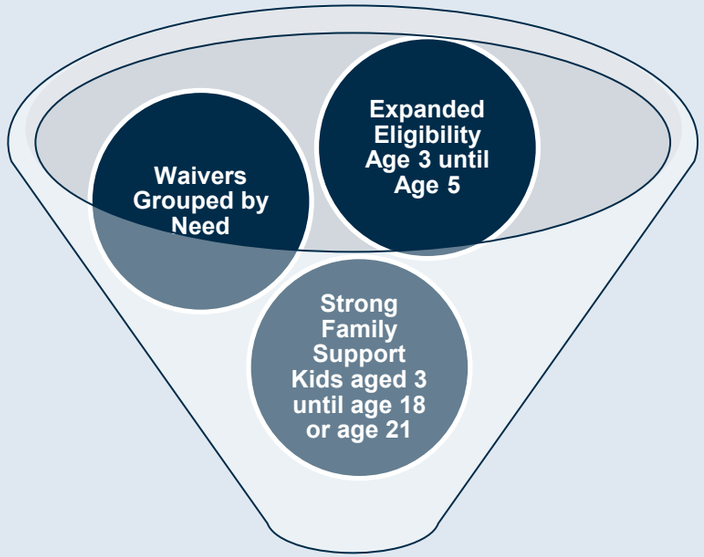
The Vision

North Dakota can build on its legacy of exceptional support for children from birth until age 3 by both modernizing and streamlining three of its existing waivers to create a system that is:

- Equitable
- Comprehensive
- Innovative

The Support: North Dakota's experienced staff and engaged advocates will form the basis for this system transformation.

The Path



A more robust HCBS waiver system, including a children's waiver that supports individuals regardless of their disability.

The Path to Waiver Modernization

ND can achieve its vision to fill the gap for people with developmental disabilities and autism by modernizing its existing waiver system.

Current State

IID/DD Waiver

ASD Waiver

Medically Fragile Waiver

Future State

Updated, Comprehensive ID/DD Waiver

- Services designed for high-needs and complex people (children and adults) with Intellectual Disabilities, Developmental Disabilities, and/or Autism.
- *Note that children from birth until age 3 will continue to be served under this waiver.*
- Modernized Level of Care (Phase Two).

New Children's Cross Disability Waiver

- Services designed for children with mild to moderate support needs living in the community:
  - New level of care (LOC) for children aged 3 until age 6 that matches Individuals with Disabilities Education Act (IDEA) Part B.
  - Modernized Level of Care for children ages 6+ (uses ID/DD LOC, Phase Two).
  - Targeted to children ages 3 until 18 or 3 until 21, not a lifespan waiver.
  - ***CDAC input is critical to waiver design and implementation.***

High-Level Roadmap for Waiver Innovation: Mapping North Dakota's Path Forward

Laying the Groundwork for Successful Change

- Before implementing major system changes, ND will first work on achieving "quick wins" in the current state.
- These actions will help improve the system's functionality families immediately.
- ND will continue to collaborate with stakeholders who will advise and guide HHS actions.

Please see the Roadmap section for more details on the timeline, including quick wins

Objective #1: Implement New Cross-Disability Children's Waiver

- Outline service array that includes community-based interventions to help families and their children.
- Build strong support for service navigation, person-centered planning, and self-direction.
- Combine existing ASD/Medically Fragile Waiver (MFW)/IDD level of care for children during the waiver launch to ensure continuity.
- For children aged 3-5: Include expanded eligibility to address the "cliff" that occurs when children turn 3.

Objective #2: Refine LOC Across Waivers, Including New Cross Disability Waiver (CDW) and Existing IID/DD Waiver

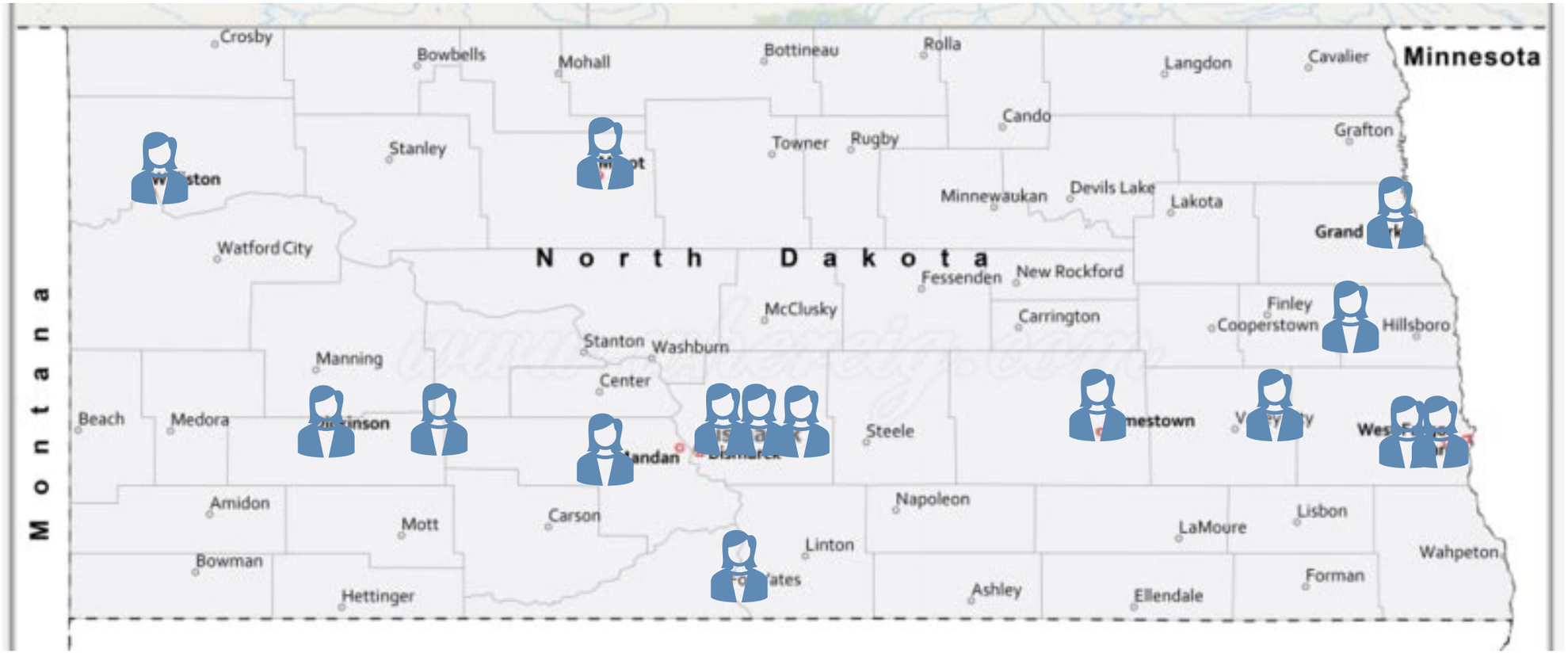
- Create modernized level of care for comprehensive IDD waiver to match AAIDD, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition DSM-5, and ICD-11 definitions.
- For children ages 5+: Use the new IDD LOC to modernize who qualifies for both the comprehensive IDD waiver and the Cross-Disability Children's Waiver.
- *Critical note: significant testing will be necessary to ensure there are no unintended effects of the LOC changes; parallel testing will be needed.*

Understanding the Role of the Cross-Disability Advisory Council


CDAC
North Dakota Cross Disability Advisory Council
2023-2025 Biennium
Carmen Troutman
Emily Vieweg
Jackie Adusumilli
Katynka Morrissette
Megan Sande
Toby Lunstad
Kim Hruby
Colette Fleck
Stephanie Nelson
Erin Peterson
Vicki Peterson
Heidi Wilhelm
Kayla Fender
Kathy Barchenger
Moe Swanson
Heather Larson
Mary McCarvel-O'Connor
Magan Paulson
Susan Karpyak
Kevin Miiller
Erin Leveton
Wanda Seiler
Jillian Salmon
Trevor Vannett

Geographical Distribution of CDAC Representatives

15 voting members from across North Dakota



= 1 voting member

Non-voting HHS Members: Jackie Adusumlli, HHS-Early Intervention; Kathy Barchenger, HHS-Medical Services; Kayla Fender, HHS-Developmental Disabilities; Kim Hruby, HHS-Special Health Services; Mary McCarvel-O'Connor, DPI-Early Intervention

Presiding Officer: Kevin Miiller

Anchoring in the WHY

Here's what the Cross Disability Advisory Council (CDAC) shared about why developing a children's cross-disability waiver is important.

Overview of the Cross-Disability Advisory Council (CDAC)

Why Does the Cross-Disability Advisory Council (CDAC) Exist?

The State wants to **partner with the community to help design the new children's cross-disability waiver**. CDAC was formed to include people with various lived experiences in the process and support true co-creation of the waiver.

How was CDAC created?

The legislature formally established CDAC as **an advisory body through Senate Bill 2276**, with the intent of advising the state on the new children's waiver. The State hired an independent facilitator who then created an application process to select members of CDAC.

Who are the CDAC members?

The CDAC facilitator selected voting members who bring important life experiences to the process, including **parents of children with disabilities, individuals with disabilities, service providers, and educators**. Experts from the state agency also participate in the process as non - voting members. See following slides for more information.

What does CDAC do?

CDAC works together to define what is going well in the current system, and to highlight opportunities for improvement. Members share their life experiences and ideas about how the future system should work. The group **creates recommendations for how the new waiver should operate** to guide the state in the design process.

The CDAC's Purpose

Slide Excerpt from CDAC Meeting

Plain Language Purpose

The Department of Health and Human Services (HHS) is planning to create a new cross-disability children's waiver. The Cross-Disability Advisory Council (CDAC) was created by law to help by sharing ideas. These ideas will help HHS develop the new waiver.

This initially includes:

1. How people can apply to the new waiver, once created.
2. What supports people need.
3. What supports from case management are helpful.
4. What quality looks like.

Core Areas for Advisory Input (as defined in statute)

Access
How people can apply to the waiver

Services
What supports people need

Case Management
What supports from CM are helpful?

Quality
What does quality look like?

CDAC members are the experts on their own lives and will provide advice and feedback to HHS based on what they have experienced, what is working well, and what could be better in the future. It is the State's responsibility to use CDAC feedback to define specific technical elements of the waiver such as level of care (LOC).

Statutory Authority for CDAC

Excerpts from Senate Bill No.2276

Duties:

The cross-disability advisory council shall participate with and **provide feedback to the department regarding the implementation, planning, and design of the cross-disability children's waiver**, level of care reform for the comprehensive developmental disabilities Medicaid home and community-based waiver, and a service option that will allow payment to a legally responsible individual who provides extraordinary care to an eligible individual through the Medicaid 1915(c) waivers.

Selection Criteria:

The cross - disability advisory council consists of up to fifteen voting members. **A majority of the council members must be family members of individuals with a disability or must be individuals with a disability themselves who receive Medicaid home and community-based services**. The remaining council members must be appointed based on their professional subject matter expertise or knowledge of the needs and interests of individuals with disabilities. The council's membership must represent different regions of the state and a broad range of disabilities relevant to the Medicaid home and community-based services.

Upon department’s request, state agency representatives shall participate with the cross-disability advisory council in a nonvoting role.

Examining CDAC's Current and Future Role

Progress Update on CDAC's Legislative Duties

CDAC's work to date has focused on advising HHS regarding design for a new cross-disability children's waiver. Remaining areas for future input include level of care design/reform, and paid family caregiver services (currently in pilot)

Area for Input	CDAC Status Update	Anticipated Future CDAC Role
Cross-disability children's waiver	CDAC has compiled detailed recommendations to advise the State on key principles in the design of a potential new cross-disability children's waiver.	CDAC will serve as a key input into the continued planning and implementation of the new waiver, if legislative funding to support the new program is passed.
Level of care design / reform	Level of care work was not funded as part of the first CDAC term. This complex work needs dedicated funding to support activities like testing and coordination with subject matter experts.	Level of care is anticipated to be the next focus area for CDAC, if HHS receives legislative funding for the parallel testing and subject matter expertise needed. CDAC would serve a critical role by offering perspectives on how level of care impacts families in need of support.
Paid family caregiver	HHS is currently piloting paid family caregiver services and collecting further information on this potential new waiver service	CDAC will review learnings from the paid family caregiver pilot (scheduled for Dec. 11th meeting) and provide input into the design of this service, including its inclusion on the potential new cross-disability children's waiver

CDAC Composition Recommendation

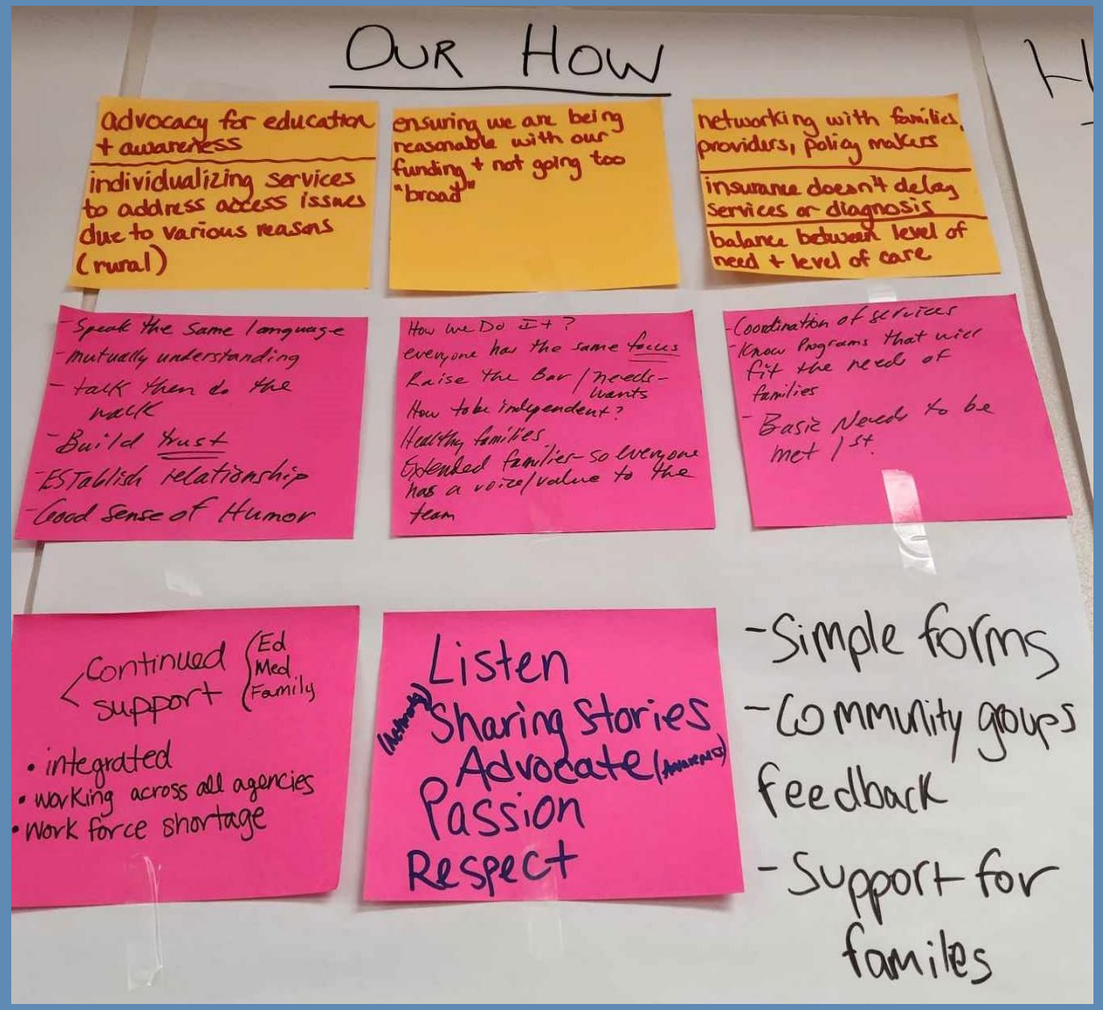
The CDAC recommends a broader composition of members for the next phase of work on Level of Care

#	CDAC Recommendation	A&M Response
C.1	For the anticipated next phase of work that includes level of care, expand the selection criteria to specify that a majority of the council members must be family members of individuals with a disability or must be individuals with a disability themselves who **currently receive** Medicaid home and community - based services, have **previously received** Medicaid home and community - based services, **or have never received** Medicaid home and community - based services.	Agree

Approach to Recommendations

Reflecting on the HOW

Here's what CDAC members shared about how they wanted to work together and help design the new waiver.



Key Themes…

- Develop shared understanding and a common language; build trust.
- Design approachable, person-friendly systems (e.g., simple forms, improved awareness).
- Establish relationships between the State and families.
- Target basic needs first and use funding responsibly.

How CDAC Input Informs the Core Areas of Waiver Design

Core Topic	Waiver Design Elements	Questions for CDAC Input
Access 	• Who qualifies for the waiver • The ages included • The process of applying to the waiver • The level of care/screening tool used	• What populations of people are most in need of waiver services? • How do families currently hear about waiver services? • What are some ideas for increasing awareness? • What do families need to feel supported in the journey to waiver services? • What information do families want before beginning an application?
Services 	• The options for services • Provider qualifications • Service limits (if applicable) • Estimates for how many people will use each service offering • Options for self-directing services	• What services do families find helpful? • What challenges do families experience when receiving services? • What natural supports do families use? How do services interact with these types of natural community supports? • Do you have ideas for new services that would help bridge gaps?
Case Management 	• Case manager qualifications • Person-centered planning supports • The process for choosing providers • Support for self-direction	• What do you appreciate about your current case managers? • What characteristics and skills are important for case managers to have? • Have you experienced any challenges with the current case management system (ex: turnover, shortages)? • What are some life transitions where you need increased support? • Do you need additional help to use self-direction successfully?
Quality 	• Quality measures • Protections for health and safety • The appeals process • Options for informal grievances	• How should a well-functioning system look and be measured? • What does quality mean to you? • What protections are needed for families and participants? • What have your experiences been like using the appeals / grievances process, if applicable?

Example: How CDAC Input Informs Service Recommendations for the New Waiver

CDAC Shares Experiences

- Members share experiences using waiver services.
- Describe gaps.
- Explain what else might help.

A&M Themes More Feedback

- A&M summarizes the CDAC input.
- CDAC reviews, confirms, and provides additional feedback.
- A&M asks questions to collect more details or additional information.

Research on Emerging Practices

- A&M researches how other states provide supports to children with disabilities and their families.
- Drafts report with examples of service definitions, provider qualifications, rates, and projected number of users.

CDAC's Report

- A&M combines CDAC input, national examples, and ND's unique factors to outline suggested service array for new cross - disability children's waiver.
- Vet and finalize report with CDAC.

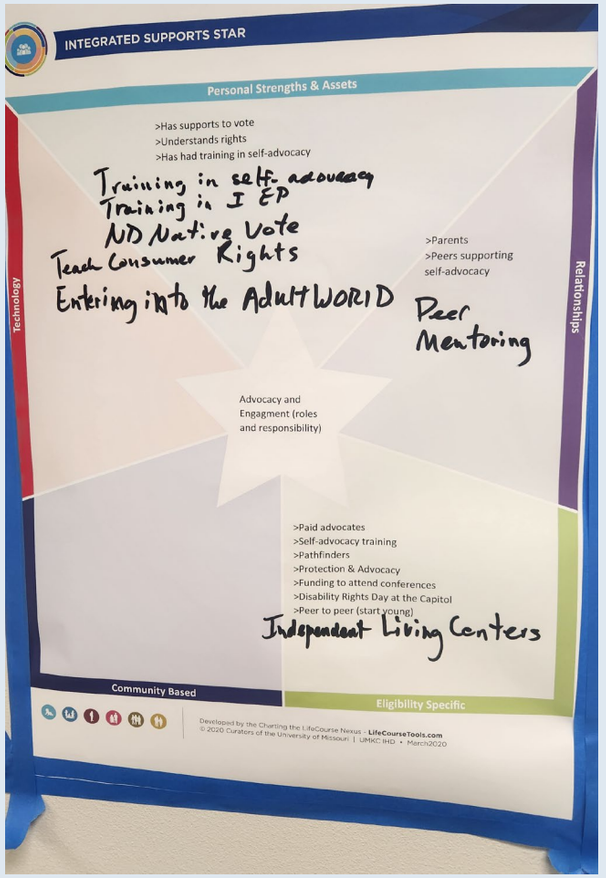
Our Work Together, with CDAC

CDAC members spent an impressive amount of time and energy to create the group's children's cross-disability waiver recommendations.

CDAC's Commitment to the Process:

- CDAC members participated in seven monthly hybrid committee meetings, often 6+ hours in length, as well as multiple additional virtual sessions when needed
- Collectively, the **15 CADC members spent over 700 hours of volunteer time working together** to define a vision for the future of children's waiver services in ND
- This extensive meeting time was in addition to optional homework / brainstorming between meetings

**Example meeting activities: Menti online polls, individual brainstorming/share-outs, and wall work with prompts and sticker voting. Throughout the report, we have included examples of slides and activities used during CDAC meetings*



Methods for Including Additional Voices

We also worked with CDAC to include opportunities for other members of the public to share their input into the process

Throughout this report, we have highlighted additional feedback from non-CDAC members, referred to within as public input. This information was collected from a variety of forums, including those highlighted below.

Public Participation Opportunities

Virtual Town Hall Meetings

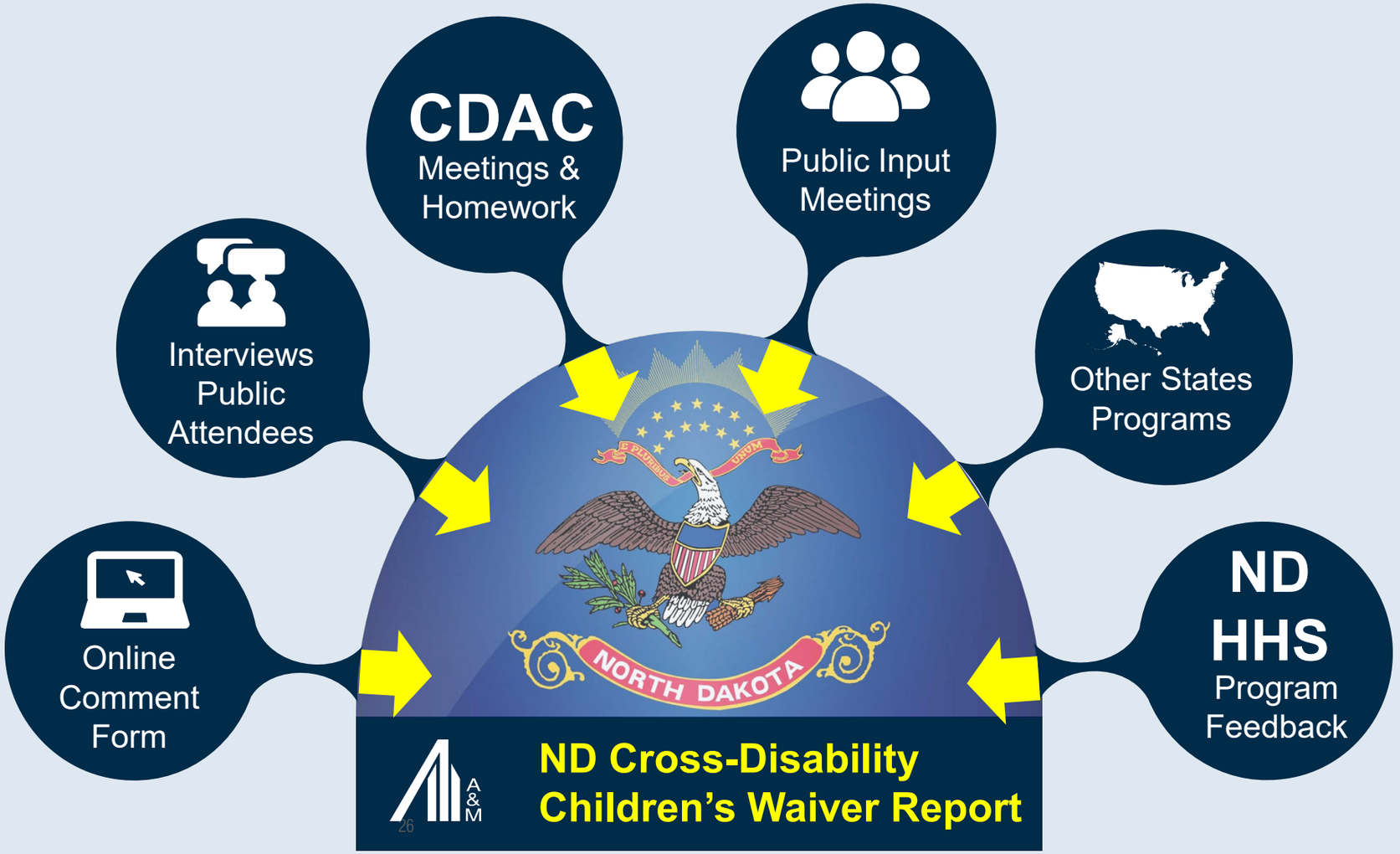
Interviews with Frequent Public Attendees

CDAC Meeting Attendance (Open to Public with Opportunities for Feedback)

Online Comment Submission Form

Our Approach Centered on CDAC Members & Included Opportunities for Public Comment

A broad range of input was gathered for this report.



Recommendations

CDAC Composition Recommendation

The CDAC recommends a broader composition of members for the next phase of work on Level of Care

#	CDAC Recommendation	A&M Response
C.1	For the anticipated next phase of work that includes level of care, expand the selection criteria to specify that a majority of the council members must be family members of individuals with a disability or must be individuals with a disability themselves who **currently receive** Medicaid home and community - based services, have **previously received** Medicaid home and community - based services, **or have never received** Medicaid home and community - based services.	Agree

CDAC Access Recommendations | General

Below are the key recommendations to make it easier for people and families to access services

#	CDAC Recommendations	A&M Response
A.1	Include clear language information about the new waiver on the HHS website. Partner with community resources to spread awareness.	Agree
A.2	Provide families with a clear understanding of the application process, including who is likely to qualify for services, before they decide to apply.	Agree
A.3	Use a family-friendly application process that is easy to understand, and trauma informed. Provide families with a simple way to ask questions and check their status.	Agree
A.4	Create an expedited version of the application process for families with children who are already receiving services under a different waiver.	Agree
A.5	Share plain language information about appeals options during the application process.	Agree

CDAC Access Recommendations | Target Population (1 of 2)

Below are the key recommendations around who the waiver should support

#	CDAC Recommendations	A&M Response
A.6	Eligible children with disabilities should be supported for the same age range in the new waiver, regardless of diagnosis.	Agree
A.7	There is an ongoing need for more services for children with behavioral health needs, and this population should be served on the new waiver.	Agree. Consider adding behavioral health to the list of target populations in the cross - disability waiver to address both the common co-occurrence with other disabilities, and the gap in services for this population.
A.8	There is a need for a new level of care for children with developmental disabilities. This extension is necessary to provide ongoing supported for children with disabilities such as muscular dystrophy, fetal alcohol syndrome, Down syndrome, and cerebral palsy.	Agree
A.9	The hospice population should potentially be included in the new cross-disability waiver to minimize need for any transfers between waivers.	The initial target population should be focused on children with ASD and MF, as well as children with ID/DD who have lower functional support needs, and the SED population. Hospice should be kept as a separate waiver population, which has its own unique services and dedicated funding. Ensure there is a pathway for families to switch waivers if needed.
A.10	The waiver should include children with any conditions on the Social Security Compassionate Allowances list.	A&M's research shows this practice is not used in any other states because it does not include an assessment of functional impairment. Keep the target population for the new waiver focused on specific populations including ID/DD, ASD, MF, and potentially behavior health (BH) needs. Utilize functional eligibility measures to determine who qualifies for waiver services, in compliance with existing federal policies around waiver eligibility. Medicaid may consider exploring broader, general Medicaid eligibility questions for children with disabilities outside of the waiver.

CDAC Access Recommendations | Target Population (2 of 2)

Below are the key recommendations around who the waiver should support

#	CDAC Recommendations	A&M Response
A.11	More support is needed for children aged 3 until age 5 who do not qualify for the traditional DD waiver and who are not yet in school.	Agree. Use a lower barrier to qualifying for kids from age 3 until age 5 to reduce the cliff families are experiencing and to allow for more school services to be in place prior to potentially screening off the waiver when the eligibility criteria changes. The waiver should continue through age 21, aligning with EPSDT and school transitions.
A.12	The waiver should continue until age 26 to align with health insurance policies.	A&M recommends that the waiver continue until age 21 to align with national standards for children's waivers.
A.13	The right people aren't qualifying for the right waivers. There are groups of people who should get waiver services, or be on different waivers, but are not screening correctly.	Agree. Consistent with the original recommendations, A&M suggests North Dakota revise the level of care process for all children's waivers to better align with newer guidance around screening.
A.14	Developing the right level of care to screen people for the waiver is critical to the waiver achieving its intended impact. Given the importance of this process, CDAC should be involved in LOC.	Agree
A.15	Currently ND Century Code 75-03-23-04 holds that if a person is found eligible for the DD waiver, adults are not able to receive services through a different waiver. This section would need to be amended to allow the person to select the waiver that best fit their assessed needs.	Agree

CDAC Services Recommendations | Service Array

Below are the key recommendations around what services children with disabilities and their families need

#	CDAC Recommendations	A&M Response
S.1	CDAC members have expressed a need for more complex care coordination resources. Families are looking for a central resource who can help with tasks such as scheduling, communications, teaming, and care coordination between multiple providers. CDAC members recommend that this be part of the role of the family navigator rather than adding a new service. This is an area where peer support would be valuable without adding a new person with whom the family would need to coordinate.	Although waiver service coordination will occur through case management, there is an additional need for some children and families for medical care coordination that is not well met today. This support should be developed outside of the waiver; however, it should be designed to complement and coordinate with waiver services and supports. Work with stakeholders to launch a health model that addresses complex care needs outside of the waiver. Additionally, explore how family navigators could help support waiver participants in navigating the system.
S.2	Offer all existing services from the MF, DD, and ASD waiver, except for residential services targeted to higher-needs populations in the DD waiver.	Agree
S.3	Pending funds availability, use contracting to add services that support transition and peer supports (ex: family training, discovery, self-advocacy skill building).	Agree
S.4	Use a family navigator to provide information and assistance for self-direction.	Agree. Another option is to add an Agency with Choice option to support families to self-direct.
S.5	Consider additional services to add based on CDAC recommendations.	Agree, please see details on the service array options within

CDAC Services Recommendations | Technology

Below are the key recommendations around how children with disabilities and their families could benefit from the use of technology

#	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. **Sample excerpt of an AT service definition:** Assistive technology means an item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities and can also support increased community inclusion, including in employment settings. *Source: DC Individual and Family Support (IFS) Waiver (1766.R00.00) | Medicaid
S.9	Consider including training/technical assistance for the child and family on the use of the device; as well as warranties.	Agree

CDAC Services Recommendations | Self-Direction

Below are the key recommendations around how self-direction should work in the new waiver

#	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

CDAC Services Recommendations | Paid Family Caregiver

The CDAC looks forward to learning from the Paid Family Caregiver pilot program and will make additional recommendations about how this should work in the new waiver at that time

#	CDAC Recommendations	A&M Response
S.14	The new children's cross disability waiver should include options for paid family caregiver.	Agree
S.15	Use learnings from the pilot to define the parameters of Paid Family Caregiver for the Cross-Disability Children's Waiver. Consider parity between self-directed, and paid family caregiver rates.	Agree. This topic is on the agenda for the next CDAC meeting, scheduled for December 11, 2025. There will time available for public comments.
S.16	Work with the CDAC to inform the Paid Family Caregiver option for the Cross Disability Children's Waiver.	Agree

CDAC Case Management Recommendations

The CDAC appreciates the state-based case managers and recommends using them, along with family navigators, in the new waiver

#	CDAC Recommendations	A&M Response
CM.1	**Family Navigator:** • Examine the current tasks of case managers. Identify areas where a new family navigator position, with lived experience, can supplement the existing case manger role and help fill gaps. • Hire and train family navigators, using lived experience to substitute for formal education. • Consider whether the family navigators can assist with support for self-direction and with complex care coordination. • CDAC members noted that the introduction of a new team member role, the family navigator, will require training for individuals and families, case managers, and providers.	Agree
CM.2	Explore caseloads to identify if more staffing needed to support the new waiver.	Agree
CM.3	Consider hiring more **state-based case managers** to support the new waiver population, based on CDAC and public feedback regarding the value of having case managers housed in the state offices.	Agree
CM.4	CDAC members suggested that the Charting the LifeCourse tools be used as an input for the person-centered plan for the CDAC, given their focus on planning for people in the context of their families. A&M agrees, and notes that there are many different types of person-centered planning tools that may be good inputs into the plan.	Agree
CM.5	Train all case management staff in the new policies and procedures regarding the cross-disability waiver.	Agree

CDAC Quality Recommendations

The CDAC recommends a quality approach that focuses on person and family centered thinking and outcomes for the new waiver

#	CDAC Recommendations	A&M Response
Q.1	Consider using the Charting the LifeCourse framework for quality management to keep a focus on outcome measures that are person and family - centered.	Agree
Q.2	Develop a case management monitoring tool that includes a focus on personal outcomes and that can be entered into an electronic system for tracking and trending.	Agree
Q.3	Moving to a new framework for quality management will require training at all levels (from individuals and their families, to providers, case managers, and others).	Agree
Q.4	The development of a new waiver and the upcoming Access Rule, provide ND with an opportunity to review and revisit its quality management strategy to determine opportunities for alignment and to add additional person and family-centered performance measures.	Agree
Q.5	Align approaches to customer satisfaction across the IID/DD, ASD, and MF waivers.	Agree
Q.6	Continue to participate in survey opportunities like NCI Child & Family survey. Seek opportunities to include children and families currently in the ASD and MF waivers.	Agree. Note that MF does not fit with the current NCI survey framework.
Q.7	Leverage requirements in the IID/DD waiver and include them in the Cross Disability Children's waiver, thereby extending these requirements to providers for all other populations.	Agree

Does The A&M Report Capture CDAC Feedback (Y/N)

Report Section	Fleck Colette	Larson Heather	Lunstad Toby	Morrisette Katynka	Nelson Stephanie	Paulson Magan	Peterson Erin	Peterson Vicki	Sande Megan	Swanson Moe	Troutman Carmen	Vannett Trevor	Vieweg Emily	Wilhelm Heidi
Access – Target Population	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Access – Journey to Services	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Technology	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Service	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Case Management	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Quality	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Road Map	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Access

Access: What Does The Topic of Access Include?

Slide Excerpt from CDAC Meeting

What do we mean when we talk about “accessing services”?

- Access is about the journey people go through to apply for and receive Medicaid waiver services. This includes everything from the time you learn about services to the time you begin services.
- **Example journey:** Someone who would like to apply for IID/DD waiver services must contact their local Human Service Center and schedule a home intake visit to begin the application process. There are several other steps people must go through before they can start waiver services, including Medicaid eligibility. We will look in more detail at the existing waiver access journeys in this section.

The Department of Health & Human Services will have to create a path for people to access the new cross-disability waiver. **CDAC members will play an important role by**:

- Sharing your experiences accessing existing waivers, including what this process felt like for you and your family and how it worked (if applicable); and
- Highlighting what is important to think about and include in the path to accessing the new waiver.

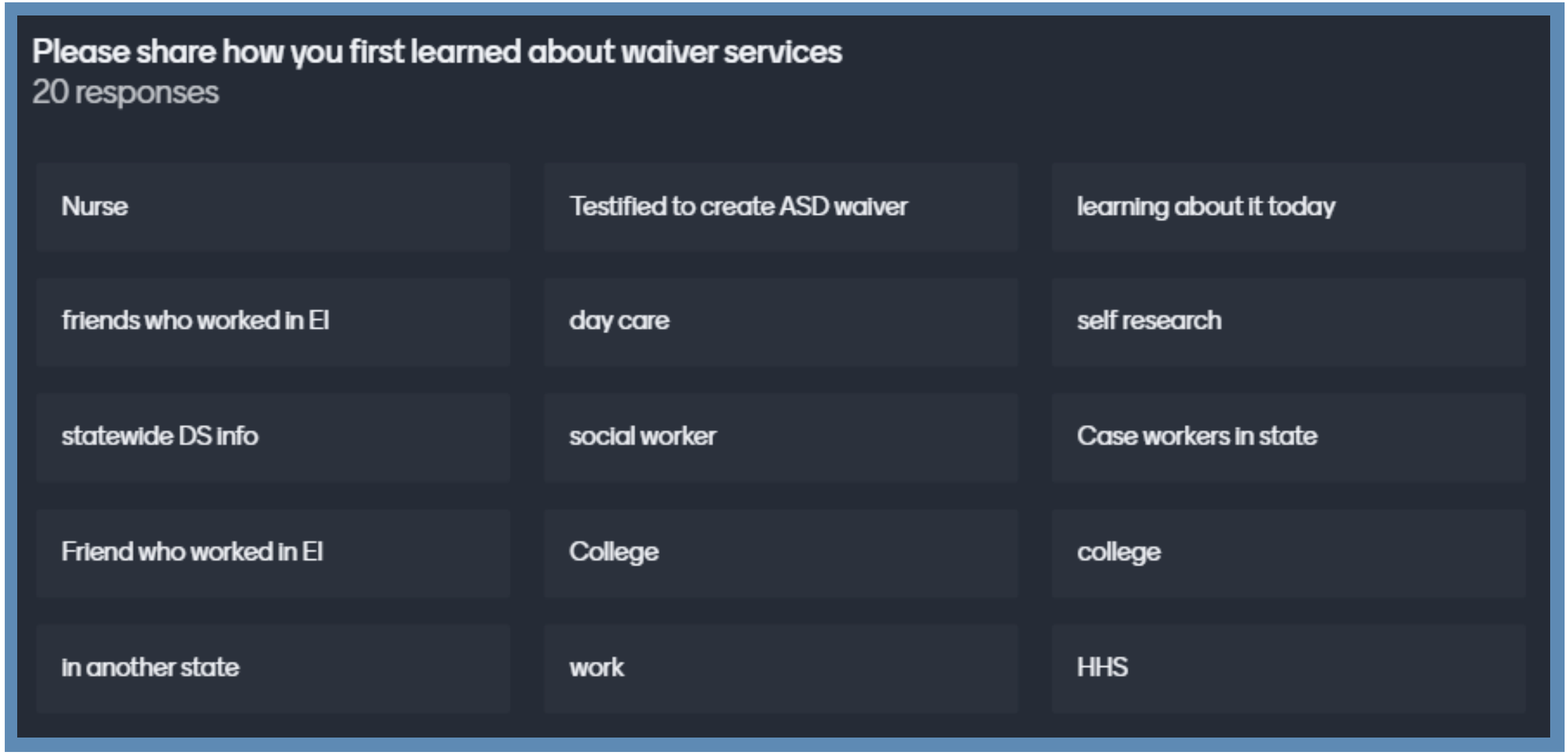
Key Questions on Access

We asked CDAC members to share their experiences and recommendations around the journey to services.

1. How do families currently hear about waiver services?
2. What are some ideas for increasing awareness?
3. What do families need to feel supported in the journey to waiver services?
4. What information do families want before beginning an application?

How Do People Learn About Waiver Services Today?

We asked CDAC members to share how they found out about the waiver.



What We Heard: CDAC Feedback on the Journey to Services (Overview)

CDAC members shared a series of recommendations about how the journey to services should look.

Subtopic	CDAC Member Feedback	A&M Response - Summary
Awareness	The State should increase **awareness of services** and consider creative information methods like QR codes directed to the website	Concur - spreading awareness online and through community partners is essential to increasing access (see next slide for peer state example)
Anticipatory Guidance	The application process should **be easy to understand** in advance of beginning the process	Concur
Anticipatory Guidance	An **online screening tool** would help families understand if they are likely to qualify before applying	Each situation is unique, but providing general guidance of who is likely to qualify helps families plan
User Friendliness	The application process should use plain language, have a single point of contact, be trauma informed, and allow open text responses	Concur - see following slides for additional guidance on user friendliness and streamlined eligibility.
Efficiency	There should be an expedited process for children switching between waivers so that there is not a gap in coverage	Concur
Appeals	Families need plain language information about the appeals process for children who are denied	Concur

Public Comment: Key Themes Related to Accessing Services

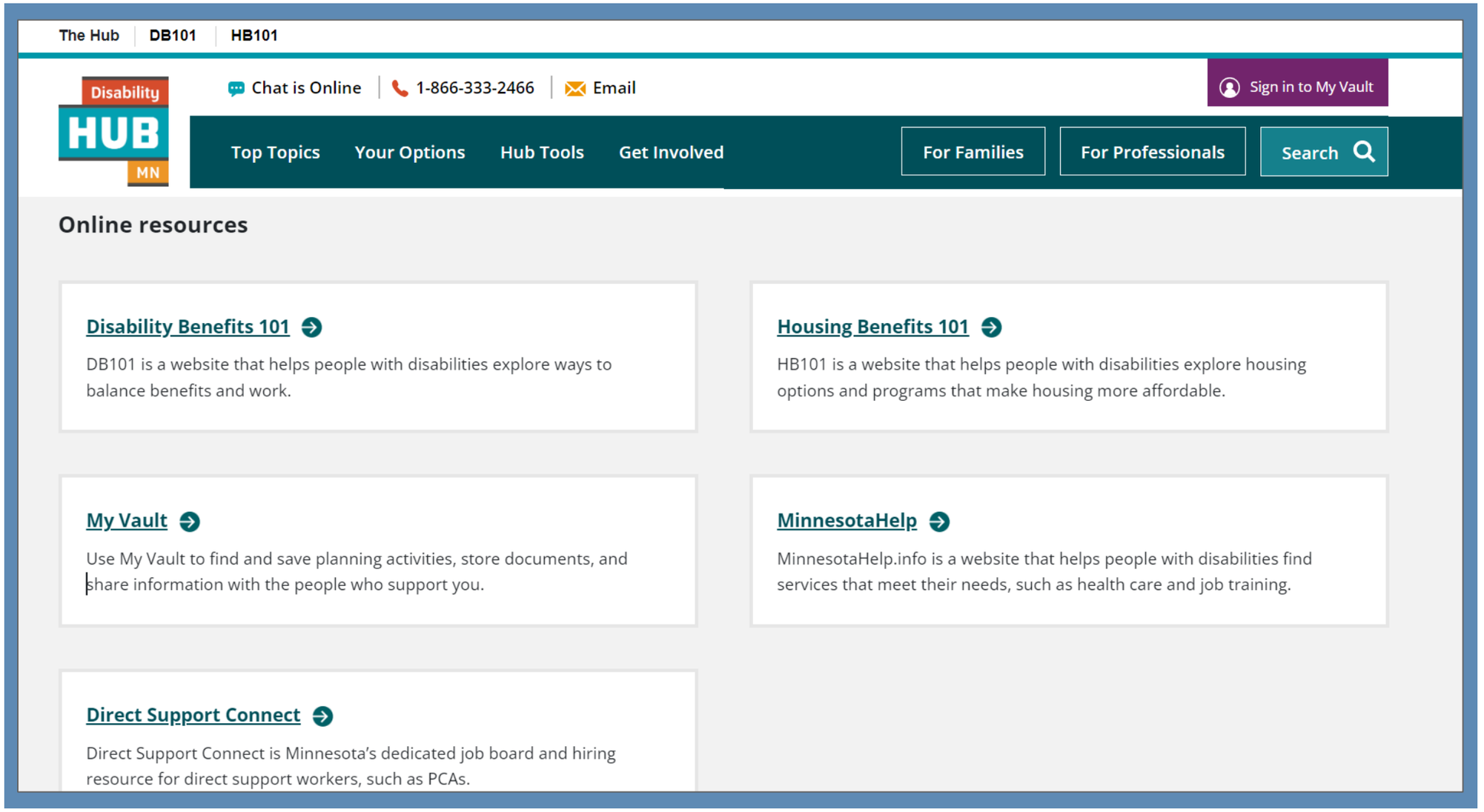
Public attendees at the listening sessions provided recommendations on the new cross - disability waiver, and on broader system opportunities to serve children more effectively.

Themes related to the journey to services from public comment included the following:

The Journey to Services

- People are concerned about **the cliff that happens at age 3:**
  - Families may not understand the process, and waiting lists for assessments are long.
  - Stopping services could lead to regression.
- Multiple families shared that the **waiting time to receive assessments is lengthy** and may result in children losing services at age 3.
- Participants felt that the **system is challenging to navigate** and that there is a need for more online information.

Example of Spreading Benefit Awareness: Minnesota Disability Hub



What Makes a System User Friendly?

Access refers to the journey individuals go through to apply for and receive waiver services. In a person - centered system, access should include both: 1) easily accessible information about services and the application process, and 2) a family friendly process for applying for services.

1. Easy to find information about services and the application process, including:

- Trusted partners and people in the community who understand the services and can share information about the application process.
- An agency website (HHS) with information about services and the intake process, including where to begin the application process and how long it will take.

2. A family friendly application process, including:

- An easy to contact place to start the intake process.
- An initial intake conversation that provides information, including estimated timelines, an overview of necessary documents, and guidance about choices down the road.
- A person-centered conversation that helps people identify supports they can use while waiting.
- One central contact throughout the application process.
- A way for families to check their application status.

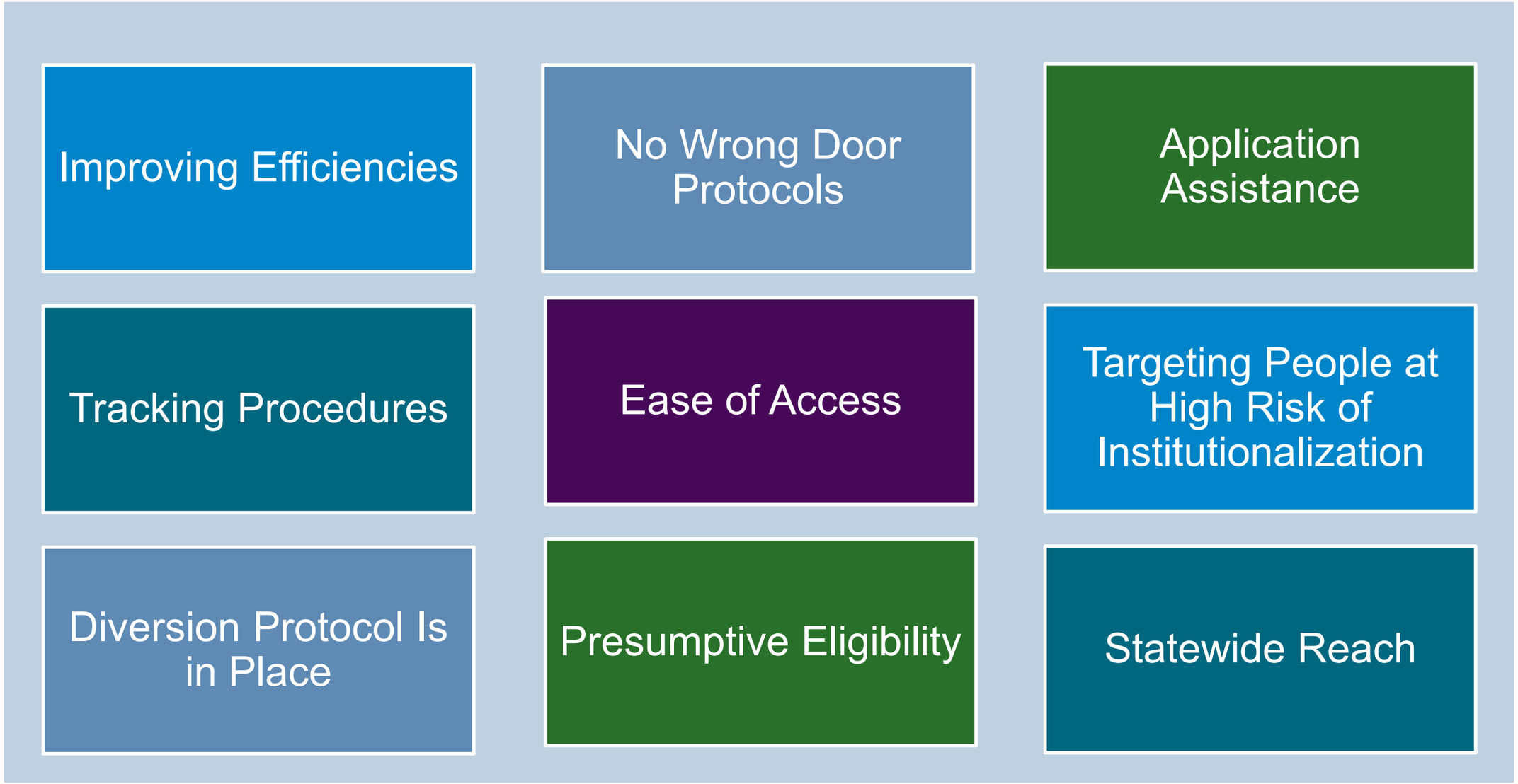
People need three buckets of support:

1) Discovery and navigation
2) Connecting and networking
3) Goods and services.

Information about how to apply for services is part of bucket #1, discovery and navigation. This bucket includes the ability to navigate and access services.

Source: LifeCourse Framework – LifeCourse Nexus (lifecoursetools.com)

National Best Practices: Key Factors in Streamlining the Eligibility Process



*Source: No Wrong Door

CDAC Access Recommendations | General

Below are the key recommendations to make it easier for people and families to access services

#	CDAC Recommendations	A&M Response
A.1	Include clear language information about the new waiver on the HHS website. Partner with community resources to spread awareness.	Agree
A.2	Provide families with a clear understanding of the application process, including who is likely to qualify for services, before they decide to apply.	Agree
A.3	Use a family-friendly application process that is easy to understand, and trauma informed. Provide families with a simple way to ask questions and check their status.	Agree
A.4	Create an expedited version of the application process for families with children who are already receiving services under a different waiver.	Agree
A.5	Share plain language information about appeals options during the application process.	Agree

Target Population & Level of Care

Target Population: How People Qualify for Medicaid Waivers

Medicaid waivers target a specific population of individuals in need of long-term supports and services (LTSS). The federal government requires states to set three major waiver criteria that individuals must meet to qualify:

1. **Income:** States must set an income limit for waiver participation. Typically, waivers have a higher income limit than the general Medicaid State Plan. In North Dakota, the waiver income limit is based upon the child's income. The family's income is waived.
2. **Conditions:** States need to determine a list of conditions that qualify an individual for an HCBS waiver. Currently, ND includes target populations like: Autism, Intellectual Disability, Developmental Disability, Medically Fragile. This waiver offers an opportunity to expand services to additional populations such as children with behavioral health needs.
3. **Functional Needs (LOC):** States must establish an institutional level of need that the waiver is targeting, such as a nursing facility, and create a process to assess whether an individual's functional needs meet this level of care (LOC).
    - HCBS waivers are designed to provide LTSS in the home and community rather than in an institution. This means that to qualify for a waiver, **the state must first determine if someone meets what is known as an institutional level of care.**

Qualifying for HCBS waivers is different than qualifying for general Medicaid. States **must include a process to measure an individual's functional needs and cannot automatically accept individuals to HCBS waivers on the basis of conditions alone.*

Understanding Level of Care

- Waivers are **designed to provide LTSS in the home and community in place of institutional settings;** therefore, individuals **must meet the need for services in an institutional setting** to qualify for waiver services
  - Eligibility for Medicaid HCBS waivers is directly linked to institutional levels of care, as waivers serve as an alternative to institutionalization in facilities such as Intermediate Care Facilities for Individuals with Intellectual Disabilities and Nursing Facilities.

- As part of the waiver eligibility process, states assess whether an individual demonstrates the need for a Level of Care (LOC) that meets the state's eligibility requirements for services in an institutional setting

- Level of Care is determined initially at admission and then recertified annually. The overall goal of Level of Care determinations is to **ensure that the right individuals are getting the right amount of care, in the right environment**. The primary purpose of this process is to achieve the following priorities:
  - Individuals who are the most in need have access to Long Term Services & Supports (LTSS).
  - Limited state resources are used to provide LTSS for that population of individuals.
  - Those individuals have the opportunity to receive LTSS in the least restrictive environment that meets their needs.

What We Heard: CDAC Recommendations on Target Population (Overview)

CDAC members shared a series of recommendations about who should be eligible for the new waiver.

Subtopic	CDAC Member Feedback	A&M Response - Summary
General Comment	Eligible children with disabilities should be supported for the **same age range in the new waiver, regardless of diagnosis.**	A&M agrees with this recommendation.
Conditions / Needs	There is an ongoing need for more services for children with **behavioral health needs**, and this population should be served on the new waiver.	A&M recommends ND consider adding this population to the new waiver-see next slide for further details.
Conditions / Needs	The **hospice population** should potentially be included in the new cross-disability waiver to minimize need for any transfers between waivers.	A&M recommends keeping the hospice waiver separate – see following slides for more information.
Conditions / Needs	The waiver should include children with any **conditions on the Social Security Compassionate Allowances list.**	A&M's research shows this practice is not used in any other states – see following slides for more information.
Ages to Include	More **support is needed for children aged 3 until age 5** who do not qualify for the traditional DD waiver and who are not yet in school.	A&M agrees and recommends a lower barrier to entry for these young children-see roadmap section for more details.
Ages to Include	The waiver **should continue until age 26** to align with health insurance policies.	A&M recommends that the waiver continue until age 21 to align with national standards for children's waivers.
General Access	The **right people aren't qualifying for the right waivers**. There are groups of people who should get waiver services, or be on different waivers, but are not screening correctly.	Consistent with the original recommendations, A&M suggests North Dakota revise the level of care process for all children's waivers to better align with newer guidance around screening.
CDAC Input	Developing the right level of care to screen people for the waiver is critical to the waiver achieving its intended impact. Given the importance of this process, **CDAC should be involved in LOC.**	A&M agrees that the state should seek stakeholder input regarding the level of care work for both waivers. CDAC presents an excellent opportunity to advise on this work.

***Recommendation:** Currently ND Century Code 75-03-23-04 holds that if a person is found eligible for the DD waiver, adults are not able to receive services through a different waiver. This section would need to be amended to allow the person to select the waiver that best fit their assessed needs.

Public Comment: Key Themes Related to Target Population

Public attendees at the listening sessions provided recommendations on the new cross - disability waiver, and on broader system opportunities to serve children more effectively.

Themes related to targeted population from public comment included the following:

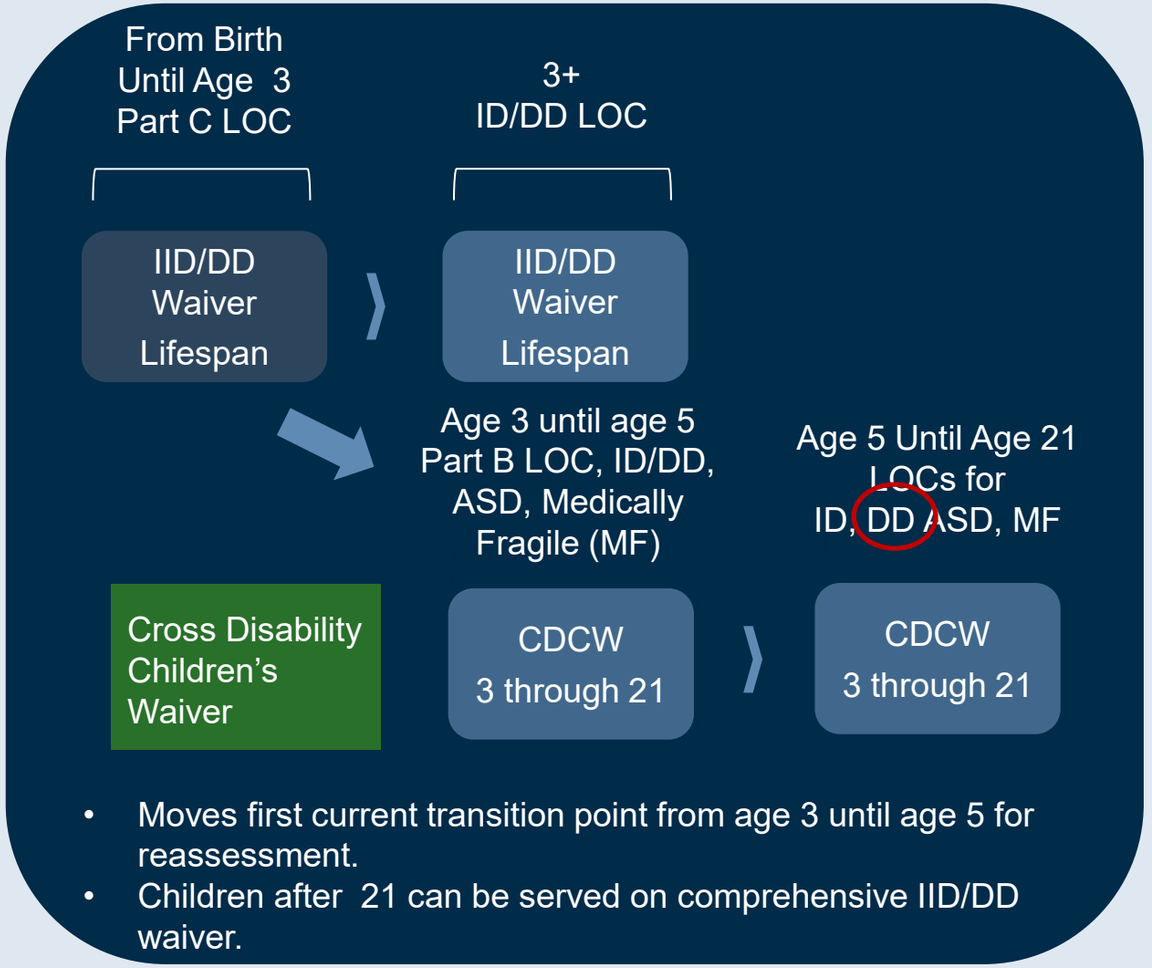
Target Population

- Attendees highlighted **additional populations where more services are needed**, including those with FASD, metabolic disorders, physical needs, and children experiencing maltreatment.
- Participants shared that there is a need to better serve children **with behavioral health needs and social/emotional needs:**
  - Commenters feel the 1915(i) does not meet behavioral health needs due to issues with income eligibility and lack of providers.
- People expressed that **assessing children at age 3 is too early**, and the PAR is not the right tool for assessing young children.
- Participants raised the issue that **Medicaid is too challenging for children with disabilities to access** and offered suggestions for addressing this.

New Level of Care: Children with Developmental Disabilities

Serving children with developmental disabilities will require the development of a new definition of developmental disability, new level of care tool, and criteria.

- Currently, North Dakota's Home and Community - Based Services system serves children with developmental disabilities until age 3 under the Intellectual and Developmental disabilities waiver. Currently, most of these children often lose services at age 3 if they do not have a co-occurring intellectual disability.
- Many children with developmental disabilities will benefit from the new Part B level of care in the Cross - Disability Children's waiver, which will cover ages 3 until age 5.
- However, once children turn 5, there is a **need for a new level of care for children with developmental disabilities**.
    - The existing level of care criteria and tools can be extended to the Cross - Disability waiver for children with autism and those who are medically fragile.
    - This extension is necessary to provide ongoing supported for children with disabilities such as muscular dystrophy, fetal alcohol syndrome, Down syndrome, and cerebral palsy.



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

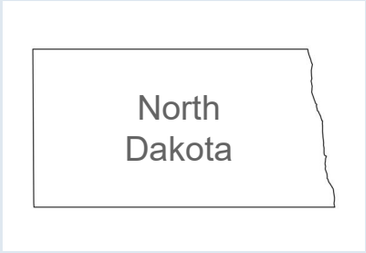
Serving children with disabilities during their earliest years yields many long terms benefits for both families and the state

- **Diagnosing children at the youngest ages is challenging**, which can make the waiver qualification process difficult
  - It is complicated to assess children at very young age with lifelong disabilities
  - Assessing IQ components of diagnosis in young children is especially hard
  - There are also often delays in completing assessments due to workforce shortages
- At the same time, we know that **young children are the most cost-effective age group to serve on waivers**
  - On average, ND kids served on the IID/DD waiver 3-5 represent a total annual Medicaid cost of $15,783. In comparison, kids 6-12 cost an average of $23,691. See appendix for more details on estimated cost breakdown by age.
- Very **young children with disabilities respond especially well to early treatment**
  - Early treatment allows for more effective and cheaper services during a child's youngest years
  - This 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, and the start of school services then represents a natural reassessment / transition period for families

*Source: Birth to 5: Watch Me Thrive!

Target Population: Ages Served

CDAC Feedback: Children ages 3-5 should be able to receive services more easily. The new waiver should cover children through age 26 to align with health insurance policies.



Children Ages 3 until ge 5:

- Data shows that many ND children are falling off the waiver at age 3 due to the eligibility criteria changing at this age.
- CDAC members and members of the public have described this as a “cliff” for children and families.

Coverage Age Limit:

- CDAC members suggested that the new waiver continue through age 26 to align with broader health insurance policies.
- Currently, none of the state’s children’s waivers continue past 21.

Children Ages 3 Until Age 5:

- Research shows that intervention is likely to be more effective and less costly when it is provided earlier in life rather than later.

Coverage Age Limit:

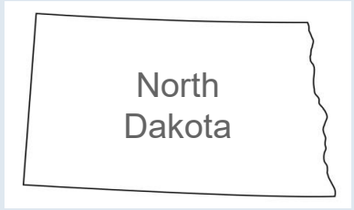
- Children’s Medicaid through Early & Periodic Screening Detection and Treatment (EPSDT) continues through age 20; special education services continue through age 21.
- Other states typically use age 18 or 21 as the limit for children’s Medicaid waivers. No other state operates a children’s waiver that goes until age 26.

Recommendation: Use a lower barrier to qualifying for kids from age 3 until age 5 to reduce the cliff families are experiencing and to allow for more school services to be in place prior to potentially screening off the waiver when the eligibility criteria changes. The waiver should continue through age 21, aligning with EPSDT and school transitions.

*Source: The Importance of Early Intervention (ectacenter.org)

Target Population: SSI Compassionate Care List

CDAC Feedback: Consider including any child with a condition on the Social Security Compassionate Allowances list.



Compassionate Care List:

- CDAC members expressed that it is too difficult for children with disabilities to access general Medicaid.
    - Many families of children with disabilities prefer Medicaid because it does not have the same limitations on therapies as many private insurance companies have.
- Medicaid waivers are financially easier for families to qualify for compared to general Medicaid, as there is a higher income limit.
    - Due to this, some families are advocating to use the waiver as one solution to general Medicaid access concerns.
- Some CDAC members recommended including the full list of compassionate care conditions on the waiver to help address Medicaid access concerns for children with disabilities.

Compassionate Care List:

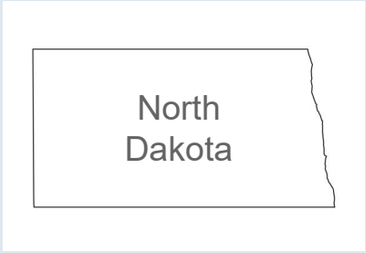
- North Dakota is one of eight 209(b) Medicaid states; defined as using at least one eligibility criterion more restrictive than the SSI program. However, North Dakota also has some income-based criteria that are less restrictive than the SSI standards used in other states.
- North Dakota's status as a 209(b) state may contribute to the feedback families shared regarding eligibility challenges. However, this criterion only applies to general Medicaid and does not apply to the waiver eligibility.
    - Medicaid waiver eligibility is distinct from general Medicaid enrollment rules. Waivers are not simply a form of insurance, but an alternative to institutional care. States must prove that someone meets functional criteria for institutional eligibility to serve them on a Medicaid waiver.
- Fourteen states offer a Medically Fragile Waiver; none of these states use the SSI list of conditions as a qualifying mechanism for this waiver.

Recommendation: Keep the target population for the new waiver focused on specific populations including ID/DD, ASD, MF, and potentially behavior health (BH) needs. Utilize functional eligibility measures to determine who qualifies for waiver services, in compliance with existing federal policies around waiver eligibility. Consider the role of both general Medicaid and private insurance in meeting the needs of children with disabilities.

*Source: Social Security Program Operations Manual

Target Population: Behavioral Health Needs

CDAC Feedback: Children with behavioral health needs should be included in the new waiver.



- We heard from both CDAC members and the public that there is a **gap in services for children with behavioral health needs.**
- One public commenter raised concerns that children with unmet behavioral health needs may end up in undesirable places such as jail or other forms of institutionalization.
- North Dakota currently operates a 1915(i) Medicaid waiver for children with behavioral health needs; however, it has a lower income limit.
- We have also received feedback that a **true cross-disability waiver** should include behavioral health, especially given the common overlap with other types of disabilities.

- Research shows that **people with ID/DD are more likely to experience behavioral health conditions**; around 40% of children with ID/DD also experience co-occurring mental health conditions.
- Studies estimate that between 50% and 75% of youth detained in the criminal justice system have a mental health or substance use disorder.
- Nationally, it is estimated that juvenile incarceration costs an average of $88,000 per year per individual.
- Wisconsin and New York, the two other states who currently operate children's cross-disability waivers, both include behavioral health.
- Nine states have waivers for kids with behavioral health needs.

Recommendation: Consider adding behavioral health to the list of target populations in the cross - disability waiver to address both the common co-occurrence with other disabilities, and the gap in services for this population. Note that significant investment will be needed to implement - see fiscal and roadmap sections for more details.

*Source: National Journal of Medicine, The co-occurrence of mental disorders in children and adolescents with intellectual disability/intellectual developmental disorder - PMC (nih.gov)
*Source: Alternatives to Detention and Confinement Literature Review (ojp.gov)

Target Population: Hospice Population

CDAC Feedback: Consider including the hospice waiver population in the new cross-disability waiver.

Hospice:

- Some CDAC members expressed that including the hospice waiver population on the cross - disability waiver may make it easier for families who would need to switch between waivers.
- However, per conversations with State leadership, switching off the hospice waiver is relatively rare. This is a unique population with a dedicated pool of funding and distinct services.

Hospice:

- Wisconsin and New York, the two other states who currently operate children's cross - disability waivers, do not include the hospice population in the cross-disability waiver.

A&M's Recommendation: Continue to serve the hospice population on the distinct hospice waiver, which has its own unique services and dedicated funding. Ensure there is a pathway for families to switch waivers if needed.

*Source: National Journal of Medicine, The co-occurrence of mental disorders in children and adolescents with intellectual disability/intellectual developmental disorder - PMC (nih.gov)

*Source: Alternatives to Detention and Confinement Literature Review (ojp.gov)

Establishing the Target Populations for Children's Waiver Services

The future of children's waivers will group children by their level of need to streamline services for the appropriate populations.

Current State

Medically Fragile Waiver (Age 3 Until Age 17)
- Medically fragile children, including those with physical disabilities

Autism Waiver (From Birth Until Age 17)
- Children with Autism Spectrum Disorder

IID/DD Waiver (No Age Limit)
Note: This waiver also serves adults with ID/DD
- Children from birth until age 3 with low-high needs (EI)
- Children ages 3+ with ID/DD, moderate to high needs

Hospice Waiver (From Birth Until Age 21)
- Children with Terminal Illnesses (less than a year of life expectancy)

CDAC Suggestion

Cross-Disability Children's Waiver: Children with low to moderate support needs (Age 3 Until Age 26)
- Medically fragile children (Age 3 Until Age 26)
- Children with Autism (Age Until Age 26)
- Children from age 3 until age 5 with ID/DD, lower needs
- Children with behavioral health needs
- Compass - ionate Care Conditions

IID/DD Waiver (No Age Limit)
- Children from birth until age 3 with low-high needs (EI)
- Children ages 3+ with ID/DD, moderate to high needs

Hospice Waiver (From Birth Until Age 21)*
- Children with Terminal Illnesses (less than a year of life expectancy)

A&M's Recs

Cross-Disability Children's Waiver: Children with low to moderate support needs (Age 3 Until Age 21)
- Medically fragile children (Age 3 Until Age 21)
- Children with Autism (Age 3 Until Age 21)
- Children aged 3 until age 55 with ID/DD, lower needs
- Children with behavioral health needs

IID/DD Waiver (No Age Limit)
- Children from birth until age 3 with low-high needs (EI)
- Children ages 3+ with ID/DD, moderate to high needs

Hospice Waiver (From Birth Until Age 21)
- Children with Terminal Illnesses (less than a year of life expectancy)

**CDAC members advised careful consideration of whether hospice should be included in the new waiver, or kept separate – see following slides for further details*

Looking Ahead: Notes on Level of Care (LOC) Moving Forward

The Importance of LOC on Waiver Access in ND

- The level of care (LOC) process is a critical waiver element that ultimately determines who qualifies for waivers.
- Establishing a balanced LOC process is **key to ensuring that waiver access is consistent and equitable.**
- Creating or revising LOC must be done with the utmost care to verify that intended outcomes occur as anticipated. This means the process in ND **will take more than a year to allow for the selection of the right tool or tools, followed by extensive testing prior to implementation.**

CDAC's Input Re: Designing the New LOC

Over the past several months, CDAC focused on high-level waiver design rather than specifics re: LOC. However, CDAC members did share the following high-level thoughts about the LOC work that lies ahead:

- CDAC should be involved in the process moving forward, given the importance of LOC to waiver access.
- First do no harm: Any changes should be purely additive in nature and include everyone who already qualifies for the ID/DD, ASD, and MF waivers in the new LOC.
  - As a closely related topic, ensure that if LOC changes and waiver access changes, there is continuity in services during the transition period, especially when moving between waivers in the future state
- Consider how needs change throughout the lifespan, and how LOC processes at different ages can reflect this.
- Include criteria in the LOC process that accounts for children who received diagnoses later in life.

CDAC Access Recommendations | Target Population (1 of 2)

Below are the key recommendations around who the waiver should support

#	CDAC Recommendations	A&M Response
A.6	Eligible children with disabilities should be supported for the same age range in the new waiver, regardless of diagnosis.	Agree
A.7	There is an ongoing need for more services for children with behavioral health needs, and this population should be served on the new waiver.	Agree. Consider adding behavioral health to the list of target populations in the cross - disability waiver to address both the common co-occurrence with other disabilities, and the gap in services for this population.
A.8	There is a need for a new level of care for children with developmental disabilities. This extension is necessary to provide ongoing supported for children with disabilities such as muscular dystrophy, fetal alcohol syndrome, Down syndrome, and cerebral palsy.	Agree
A.9	The hospice population should potentially be included in the new cross-disability waiver to minimize need for any transfers between waivers.	The initial target population should be focused on children with ASD and MF, as well as children with ID/DD who have lower functional support needs, and the SED population. Hospice should be kept as a separate waiver population, which has its own unique services and dedicated funding. Ensure there is a pathway for families to switch waivers if needed.
A.10	The waiver should include children with any conditions on the Social Security Compassionate Allowances list.	A&M's research shows this practice is not used in any other states because it does not include an assessment of functional impairment. Keep the target population for the new waiver focused on specific populations including ID/DD, ASD, MF, and potentially behavior health (BH) needs. Utilize functional eligibility measures to determine who qualifies for waiver services, in compliance with existing federal policies around waiver eligibility. Medicaid may consider exploring broader, general Medicaid eligibility questions for children with disabilities outside of the waiver.

CDAC Access Recommendations | Target Population (2 of 2)

Below are the key recommendations around who the waiver should support

#	CDAC Recommendations	A&M Response
A.11	More support is needed for children aged 3 until age 5 who do not qualify for the traditional DD waiver and who are not yet in school.	Agree. Use a lower barrier to qualifying for kids from age 3 until age 5 to reduce the cliff families are experiencing and to allow for more school services to be in place prior to potentially screening off the waiver when the eligibility criteria changes. The waiver should continue through age 21, aligning with EPSDT and school transitions.
A.12	The waiver should continue until age 26 to align with health insurance policies.	A&M recommends that the waiver continue until age 21 to align with national standards for children's waivers.
A.13	The right people aren't qualifying for the right waivers. There are groups of people who should get waiver services, or be on different waivers, but are not screening correctly.	Agree. Consistent with the original recommendations, A&M suggests North Dakota revise the level of care process for all children's waivers to better align with newer guidance around screening.
A.14	Developing the right level of care to screen people for the waiver is critical to the waiver achieving its intended impact. Given the importance of this process, CDAC should be involved in LOC.	Agree
A.15	Currently ND Century Code 75-03-23-04 holds that if a person is found eligible for the DD waiver, adults are not able to receive services through a different waiver. This section would need to be amended to allow the person to select the waiver that best fit their assessed needs.	Agree

Waiver Service Options

Service Options: What Does This Topic Include?

Slide Excerpt from CDAC Meeting

What do we mean when we talk about “service options”?

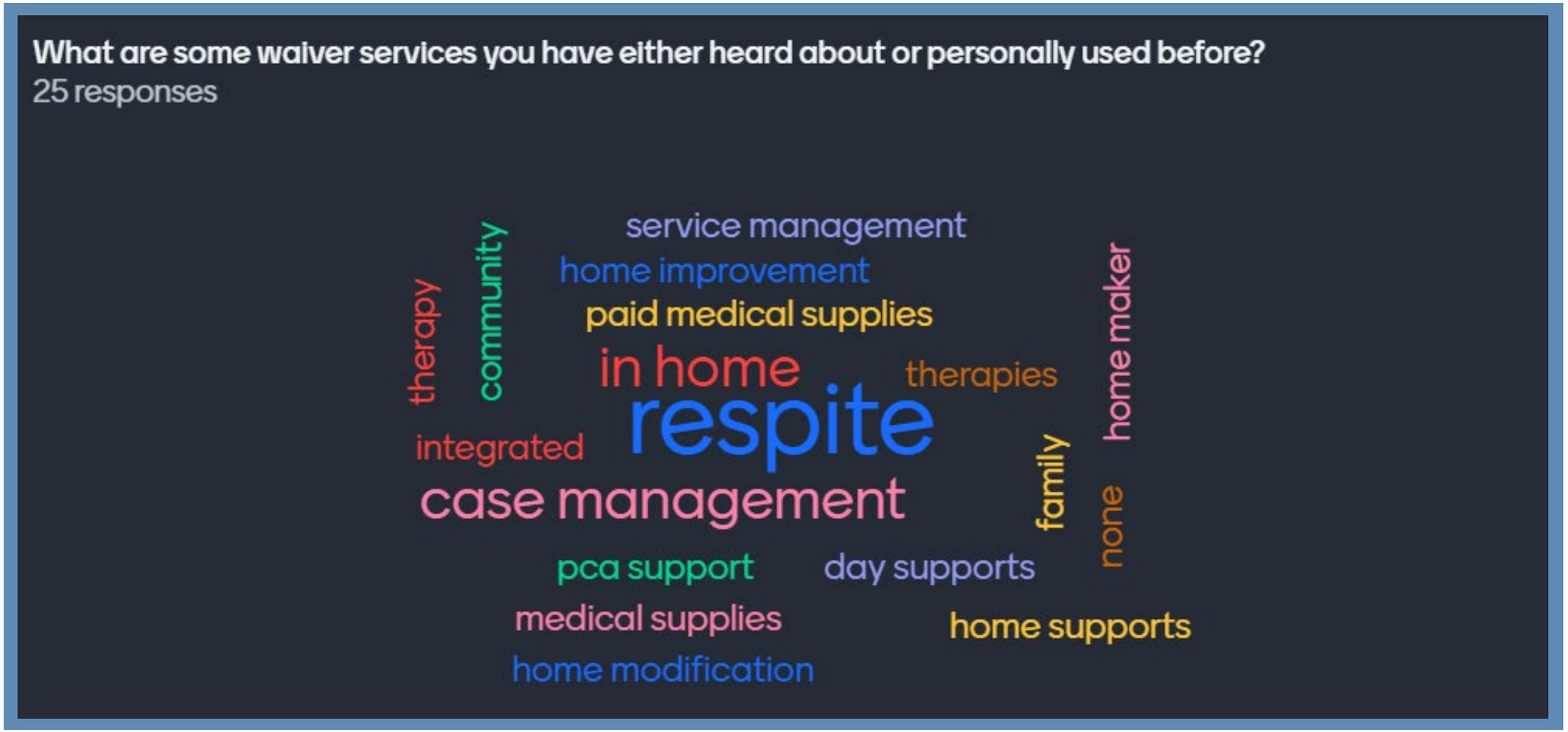
- Service options describes the types of programs, items, and supports that people can use when on an HCBS waiver.
- Examples of waiver services include respite care, in-home supports, and employment supports.

The Department of Health & Human Services will need to outline what services will be included on the new cross - disability waiver. **CDAC will play an important role by**:

- ➢ Sharing your experiences using other waiver services, including what has been most helpful to you.
- ➢ Highlighting other types of services that would be beneficial.

What Waiver Services Do CDAC Members Know About?

We asked CDAC members to share examples of waiver services they have heard about or used before.



*PCA stands for Personal Care Attendant. A Personal Care Attendant is an individual who provides assistance to people with disabilities, chronic illnesses, or those who need help with daily living activities.

Understanding Types of Eligibility-Based Supports and Services

CDAC Scope

Medicaid State Plan	HCBS Waivers
Medicaid is a program that helps pay for medical services for qualifying low - income adults, children, pregnant women, older adults, and people with disabilities. Medicaid also provides initial and periodic health check-ups for children from birth until age 20 years old through a program called EPSDT. **Examples of services:** • Pediatrician visits • Ambulance • Hospitalization • Dental care • Prescription drugs • Therapies	Waivers are a type of Medicaid program targeted to specific populations of people based on demonstrated needs/types of disability. Waivers provide services that help people meet their needs in a home and community setting instead of institutional settings. HCBS waivers have a different qualification process than general State Plan Medicaid. **Examples of services:** • Supported employment • Independent habilitation • Environmental adaptation • Equipment and supplies

Individuals eligible for ND Medicaid can access:

Medicaid State Plan Services

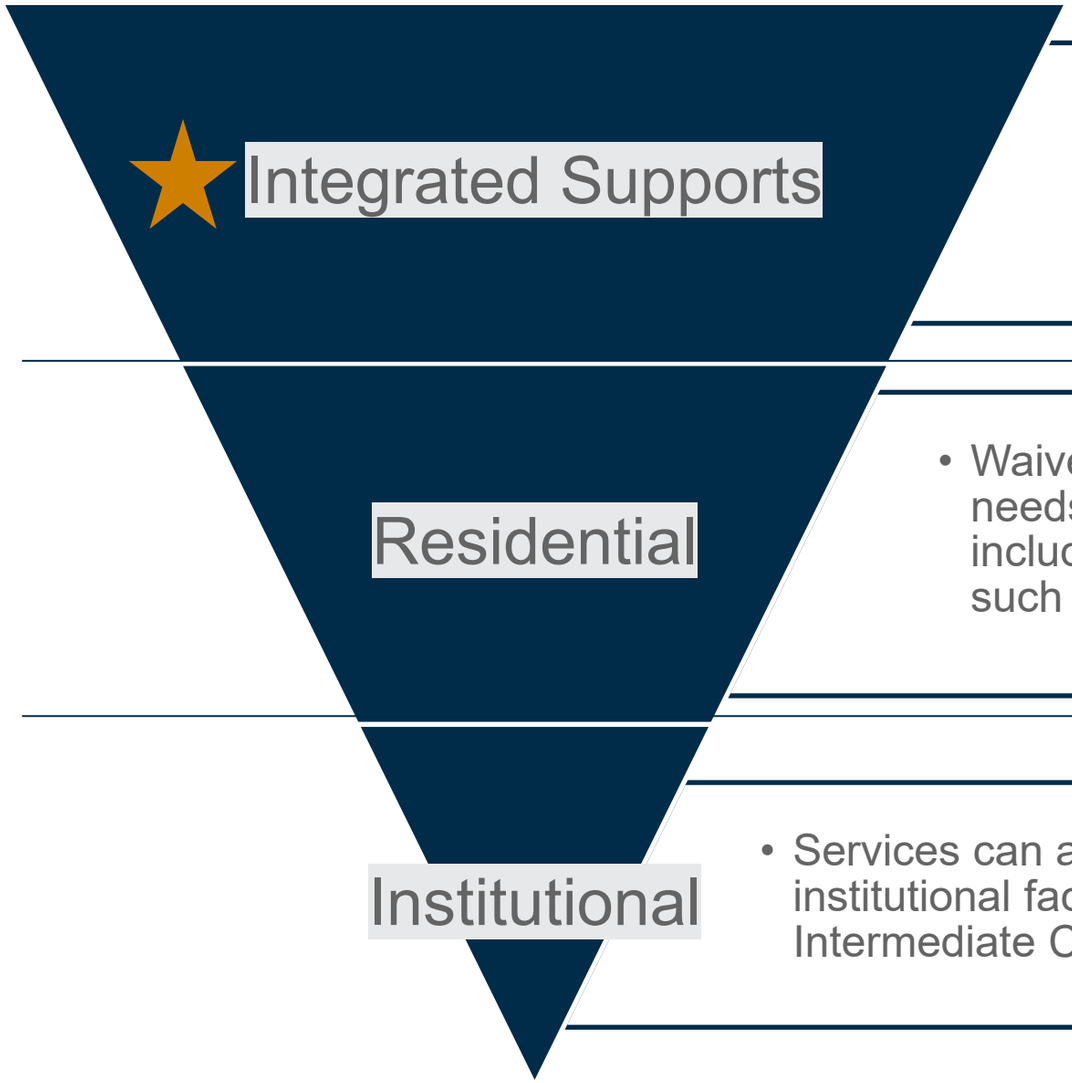
Individuals eligible for ND HCBS Waivers can access:

HCBS Waiver Services + Medicaid State Plan Services

Cross-Disability Waiver Services

Overview of Long-Term Service and Supports Delivery Models

Types Long-Term Services and Supports (LTSS)



Integrated Supports

- Low-cost waiver services designed to wrap around natural supports in the community

Residential

- Waiver services for higher needs individuals that include residential options such as group homes

Institutional

- Services can also be provided in institutional facilities such as an Intermediate Care Facility (ICF)

Cross-Disability Waiver Services

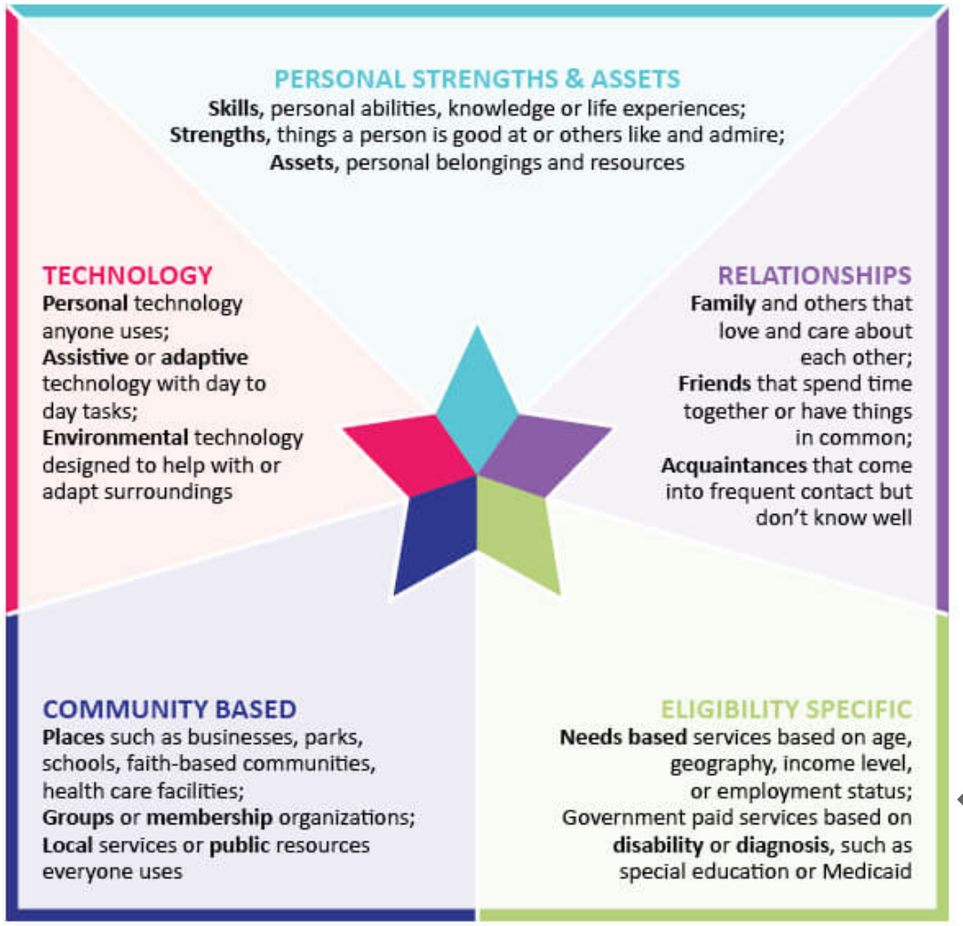
Medicaid HCBS Waiver Services

Understanding Integrated Supports

Slide Excerpt from CDAC Meeting

The new waiver will be focused on integrated supports.

- 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)

Slide Excerpt from CDAC Meeting

Understanding Life Domains

People lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life. As we think about what services should be in the cross - disability children's waiver, we will want to think about all of the life domains.

Daily Life & Employment

What a person does as part of everyday life - school, employment, volunteering, communication, routines, life skills.

Safety & Security

Staying safe and secure - emergencies, well-being, guardianship options, legal rights and issues.

Community Living

Where and how someone lives - housing and living options, community access, transportation, home adaptations and modifications.

Social & Spirituality

Building friendships and relationships, leisure activities, personal networks, and faith communities.

Healthy Living

Managing and accessing health care and staying well - medical, mental health, behavioral health, development, wellness and nutrition.

Advocacy & Engagement

Building values roles, making choices, setting goals, assuming responsibility and driving how one's own life is lived.

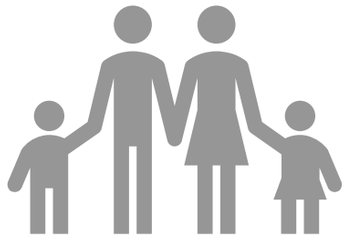
*Source: [Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)]

What Kind of Services Will the Cross-Disability Waiver Provide?

Slide Excerpt from CDAC Meeting

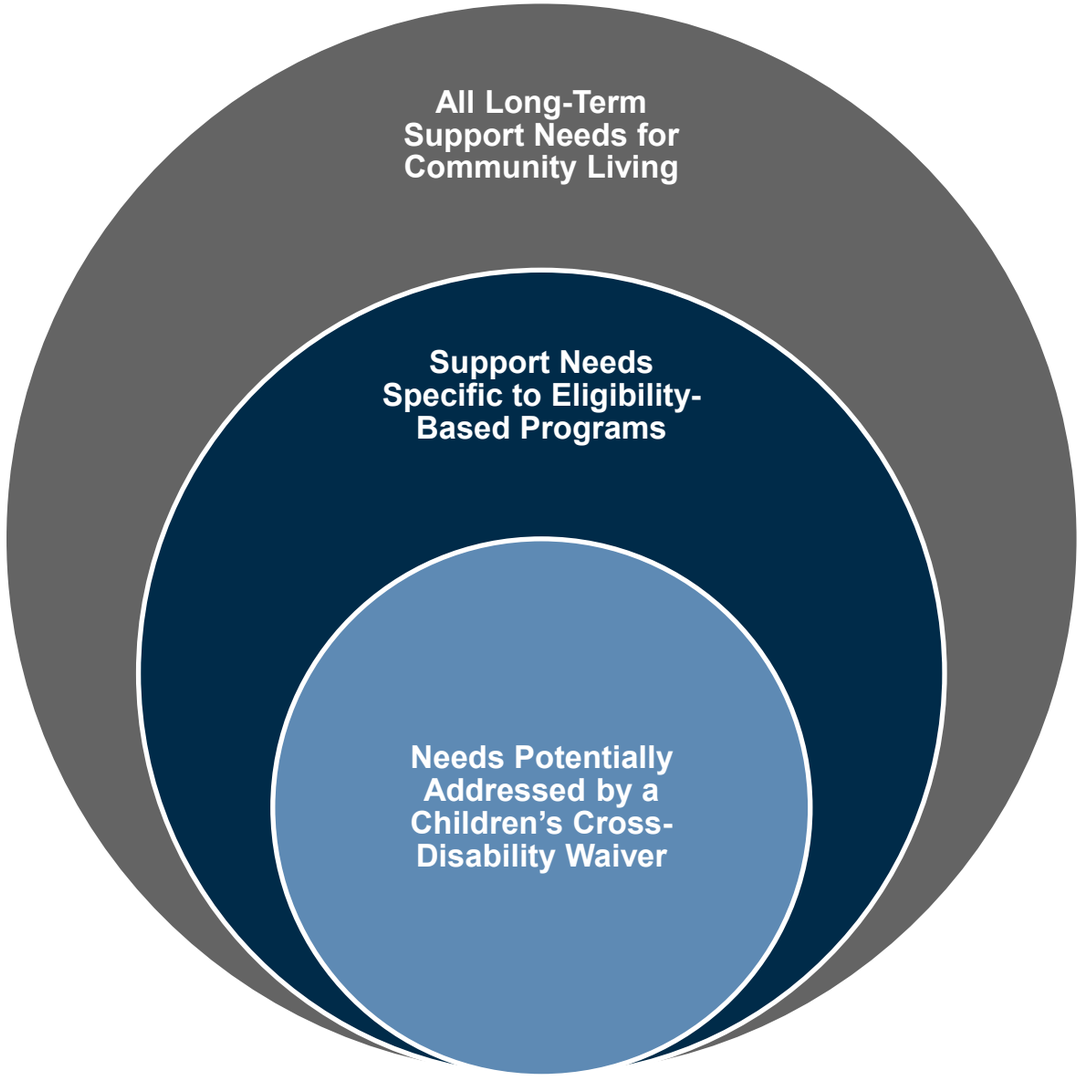
Understanding the framework for the cross-disability waiver service array.

- The new waiver will be a **supports waiver**, also known as an individual and family support waiver (IFS) waiver.
- Supports waivers are built to **wrap around individuals who are living in the community.**
- These waivers are designed with the idea that participants are also getting **support from family and/or friends.**
- Supports waivers are targeted to individuals who live in an independent environment; therefore, these types of waivers **do not include residential services.**
- These types of waivers focus on services that complement existing **integrated supports and typically prioritize community connection.**



Approach to Collecting CDAC Input on Support Needs

CDAC discussions focused on first identifying holistic needs before mapping supports to address these needs, including eligibility specific services



- CDAC began brainstorming by first thinking about the different types of supports individuals need to live a good life in the community.
- We intentionally requested that CDAC members think holistically about all types of needs across the lens of the integrated supports star

- We then organized support needs into the categories of the integrated supports star, including needs that mapped to eligibility-based supports such as the Medicaid State Plan and HCBS waiver services

- Finally, we worked together with CDAC to identify which of the eligibility-based supports could potentially be addressed by a new cross-disability children's waiver and highlighted these recommendations

Process for Organizing CDAC Feedback on Service Needs

CDAC discussions focused on first identifying holistic needs before mapping supports to address these needs, including eligibility specific services

- We began with broad brainstorming activities designed to identify support needs across all areas of the integrated star, including both eligibility-based supports and those in areas like family, community services, and technology
- To help ensure we considered all areas of life, we used the concept of **life domains** to organize our thoughts (see next slide for details on life domains)
- We worked together in each life domain to organize identified needs by the appropriate area of the integrated supports star, with a **focus on how the new waiver could fit into the bigger picture and potentially help bridge identified gaps**
- Note that slides 64-69 include feedback on eligibility supports that applies to programs outside the children's cross-disability waiver. The intent is to capture the scope of our brainstorming work prior to isolating recommendations specific to the waiver.

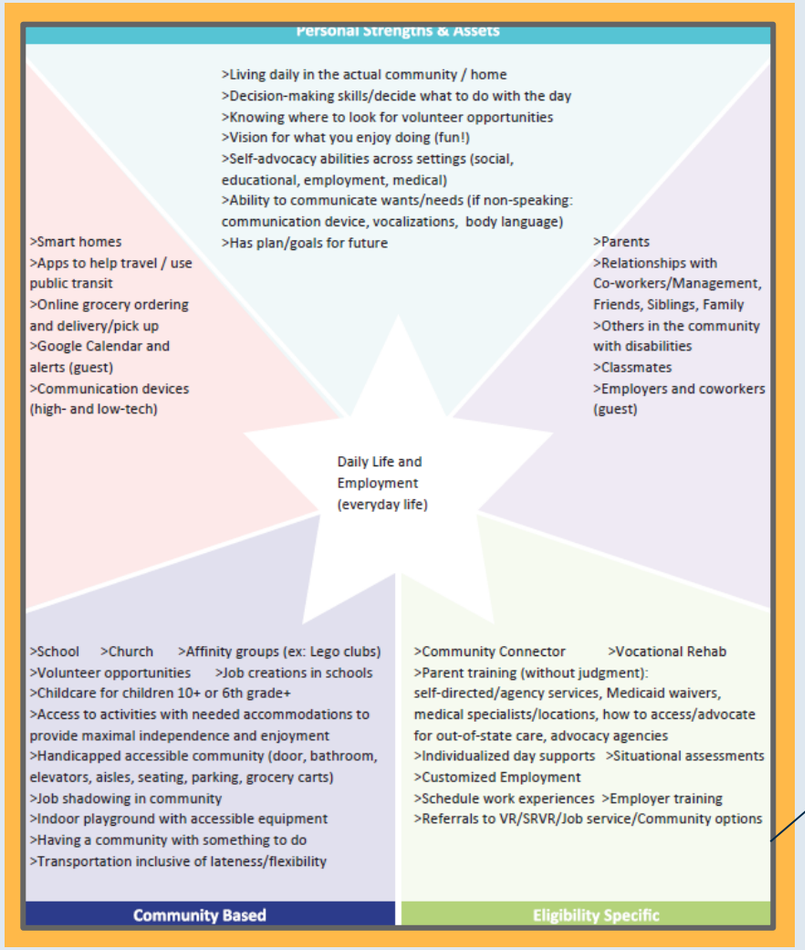
Integrated Services and Supports Across the LifeCourse

Holistic Focus Across Life Domains

*Source: Charting the LifeCourse Nexus (UMKC IHD)

Integrated Supports: Daily Life and Employment

What a person does as part of everyday life-school, employment, volunteering, communication, routines, and life skills.



CDAC Feedback on Eligibility-Based Support Needs*

- **Parent training** is critical to supporting daily living for children with disabilities, including topics like self-direction, advocacy, and access.
- **Pre-employment supports** such as vocational rehab, work experiences, and customized employment play an important role in facilitating employment for people with disabilities.
- **Starting employment-related services early** allows families to successfully plan for the transition into young adulthood.

**CDAC's feedback on eligibility-based support needs includes information that applies to other programs outside the cross-disability children's waiver (ex: Medicaid State Plan services); the report later highlights recommendations that are specific to the cross-disability children's waiver separately from this initial brainstorming work*

*Source: Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)

Integrated Supports: Community Living

Where and how someone lives-housing and living options, community access, transportation, home adaptations and modifications.

CDAC Feedback on Eligibility-Based Support Needs*

- CDAC discussed how helpful peer mentoring is in building skills and relationships for successful community living.
- Support from case managers is critical to enabling community living.
- Some members discussed needing more help with transportation.
- Therapies are also critical to supporting community living. Examples include PT, OT, SLP, behavioral health, ABA, recreational, and play therapies. (Note that these services are covered through the Medicaid State Plan).

**CDAC's feedback on eligibility-based support needs includes information that applies to other programs outside the cross-disability children's waiver (ex: Medicaid State Plan services); the report later highlights recommendations that are specific to the cross-disability children's waiver separately from this initial brainstorming work*

*Source: Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)

Integrated Supports: Healthy Living

Managing and accessing health care and staying well-medical, mental health, behavioral health, developmental, wellness and nutrition.

CDAC Feedback on Eligibility-Based Support Needs*

- Key services that support healthy living in the community include therapies, medical supply assistance, and nutritional supports.
- Families need more help with **complex care coordination.**
- **Behavioral health support** also plays a role in healthy living.
- Incentives may be needed to increase flexibility and access to services, especially in more rural areas.

**CDAC's feedback on eligibility-based support needs includes information that applies to other programs outside the cross-disability children's waiver (ex: Medicaid State Plan services); the report later highlights recommendations that are specific to the cross-disability children's waiver separately from this initial brainstorming work*

*Source: Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)

Integrated Supports: Social and Spirituality

Building friendships and relationships, engaging in leisure activities, developing personal networks, and participating in faith communities.

CDAC Feedback on Eligibility-Based Support Needs*

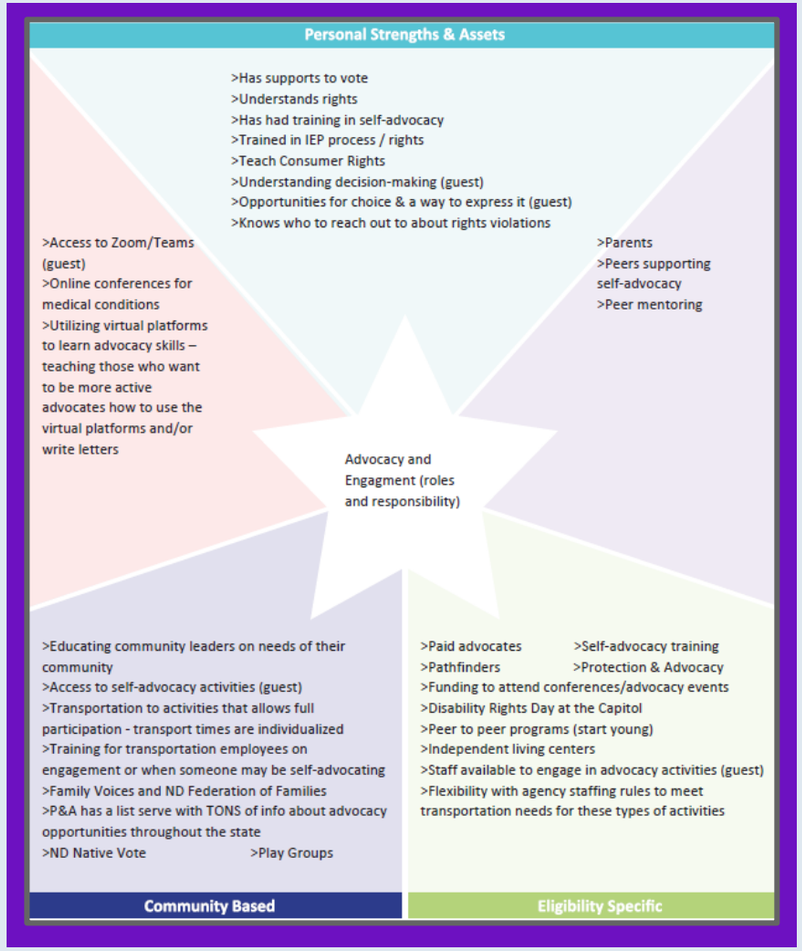
- Support for group outings helps children build and maintain relationships.
- Families benefit from **parent-to-parent information sharing** to help support children and build their networks.
- Families want to support their children in building relationships of all kinds, including friendships and intimate relationships.

**CDAC's feedback on eligibility-based support needs includes information that applies to other programs outside the cross-disability children's waiver (ex: Medicaid State Plan services); the report later highlights recommendations that are specific to the cross-disability children's waiver separately from this initial brainstorming work*

*Source: Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)

Integrated Supports: Advocacy and Engagement

Building valued roles, making choices, setting goals, assuming responsibility, and driving how one's own life is lived.



CDAC Feedback on Eligibility-Based Support Needs*

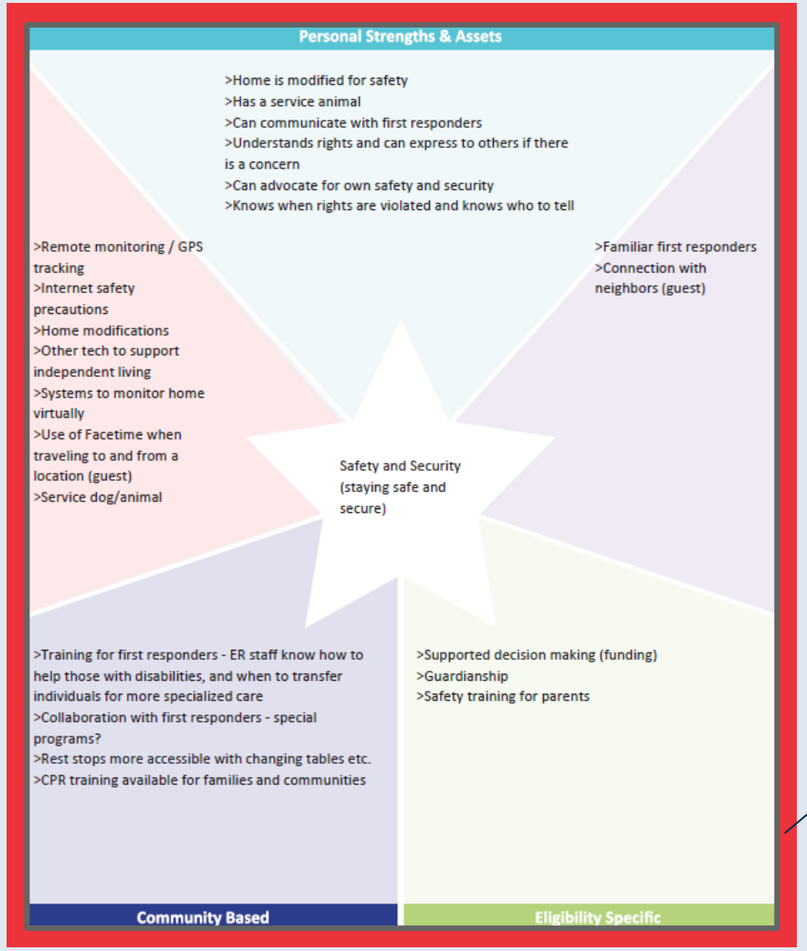
- **Self-advocacy training** helps children with disabilities learn how to confidently advocate for themselves.
- **Peer-to-peer programming** is a core element that supports advocacy.
- Families need staff available to help support advocacy activities and appreciate flexibility with staffing to help facilitate participation.

**CDAC's feedback on eligibility-based support needs includes information that applies to other programs outside the cross-disability children's waiver (ex: Medicaid State Plan services); the report later highlights recommendations that are specific to the cross-disability children's waiver separately from this initial brainstorming work*

*Source: Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)

Integrated Supports: Safety and Security

Staying safe and secure: emergencies, well - being, guardianship options, legal rights and issues.



CDAC Feedback on Eligibility-Based Support Needs*

- Safety and security applies both in the home and in the community, especially for children who may elope.
- Supported decision-making and guardianship are two options to help protect the legal rights of individuals.
- Families benefit from things like **safety training** to help prepare them to successfully navigate challenges.

**CDAC's feedback on eligibility-based support needs includes information that applies to other programs outside the cross-disability children's waiver (ex: Medicaid State Plan services); the report later highlights recommendations that are specific to the cross-disability children's waiver separately from this initial brainstorming work*

*Source: Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)

Mapping CDAC Feedback to Potential New Services

Below are some of the key, recurring CDAC themes that have been shared by the group, mapped out to potential waiver services. Transition services are broken out on the next slide.

Potential New Service	CDAC Input
Complex Care Coordination	Families need more support for complex care coordination, including access to and coordination with out of state providers.
Peer support (kids)	Kids need peers who can help support community integration.
Home/chore support	Families are seeking help with chores like cooking and laundry so that they can focus on taking care of their children.
Support broker (help navigating self-direction)	Families need help navigating self - direction
Transportation*	Transportation services are not sufficient.
Music / play therapy	Play therapy and music therapy are valuable.
Emergency respite	Families need a break and want respite. They recommend the traditional planned respite (already included in waivers) as well as emergency respite, as needed.
Additional peer supports and parent training for family members.	Families need support and training, especially to help children navigate life changes successfully.
Crisis Support (see also emergency respite, above)**	Families are seeking crisis supports for children who are dually diagnosed with intellectual disabilities and behavioral health conditions

Notes :
**Medical transportation is currently offered through the State Plan. Consider including transportation as part of habilitation/ integration services. CMS prohibits including medical transportation in a waiver*
***The 1915i includes a wide array of support for children with behavioral health conditions but has a 150% FPL income limit, whereas the cross-disability children's waiver would have 300% FPL limit.*

Mapping CDAC Feedback to Potential New Services: Transition Supports

Below are some potential services that may help with the transition goals shared by CDAC members.

Potential New Service	CDAC Input
Discovery (employment).	Support is needed to help kids learn about and explore career options.
Training: financial literary.	Children need help learning how to navigate finances.
Training: travel.	Children need help learning how to use transportation.
Training: building decision-making skills.	Children need help learning practical life skills like decision-making and how to use supported decision-making.
Training: navigating healthcare / insurance.	Children need help to learn about medical care. Families also need help learning how to navigate complex care.
Community navigation and integration.	Support is needed to help kids integrate into the community.
Self-advocacy skill building.	Support is needed to help children advocate for themselves.
Additional support to learn how to be an employee (pre-vocational services).	Support is needed to learn how to be an employee.

What Service Is The Most Important To Invest Funds

Voting	%	Potential New Service
17	23%	Parents: Additional peer supports and parent training for family members
15	20%	Crisis intervention
12	16%	Transition training for kids
10	13%	Consider including transportation as part of habilitation / integrated services
6	8%	Self-advocacy skill building
4	5%	Home/ chore support
4	5%	Music / play therapy
3	4%	Peer support (kids)
2	3%	Discovery (employment)
2	3%	Additional support to learn how to be an employee (pre-vocational services)
75	100%	TOTAL

Each member received **five votes and could split votes as desired:**

5 4/1 3/2 3/1/1 2/2/1 2/1/1/1 1/1/1/1/1

Additional Feedback on Eligibility-Based Services: Complex Care Coordination

CDAC Feedback: Families need more support to coordinate care for children with complex medical needs.

- CDAC members have expressed a need for more complex care coordination resources.
- Families are looking for a central resource who can help with tasks such as scheduling, communications, teaming, and care coordination between multiple providers.
- CDAC members recommend that this be part of the role of the family navigator rather than adding a new service. This is an area where peer support would be valuable without adding a new person with whom the family would need to coordinate.

- There are examples of some level of care coordination in other state waivers, notably Pennsylvania's Medical Support Assistance service.
- However, no national waiver exactly matches what we are hearing from North Dakotans as a need.
- Rather, there are multiple Medicaid health models outside of waivers that encourage and enhance provider care coordination.

Recommendation: Although waiver service coordination will occur through case management, there is an additional need for some children and families for medical care coordination that is not well met today. This support should be developed outside of the waiver; however, it should be designed to complement and coordinate with waiver services and supports. Work with stakeholders to launch a health model that addresses complex care needs outside of the waiver. Additionally, explore how family navigators could help support waiver participants in navigating the system.

*Source: National Journal of Medicine, The co-occurrence of mental disorders in children and adolescents with intellectual disability/intellectual developmental disorder - PMC (nih.gov)
*Source: Alternatives to Detention and Confinement Literature Review (ojp.gov)

Public Comment: Key Themes Related to Services

Public attendees at the listening sessions provided recommendations on the new cross - disability waiver, and on broader system opportunities to serve children more effectively.

Themes related to services from public comment included the following:

Services

- Participants shared that it would be helpful to have **more services to support behavioral health needs** and that these services should also be included on the cross-disability waiver.
- Families shared that **workforce** issues could impact their ability to access services, especially in rural areas.
- Attendees suggested **expanding options for self-direction** and provided input on opportunities to improve the program, including:
  - A liaison for families;
  - Additional training resources for families;
  - More training for ID/DD case managers to support families.

CDAC Service Recommendations | Array

Below are the key recommendations to make it easier for people and families to access services

#	CDAC Recommendations	A&M Response
S.1	CDAC members have expressed a need for more complex care coordination resources. Families are looking for a central resource who can help with tasks such as scheduling, communications, teaming, and care coordination between multiple providers. CDAC members recommend that this be part of the role of the family navigator rather than adding a new service. This is an area where peer support would be valuable without adding a new person with whom the family would need to coordinate.	Although waiver service coordination will occur through case management, there is an additional need for some children and families for medical care coordination that is not well met today. This support should be developed outside of the waiver; however, it should be designed to complement and coordinate with waiver services and supports. Work with stakeholders to launch a health model that addresses complex care needs outside of the waiver. Additionally, explore how family navigators could help support waiver participants in navigating the system.
S.2	Offer all existing services from the MF, DD, and ASD waiver, except for residential services targeted to higher-needs populations in the DD waiver.	Agree
S.3	Pending funds availability, use contracting to add services that support transition and peer supports (ex: family training, discovery, self-advocacy skill building).	Agree
S.4	Use a family navigator to provide information and assistance for self-direction.	Agree. Another option is to add an Agency with Choice option to support families to self-direct.
S.5	Consider additional services to add based on CDAC recommendations.	Agree

Waiver Service Modalities: Technology

Understanding The Importance of Technology as Part of the Integrated Supports Framework

The Role of Technology in the Bigger Picture of Waiver Services

- Technology can be both a waiver service-such as assistive technology-and a modality for delivery of waiver services
- Technology is part of the integrated supports framework and plays a complementary role to other supports

Benefits of Technology as a Modality

- 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

Technology First as a National Framework

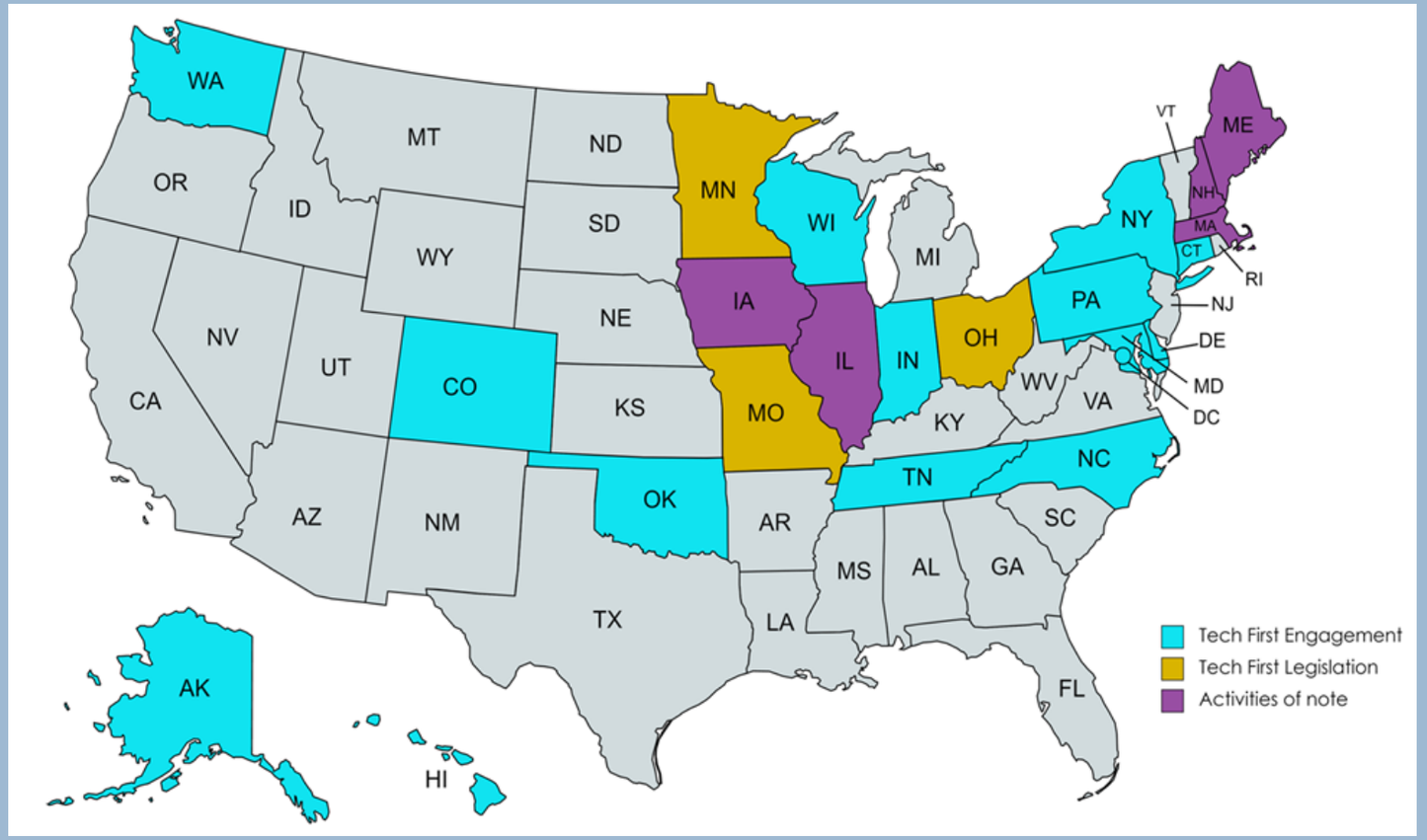
What is Technology First?

It is a “framework for systems change where technology is considered first in the discussion of support options available to individuals and families through person-centered approaches to promote meaningful participation, social inclusion, self-determination, and quality of life.”

In 2020, twenty-two states had **Technology First related initiatives and/or legislation:**

- Statewide policy or initiative;
- Active Implementation Frameworks;
- Fidelity and data-driven decision-making.

The growing national adoption of technology first indicates the value states across the country see in utilizing technology to support services



The Children’s Cross - Disability Waiver is an opportunity for North Dakota to continue to make advancements in the use of technology

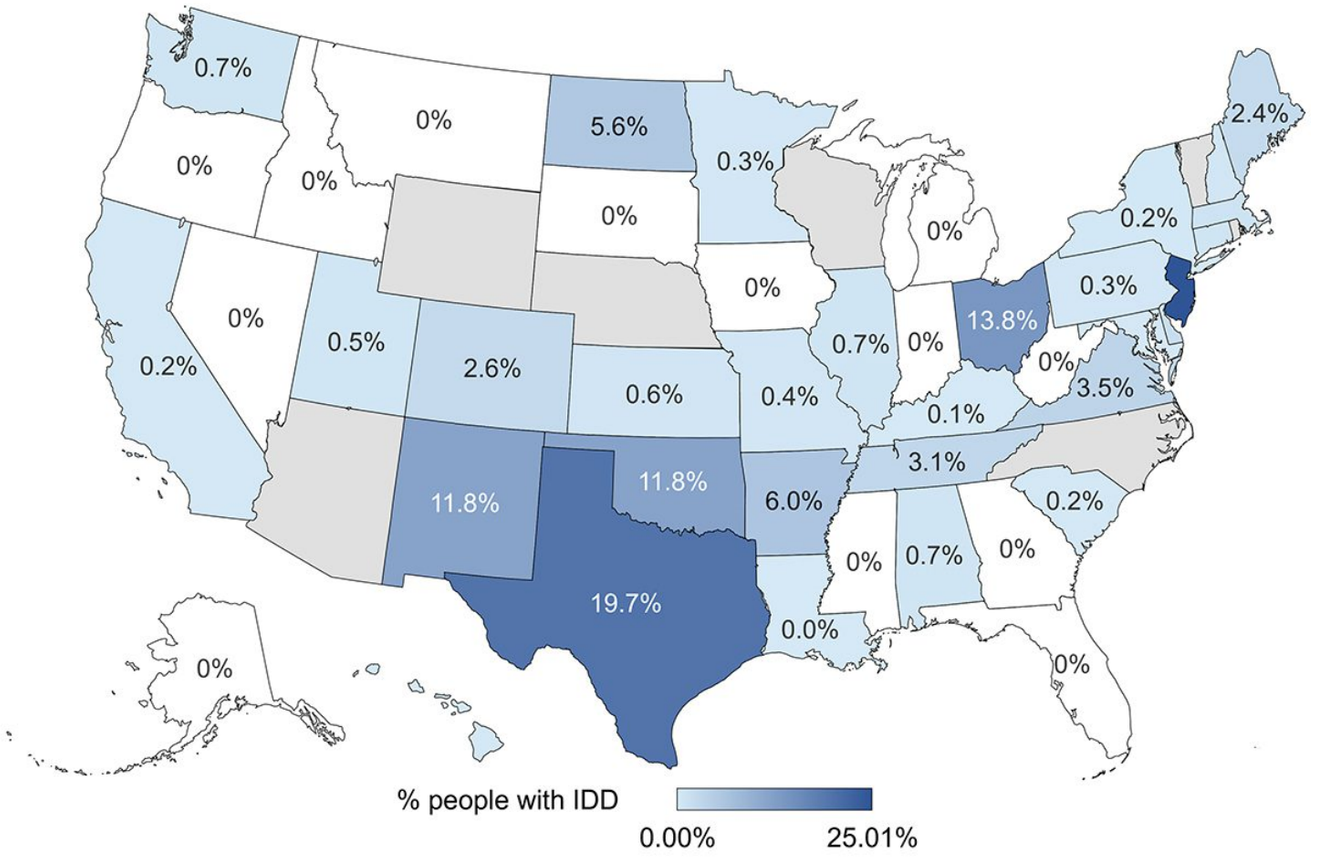
*Source: Technology First | State of the States in Intellectual and Developmental Disabilities (ku.edu)

Percentage of People with ID/DD Projected to Receive Assistive Technology

While 71% of states provide Assistive Technology Services, less than 3% of people were projected to receive AT services. Additionally, being a Technology First state is not yet impacting HCBS allocations. How can ND increase the use of technology?

A recent study found that:

- Technology First states were more likely to allow virtual service delivery in their HCBS IID/DD waiver.
- However, Tech First states were not more likely to offer any of the following technology services:
  - Assistive Technology;
  - Environmental Modifications;
  - PERS;
  - Remote Monitoring;
  - Specialized Medical Equipment.
- They also did not project providing these services to more people or project spending more money on these services.
- **ND is above the national average in use of technology** to support home and community-based services.



*Sources: Technology First Yet to Impact HCBS Allocation - The Council on Quality and Leadership (c-q-l.org); Assistive Technology for People with IDD in Medicaid HCBS - The Council on Quality and Leadership (c-q-l.org)

Understanding the Current State: ID/DD Waiver

Discussing what is working, opportunities, and lessons learned from the pandemic and current approach.

Waiver	Services with Virtual or Remote Support Option	Context, Limitations, Safeguards
ID/DD	• Independent Habilitation • Individual Employment Support • Behavior Consultation • Parenting Support • Infant Development	• 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. • The use of cameras in bathrooms or bedrooms, which impacts the participant's dignity and privacy, is not permitted. • 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. • The participant's services may not be delivered via virtual support 100% of the time. • 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. • Provider must use a HIPAA-compliant service delivery method (e.g., Microsoft Teams, Zoom for Healthcare). • Virtual supports are not a system to provide surveillance or for staff convenience.

Understanding the Current State: ASD Waiver

Discussing what is working, opportunities, and lessons learned from the pandemic and current approach.

Waiver	Services with Virtual or Remote Support Option	Context, Limitations, Safeguards
ASD	• Remote Monitoring • Case Management	• Privacy of the individual must be respected at all times, such as in the bathroom or while bathing. • Remote Monitor Service is not covered through Assistive Technology Service. • Telehealth will be allowed for Service Management, but waiver will continue to require 2 home visit to meet health, safety, and welfare. • 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. • 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.

**Remote/virtual supports are not used in the medically fragile or hospice waivers (exception: case management allowed virtually through App K).*

CDAC Feedback on Technology in Waivers

Technology: What We Heard from CDAC Members

- They are interested in having online tools but also recognize the value of having a person to talk with by phone.
- Not everyone has internet access or a computer.
- Members recommend self-paced learning opportunities for families to support skill building and knowledge attainment.
- Technology can help support children who wander to be safer, for example, GPS tracking, remote monitoring, alarms on doors, communication devices, use of apps, subscriptions, etc.
- Members suggested that virtual/remote supports might help people living in rural areas increase access to services.
- Consider assessments to understand when technology may be an option for children to increase skill building and independence.
- Training is important for the child and their family to support the child in using the technology.
- Not all technology requires a clinician.
- Technology can be useful to help people who speak other languages have access to the waiver and services.

CDAC Services Recommendations | Technology

Below are the key recommendations around how children with disabilities and their families could benefit from the use of technology

#	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. **Sample excerpt of an AT service definition:** Assistive technology means an item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities and can also support increased community inclusion, including in employment settings. *Source: DC Individual and Family Support (IFS) Waiver (1766.R00.00) | Medicaid
S.9	Consider including training/technical assistance for the child and family on the use of the device; as well as warranties.	Agree

Self-Direction

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

Slide Excerpt from CDAC Meeting

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 service
  - Medically Fragile Waiver: self-direction waiver,
  - ASD Waiver: allows for self-directed respite.
- 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*

CDAC Experiences with Self-Direction

CDAC Members shared their thoughts and experiences with self-directing their services.

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

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.

What Types of Support are Available for Self-Direction?

Slide Excerpt from CDAC Meeting

States provide resources to assist participants and their families in successfully self-directing services.

How Do Service Coordinators / Case Managers Help?

Slide Excerpt from CDAC Meeting

Service Coordinators Can…

- Help you create your **Individual Support Plan**
- Provide ongoing **case management**
- Connect you with a Support Broker *(in states with a Support Broker - not currently ND)*

How Can Support Brokers Help?

Slide Excerpt from CDAC Meeting

Support Brokers Can…

- **Train** you on the program
- Help you create your **self-directed budget**
- Help you **manage your self-directed workers**
- Help you **monitor your spending**

**Please note that ND does not currently have support brokers as an option*

How Does a Financial Management Services Company (FMS) Help?

Slide Excerpt from CDAC Meeting

FMS…

- **Pay** your self-directed workers
- Handle your **taxes and insurance** as an employer

How Do Self-Directed Workers Help?

Slide Excerpt from CDAC Meeting

Self-Directed Workers…

- **Provide** your self-directed services
- Note: You do not personally pay your workers

How Do Informal Supports Help?

Slide Excerpt from CDAC Meeting

Informal supports…

- Could include **supported decision-making**
- Supported decision-making is a way to get help with making or communicating your decisions

CDAC Feedback on Self-Direction

CDAC Members shared their ideas and experiences with self-direction.

Subtopic	CDAC Member Feedback	A&M Response
Challenges	Members shared potential concerns with self-direction, including: • Difficulty getting paid. • Risk of having to go back on provider waitlist if switching off self-direction. • Challenges hiring new staff. • Concerns over responsibility of W2, liability, etc.	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.
Opportunities	Members also shared benefits of self-direction, including: • Options for individualized training to match unique needs of families and children. • Increased flexibility. • More choice in staffing.	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.
Staffing	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 about this option, 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.
Support	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.

Information & Assistance is a Critical Success Factor

A well-designed approach to information & assistance is critical for successfully scaling a self - directed services program.

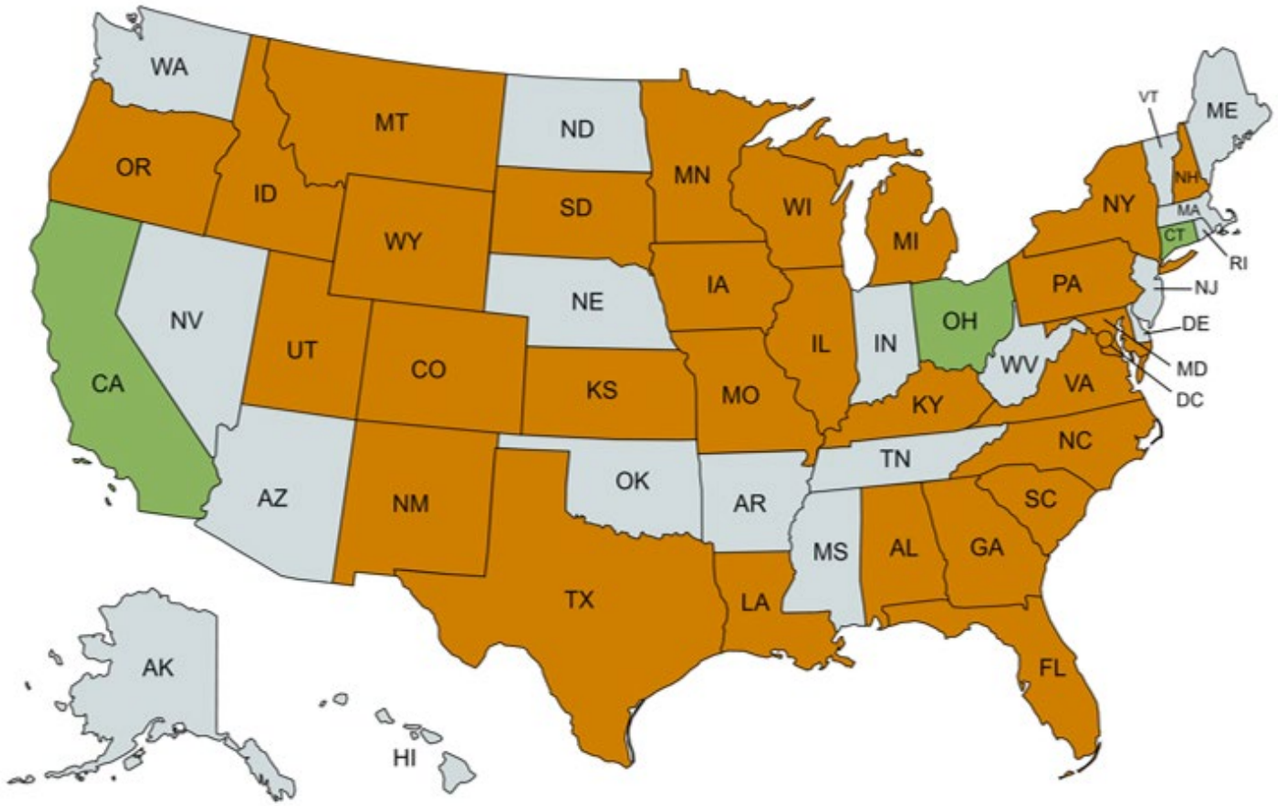
CMS Core Service Definition:

Service/function that assists the participant (or the participant's family or representative, as appropriate) in arranging for, directing, and managing services. Serving as the agent of the participant or family, the service is available to assist in identifying immediate and long-term needs, developing options to meet those needs, and accessing identified supports and services. Practical skills training is offered to enable families and participants to independently direct and manage waiver services. Examples of skills training include providing information on recruiting and hiring personal care workers, managing workers, and providing information on effective communication and problem-solving. The service/function includes providing information to ensure that participants understand the responsibilities involved with directing their services. The extent of the assistance furnished to the participant or family is specified in the service plan. This service does not duplicate other waiver services, including case management.

State Approaches to Information & Assistance(I&A) for Self-Direction

I&A National Landscape: Waiver Service

32 states provide I&A as a **waiver service** for **some** or **all** of their HCBS waivers for people with I/DDs.



- **32 states** have an Information & Assistance (Support Broker) waiver service specifically for self-direction
- I&A is offered as a waiver service because it gives the person a **choice of providers**. Additionally, there may be an **additional federal match** for waiver services, instead of the administrative match.
- In some states, this is an included part of case management services.
- Note that Information & Assistance (Support Broker) is not currently a standalone service within ND waivers and is not a formal expectation of case management, but it is being implemented in practice.

Roles and Responsibilities

Thinking about roles of Case Managers and Support Brokers.

There is **significant variance in how states manage the roles** of the Program Coordinator (if a state has one), a Case Manager, and a Support Broker. CMS has allowed variation in who provides a person with information and assistance.

Case Manager

Typical duties include:

- Evaluation and/or re-evaluation of the level of care.
- Assessment and/or reassessment of the need for waiver services.
- Development and/or review of the service plan.
- Coordination of multiple services and/or among multiple providers.
- Linking waiver participants to other federal, state and local programs.
- Monitoring the implementation of the service plan and participant health and welfare.
- Addressing problems in service provision.
- Responding to participant crises.
- For waivers with cost or service duration limits, monitoring to detect and resolve situations when the needs of an individual might exceed the limit(s) to ensure health and welfare of waiver participants.
- Additionally, they may have a role in providing Information & assistance for people who self-direct.

Support Broker

Typical duties include:

- Help for participants to manage their waiver services.
- For example, assistance might be provided to help the participant locate workers who furnish direct supports or assist in crafting the service plan.
- The type and extent of the supports that must be available to participants depend on the nature of the self-direction opportunities provided under the waiver.

Recommendation:

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.

CDAC Services Recommendations | Self-Direction

Below are the key recommendations around how self-direction should work in the new waiver

#	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

Services: Paid Family Caregiver

Paid Family Caregiver

Family Paid Caregiver 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.

Recommendation:
Families on CDAC stressed the importance of offering an option for Paid Family Caregiver in the new waiver. Use learnings from the pilot to define the parameters of Paid Family Caregiver for the Cross-Disability Children's Waiver. Consider parity between self-directed, and paid family caregiver rates.
Work with the CDAC to inform the Paid Family Caregiver option for the Cross Disability Children's Waiver.

Note:
This topic is on the agenda for the next CDAC meeting, scheduled for December 11, 2025. There will time available for public comments.

CDAC Services Recommendations | Paid Family Caregiver

The CDAC looks forward to learning from the Paid Family Caregiver pilot program and will make additional recommendations about how this should work in the new waiver at that time

#	CDAC Recommendations	A&M Response
S.14	The new children's cross disability waiver should include options for paid family caregiver.	Agree
S.15	Use learnings from the pilot to define the parameters of Paid Family Caregiver for the Cross-Disability Children's Waiver. Consider parity between self-directed, and paid family caregiver rates.	Agree. This topic is on the agenda for the next CDAC meeting, scheduled for December 11, 2025. There will time available for public comments.
S.16	Work with the CDAC to inform the Paid Family Caregiver option for the Cross Disability Children's Waiver.	Agree

Case Management / Support Coordination

Support Coordination: What Does This Topic Include?

Slide Excerpt from CDAC Meeting

What do we mean when we talk about “support coordination”?

- Support coordination describes the assistance families need to successfully identify resources, plan waiver services, and navigate life changes.
- Support coordination is often referred to as “case management.”

The Department of Health & Human Services will have to outline what support coordination will look like in the new cross-disability waiver. **CDAC will play an important role by**:

- Sharing your experiences navigating supports, including what has been most helpful.
- Highlighting other forms of support coordination that would be helpful.

Understanding Person-Centered Planning & Case Management

- Person-Centered Practices is the result of developing and implementing individualized plans, based on a person's preferences, strengths and choices for their life. A person's life is realized in a meaningful way when family, friends, community members, and service providers actively listen to what matters to a person, by respecting and honoring their strengths, culture, hopes and dreams. Every person deserves happiness and a life they desire. - ND Person-Centered Practices Draft Definition

- Person-centered planning is a requirement for Medicaid home and community-based services (HCBS). In order to receive Medicaid reimbursement for HCBS, there must be a person-centered service plan that addresses the person's needs and the services that they will receive

- Case management consists of services which help people receiving HCBS gain access to needed medical, social, educational, and other services

CDAC Ideas About Support Coordination

What do we mean when we talk about “support coordination”?

CDAC Feedback on Case Management

CDAC Members shared their experiences with waiver case management.

Subtopic	CDAC Member Feedback
Benefits	Members expressed appreciation for their HHS-based case managers and shared examples of how they have been helped with planning and navigation.
Challenges	Turnover is difficult because it makes it hard to build relationships, and repeatedly sharing your story can be traumatic.
Staffing	There is a shortage of rural case managers in some waivers.
Transitions	Transitions are a key element that families think about when considering children with disabilities. Families need support to plan for and think about transitions-early and often. CDAC members especially stressed the need to start early with transition planning to adult services.

Case Management: A Key Support Through Transitions

CDAC members repeatedly discussed the importance of transitions.

- One of the major themes throughout discussions with CDAC members was the importance of planning for successful transitions.
- Transitions are particularly important for children, and their families.
- Examples of common life transitions can include starting school, graduating, or getting a job.
- Case managers play a critical role in helping families plan for these transitions.
- We asked CDAC members to share what transitions they think about and their goals and needs in these areas-see the following slides for a summary of CDAC responses.

Providing Integrated Support Across the Lifespan

Slide Excerpt from CDAC Meeting

Transition Point: Assessment for IID/DD Waiver and Cross-Disability Waiver

Transition Point: Reassessment with Revised LOC

Transition Point: IFS Waiver ends; Determine future support as needed

Infancy (under three):
- All children served on Comprehensive Waiver

Early Childhood (Age 3 Until Age 6):
- High-needs ID/DD/ASD: Comprehensive Waiver
- Moderate/mild Needs: IFS Waiver

School Age – Transition Age:
- High-needs ID/DD/ASD: Comprehensive Waiver
- Moderate/mild Needs: IFS Waiver

Adulthood - Aging:
- High-needs ID/DD/ASD: Comp. Waiver
- Moderate/mild Needs: HCBS Waiver, State Plan, Vocational Rehab

Comprehensive IID/DD Waiver: Provides services for high-needs individuals with intellectual and/or developmental disabilities and autism from birth to death.

Cross Disability Children's Waiver: Provides services to children from age 3 until age 18 (or up to age 21) with mild to moderate support needs.

HCBS Waiver: Serves individuals with physical and other disabilities aged 18 until age 64, and seniors aged 65+.

*Image Credit: https://www.lifecoursetools.com/lifecourse-library/exploring-the-life-stages/

Slide Excerpt from CDAC Meeting – Activity Responses

Planning for Life Transitions: Supporting Families Through Major Changes

Infant (under 3):
- Birth (adjust to family addition, new dynamics)
- Getting diagnosed

School age (Age 6 Until Age 17):
- 3rd Grade
- Starting middle school
- Starting high school
- Getting driver's license

Adulthood (22+)
- Apartment to home ownership
- Transition from child to adult waiver services / end waiver

Early Childhood (Age 3 Until Age 5)
- Turning 3/ending EI
- Starting preschool
- Transitioning from Part C to Part B services
- Starting kindergarten/ elementary school

Transition Age / Young Adult (Age 18 Until Age 21)
- Age 18-guardianship, supported decision making
- High school graduation
- Starting tech school/college
- Turning age 21
- Transitioning into the workforce
- Moving out of parents' home
- Starting adult healthcare services/ pediatric to adult medical

Additional Transitions:

- Career changes;
- Relationships (social or romantic);
- Adoption (adjusting to family additions);
- Transition to life without parents.

Other Considerations:

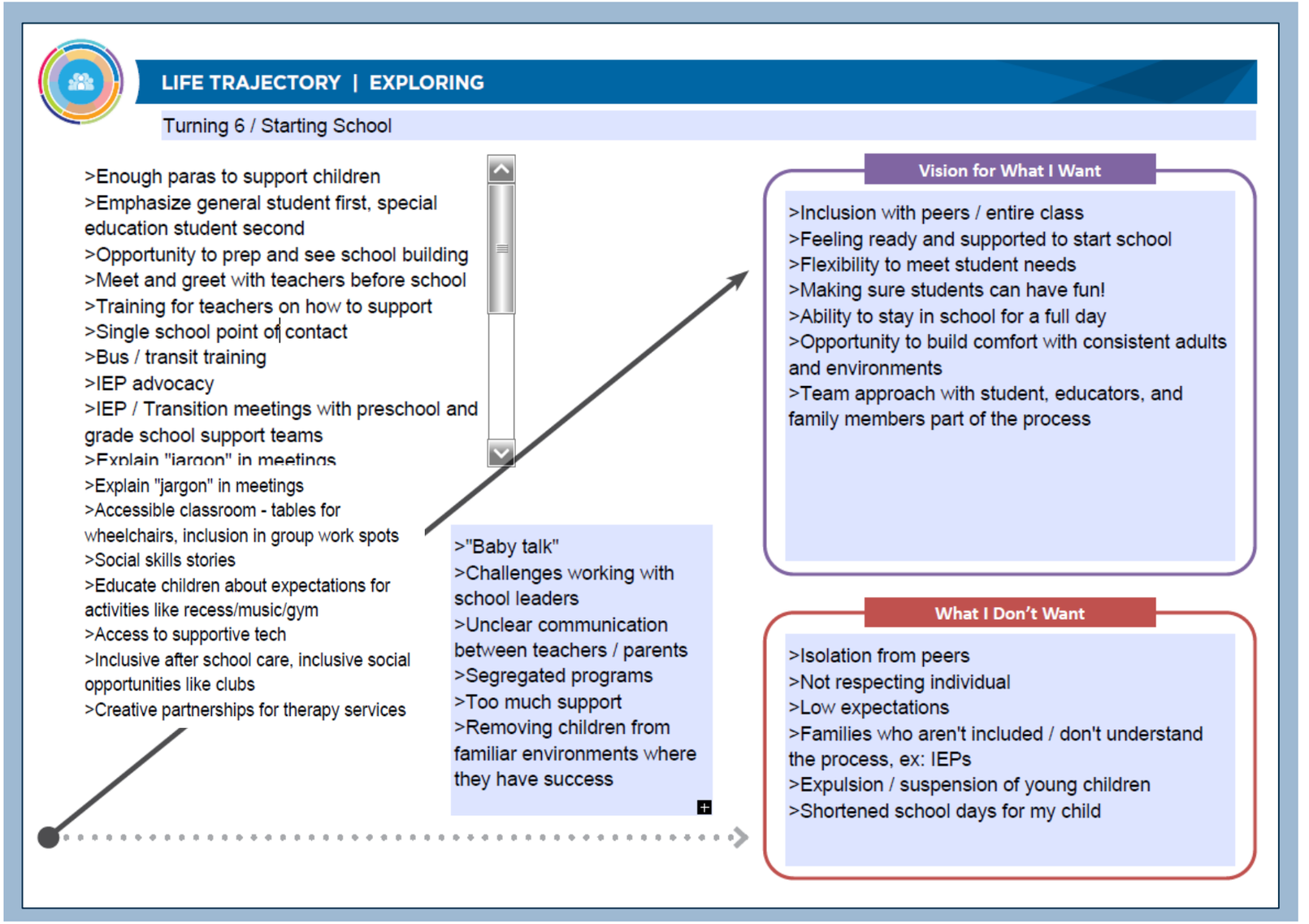
- How to meet health and safety requirements;
- Choices in life-what to do, how to plan to get there;
- Paying for changes;
- Support during change;
- Transportation;
- Financial planning;
- Long-term future;
- Health needs/meds.

*Image Credit: https://www.lifecoursetools.com/lifecourse-library/exploring-the-life-stages/

Life Trajectory for Transition Planning-Turning 6/Starting School

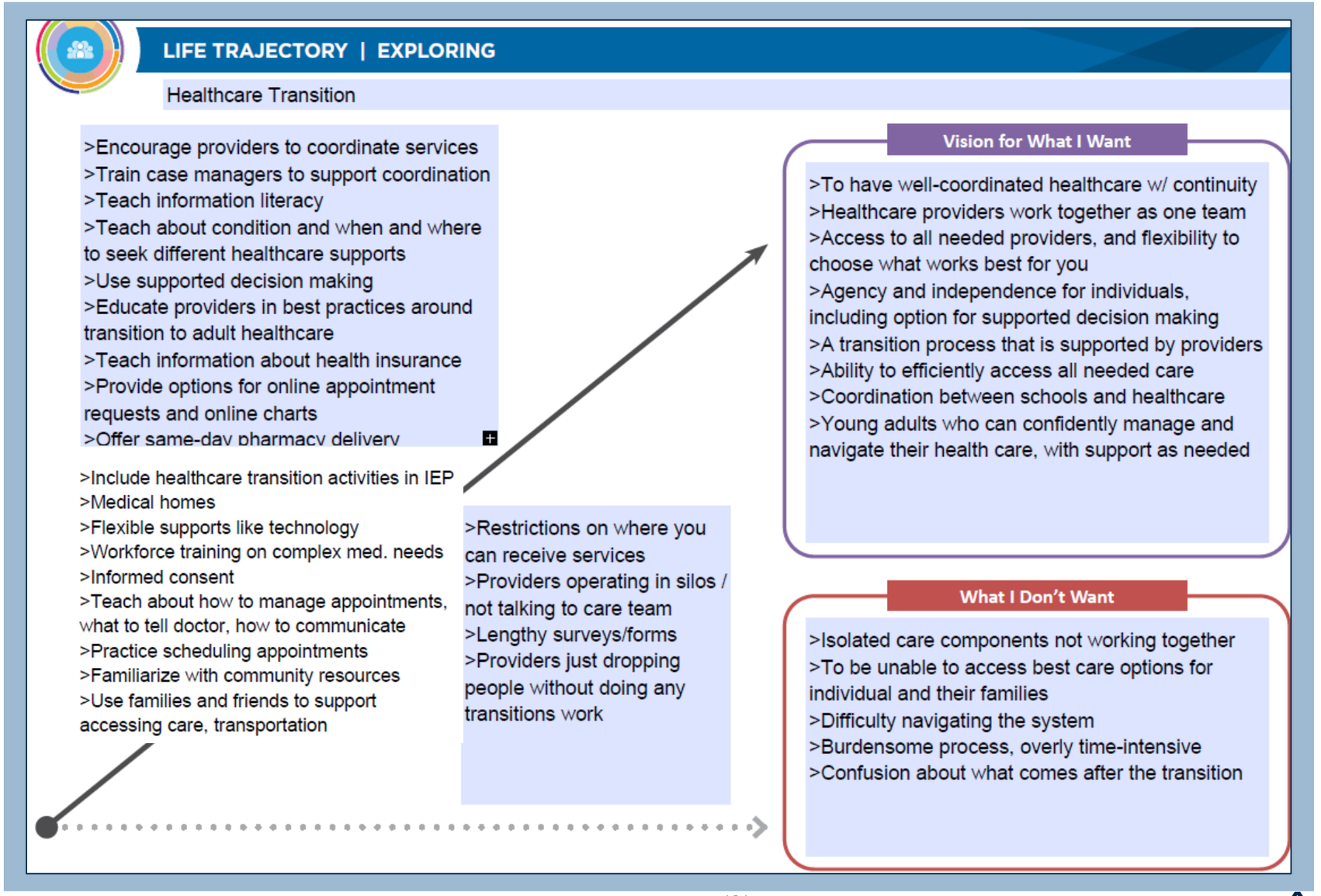
Slide Excerpt from CDAC Meeting – Activity Responses

- Over the next two slides, we have pasted the compiled trajectories based on the group's feedback regarding transition.
- We know these will be too small to read on the slides-we will share a paper copy for those in the room and an online photo in the virtual meeting.
- We have also emailed the document with these trajectories to the group in advance.



Life Trajectory for Transition Planning-Medical Transition to Adulthood

Slide Excerpt from CDAC Meeting – Activity Responses



Public Comment: Key Themes Related to Case Management

Public attendees at the listening sessions provided recommendations on the new cross-disability waiver and broader system opportunities to serve children more effectively.

Themes related to case management from public comment included the following:

Case Management:

- Participants shared positive stories of how **case managers have helped** them.
- Attendees shared feedback about **additional support that would be helpful from case managers**, including:
  - Information on services and resources in their area;
  - Anticipatory guidance to navigate the eligibility changes at age 3.
- Participants asked questions about who would provide **case management on the new waiver.** One participant provided feedback that they felt state case managers were better positioned to provide consistent and responsive support coordination.
- People expressed that case managers should be able to **substitute lived experience for a 4-year degree.**

National Approaches to Case Management

ID/DD Waiver Provider Models

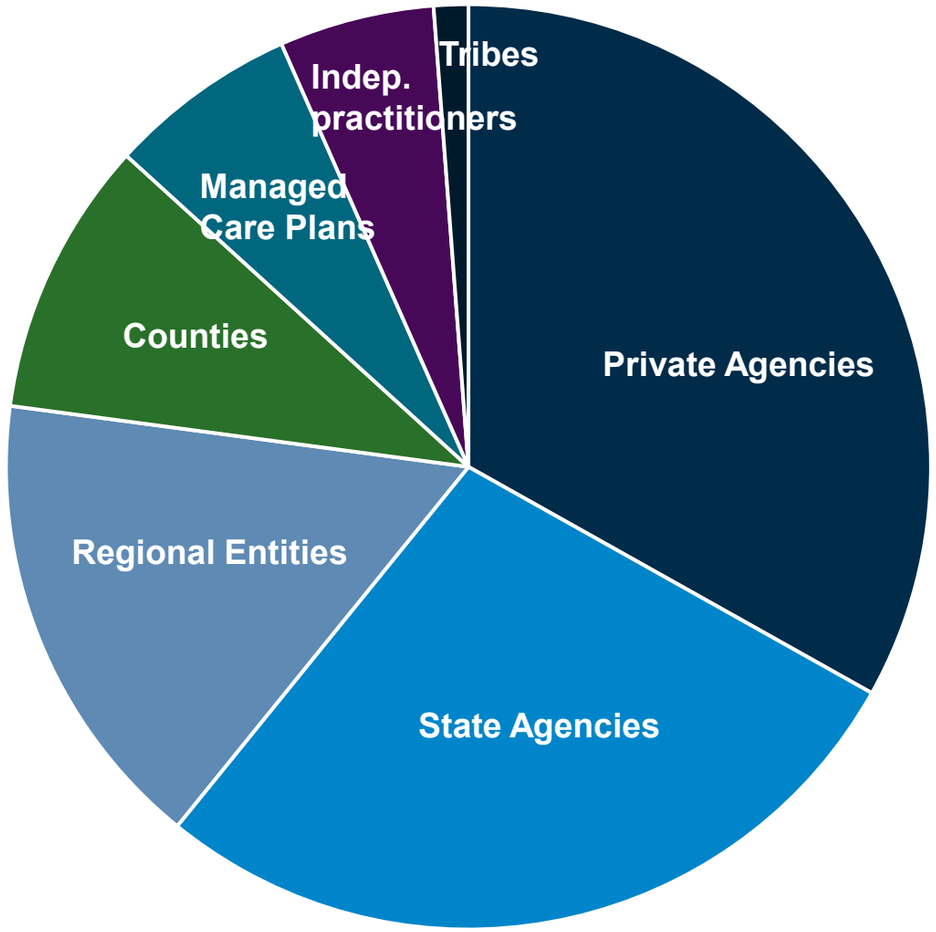
Research from NASDDDS and MACPAC outlines seven different provider models for DD case management services:

- Private Agencies
- State Agencies
- Regional Entities
- Counties
- Managed Care
- Independent Practitioners
- Tribes

According to NASDDDS' research, the two most common delivery models for case management by far are 1) private agencies and 2) state agencies. Over 15% of states also utilize at least a partial form of regional and/or county-based case management providers.

Case Management Provider Types Utilized by State DD Systems

**Note that some states use multiple types of providers*



Considerations for Two Most Common Case Management Structures

	Private Agency Case Management	State Agency Case Management
Benefits	• Allows more flexibility in reimbursement structure for case managers (determined by private agency). • Opportunity to utilize national learnings from provider agencies who operate in multiple states. • Potential benefits resulting from competition amongst private providers.	• Existing strong reputation and popularity of the model in North Dakota. • Minimizes the risk of potential conflict of interest with service providers. • Supports centralized data keeping. • Supports standardization and equity. • Supports implementation of future changes. • Allows the state to balance workload among case-mangers.
Challenges	• Reduces state's ability to oversee case managers directly, limiting the ability to define job duties, reimbursement rates, and training requirements. • Would require changing from existing model of state agency case management; this involves significant work to rewrite and establish new policies and procedures. • Families with existing case managers will potentially need to switch to different case managers if the system changes from the current structure. • Less ability to "own" all data and analytics. • Need to create additional conflict of interest protections.	• The state job class structure may make implementing credentialing structures or rewarding high performers more complex. • State staff may face pressure to learn how to provide case management to other populations, not just developmental disabilities. • The state responsibility to encourage innovation.

Capacity: Case management is a critical component of capacity, as limited case manager staffing can result in a de facto waiting list for services. For example, the ASD waiver has had difficulty increasing capacity among private case managers, which can delay services. Using state agency case managers allows the state to distribute loads in a more agile manner in response to demand shift cases, and ramp up staffing as needed.

Case Management Approaches in Existing Cross Disability Waivers

Two states currently offer cross-disability waivers: New York and Wisconsin. Both states approach case management differently.

Waiver Name	Target Populations	Age Limits	Case Management Governance Structure	Case Management Provider Model
New York				
NY Children's Waiver (4125.R06.00)	Physically Disabled, Disabled (Other), HIV/AIDS, Brain Injury, Medically Fragile, Technology Dependent, ID/DD, Autism, SED.	• SED: From Birth Until Age 18 • All Others: From Birth until Age 20	State Plan Targeted Case Management (TCM)	Health homes
Wisconsin				
WI Children's Long-Term Support Waiver Program (0414.R04.00)	Physically Disabled, Disabled (Other), Autism, ID/DD, SED.	From Birth Until Age 21	Waiver Service	Local contracted HHS agencies or subcontracted case management entities, may include county human/social service depts, subcontractors, or tribal entities.
WI Family Care Waiver (0367.R04.00)	Aged, Physically Disabled Disabled (Other), ID/DD.	• Aged: 65+ • Physically disabled: 18 - 64 • IDD:18+ • Other:18+	Waiver Service	Managed Care Organization (MCO) Prepaid Inpatient Health Plan (PIHP) - led Interdisciplinary Care Management Team (IDT) consists of at least one RN and one social services coordinator.

***State Plan Targeted Case Management (TCM):** Medicaid State Plan case management services aimed specifically at special groups of enrollees, such as those with developmental disabilities or chronic mental illness.

Peer State Case Management Practices

North Dakota's peer states utilize a mix of case management governance structures and providers.

- North Dakota's peers deliver case management to IID/DD waiver participants either through State Plan TCM or as a dedicated waiver service.
- These peer states provide case management through private agencies, state agencies, managed care plans, or a combination / hybrid approach.
- North Dakota's current IID/DD waiver delivers case management as an administrative service, with state agency case managers.
  - The ASD and MF waivers both offer case management as a waiver service. The ASD waiver, uses private agency providers, while the MF waiver utilizes state agency case managers.

	Governance Structure			Provider Model		
	Waiver Service	State Plan TCM	Other	Private Agencies	State Agencies	Managed Care
Idaho		X		X		
Iowa		X		X		X
Kansas		X				X
Minnesota	X				X	
Montana		X			X	
Nebraska		X			X	
North Dakota	X (MF, ASD)		X (DD - admin)	X (ASD)	X (DD, MF)	
South Dakota	X			X		
Wyoming	X			X		

Case Management Job Functions

Moving forward, North Dakota will need to make strategic decisions regarding the implementation and sustainability of case management services.

1. **What job functions will case managers perform?**

2. **Will additional functions be completed by a support coordinator or support broker?**

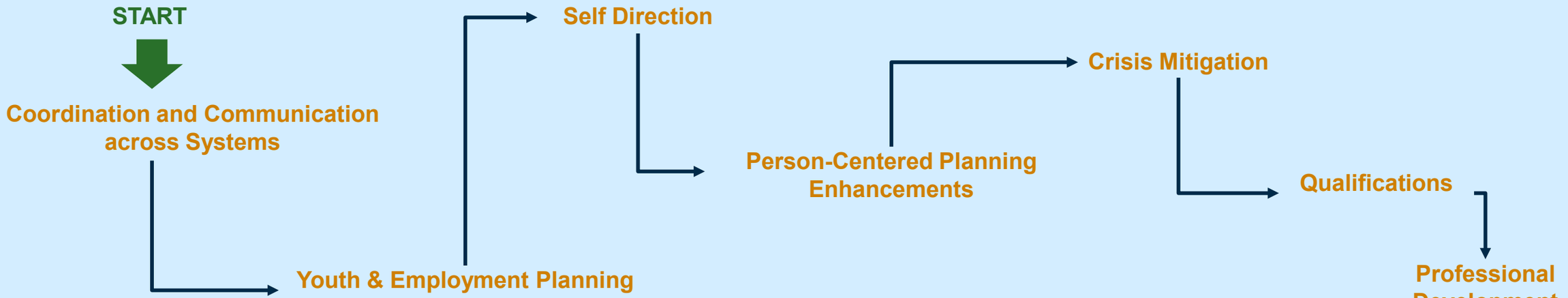
Standard Functions:

- Eligibility determinations
- Plan development
- Crisis Management
- Monitoring

Innovative Functions:

- Case manager as a support coordinator
- Assisting the individual to self-direct services

Implementation Consideration Roadmap:



CDAC Case Management Recommendations

The CDAC appreciates the state-based case managers and recommends using them, along with family navigators, in the new waiver

#	CDAC Recommendations	A&M Response
CM.1	**Family Navigator:** • Examine the current tasks of case managers. Identify areas where a new family navigator position, with lived experience, can supplement the existing case manger role and help fill gaps. • Hire and train family navigators, using lived experience to substitute for formal education. • Consider whether the family navigators can assist with support for self-direction and with complex care coordination. • CDAC members noted that the introduction of a new team member role, the family navigator, will require training for individuals and families, case managers, and providers.	Agree
CM.2	Explore caseloads to identify if more staffing needed to support the new waiver.	Agree
CM.3	Consider hiring more **state-based case managers** to support the new waiver population, based on CDAC and public feedback regarding the value of having case managers housed in the state offices.	Agree
CM.4	CDAC members suggested that the Charting the LifeCourse tools be used as an input for the person-centered plan for the CDAC, given their focus on planning for people in the context of their families. A&M agrees, and notes that there are many different types of person-centered planning tools that may be good inputs into the plan.	Agree
CM.5	Train all case management staff in the new policies and procedures regarding the cross-disability waiver.	Agree

Defining Quality: How Will We Know the Waiver is Working Well?

In Plain Language, When We Ask About Quality, What Does This Topic Include?

Slide Excerpt from CDAC Meeting

What do we mean when we talk about "quality"?

- When we talk about quality, we are talking about how well a waiver program works.
- During today's session, we will discuss aspects of quality, including:
  - How to define what a well-functioning program looks like
  - Ways to measure success of a program
  - Safeguards for protecting the health and welfare of participants

The Department of Health & Human Services will have to outline quality measures and protections for the new cross-disability waiver. **CDAC will play an important role by**:

- Sharing ideas for what makes a program good, and how we can measure these things
- Suggesting possible protections to ensure the health and safety for children and families

Hearing from the CDAC

We asked CDAC members to share their experiences and knowledge about quality.

What is one word you think of when you hear the word quality?

Join at Menti.com | use code: 4297 8434

Some Thoughts on Quality

Slide Excerpt from CDAC Meeting

We shared quotes on quality to prompt CDAC members to think about the different ways to approach quality.

Quality is defined at the point of interaction between the staff member and the individual with a disability."

- John F. Kennedy

"Quality can and should be measured according to what people want and need and get."

-Cathy Ficker Terril

"Do the best you can until you know better. Then when you know better, do better."

- Maya Angelou

"Managing any risk begins with learning what is "important to" the person as well as what is "important for", and helping to find a good balance between them. Often risk is significantly diminished when our understanding of what the person wants deepens and we find reasonably safe ways for the person to get it. In other instances understanding how important something is leads to better ways to support the person."

- Michael Smull

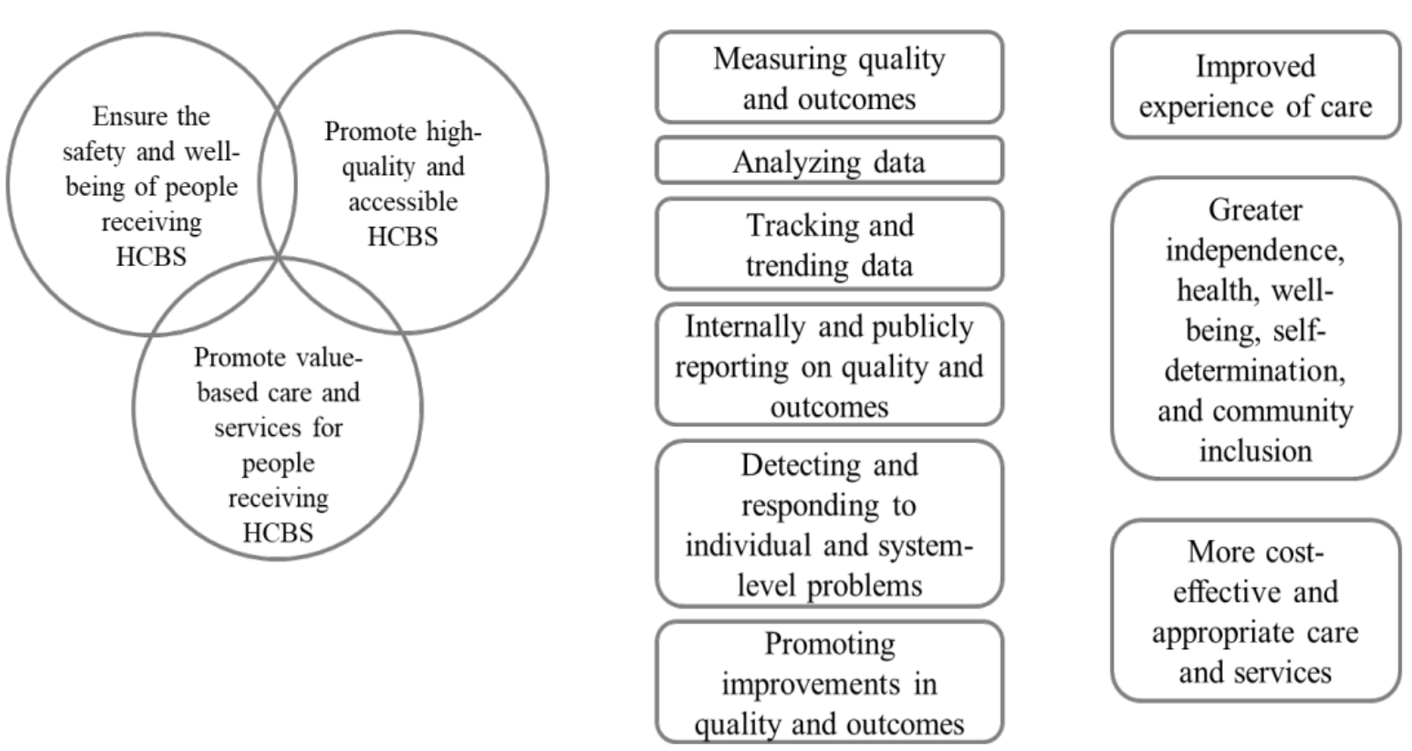
"It is important to help people have positive, healthy experiences, adequate support, and ample opportunities to learn and make mistakes so that they can have better outcomes later in life."

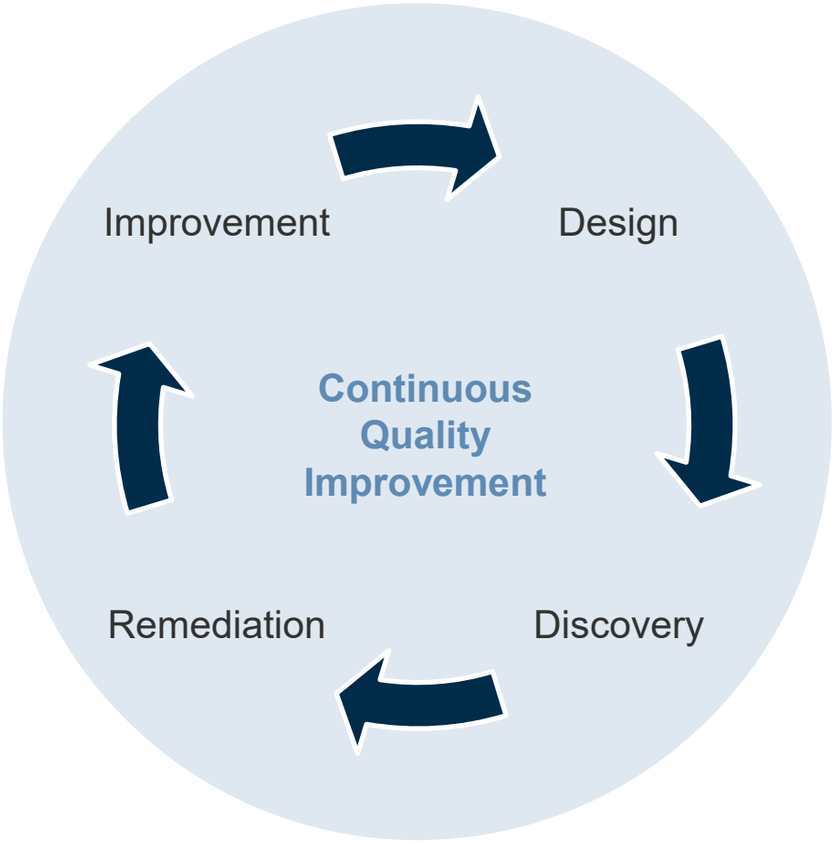
- Dr. Sheli Reynolds,

Slide Excerpt from CDAC Meeting

Background from the Centers for Medicare & Medicaid Services HCBS Quality Framework

HCBS Quality Framework





*Source: CMS, Introducing a New Database for Users of the CAHPS Home and Community-Based Services (HCBS CAHPS) Survey - BROWN (ahrq.gov)

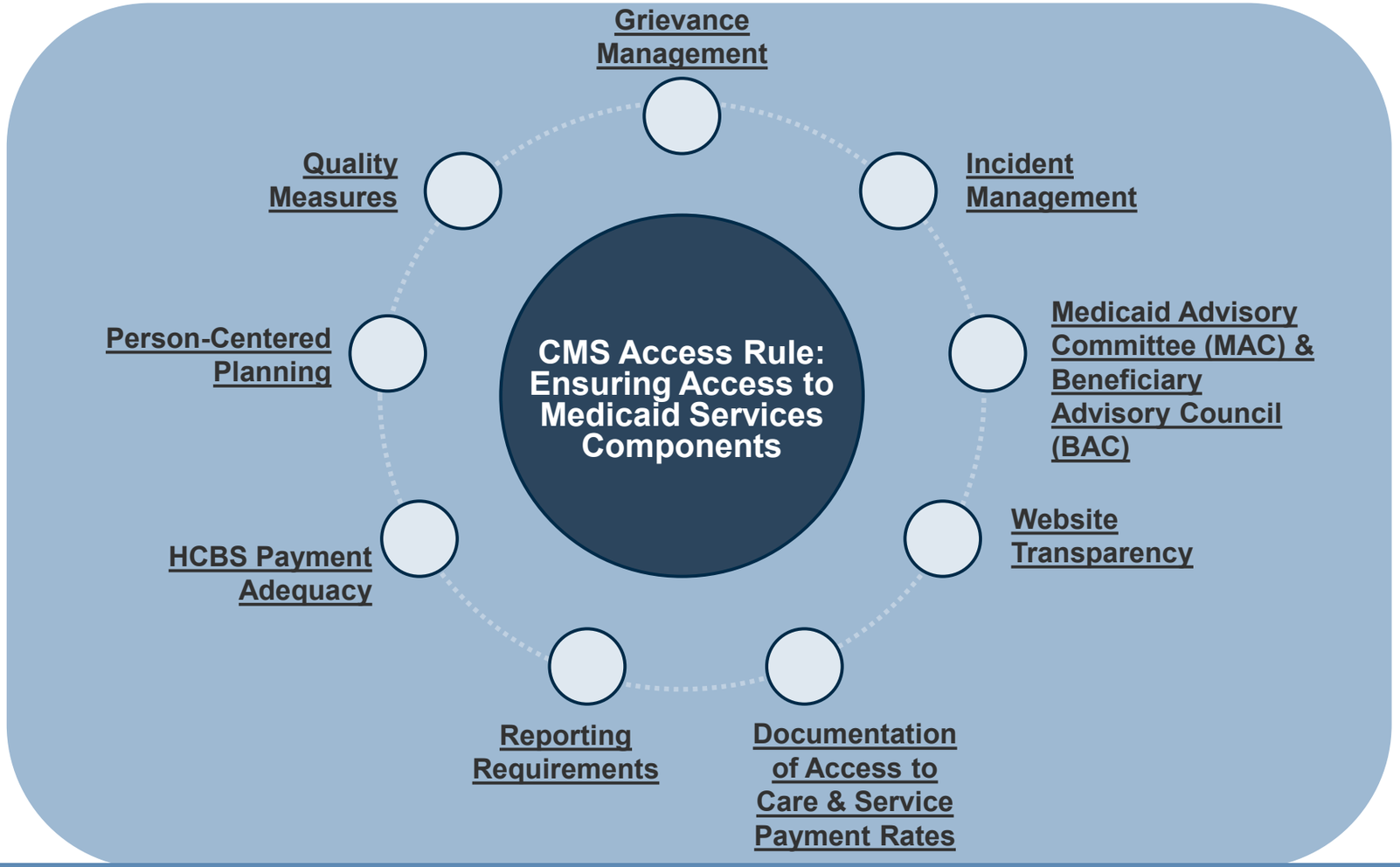
CMS Access Rule | Main Components

Opportunity

Understanding the rule requirements to **guide planning** and **inform system transformation** to ensure access to services and federal **compliance.**

Summary

The rule includes changes to current requirements as well as new requirements in both **fee-for-service (FFS) and managed care delivery systems**. This overview highlights the impacts the rule may have on state operations under traditional §1915(c), §1915(i), §1915(j), §1915(k), and §1115 **home and community-based waiver programs**.



*This resource serves to provide a summary of the key compliance components. It is **not** inclusive of all requirements and is subject to change as CMS releases planned sub - regulatory guidance.*

*Source: CMS, Introducing a New Database for Users of the CAHPS Home and Community-Based Services (HCBS CAHPS) Survey - BROWN (ahrq.gov)

Quality Measures

Overview

Provides a set of nationally standardized, scientifically supported measures to assess HCBS quality and outcomes, reducing the time and resources required by states to identify, assess, and implement measures for use in HCBS programs. Creates opportunities for comparative quality data on HCBS programs in health and quality of life outcomes for underserved populations, and potential differences in outcomes based on race, ethnicity, sex, age, rural/urban status, disability, and language.

Components

- Basis and Scope
- Definitions
- Responsibilities of the Secretary
- Process for Developing and Updating the HCBS Quality Measure Set
- Phasing in of Certain Requirements
- Consultation with Interested Parties
- Application to Other Authorities

Requirements Summary

- ✓ Use of the HCBS Quality Measure Set in sections §1915(c), §1915(i), §1915(j), and §1915(k)
- ✓ Data stratification by multiple demographics, including race, ethnicity, and gender

Key Considerations

- ❑ Education and Training
- ❑ Experience of Care Survey Implementation
- ❑ Data Sharing, Collection, Aggregation, Stratification, Analysis, and Reporting
- ❑ Regulatory and Policy Modifications
- ❑ Provider Agreements and / or Contract Modification
- ❑ APD for Enhanced Funding for Improvement of Claims Processing and Information Retrieval Systems
- ❑ QIO or QIO - like Entity

Finalized Applicability Dates:

July 2028 - HCBS Quality Measure Set
July 2032 - Data stratification

*KZ completed review

Quality Measures

	Finalized Requirements
Basis and Scope § 441.312(a)	• **Use of the HCBS Quality Measure Set** in section 1915(c) waiver programs promotes public transparency related to the administration of **Medicaid-covered HCBS.**
Definitions § 441.312(b))	• **Attribution rule:** The process States use to **assign beneficiaries to a specific health care program** or **delivery system** for the purpose of calculating the measures in the HCBS Quality Measure Set. • **Home and Community-Based Services Quality Measure Set:** To mean the **Home and Community-Based Services Quality Measures for Medicaid,** established and updated by the Secretary through a process that allows for public input and comments, including through the Federal Register.

Responsibilities of the Secretary § 441.312(c)	• Secretary will identify and update**, no more frequently than every other year,** through a process that allows for public input and comment, the **quality measures** to be **included in the HCBS Quality Measure Set.**
	• The Secretary to make technical updates and corrections to the HCBS Quality Measure Set annually as appropriate
	• The Secretary will **solicit comments,** no more frequently than every other year, from States to:
	  ○ **Establish priorities** for the **development** and advancement of the **HCBS Quality Measure Set.**
	  ○ **Identify newly developed** or other **measures** that should be **added**, including **to address gaps in the measures.**
	  ○ Identify measures that should be **removed** as they **no longer strengthen** the **HCBS Quality Measure Set.**
	  ○ Ensure that all measures included in the HCBS Quality Measure Set are **evidence-based**, are **meaningful** for States, and are **feasible** for State-level and program-level reporting as appropriate.

Process for Developing and Updating the HCBS Quality Measure Set § 441.311(d))	• The Secretary will:
	  ○ Inform States on **how to collect and calculate data** on the identified measures.
	  ○ Provide a **standardized format** and **reporting schedule** for reporting the measures.
	  ○ **Provide procedures** that States must follow in reporting the measure data.
	  ○ **Identify specific populations** for which States must report the measures.
	  ○ **Identify the measures that must be stratified** by race, ethnicity, sex, age, rural/urban status, disability, language or such other relevant factors.

Quality Measures

	Finalized Requirements
Phasing In of Certain Reporting § 441.311(e) and (f))	• **Timing by which measures must be stratified:** o 25% of the measures for specified reporting should be stratified within 4 years after the effective date of these regulations. o 50% of such measures by 6 years after the effective date of these regulations. o 100% of measures by 8 years after the effective date of these regulations.
Consultation with Interested Parties § 441.312(g)	• Secretary must **consult to specify and update the quality measures** established in the HCBS Quality Measure Set with a **list of interested parties** including: o State Medicaid Agencies and agencies that administer Medicaid-covered HCBS; Health care and HCBS professionals, providers, and direct care workers; Consumers and national organizations representing consumer organizations; Individuals with expertise in HCBS quality measurement, voluntary consensus standards-setting organizations and other organizations involved in the advancement of evidence-based measures of health care; and other interested parties the Secretary may determine appropriate.
Application to Other Authorities §§ 441.474(c), 441.585(d), and 441.745(b)(1)(v))	• Apply **quality measurement requirements** to sections **1915(c), (i), (j), and (k)** to ensure **consistency** and **alignment** in reporting requirements across HCBS authorities.

CMS Access Rule | HCBS Quality Measure Set

The HCBS Quality Measure Set is a set of nationally standardized quality measures for Medicaid-funded HCBS.

- Intends to help states and the disability service system evaluate and improve quality for those receiving home and community-based services.
- The HCBS Quality Measure Set is “intended to promote more common and consistent use, within and across states, of nationally standardized quality measures in HCBS programs, and to create opportunities for CMS and states to have comparative quality data on HCBS programs.”
- The HCBS Quality Measure Set details CMS-recognized measurement tools, the method for collecting data, the associated assurance and sub-assurances, as well as some broad considerations for implementation.
- In addition to some measures focused on specific service areas, the measurement tools and their authors listed in the HCBS Quality Measure Set include:
  - Consumer Assessment of Healthcare Providers and Systems (CAHPS)-ND is using this now as part of their external quality review. It is an adult tool.
  - National Core Indicators (NCI)-ND is using this now for their IID/DD waiver (children and adults).
  - Personal Outcome Measures (POM)-ND is using this now for their IID/DD waiver (children and adults).
- The proposed rule would require states to report every other year on the HCBS Quality Measure Set for their HCBS programs.

*Sources: Measuring and Improving Quality in Home and Community-Based Services | Medicaid; CMS Releases HCBS Quality Measure Set Measure Summaries, Including The POM - The Council on Quality and Leadership (c-q-l.org)

Thinking About Personal Outcomes

Slide Excerpt from CDAC Meeting

Quality should measure not only system processes but also whether services are making difference in people's lives.

- Personal outcomes start with a belief that every person has something to communicate and a vision for their own good life, and that it is our collective job to understand and support that.
- Personal outcomes are measured based on the desires of the person and the degree to which the person wants the outcome. As an example, when we look towards community integration, we need to ask questions like:
  - Is the person interested in trying new things? Meeting new people?
  - What activities are meaningful to them?
  - What is happening through the HHS service delivery system to support that outcome?
- People achieve personal outcomes when services consistently support what is most important to and for the person.
- The CDAC members discussed personal outcomes that help achieve the Charting the LifeCourse Framework principle that *people lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life.*

*Source: Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)

Themes from the CDAC Discussion of Quality Overall

CDAC members shared their thoughts on quality with respect to the Cross - Disability Children's waiver.

- Members recognized that the Cross-Disability Waiver work is more than just identifying services that a child might need; the quality of those services is also important.
- Members were supportive of a quality management system that looked at outcomes for the children in the waiver.
    - Members did express that if a child does not meet an outcome, this should result in a person-centered planning meeting to review the goal and understand the circumstances leading to the lack of goal attainment (versus putting the child at risk for being discharged from services for not meeting their goal).
    - They also recognized that personal outcomes could mean that the person receiving services (and their families) has a role in defining their own quality.
    - Members recognized that this is a shift in approach and would require training.
- Members talked about what personal outcomes mean in a children's waiver and whether generally this should apply to the children themselves, or their families. There was a recognition that this shifts as the child ages, but members recommended that this generally include an understanding of children in the context of their family.
- Members appreciate that HHS currently offers opportunities for public comment with respect to quality, including opportunities for people to participate during the day, and in the evening.

Public Comment: Key Themes Related to Quality

Public attendees at the listening sessions provided recommendations on the new cross - disability waiver and on broader system opportunities to serve children more effectively.

Themes related to quality from public comment included the following:

Quality

- Participants provided input that they would like to see additional quality metrics, especially around self-direction.
- Other suggestions included timelines from services being entered in the plan until receipt, and metrics around care coordination.

Personal Outcomes & the Life Domains

Life domains are the different aspects and experiences of life that we all consider as we age and grow, such as daily life, community living, and healthy living.

CDAC members were asked to think about each life domain and share an example of a personal outcome that might fit into each.

Daily Life & Employment

What a person does as part of everyday life–school, employment, volunteering, communication, routines, life skills.

Community Living

Where and how someone lives – housing and living options, community access, transportation, home adaptations and modifications.

Healthy Living

Managing and accessing health care and staying well – medical, mental health, behavioral health, developmental, wellness and nutrition.

Safety & Security

Staying safe and secure – emergencies, well-being, guardianship options, legal rights and issues.

Social & Spirituality

Building friendships and relationships, leisure activities, personal networks, and faith community.

Advocacy & Engagement

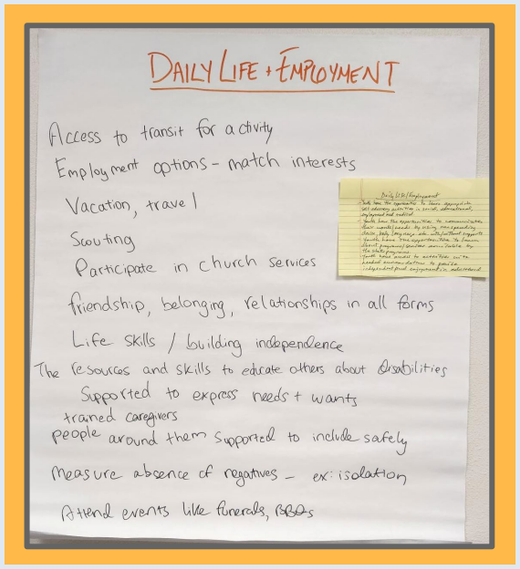
Building valued roles, making choices, setting goals, assuming responsibility and driving how one's own life is lived.

Notes: (1) In the following slides, A&M recategorized some CDAC feedback to match life domains.
(2) Public members in attendance were welcome to participate, but none did.

*Source: Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)

Personal Outcomes & the Life Domains: Daily Life and Employment

What a person does as part of everyday life-school, employment, volunteering, communication, routines, and life skills.



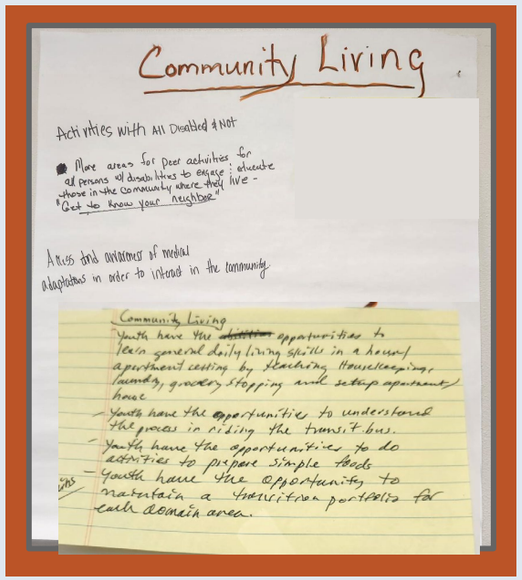
CDAC Ideas on Personal Outcomes

- Participants are supported to learn age-appropriate life skills and build their independence.
- Participants are supported to engage in discovery and have opportunities to learn about activities available in the community as well as through state programs.
- Youth have opportunities and individualized support and accommodations, as needed, to do activities that include people with and without disabilities.
- Activities that take place in the community offer the opportunity for inclusion (scouting, church events, etc.).
- Quality measures should include the absence of negatives like isolation and loneliness.
- Participants are supported to learn general living skills in a real-life setting, for example, laundry, grocery shopping, cooking, and setting up an apartment or home.
- Employment goals match teens' interests.

*Source: [Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)]

Personal Outcomes & the Life Domains: Community Living

Where and how someone lives-housing and living options, community access, transportation, home adaptations, and modifications.



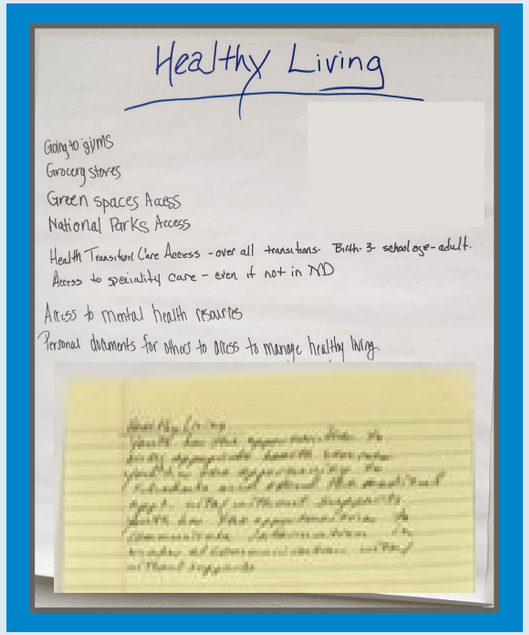
CDAC Ideas on Personal Outcomes

- Participants have access to home and vehicle adaptations needed to support them to live in the community.
- Participants have the opportunity to access to transportation to attend activities in the community that support their goals.
- Participants are supported in meeting their neighbors.
- Participants have the opportunity for travel training, including learning how to ride the transit bus.

*Source: Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)

Personal Outcomes & the Life Domains: Healthy Living

Managing and accessing health care and staying well-medical, mental health, behavioral health, developmental, wellness, and nutrition.



CDAC Ideas on Personal Outcomes

- People are supported to use community resources to promote healthy living, including using gyms and local and national parks, and learning how to make healthy choices at the grocery store.
- Participants are supported in scheduling and attending their medical appointments, with assistance as needed.
- There is care coordination that, among other things, supports access to behavioral health resources.
- Participants are supported in health care transitions, including transitioning from Medicaid if they leave the waiver, and to the adult medical systems.

*Source: [Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)]

Personal Outcomes & the Life Domains: Social and Spirituality

Building friendships and relationships, leisure activities, personal networks, and faith communities.

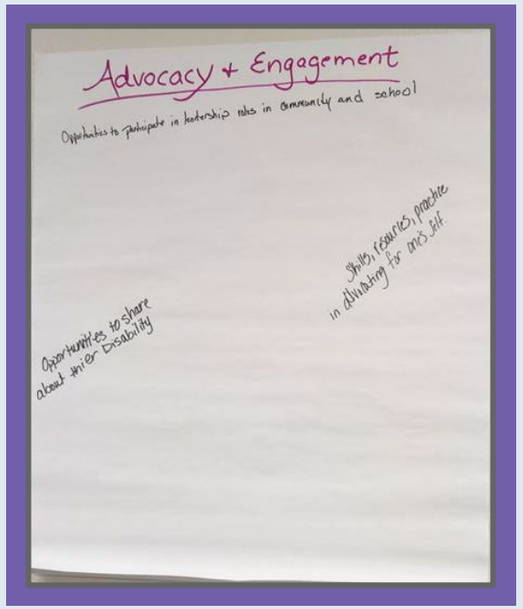
CDAC Ideas on Personal Outcomes

- Participants are supported in building, maintaining, and sustaining friendships and other relationships; for teens, this may include learning about healthy dating and relationships.
- Participants have the opportunity to engage with other people with similar disabilities (peer - to - peer) and in inclusive settings.
- Participants are supported in attending church services;
    - Efforts are made to find and support welcoming congregations.

*Source: [Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)]

Personal Outcomes & the Life Domains: Advocacy and Engagement

Building valued roles, making choices, setting goals, assuming responsibility, and driving how one's own life is lived.



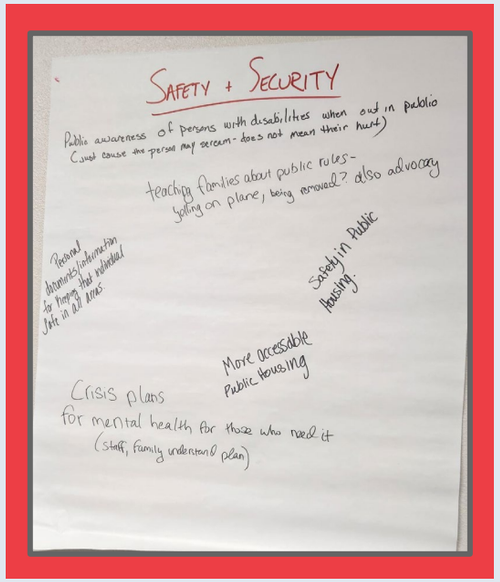
CDAC Ideas on Personal Outcomes

- Participants are supported to build self-advocacy skills in a variety of settings, as evidenced, in part, by:
  - They can express their needs and wants, with and without support.
  - They have the support and opportunity to practice advocating for themselves.
  - They know about their own disabilities and educate others in their communities.
- Participants are supported to communicate in a variety of ways, including through body language.
- Participants have opportunities to engage in leadership roles.
- Participants have the opportunity to engage in peer-to-peer activities.
- Transition-age participants have the opportunity to build and maintain their own transition portfolios to support planning.

*Source: Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)

Personal Outcomes & the Life Domains: Safety and Security

Staying safe and secure-emergencies, well-being, guardianship options, legal rights, and issues.



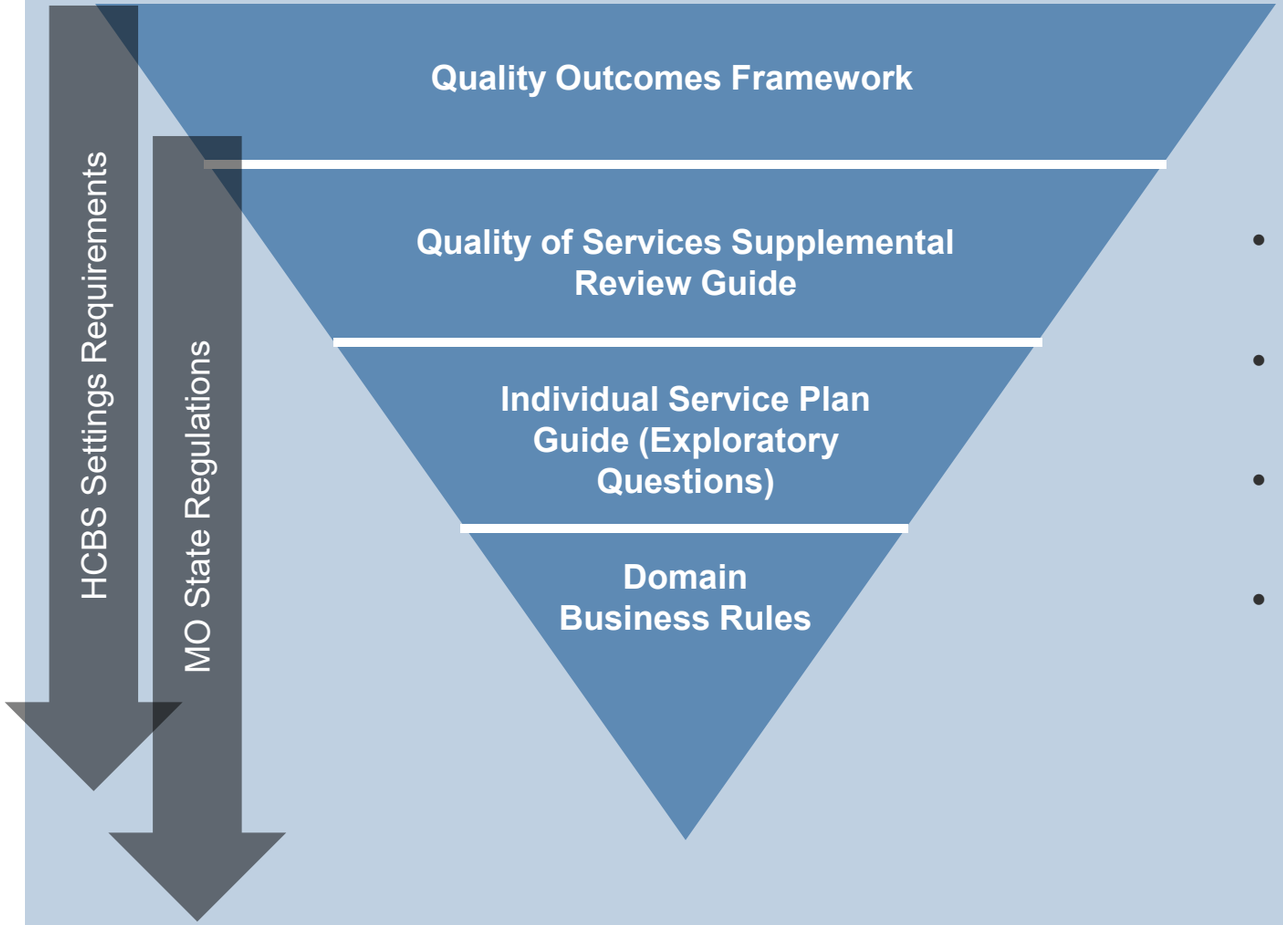
CDAC Ideas on Personal Outcomes

- Participants are supported safely.
- There is an individual understanding and documentation of what the participant needs to feel safe.
- Families are educated on how to keep participants safe.
- There are crisis plans for participants who need them;
  - Family members and staff are trained on and understand the plan.

*Source: [Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com)]

State Example: Missouri's Approaches to Quality Outcomes (1 of 3)

A&M connected with a Missouri SME to learn more about their approach.



Overview of Approach

- MO developed a Quality Outcomes Framework that is plain-language and straightforward.
- The Quality Outcomes Framework is based on Charting the LifeCourse.
- Their Services Review Guide is not a survey or an interview; it's based on observation.
- The contents of that document heavily inform their other quality management tools.

State Example: Missouri's Approaches to Quality Outcomes (2 of 3)

Stakeholder Engagement

1. People Participate in Meaningful Daily Activities of Their Choice
   Daily Life
2. People Are Active Members of their Communities While Determining Valued Roles and Relationships through Self-Determination
   Social & Spirituality
3. People Have Opportunities to Advocate for Themselves, Others and Causes They Believe In, Including Personal Goals and Dreams
   Citizenship & Advocacy
4. People are Educated about Their Rights and Practices Strategies to Promote Their Safety and Security
   Safety & Security
5. Families are Provided with Knowledge That Empowers Them to Facilitate Opportunities for the Individual's Self Determination Throughout the Course of His or Her Life
   Supports for Families
6. People Live in Communities They Choose, With Whom they Choose, and in Homes and Environments Designed to meet their needs
   Community Living
7. People Are Able to Choose Health/Mental Health Resources and Are Supported in Making Informed Decisions regarding their Health and Well-Being
   Healthy Living

Each Missouri quality outcome has a description and a series of **"talking points"** that are designed to help the user determine if an outcome has been met.

Example Talking Points for *Daily Life* Outcomes:

- Do you have people who explain options and choices in a way that make sense to you?
- When was the last time you tried something new?

Missouri quality outcomes are measured annually using data collected by the Division of Developmental Disabilities.

State Example: Missouri's Approaches to Quality Outcomes (3 of 3)

Daily Life-People Participate in Meaningful Daily Activities of Their Choice

This outcome is designed to support individuals in informing choices and encouraging self-determination in pursuing daily activities of their choice while exploring the full range of options, including employment, volunteering, use of free time and participating in activities of their choice. Outcomes and supports should be individualized to assist in achieving maximum potential.

TALKING POINTS:

- Do you have people who explain options and choices in a way that makes sense to you?
- Do these explanations help you make informed decisions about your options?
- When was the last time you tried something new?
- Would you like to try something new? What needs to happen in order for you to try something new?
- Have you had the chance to explore a variety of opportunities to determine areas of interest? How do you spend your day?
- What do you like most/least about your day?
- Is there anything you would like to change?

Social & Spirituality-People Are Active Members of Their Communities While Determining Valued Roles and Relationships through Self-Determination

This outcome is about presence and participation in the community, based on interests determined by the individual. Individuals are integrated into their community, including community service, in the same way as neighbors and fellow community members. Individuals have natural supports in their lives and relationships that are not based on their disability.

TALKING POINTS:

- Do you know about community activities and choose which ones to participate in?
- Do you have the support you need to participate in these community activities?
- Are you able to get to community activities of interest?
- Do you have the support you need to develop and maintain relationships with other community members?
- Are you a regular member of a church, social group, and/or community organization that is not related to having a disability?
- Do you spend time with people in your community who are not paid to provide you with support services?
- Do you enjoy community activities (such as shopping, going out to eat, etc.), and are you able to do these activities?
- Are you supported to explore and practice your religious beliefs?

Building on Strengths and Filling Gaps

Understanding the current state of how North Dakota measures personal outcomes.

Subtopic	Current State
Case Management Monitoring	• ND currently conducts case management monitoring to ensure that people are receiving the amount, duration, and scope of approved services, and that people are progressing towards meeting their individualized goals. • For the IID/DD waiver, case managers have guidance on monitoring and a tool for observation, but not specific questions, which makes it harder to track and trend across the system because they are entering notes.
Waiver Assurances	• HHS is working to align assurances across their waivers. Currently, the state uses different reporting cycles.
Customer Satisfaction	• IID/DD waiver has a formal grievance process within HHS; ASD and MF do not, but there is an informal process that people use. • ASD & IID/DD waiver currently does a customer satisfaction survey.
National Core Indicators (NCI)	• NCI is a national effort to measure and improve the performance of state developmental disabilities, aging, and physical disabilities service systems. ND participates in relevant surveys for the ID/DD population and for the aging and disability waiver: 2022-2023 surveys completed for the IID/DD system: Adult Family; Child Family; State of the Workforce (also did 2021-2022). 2023-2024 surveys in progress: Family/Guardian; In - person. Additionally, aging services completed the in - person survey with the National Core Indicators (NCI-AD) for the 2022-2023 survey cycle.
Consumer Assessment Of Healthcare and Provider Systems (CAHPS)	• HHS does not currently use the CAHPS survey for IID/DD, ASD, or MF waivers; it is being used as part of external quality review. The CAHPS survey is designed to assess the experiences of adult Medicaid beneficiaries who receive long-term services and support from State HCBS programs. Given the adult focus, it is not the right tool for the Cross-Disability Children's waiver.
CQL Accreditation	• The IID/DD waiver currently requires CQL accreditation for its provider network.
Child Core Set Metrics	• The Child Core Set includes a range of children's quality measures encompassing both physical and mental health. These measures include a focus on preventative health.

CDAC Quality Recommendations

The CDAC recommends a quality approach that focuses on person and family centered thinking and outcomes for the new waiver

#	CDAC Recommendations	A&M Response
Q.1	Consider using the Charting the LifeCourse framework for quality management to keep a focus on outcome measures that are person and family - centered.	Agree
Q.2	Develop a case management monitoring tool that includes a focus on personal outcomes and that can be entered into an electronic system for tracking and trending.	Agree
Q.3	Moving to a new framework for quality management will require training at all levels (from individuals and their families, to providers, case managers, and others).	Agree
Q.4	The development of a new waiver and the upcoming Access Rule, provide ND with an opportunity to review and revisit its quality management strategy to determine opportunities for alignment and to add additional person and family-centered performance measures.	Agree
Q.5	Align approaches to customer satisfaction across the IID/DD, ASD, and MF waivers.	Agree
Q.6	Continue to participate in survey opportunities like NCI Child & Family survey. Seek opportunities to include children and families currently in the ASD and MF waivers.	Agree. Note that MF does not fit with the current NCI survey framework.
Q.7	Leverage requirements in the IID/DD waiver and include them in the Cross Disability Children's waiver, thereby extending these requirements to providers for all other populations.	Agree

Fiscal Implications

Understanding Medicaid Waiver Spending

Slide Excerpt from CDAC Meeting

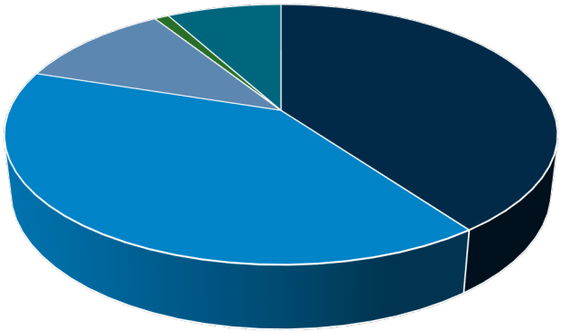
Mapping major spending elements associated with waivers is important to understanding the true cost of adding /modifying waiver slots and services.

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

Projecting the Cost of Creating a New Cross-Disability Children's Waiver

The true cost of creating a new waiver includes both ongoing service costs **and** system innovation costs to support successful systems-level change

System Innovation Costs
Time-limited, supports start-up planning

North Dakota will need to invest heavily in the process of thoughtfully redesigning their system over several years, likely seeking help from national experts along the way

Program Operation Costs
Ongoing, supports continued services

These ongoing expenses represent the anticipated cost of running the program and delivering services once the program is created and achieves steady state operations

Understanding System Innovation Costs for the New Cross-Disability Children's Waiver

Systems innovation efforts help set new waivers up for success by aligning programs and policies to support the achievement of waiver goals

This type of systems-level change requires extensive work to first establish a strong foundation for the new program, including:

- Review of national level of care tools and extensive year long + testing process to ensure no unintended consequences from changes
- Creation of new system definitions and criteria for ID / DD
- Assessment / redesign of current case management structure
- Market scan of service provider rates and adequacy review
- Procurement of providers for new services / populations
- Redesign of application, eligibility, and quality process flows
- Staff augmentation to guide creation of and support delivery of new program – self-advocate and community coordinator
- Continued investment in community engagement (ex: CDAC)
- Writing of new waiver program application and oversight/management of extensive federal negotiation process between ND and CMS

Estimating Service Delivery Costs for the New Cross-Disability Children's Waiver

Systems innovation efforts help set new programs up for success by aligning programs and policies to support the achievement of waiver goals

Calculating ongoing waiver service delivery costs involves a number of related inputs that will be affected by final policy decisions, including:

- Approach to **waitlists**: will the new waiver include enough slots to cover anticipated growth in the ASD population?
- **Additional populations** covered by the waiver: will the new waiver include children with behavioral health needs?
- The **level of care** / "qualifying bar" at different ages: will the new waiver widen the door to serve more children 3-5?
- Services: will the new waiver include **new services** not already offered by existing ND children's waivers?

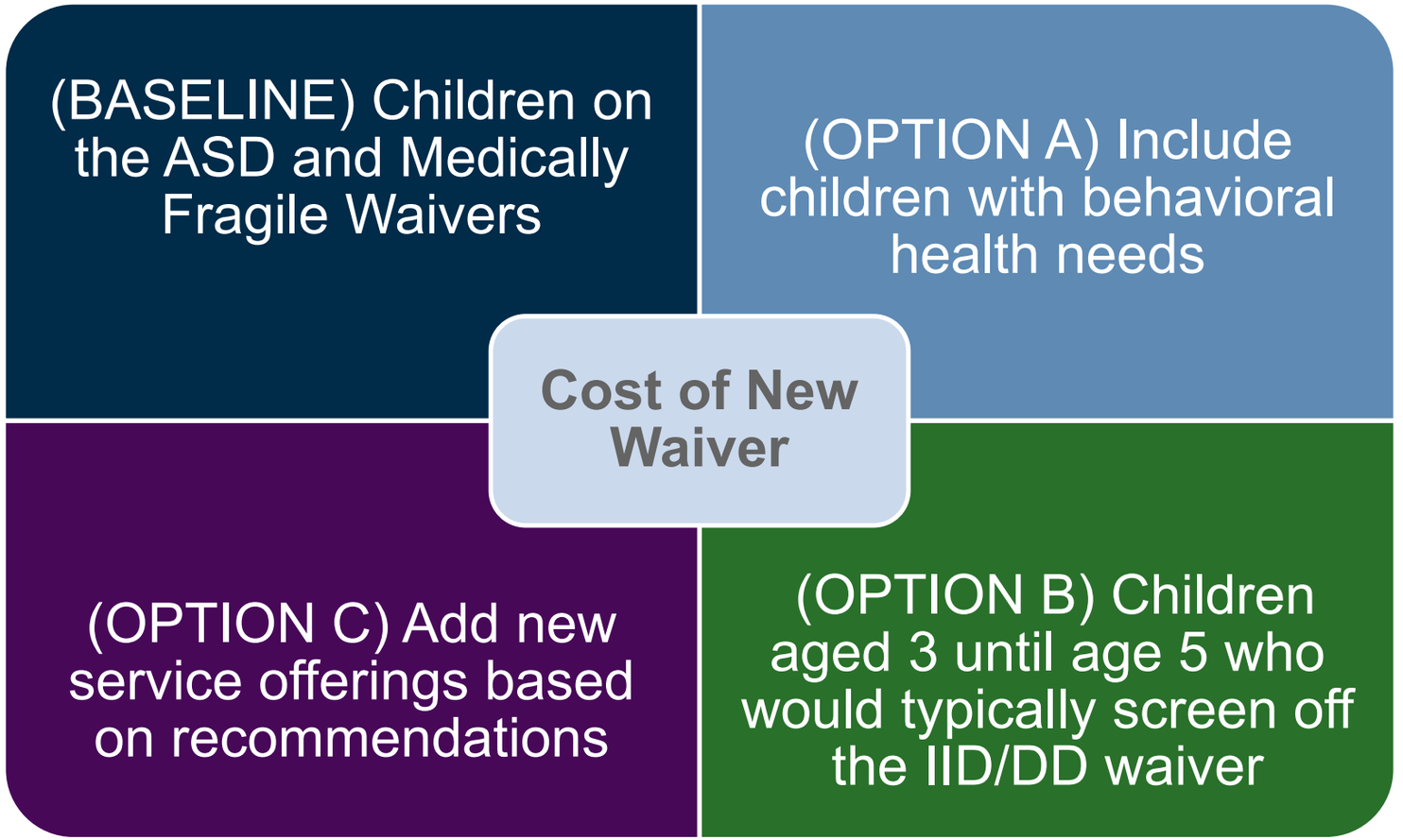
Projecting service delivery costs for a new program requires combining data multiple sources to form the basis for initial program spending projections, including data such as:

- **Historical expenditures from existing ND waivers** can serve as a baseline input to understanding how existing populations on ND's waivers today currently utilize services
- **National waiver program information** provides an insight into the potential costs associated with serving populations not yet covered by North Dakota children's waivers
    - Similarly, national waiver information also offers perspective on the potential cost of new services
- **Estimating costs for the new waiver requires joining information about existing populations / services with national data on potential new populations / services** and creating educated projections based on these inputs

Predicting Service Delivery Costs for the New Children's Cross-Disability Waiver (CDCW)

Estimating the cost for the new waiver requires both understanding existing costs for the ASD and MF waivers, and predicting costs for new elements, including expanded services and populations.

Part 1: Baseline Costs for Existing ASD+MF Slots, **Part 2:** Projected Additional Cost for Expanding ASD Slots to Avoid Waitlist



Optional add-on costs / enhancements

New cost, optional expanded service offerings

(BASELINE) Approach to Estimating Core Cost Elements for Existing Populations

Understanding baseline costs for the new cross-disability children's waiver requires utilizing data on existing populations already served today, namely those who are right now receiving services via the ASD or MF waivers

Existing Waiver Services*

- Identified service cost projections in most recent CMS approval documents for ASD and MF waivers (Appendix J)**
- Added 25% projected increased to reported service utilization estimates, based on individuals having access to a larger list of services in the new waiver (CDC waiver will combine, at minimum, services from ASD and MF waivers)

Medicaid State Plan Services

- Identified Medicaid State plan service cost projections in Appendix J of waiver documents (see above)
- No additional factor added to cost projections, as access to State Plan services will remain consistent

Case Management Services

- Calculated current DD case management (DDPM) cost per participant using department-report "all-in" figure and a recommended target case load of 1 DDPM: 40 waiver participants
- Utilized per person DDPM cost to project cost of any new slots and corresponding number of new DDPMs needed

Additional Costs

- Additional costs include waiver slot management software and Fiscal Management costs
- Slot management cost projections utilized the 2024 rate / slot, with projected yearly cost increase of 5% / slot
- Fiscal Management costs were based on national scan of state-reported cost estimates in 1915c waivers

**The service cost for the baseline waiver populations (ASD, MF) is based on figures for waiver services that are currently offered in either the Medically Fragile and/or ASD Waivers; costs for potential new services are included in separate calculations as part of Component C: new services*

*** Service costs do not include the case management costs reported in ASD waiver service projections; the recommendation for case management under the new waiver is to instead provide case management through the state case managers (DDPMs) who currently serve the IID/DD waiver. This cost is accounted for separately under case management.*

(BASELINE, Part 1) Projected Cost of Serving Existing ASD/MF Waiver Populations on CDCW

The below costs illustrate the projected total expense of serving the population of children already enrolled in the ASD/MF waivers today. Note much of these costs already exist in the waiver system today and would be migrated to the new cross-disability waiver.

Population	Current Slots	Waiver Services (Current Costs + 25%)	State Plan Services	Case Management (DDPM Ratio: 1/40)	Additional Costs (Slot management, FMS)	Total Project Costs
ASD	345	$1,920,291	$3,475,875	$823,308	$556,160	**$6,775,634**
Medically Fragile	50	$417,761	$1,537,600	$119,320	$80,603	**$2,155,284**
ASD + MF	395	$2,338,051	$5,013,475	$942,628	$636,763	**$8,930,917**

Baseline Estimate for Cost of Serving Existing Populations on New Cross Disability Children's Waiver

- **Total Costs:** ~$9 million
- **Participants:** ~400 participants
- **Average:** Approximately $22.5k/participant

Note: The Federal Government pays for 51.55% percent of North Dakota's Medicaid costs, including waiver expenses

(BASELINE, Part 2) Approach to Estimating Additional Slots Needed to Serve ASD Population

Additional slots will be needed to avoid a waitlist for services in the coming years, regardless of the status of the new waiver

- Based on the current volume of ASD waiver applications, and the continued growth in ASD prevalence, it is anticipated that the ASD waiver will run out of open slots in the near future
- If no changes are made to the current system, this means that there will very likely be a waitlist for the ASD waiver
- To avoid developing a waitlist on the new waiver as a result of this need, we worked with the State to project the anticipated number of additional slots that would be required to address the need for more ASD waiver slots
- We utilized two key data inputs to estimate the true need for ASD waiver slots
  - ND monthly application data and qualification percentages
  - Peer state population percentages served on ASD waivers

Rough projections indicate that **within the next few years there will be a need for an estimated additional 126 waiver slots to address the need for ASD services and avoid waiver waitlists**

➢ It is our recommendation that ND proactively include these slots in the design of the new waiver

(BASELINE, Part 1 and 2) Projected Cost to Meet the Growing Need for ASD Services

The below costs illustrate the projected total expense of serving the ASD/MF population, **assuming the creation of additional slots** to address the growing need for ASD waiver services already seen today.

Population	Slots	Waiver Services (Current Costs + 25%)	State Plan Services	Case Management (DDPM Ratio: 1/40)	Additional Costs (Slot management, FMS)	Total Project Costs
Existing MF + ASD Slots	395	$2,338,051	$5,013,475	$942,628	$636,763	**$8,930,917**
New Slots	126	$701,324	$1,269,450	$300,686	$203,119	**$2,474,579**
Total	521	$3,039,375	$1,243,314	$6,282,925	$747,645	**$11,405,497**

Baseline Estimate for Serving ASD/MF Populations on New Waiver, Adding Slots to Avoid Waitlists

- **Total Costs:** ~$11.5 million
- **Participants:** ~500 participants
- **Average:** Approximately $22k/participant

Note: The Federal Government pays for 51.55% percent of North Dakota's Medicaid costs, including waiver expenses

(OPTION A): Approach to Estimating Cost of Adding Behavioral Health Population to the Waiver

- Both CDAC members and public commenters described a gap for children with behavioral health needs, and voiced that a true cross-disability waiver should include behavioral health, especially given the common co-occurrence
- A&M agrees with the CDAC recommendation to add behavioral health to the children's cross-disability waiver and worked with the State to estimate projected number of slots and costs associated with slots
- We conducted a national scan of states serving children with behavioral health needs and selected a group of model states off which to base ND's projections (see next two slides for further information)

Rough projections based on our national scan and conversations with the State indicate that North Dakota would **serve an estimated 155 children with behavioral health needs**

(OPTION A) Examining National Costs to Serve Kids with Behavioral Health Needs

Several states serve kids with behavioral health needs using a dedicated waiver for this population; A&M utilized the states in blue as the best models for estimating expenditures. See Appendix for more information on national scan and selection methodology.

State	Criteria	Waiver Slots	State Pop. Under 25	Percent of Pop. Under 25 Served	Average Waiver Services Spend Per Person	Average Total Medicaid Spend Per Person	Total Waiver Services Spend, Across All Participants	Total Medicaid Spend, Across All Participants
Iowa	SED	1,860	1,020,800	0.182%	$6,500	$15,323	$12,155,000	$28,500,575
Michigan	SED	969	3,069,400	0.032%	$14,600	$24,811	$14,147,400	$24,041,559
Ohio	SED	1,235	3,619,900	0.034%	$3,200	$13,443	$3,952,000	$16,602,105
South Carolina	SED	360	1,585,600	0.023%	$12,000	$60,422	$4,320,000	$21,752,060
Texas	SED	3,591	10,545,200	0.034%	$5,000	$21,713	$17,955,000	$77,971,239
Average	**SED**	**1,603**	**N/A**	**.061%**	**$8,300**	**$27,142**	**$52,529,300**	**$33,773,508**

(OPTION A) Projected Cost of Serving Children with Behavioral Health Needs on CDCW

The below costs illustrate the projected total expense of serving children with behavioral health needs on the new waiver, based on a national scan of children's behavioral waivers and conversations with the State. Larger ranges are included in the appendix.

Population	Projected Slots	Waiver Services (Based on national scan)	State Plan (Based on national scan)	Case Management (DDPM Ratio: 1/40)	Additional Costs (Slot management, FMS)	Total Projected Costs
Behavioral Health	155	$1,281,382	$2,925,688	$369,892	$249,869	**$4,826,831**

Estimated Cost of Serving Children with Behavioral Health Needs on the New Cross Waiver

- **Total Costs:** ~$4.8 million
- **Participants:** ~150 participants
- **Average Spend:** Approximately $31k/participant

Note: The Federal Government pays for 51.55% percent of North Dakota's Medicaid costs, including waiver expenses

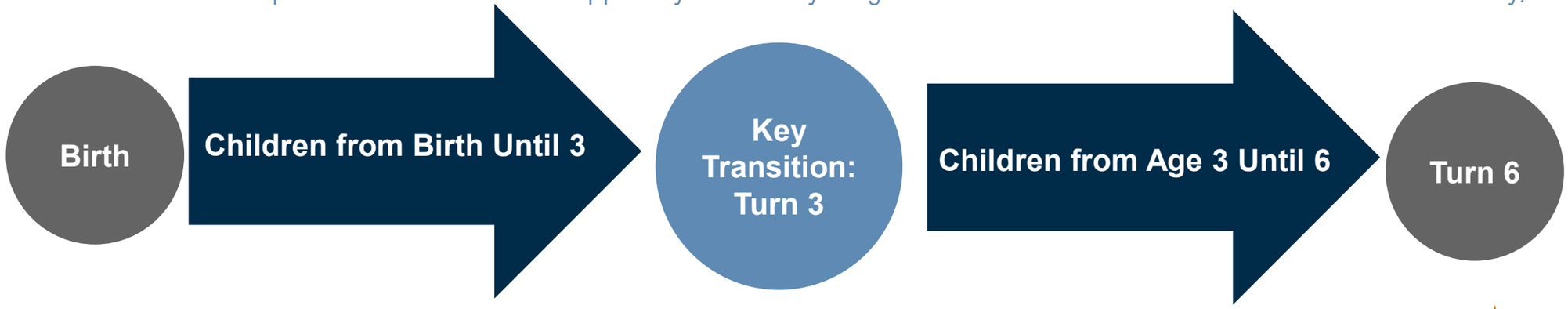
(OPTION B): Approach to Estimating Cost of Expanding Access for Kids 3-5

- North Dakota provides strong support for children with disabilities ages birth until three (see slide 170)
- Eligibility requirements change at age three, which results in many children falling off the waiver (see slide 171)
- At the request of the legislature, the State, CDAC members, and the public, A&M has projected costs associated with increasing access for kids 3-5
- Specifically, this would mean lowering the eligibility requirements for children from ages three until five, so that more children would continue to qualify for waiver access past their third birthday
- A&M examined Part B IDEA data to understand the subset of children who could potentially be served on the cross-disability children's waiver if eligibility is expanded; **ND will need to decide how to prioritize investment in the waiver to determine how widely this door can r be opened / how many new children 3-5 will be served**

The cost of expanding access for children from age 3 until 5 **ultimately depends how widely the State choses to open the door,** and what the new level of care / eligibility process looks like

(OPTION B) Understanding the Current Service Landscape for Young Children with Disabilities

IDEA and Medicaid provide two of the core support systems for young children with disabilities in states across the country, including North Dakota



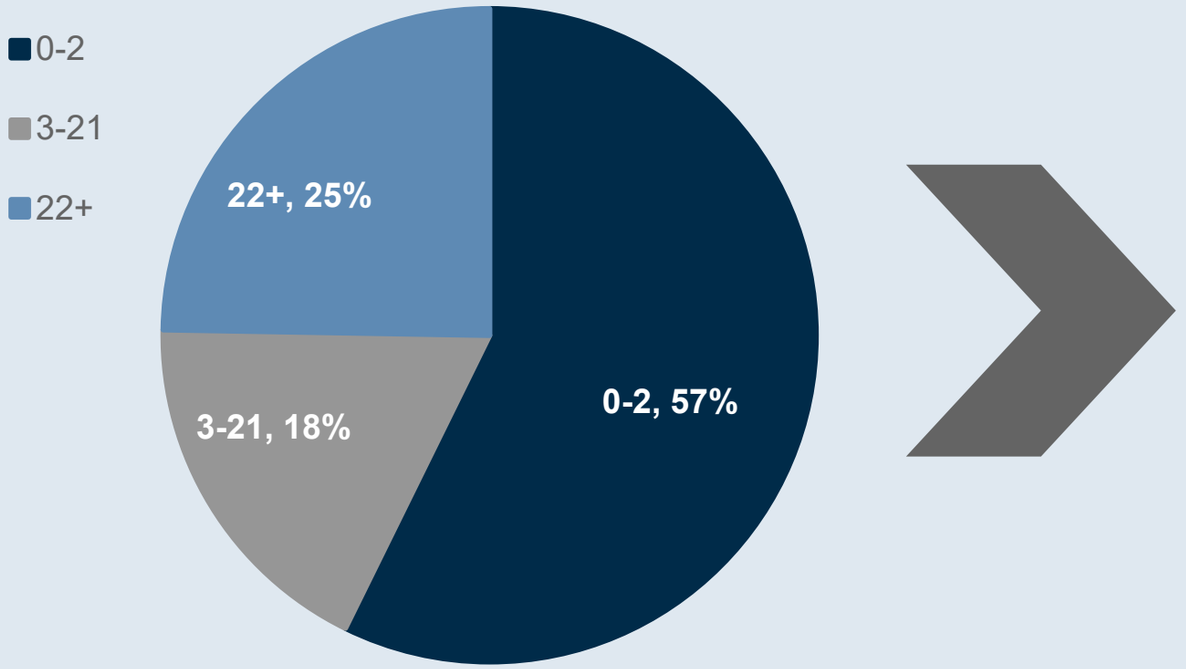
	Children from Birth Until 3	Key Transition: Turn 3	Children from Age 3 Until 6
IDEA Programs	• Part C of the IDEA serves children with disabilities 0-3 • Also known as Early Intervention Services (EIS)	Eligibility for IDEA programming changes when children turn 3	• Part B of the IDEA serves children with disabilities 3-21 • Focused largely on school-based supports and serviced
ND Medicaid Waiver Access	• **Eligibility:** IID/DD waiver utilizes eligibility requirements similar to Part C • Leads to strong waiver services for kids birth until 3	Eligibility for ID/DD waiver changes when children turn 3	• **Eligibility:** IID/DD waiver utilizes new eligibility requirements (same requirements used for all ages 3+) • No longer mirrors IDEA Program Requirements • Leads to many children falling off the waiver around their 3rd birthday

Recommendation:
Include a new, easier eligibility process for kids 3-5 to qualify for the cross-disability children's waiver to provide continued Medicaid waiver support for very young children with disabilities. Consider aligning this new eligibility with Part B of IDEA.

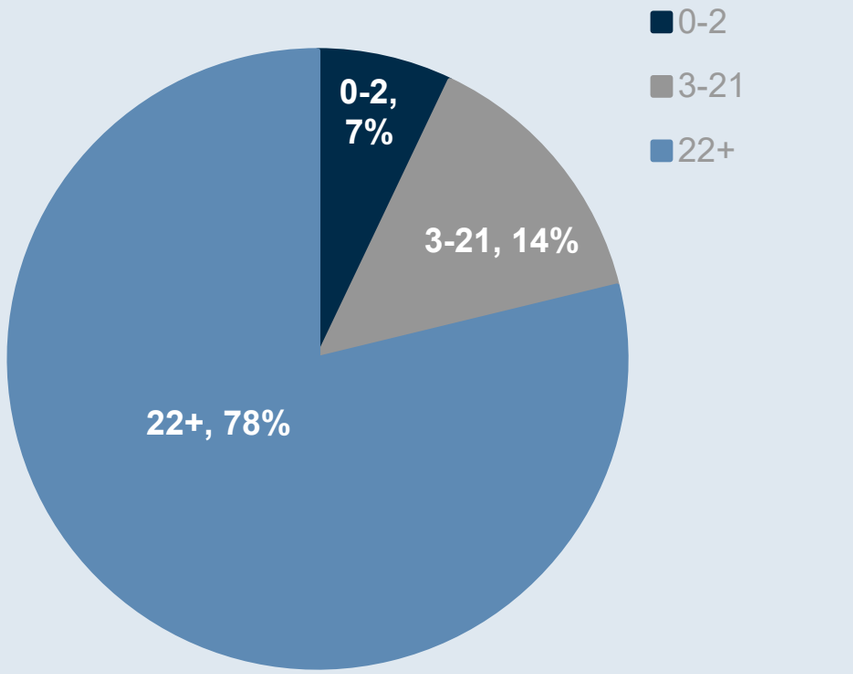
(OPTION B) North Dakota's Waivers: A Solid Foundation for Children Under Three

North Dakota's Developmental Disabilities (IID/DD) Waiver already delivers supports to the youngest children (from birth until age 3) in a highly cost-effective manner.

Percent of Total IID/DD Waiver Participants By Age Range



Percent of Total IID/DD Waiver Participant Spending By Age

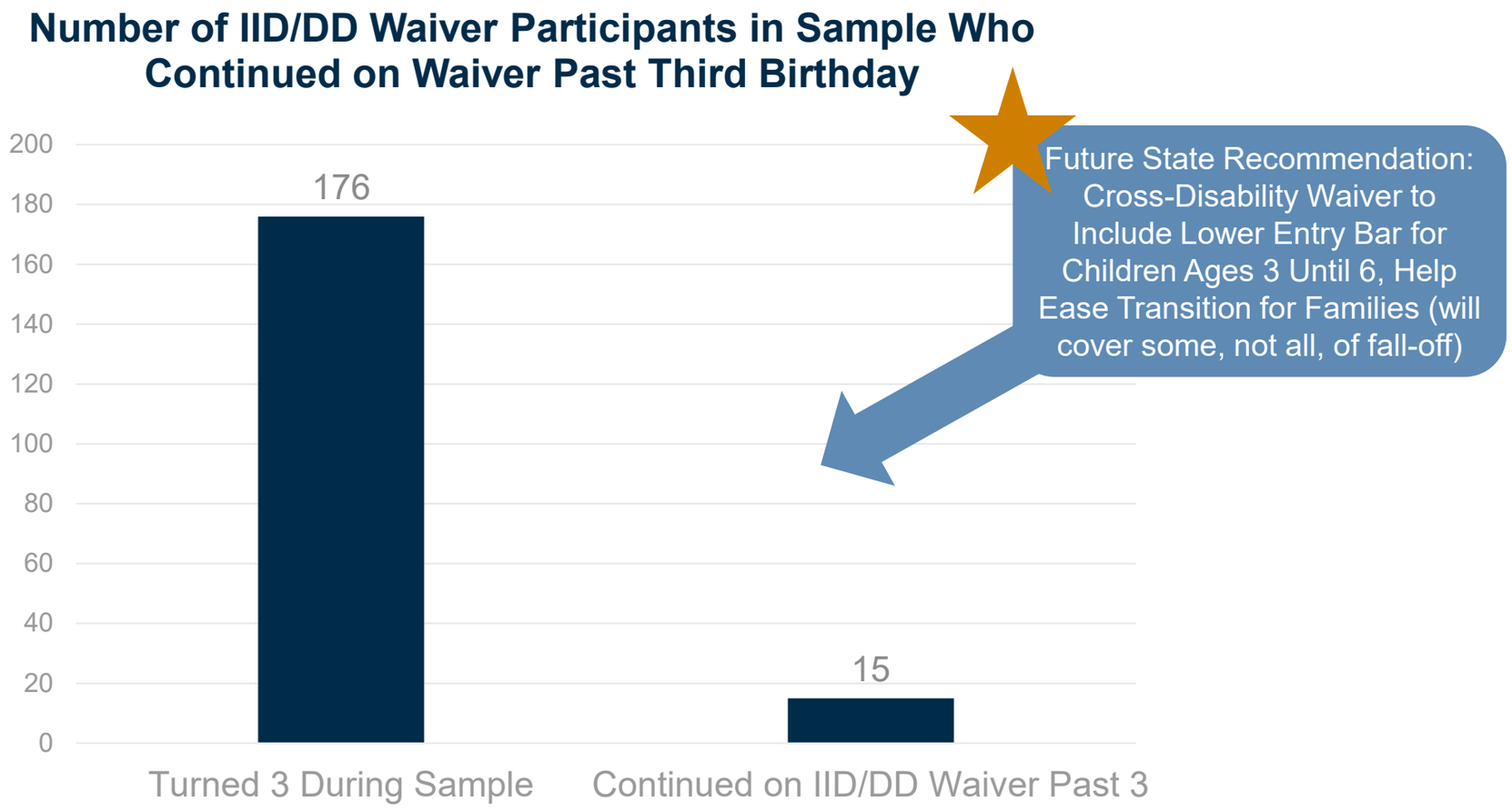


- Those from birth until age 3 make up the largest share of participants but the smallest share of spending.
- Evidence supports that investments in children at this earliest age group provide the most benefit.
- Waiver eligibility also increases access to Medicaid state plan services, including EPSDT for children, because of the income and asset waiver.

(OPTION B) The Opportunity: Improving The Experience for Young Children Aged 3 Until Age 5

North Dakota's IID/DD Waiver offers strong support for children under three; however, previous stakeholder interviews and data analysis indicate there is a significant drop-off at age three, when young children still do not yet have access to additional school supports.

- 91% of waiver participants who turned three during the 2018-2021 sample period did not continue beyond their third birthday (mix of denials and families who chose not to continue services).
- Anecdotally, stakeholders described a perceived "cliff" at age three-often losing not only waiver but also the income / asset waiver many are using to access Medicaid insurance.
- According to interviews with State staff, the IID/DD Waiver regularly experiences significant year-to-year turnover, with around 800-900 people moving off yearly, many of whom are age three.



(OPTION B) Cost of Increasing Medicaid Waiver Access for Kids Ages 3 Until 5

Given the large number of children who screen off the waiver at age 3, the State will need to make decisions about how widely to open this door.

Population	Potential Slots	Waiver Services	State Plan	Case Management	Additional Costs	Total Costs
Ages 3-5 Expansion	840	$5,841,063	$4,457,054	$2,003,956	$1,368,948	**$13,671,022**

Explanation of the Above Cost Elements – Understanding Projections to Expand Access for Kids 3-5

- **Potential slots:** This number represents the universe of possible additional children who might be served on the new cross-disability children's waiver, if a lower eligibility threshold is established for children from ages 3 until 5
  - This figure is calculated using Part B breakout numbers by disability type to identify target populations (ASD, TBI, DD, Other). 840 is the difference between children ages 3-5 served on the IID/DD waiver and those served on Part B.
  - **It is likely the actual number of additional children served would be smaller, depending on the functional level of care established for this age. This number represents the upper limit of possible individuals in the target population.**
- Waiver Services and State Plan Service Costs: These figures are based on a blended estimate of Medicaid claims data for children ages birth until 3 and age 3 until 5, to reflect the fact that new children continuing on the waiver would represent a lower acuity.
- Case Management and Additional Costs: Numbers are calculated consistent with previous figures (assuming 1:40 DDPM ratio)

Note: Any additional costs from 3-5 expansion would be phased in across three years as increased access out for children ages 3+. Costs reflect total expenditures; North Dakota receives federal match of 51.55% towards all Medicaid waiver costs.

(OPTION C): Approach to Estimating Cost of Adding New Waiver Services

- As a minimum, the new cross-disability children's waiver will include the services currently offered on the MF and ASD waivers to ensure continuity in coverage
- CDAC also explored whether there were additional services that should be included on the new waiver and created a list of potential new services to add
- The cost of adding new services to the waiver is highly variable and depends on several factors, including how many slots are added and whether new services are "capped" with individual budget limits
    - Policy decisions on waiver size must first be made in order to understand cost of potential new services
- A&M conducted national research to identify estimated utilization and cost for potential new services based on other states who already offer a similar version of said service

Due to the significant policy decisions remaining, there are currently wide variations in final waiver slot numbers. Thus, there is a significant range for how much it would cost to add a new service. We have included baseline data on services to inform final cost calculations once slot numbers are determined, and included one example of how different slot numbers might affect total cost.

(OPTION C) Examining National Utilization Data on Potential New Waiver Services

A&M utilized a national scan to identify states already offering similar services and new options proposed by CDAC

Service Name	Average Anticipated Utilization (Based on national scan)	Average Cost / Participant (Based on national scan)
Community Learning Service	20%	$20,778
Crisis – Center Based Respite	1%	$25,368
Discovery	3%	$1,657
Homemaker	10%	$3,618
Life Skills	20%	$9,214
Peer Supports	20%	$2,500
Family Caregiver	25%	$28,296

(OPTION C) Example of Variable Cost Projections for New Services: Homemaker / Chore

A&M estimated the potential cost of adding homemaker services, using existing services in other children's waivers as an example.

Populations	Slots	Total Projected Cost
Lowest Cost – Only Foundational Populations Included (Existing MF/ASD already served, additional ASD slots)	521	$180,191
Medium Cost – Foundational Populations + Behavioral Health	676	$233,799
Highest Cost – Foundational Populations + Behavioral Health + Complete Expansion for Ages 3-5	1516	$524,228

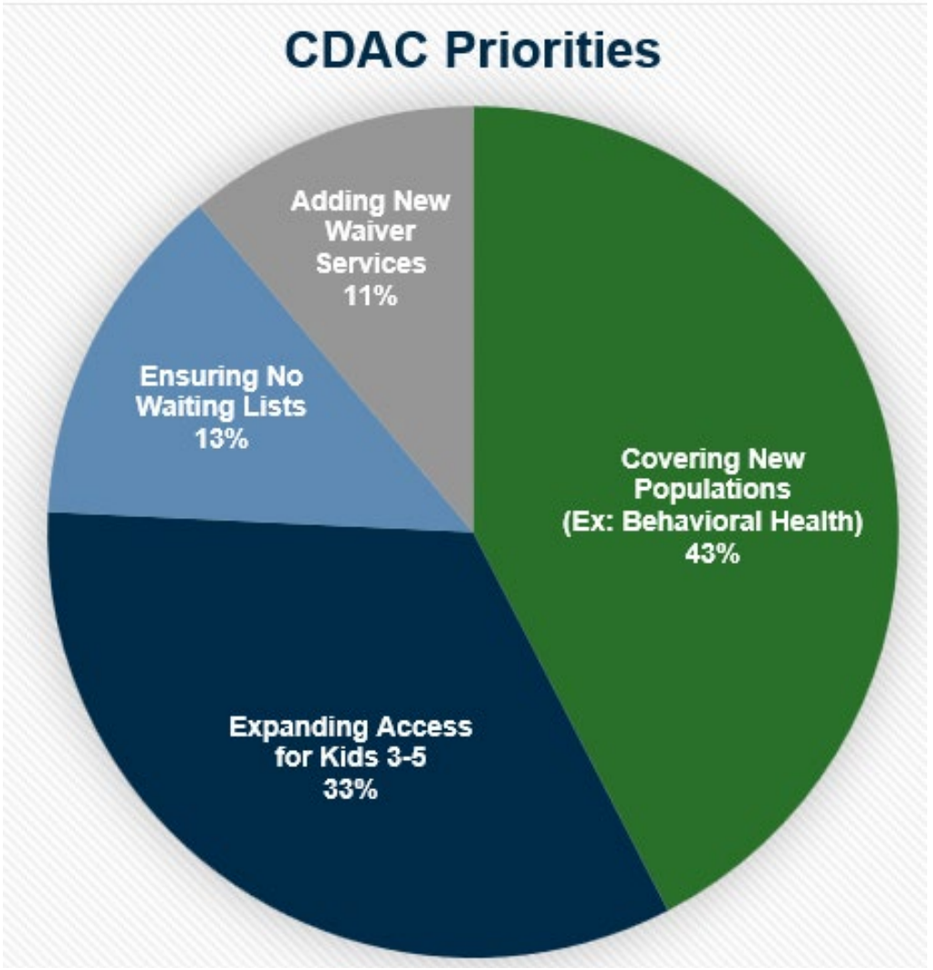
The above table illustrates how dramatically costs for adding new services will shift based on the final populations included in the new cross-disability children's waiver, with large fluctuations possible. The State will need to consider how both slots and services operate as connected levers that impact the total waiver cost

Asking CDAC to Prioritize: How Would You Invest Additional Funds?

Voting	%	Potential New Service
19	42%	**Increasing Access for Additional Populations** (Behavior Health, CP, FASD, DS, MS…)
15	33%	**Expanding Access for Kids 3-5** (Reducing the "Cliff" for young children being re-assessed)
6	13%	**Ensuring No Waiver Waiting List** (Ability to access wavier as soon as you qualify)
5	11%	**Adding New Wavier Services** (ex: Chore/homemaker)

Each member received **three votes (3) and could split votes as desired:**

3 2/1 1/1/1



Roadmap

Developing a Roadmap to Implementation

Sustainable systems change takes time, external support, full - time employee (FTE) effort, and funding.

- The following slides propose a **three-step roadmap that spans multiple bienniums**. Each step includes milestones needed to support the launch and sustainability of a cross-disability children's waiver. There will be opportunities for HHS to demonstrate measurable progress throughout the journey. Additionally, recognizing the time it will take to achieve the new waiver, each phase will include action steps to address service gaps while North Dakota builds towards the new cross-disability waiver. We roughly estimate that each phase spans two years.
- Note that the first step is legislative approval, which is expected around June 2025, when the session ends. Pre - work can be done, but it will be pending that approval.
- Additionally, some steps in this process will take time and are beyond HHS's control. Factors such as CMS approvals and IT configurations and enhancements are managed by external parties and may impact deadlines.

Legislative Approval

Phase 1:
Laying the Foundation

Phase 2:
Launching the Cross - Disability Waiver

Phase 3:
Stabilizing & Improving

Phase One: Laying the Foundation for Sustainable Change (1 of 2)

Laying the foundation for sustainable change.

Now that HHS has received detailed feedback from the CDAC members and the public, there is both pre-work to be done and opportunities for quick wins.

- **Improving the Front Door to Services**
  - Develop combined front door and application process for all children's populations.
  - Use plain language materials.
  - Modernize definition of intellectual disability to match the AAIDD definition. Remove requirement for Active Treatment.
  - Understand options to provide access to a psychiatrist to expedite enrollment; implement pending fiscal impact. Consider whether a psychiatric physician's assistant could provide the required testing.
  - Determine plan for children with Severe Emotional Disturbance (SED). This population faces a gap in HCBS coverage. Analyze population data and unmet need and plan for potential coverage through the cross - disability children's waiver.
  - Currently ND Century Code 75-03-23-04 holds that if an adult is found eligible for the IID/DD waiver, they are not able to receive services through a different waiver. This section would need to be amended to allow the person to select the waiver that best fit their assessed needs.
- **Supporting People and Families with Navigation and Person-Centered Case Management**
  - Determine future state roles for state delivery of case management, as well as family navigation. Seek opportunities to reduce administrative responsibilities so that case managers can focus on person and family-centered practices.
  - Understand and develop qualifications for each role; create position descriptions.
  - Project future needs, estimate caseloads aligned with those needs, and plan for any necessary transitions.
- **Target Population and Level of Care**
  - Explore options and select a tool or tools for use in the new cross \-disability children's waiver.
  - Develop and plan to test criteria once the waiver is launched.

Phase One: Laying the Foundation for Sustainable Change (2 of 2)

Laying the foundation for sustainable change.

- **New Services**
  - **Supporting People and Families to Self- Direct Services:** Explore options for offering support broker and information and assistance supports.
  - **Transition Supports**: Launch transition supports that can be offered ahead of the waiver to fill gaps, meet needs, and build provider capacity and HHS experience offering these supports ahead of the waiver launch.
  - **Complex Care Coordination**: Plan for complex care coordination as a Medicaid state plan service
- **Find Opportunities for Alignment and Efficiencies Across Programs**
  - **Process Alignment:** Map processes for waiver administration across the IID/DD, ASD, and MF waivers. Look for opportunities to align and improve processes.
  - **Provider Qualifications**: Review provider qualifications across waivers and seek opportunities for alignment.
  - **Rates:** Review rates and seek opportunities for alignment.
  - **Quality:** Review waivers for opportunities to align measures. Understand and plan for the impact of the pending CMS Access Rule. Continue NCI surveys and consider opportunities to expand populations. Plan for using CQL accreditation across populations, including exploring the option of state certification.
- **Build a Sustainable Infrastructure to Stay on Track and Report Progress**
  - Stand up **Project Management** with a governance structure for regular reporting, guidance, and risk escalation and mitigation.
  - Stand up **Change Management** to support internal and external stakeholders in being ready for this change.
  - Determine whether changes to IT systems are configurations or enhancements, and get these on the roadmaps.
- **Deep Stakeholder Engagement to Build the Future State Together**
  - Develop and launch a multi-layered engagement strategy for input and to develop opportunities for double-loop learning to guide implementation.

Phase Two: Launching the Cross - Disability Children's Waiver

With the foundation in place, develop, submit, and launch the Cross - Disability Children's waiver.

- **Target Population and Level of Care**
  - Include existing target populations as defined in the ASD and MF waiver.
  - Add children aged 3 until age 5 that would meet Part B eligibility criteria.
  - Add children with Severe Emotional Disturbance.
  - Study population prevalence and project slots needed.
  - Plan for potential waiting list, in case not all slots are funded. Identify areas to seek reserved capacity.
  - Update level of care for the IID/DD waiver.
  - Test and implement level of care tools for each target population.
- **Services**
  - Collaborate with existing providers to serve multiple populations; recruit new providers, especially for new populations and new services.
  - Determine which new services to offer, pending funds availability.
  - Project utilization and cost.
  - Launch complex care coordination *(maybe P3).*
- **Write and Submit Waiver for Approval**
  - Draft the waiver, incorporating all the work completed in Phase One.
  - Submit the waiver to CMS and engage in negotiations.
  - Update regulations, policy, and guidance accordingly.
- **Build a Sustainable Infrastructure to Stay on Track and Report Progress**
  - Continue to track, coordinate, and report on progress across workstreams.
  - Continue to build readiness for change.
- **Deep Stakeholder Engagement to Build the Future State Together**
  - Refresh and continue to implement engagement plan.

Phase Three: Lessons Learned, Sustainability, Improvement

Lessons learned and next steps for sustainable systems change in how ND supports children with disabilities.

- **Target Population and Level of Care**
  - Include existing populations from the ASD and MF waivers.
  - Add children aged 3 until age 5 who meet Part B eligibility criteria.
  - Add children with Severe Emotional Disturbance.
  - Test and implement tools for each group.
- **Case Management**
  - Review case loads and function allocation.
  - Continue to evaluate whether family navigators should be offered as a waiver service or provided through other Medicaid funding.
- **Services**
  - Pending fund availability, consider adding additional CDAC-recommended services.
- **Build a Sustainable Infrastructure to Stay on Track and Report Progress**
  - Continue to track, coordinate, and report on progress across workstreams.
  - Continue to support readiness for change.
- **Deep Stakeholder Engagement to Build the Future State Together**
  - Seek feedback from waiver participants and their families to understand what's working well and where there are opportunities for improvement.

Appendix

Key Terms and Acronyms

Key Terms (1 of 2)

- **Access**: The journey people go through to apply for and receive waiver services
- **Advocacy and Engagement**: Building valued roles, making choices, setting goals, assuming responsibility and driving how one's own life is lived
- **CMS Access Rule**: Goal of the proposed rule is to inform systems transformation in key areas of workforce, rate setting, person-centered planning, quality, and stakeholder engagement. Proposed rule includes changes to current requirements as well as newly proposed requirements in both fee-for-service and managed care delivery systems
- **Community Living**: Where and how someone lives- housing and living options, community access, transportation, home adaptations and modifications
- **Cross-Disability Waiver**: The new waiver that CDAC members are helping to design. This waiver will support children and their families to live in their own homes in the community. It will be based upon the child's functional needs.
- **Daily life and employment**: What a person does as part of everyday life–school, employment, volunteering, communication, routines, life skills
- **EPSDT:** The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. EPSDT is key to ensuring that children and adolescents receive appropriate preventive, dental, mental health and specialty services. (Early and Periodic Screening, Diagnostic, and Treatment | Medicaid)
- **HCBS Quality Measure Set**: A set of nationally standardized quality measures for Medicaid-funded HCBS. The HCBS Quality Measure Set promotes more common and consistent use within and across states of nationally standardized quality measures in HCBS programs. (Home and Community-Based Services (HCBS) Quality | Medicaid)
- **Home and Community-Based Services Waiver**: Home- and Community-Based Services (HCBS) are types of person-centered care delivered in the home and community. A variety of health and human services can be provided. HCBS programs address the needs of people with functional limitations who need assistance with everyday activities, like getting dressed or bathing. HCBS are often designed to enable people to stay in their homes, rather than moving to a facility for care. HCBS programs are often funded by state waivers. Waivers are part of a state's Medicaid program, but they provide a special group of services to a certain population. (Home- and Community-Based Services | CMS)
- **Level of Care**: All waivers require individuals to meet criteria set by the state and based on level of need. In order to receive waiver services, eligible individuals must demonstrate the need for a Level of Care (LOC) that would meet the state's eligibility requirements for services in an institutional setting.(State Medicaid Plans and Waivers | CMS)

Key Terms (2 of 2)

- **Life Domains**: Life domains are the different aspects and experiences of life that we all consider as we age and grow. Individuals and families plan for the present and future life outcomes that take into account all life domains and have opportunities for life experiences that build self-determination, social capital, economic sufficiency, and community inclusion. (Exploring the Life Domains – LifeCourse Nexus (lifecoursetools.com))
- **Person-Centered Practices**: Person-Centered Practices is the result of developing and implementing individualized plans, based on a person's preferences, strengths and choices for their life. A person's life is realized in a meaningful way when family, friends, community members, and service providers actively listen to what matters to a person, by respecting and honoring their strengths, culture, hopes and dreams. Every person deserves happiness and a life they desire (ND Person-Centered Practices Draft Definition)
- **Quality:** How well a waiver program works. Through HCBS quality initiatives, CMS seeks to maximize the quality of life, functional independence, health, and well-being of HCBS participants. (Home and Community-Based Services (HCBS) Quality | Medicaid)
- **Self-Direction**: An option where you can serve as your own boss and control your waiver services, deciding how to use approved services, who works for you, your worker's schedules and pay, worker training, and where you receive services
- **Service Options**: Describes the types of programs, items, and supports that people can use on a waiver
- **Social and Spirituality**: Building friendships and relationships, leisure activities, personal networks, and faith community
- **Support Coordination**: The assistance families need to successfully identify resources, plan waiver services, and navigate life changes; often referred to as case management
- **Supports Waiver**: waivers build to wrap-around individuals who are living in the community and also receiving support from family and/or friends. These waivers do not include residential services and typically prioritize community connection.
- **Target Population**: States' determination of who a Medicaid waiver will serve (i.e. children with intellectual or developmental disabilities)

Key Acronyms

- **A&M**: Alvarez & Marsal
- **AAIDD:** American Association on Intellectual and Developmental Disabilities
- **AIDD**: Administration on Intellectual and Developmental Disabilities
- **ASD**: Autism Spectrum Disorder
- **BH**: Behavioral Health
- **CAHPS**: Consumer Assessment of Healthcare Providers and Systems
- **CCS**: Coordinator of Community Services
- **CDAC**: Cross-Disability Advisory Council
- **CDW**: Cross-Disability Waiver
- **CMS**: Center for Medicare and Medicaid Services
- **COB**: Coordination of Benefits
- **CoP**: Community of Practice
- **CQL**: The Council on Quality and Leadership
- **DD:** Developmental Disabilities
- **DDA**: Developmental Disabilities Administration
- **DDPM**:: Developmental Disabilities Program Manager
- **HHS:** Department of Human Services
- **DS**: Disability Services
- **DSM**: The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
- **DSPS**: Direct Support Professionals
- **EI**: Early Intervention
- **EPSDT**: Early and Periodic Screening Detection and Treatment
- **FASD**: Fetal Alcohol Spectrum Disorder
- **FFP**: Federal Financial Participation
- **FFS**: Fee-for-Service
- **FMS**: Financial Management Services
- **FTE**: Full-time employe
- **HAC**: Health Assessment and Coordination
- **HCBS**: Home and Community-Based Services
- **HSC**: Human Services Center
- **I/DD**: Intellectual / Developmental Disabilities
- **ID/DD**: Intellectual Disabilities / Developmental Disabilities
- **ID**: Intellectual Disabilities
- **IDEA**: Individuals with Disabilities Education Act
- **IDS**: Individual Goods and Services
- **IDT**: Interdisciplinary Care Management Team
- **IEP**: Individual Education Program
- **IFS**: Individual and family support
- **ISP**: Individual Support Plan
- **LMA**: Legislative Management
- **LOC**: Level of Care
- **LOS**: Length of Stay
- **LTSS**: Long-Term Services and Supports
- **MACPAC**: Medicaid and CHIP Payment and Access Commission
- **MCO**: Managed Care Organization
- **MF**: Medically Fragile
- **MFW**: Medically Fragile Waiver
- **NASDDDS**: National Association of State Developmental Disabilities Directors
- **NCI**: National Core Indicators
- **NCI-AD**: National Core Indicators
- **ND: North Dakota**
- **NWD**: No Wrong Door
- **ODP**: Office of Developmental Programs
- **OT**: Occupational Therapy
- **P2P**: Parent to Parent
- **PAR**: ND Assessment Tool
- **PCP**: Person-Centered Planning
- **PDS**: Participant Directed Services
- **PIHP**: Prepaid Inpatient Health Plan
- **POM**: Personal Outcome Measures
- **PPD**: A purified protein derivative (PPD) skin test is a test that determines if you have tuberculosis (TB).
- **PT**: Physical Therapy
- **SED**: Severe Emotional Disturbance
- **SSA**: Social Security Administration
- **SSC**: Support and Service Coordination
- **SSI**: Supplemental Security Income
- **TCM**: Targeted Case Management
- **UMKC-IHD**: University of Missouri, Kansas City – Institute for Human Development

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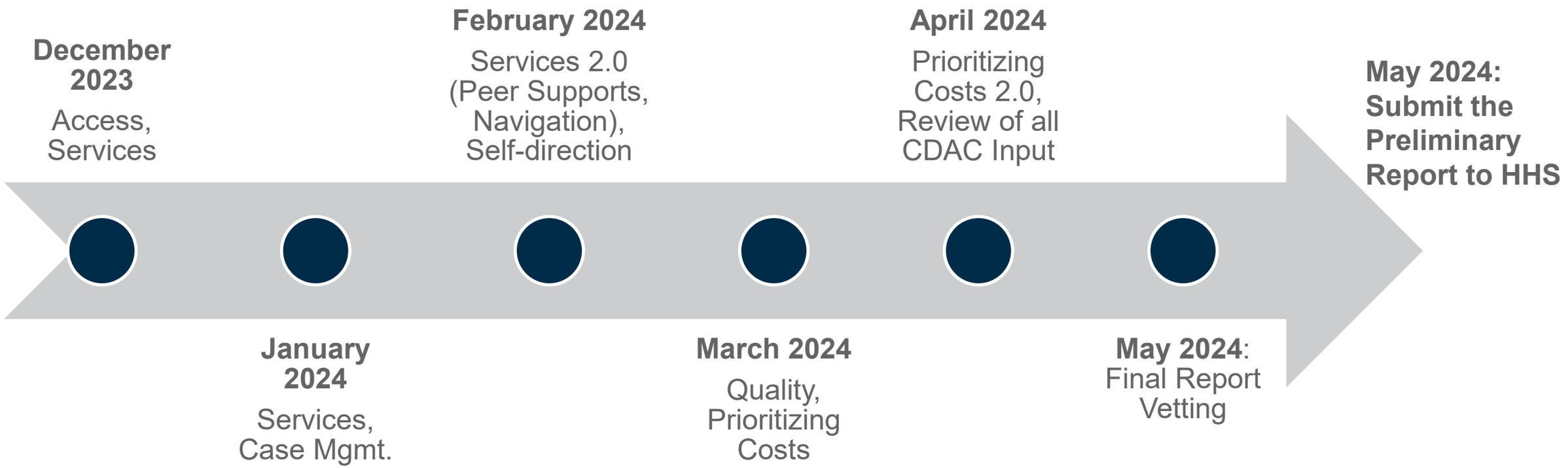
Cross Disability Advisory Committee

Overview of the CDAC Engagement Process

Slide Excerpt from CDAC Meeting

CDAC met monthly from December 2023-May 2024 to provide input regarding the design of the new cross-disability waiver.

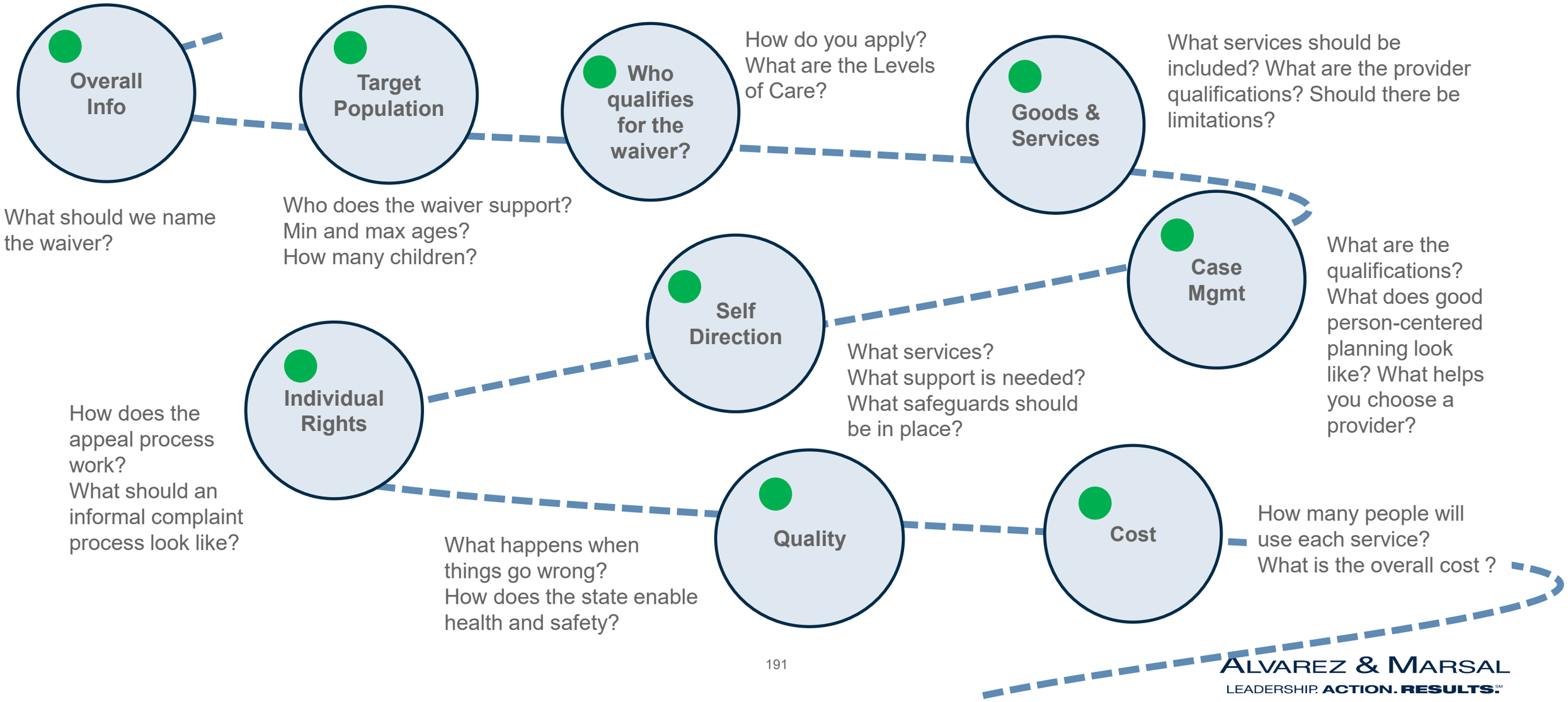


Note that CDAC will continue to meet quarterly following submission of the May 2024 report

How the CDAC Helps: Advising on HCBS Design Elements

Slide Excerpt from CDAC Meeting

To create the Cross Disability Children's waiver, ND will need to submit an application to the Centers for Medicare and Medicaid Services. The CDAC met regularly to provide input on key areas of waiver design.



Meet the CDAC Members

Cross-Disability Advisory Council

Last	First	Member	Representing
Adusumilli	Jackie	Non-Voting	HHS – Early Intervention
Barchenger	Kathy	Non-Voting	HHS – Medical Services
Fender	Kayla	Non-Voting	HHS – Developmental Disabilities
Fleck	Colette	Voting	Fort Yates
Hruby	Kim	Non-Voting	HHS – Special Health Services
Karpyak	Susan	Voting	Dickinson
Larson	Heather	Voting	Portland
Lunstad	Toby	Voting	Mandan
McCarvel-O'Connor	Mary	Non-Voting	DPI – Early Intervention
Miiller	Kevin	Non-Voting	Presiding Officer
Morrissette	Katynka	Voting	Bismarck
Nelson	Stephanie	Voting	Jamestown
Paulson	Magan	Voting	Taylor
Peterson	Vicki	Voting	Bismarck
Peterson	Erin	Voting	Grand Forks
Sande	Megan	Voting	Fargo
Swanson	Moe	Voting	Valley City
Troutman	Carmen	Voting	Williston
Vannett	Trevor	Voting	Bismarck
Vieweg	Emily	Voting	Fargo
Wilhelm	Heidi	Voting	Minot

Meet the CDAC Members: Colette Fleck (Voting Member)

Colette Fleck lives in Solen, North Dakota, and works in Fort Yates. She has worked in education for forty years. Presently, she provides transition services for students in grades 9-12 who receive special education services at Standing Rock Community School. She has assisted families in applying for the Autism Waiver, Medicaid Waiver, Medically Fragile and 1915 Program.

Colette helps students get the services they need. Her goal is for all students or adults to have access to services so the waiver can individually meet each student or adult needs if the person does not qualify for the other waivers or 1915 Programs. I hope the CDAC can use its influence so more services can be available for all students and adults facing challenging issues regardless of income, etc.

As a member of many committees and organizations, Colette's goal is to help bring awareness, advocacy and educational assistance to students and families. She collaborates with many staff, outside agencies and numerous businesses to provide the skills and training necessary for each student to succeed in the real world.

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Meet the CDAC Members: Susan Karpyak (Voting Member)

My name is Susan M. Karpyak and I reside in Dickinson. I sit on the CDAC as a voting member and advocate for my daughter, Eden. At age 3, Eden was diagnosed with a genetic mutation on a newly discovered gene along her chromosome 9. Doctors believed that this mutation was responsible for her delay in speech, motor, and cognitive development. Her diagnosis devastated me at first; however, once I processed the grief over the child I thought I'd have, I started to celebrate the one God gave me. I used her diagnosis as a source of inspiration rather than heartache.

Our pediatrician noticed a developmental delay with Eden at age 6 months and referred us to Early Intervention. I credit the treatment that she received there for how she was able to gain the strength to walk and start to communicate. We were able to access Occupational Therapy, Physical Therapy, and Speech Therapy. Eden is 9 now and remains nonverbal; however, she is working with a communication device. I live in gratitude for the support we have received in North Dakota.

My overarching goal as a parent advocate is to help build a world that embraces disability and understands that there isn't one "correct" human experience. We have been fortunate in our journey to have had a strong support network. I wanted to participate in CDAC to share our story and be a voice to lawmakers on the criticality of ensuring that all children with disabilities in North Dakota have access to the proper care and support they need to live a fulfilling life.

Meet the CDAC Members: Heather Larson (Voting Member)

My name is Heather Larson. I am a registered nurse and I live in Portland, North Dakota. I am the parent of a child with a disability, which has opened my eyes to a whole new world. It has helped empower my family and me to speak up for the rights and needs of people living with disabilities.

I think it's important to advocate for individuals with disabilities. One of the most important barriers I encountered was the amount of time proving and re-proving that my daughter had a disability and the countless hours of meetings and assessments required just to prove she needed the assistance and continuation of care.

I want anyone who needs assistance to have a clear understanding of the process and to make the process easier for all. Advocating for children with disabilities is essential for building a more just, inclusive, and compassionate society where every child has the opportunity to thrive and reach their full potential.

Meet the CDAC Members: Toby Lunstad (Voting Member)

I wanted to be on CDAC to help children and families have access to the supports and care they need as they navigate life with a disability. My daughter has a rare disease which has resulted in lifelong neurodevelopmental symptoms. She utilizes the ND IIDD/DD Waiver, and we often travel out of state for her medical care. Through the years, I have built connections with other families who have a similar path. These connections have taught me about the gaps in the ND Waivers. I want North Dakota to be a place where all individuals have access and opportunity to live in their communities. My daughter has inspired me to be more active as an advocate to help ensure this opportunity for her and other children. I believe being part of CDAC will help me achieve my goal of helping improve the lives of children and adults with disabilities in North Dakota as well as providing support to them and their families.

Meet the CDAC Members: Katynka Morrisette (Voting Member)

I am a voting member of CDAC from Bismarck, North Dakota. My husband, Joe, and I have 3 young children with complex medical diagnoses. Their conditions require many medical specialists outside of the state, and they are primarily managed between the Cleveland Clinic and Sanford Children's in Sioux Falls.

I wanted to become a member of CDAC after learning about the plan to create a Children's Cross-Disability Waiver because I felt our lived experience with the Medically Fragile Waiver would be beneficial in assessing what should be continued or added in a new waiver. Having children with a rare diagnosis, as well as various developmental delays, has given me an opportunity to connect to families all over the state who share similar needs.

The more rare a condition is, the less likely the needs of that child and family will be brought to the table for discussion, especially in a rural state. I wanted to use my voice to be able to speak up and advocate for families like ours who have more rare diseases and making sure they are being recognized and considered. I feel as medical care continues to advance, we will be able to diagnosis and further progress treatment in more rare diseases, and I hope that North Dakota will be on the forefront of supporting our local families to ensure children can thrive here and live fulfilled lives.

Meet the CDAC Members: Stephanie Nelson (Voting Member)

Stephanie Nelson, from Jamestown, ND, currently serves as the Chief Operating Officer at Anne Carlsen. She brings over two decades of experience in health and human services and a deep commitment to advocating for individuals with disabilities, especially children. Beginning her career as a speech-language pathologist, Stephanie has worked with children of all abilities. Since joining Anne Carlsen in 2001, she has held various roles within the organization, including Speech Language Pathologist, Resource Center Specialist and Ideation Center Director, before assuming her current leadership position in 2017. Stephanie's educational background includes a Master of Science in Speech-Language Pathology from the University of Nebraska-Lincoln, a Graduate Certificate in Assistive Technology from Northern Arizona University, a Master of Arts in Leadership from the University of Jamestown, and a Bachelor of Science from Minnesota State University-Moorhead.

In her role as COO, Stephanie provides leadership, guidance, and direction to Anne Carlsen's operations statewide, overseeing services and programming for children and families from birth through adulthood. Anne Carlsen, with service locations in 8 communities across North Dakota, annually serves over 3,000 individuals. The organization's comprehensive services include Early Intervention, outpatient speech, occupational, and physical therapy, as well as a Behavioral Health/Autism program offering applied behavioral analysis (ABA), service management, and respite services. Anne Carlsen's roots in Jamestown are deep, with a focus on serving children and young adults with medically and behaviorally complex needs through its residential program (ICF-IID), fully accredited school, and specialized pediatric therapy services. Additionally, Anne Carlsen offers community-based residential habilitation, day habilitation, employment/vocational services, and in-home supports.

Stephanie's dedication to advocating for individuals with disabilities extends beyond her professional role. Her personal connections to family members and friends with disabilities fuel her passion for ensuring that individuals with disabilities can lead independent lives and access the necessary resources and support to thrive. As a voting member of the Cross Disability Advisory Council she hopes to contribute to the advocacy and planning efforts that will provide more options and flexibility for children and families who need consistent and impactful services and support in North Dakota.

Meet the CDAC Members: Magan Paulson (Voting Member)

I am Magan Paulson and I live in Taylor, North Dakota. I have a 15-year-old daughter with Down Syndrome who is also hearing impaired. I am a school counselor who works closely with kids with disabilities. My purpose for participating on CDAC is to advocate for families by voicing their needs, which will hopefully result in future benefits from improved services. As someone who lives 30 miles from town, I also offer the perspective of those who are caregivers to those with disabilities in rural areas and the additional challenges we face in receiving services.

Meet the CDAC Members: Erin Peterson (Voting Member)

My name is Dr. Erin Peterson and I reside in Grand Forks, North Dakota with my husband, Brody and our daughter, Everly (8). I originally applied to be on this council because I know first-hand the positive impact a service such as this can have on a child with a disability's overall well-being, along with the family. I would love this opportunity for all qualifying children in the state of North Dakota and have enjoyed my time advocating and working for them.

Our daughter, Everly was born with a very rare and life-threatening syndrome called Megacystis Microcolon Intestinal Hypoperistalsis Syndrome (MMIHS for short). The complexity of the name aligns perfectly with the complexity of this syndrome. There is no present cure for MMIHS and at the time of her diagnosis, we were told the rarity was 1 in 240 million. MMIHS affects the motility of the bladder and gastrointestinal system and because of this, Everly does not eat by mouth. Instead, a supplemental nutrition called TPN is delivered straight into her bloodstream through her central line catheter for 16 hours a day. Therefore, you will most likely see Everly sporting a backpack that holds her calories for the day. Everly also has a g-tube for medication administration, an ostomy to help rid her body of abdominal extension, and is catheterized every 4-6 hours. She has specialists in Grand Forks, Fargo, Sioux Falls, and Omaha. She has had seven surgeries in her little life and completes a multi organ transplant evaluation every other year. Properly caring for Everly's various needs is certainly not a one-person job. Everly is currently on the DD waiver, something we rely on heavily. Our family has also helped advocate for more slots on the Medically Fragile Children's Waiver in the past.

The saying that a mom (or any caregiver) must wear many different hats has taken on a life of its own with Everly. One of my most important hats I proudly wear as Everly's mom is her advocate. My biggest goal in life is to do everything in my power to provide Everly the quality life that she so deserves and with this comes advocating for her day in and day out. I have learned through experience that when you have a medically fragile child, it is not a question of will you need to advocate for them that day, but in which arena will you be advocating on that day? My daily roles with Everly, beyond mom, have included primary medical caretaker, advocate, teacher, and one-on-one paraprofessional, to name a few. I have spent time in the U.S. Capitol and at other various large-scale medical conferences advocating for rare diseases such as MMIHS. I am also the vice president of the MMIHS non-profit organization, founded in 2017. My experience with Everly has opened a whole new world of education, something formerly known to me as a classroom setting.

Meet the CDAC Members: Vicki Peterson (Voting Member)

I reside in Bismarck, ND. I have two children; Erik who is 32 and Aaron who is 22 and has autism, intellectual disabilities, and chronic health conditions. I am a Family Consultant for Family Voices of ND and have been doing family support for 20 years. I have served on several coalitions and boards throughout my career, including: member of the ND Autism Task Force, ND IDEA Advisory Committee, ND Oral Health, and Pathfinder Board Member. I am also working currently with families through the Pediatric Mental Health Care Access Program. Family Voices of ND is the Family-to-Family Health Information Network in ND. As a Family Consultant I support families who have children and youth with disabilities, chronic health, and special health care needs. I support professionals who are also working with families.

I applied to become a member of the ND Cross-Disability Coalition hoping that I could contribute my lived experience and the experiences I encounter with those I support and work with. I am excited to see the possibilities. That could come from being at the ground level of creating a new program that could benefit more children and give access to the varied services that families are needing to seek out to help support their children and youth. I had worked with the creation of the ND Medical Fragile Waiver in the past as well. I have had experience in all ND Medicaid Home and Community Based Services and the Medicaid waivers in the state. I have given input, worked with, and helped families apply for services in ND, all services.

I have lived experience with my son, Aaron, through many services and many stages in life. Aaron began to access services at a very young age. He has been through ND Early Intervention Program, Early Childhood Special Education, transition to youth and youth in schools, and continued education through the Life Education program at BPS. He has now transitioned into a young adult. My son has and is still accessing the ND Developmental Disability Waiver. My son has experienced great service and some not-great services. I feel there is always work that can be done to improve the lives of those with special needs and their families. In turn this will create a very cohesive community. Our family has been fortunate to live in Bismarck where services are located. I have worked with many rural families that have not had that benefit.

I am a lobbyist for children and youth along with their families who have disabilities and special needs. I have testified within my employment, from lived experience, and on behalf of families in ND. I feel it is very important to speak out and to do our best to make lives better and our community stronger as it grows in acceptance.
I am happy to have the opportunity to have input on the new Cross-Disability Waiver and hopefully to then improve on the existing waivers in this process. Thank you for the opportunity.

Meet the CDAC Members: Megan Sande (Voting Member)

My name is Megan Sande and I live in Fargo, ND. From my experience as the parent of a child with a disability, I know that navigating the system is very difficult. You don't know what questions to ask, where to go for help, what services your child could qualify for, which ones are most useful, etc. Fortunately, we've had access to some very helpful case managers and have had the time and resources to get our child the support he needs. I believe there are many families and children that aren't in that situation, and I am hopeful that the CDAC can accomplish making things clearer and easier for families.

Meet the CDAC Members: Moe Swanson (Voting Member)

Moe Swanson has personal experience of navigating the complex, siloed design of services for children with special health care needs and disabilities, both as a parent and as a professional.

She has been in the disability field for 29 years as a Direct Support Professional working is services that are offered to North Dakotans within North Dakota's Developmental Disabilities Waiver. After receiving a prenatal diagnosis with her second child, Moe started assisting families in navigating services and offering emotional support through her position at Family Voices of ND and also in the role of an Experienced Parent with the ND Part C system. Her child, a graduate of ND Part C Early Intervention Services, now 15, has a complex form of congenital heart disease and has had access to Waivered Medicaid through the ND Childrens Hospice Waiver.

In 2019, Moe expanded her reach to assisting families and individuals by starting Encompass Family Support Services and becoming a Licensed ND Developmental Disabilities Provider and ND Autism Waiver provider.

Meet the CDAC Members: Carmen Troutman (Voting Member)

My name is Carmen Troutman and I live in Williston. I have a daughter with a disability, and wanted to be on CDAC both for my daughter and for other children to get the help they need through waivers. My hope is that CDAC can promote inclusion for those who don't qualify due to gaps in coverage and help families get what they need most out of the waivers.

My daughter has Vascular Ehlers Danlos Syndrome, Hypermobile Ehlers Danlos Syndrome, Mast Cell Activation Syndrome, Postural Orthostatic Tachycardia Syndrome, Vocal Chord Dysfunction, Endometriosis, Polycystic Ovarian Syndrome, Migraines, and a Cavernous Hemangioma. She has a shortened life span expectancy from vEDS. We travel all over the state and occasionally out of state for medical care. We've had to go as far as Oklahoma.

It is important to know how many kids aren't eligible for waivers. When I first learned about waivers, my daughter just turned 18. Due to her medical conditions, she needs special foods cooked for her, which is a large expense and time consuming. Sometimes she can't perform daily tasks. She hasn't been able to get a job due to her limitations. I think there needs to be more help for disabled kids transitioning to adulthood. My daughter wants to be independent and live on her own, maybe even go to college, but those things are going to be challenging for her.

Meet the CDAC Members: Trevor Vannett (Voting Member)

My name is Trevor Vannett. I have cerebral palsy. My goal is to help other people with disabilities.

I advocate for people disabilities all over the state of North Dakota. I am heavily involved with the following: North Dakota State Council on Developmental Disabilities, State Rehab Council, ARC of ND/Bismarck Board, Dakota Center for Independent Living Board, Consumer Advisory Council, and other boards. I want to make this world a better place for people with disabilities, providing them the same opportunities as everyone else.

I watch sports and watch people with disabilities playing sports.

Meet the CDAC Members: Emily Vieweg (Voting Member)

I am Emily Vieweg and I live in Fargo, ND. I am a parent of two children with disabilities. My goal as a member of CDAC is to ensure that children and families who need services get those services. Children with disabilities grow to be adults with disabilities. Disabilities do not just end at age 13, or 15, or 18, or 21. I wish to make the transition from childhood disability waiver services to adult waiver services more seamless and efficient.

Personally, I manage daily life with BiPolar II disorder, Depression, Anxiety, and possible ADHD. I am also a single mother.

Meet the CDAC Members: Heidi Wilhelm (Voting Member)

My name is Heidi Wilhelm, and I live in Minot. As a member of CDAC, I would love to see this team help North Dakota move into a new way of seeing and dealing with disabilities. I am a mother of 4 boys aged 19 ,17, 13, and 11. Two of my sons have Autism and one has Spina Bifida with severe mental health issues. I wanted to be a part of the CDAC so that I could help other families like mine who struggled with qualifying for DD services. I also wanted to help kids during transitions because I see a lot of kids fall through the cracks when they are transitioning.

Meet the CDAC Members: Jackie Adusumilli (Non-Voting Member)

Jackie Adusumilli has a Master's degree in educational leadership and has over 10 years in the field with extensive experience in early childhood and special education. She has worked as an early interventionist, early childhood special education teacher, and Part C Administrator/Coordinator. Jackie has a background in cross-cultural competencies and educational leadership. She has experience in developing state policy and procedures around federal regulations for the Part C system.

Meet the CDAC Members: Kathy Barchenger (Non-Voting Member)

My name is Katherine Barchenger and I have been a licensed Social Worker since 1990. For the past 28 years I have been working for Health & Human Services, within various positions. My focus has been working for youth and families in assisting them in finding ways to deal with their unique needs and developing programs within Medical Services to assist in addressing these needs. At present, I am the Children's Waiver Administrator within the Medical Services division, overseeing three of the ND 1915c waivers - Autism, Medically Fragile and Children's Hospice. This also includes the task of developing the policies and service to incorporate the waiver into a usable program that allows families to acquire services to handling issues that may be caused by a diagnosis of autism spectrum disorder, medically fragile needs or possible end of life of child.

Meet the CDAC Members: Kayla Fender (Non-Voting Member)

Kayla Fender has over 17 years of experience working in the Developmental Disabilities field. Kayla has worked in the Developmental Disabilities Section of the Department of Health and Human Services since the beginning of 2017, in varying positions. As the Services Administrator, her duties include consultation and oversight for the programs, policies, and administration of children and adult services through the Traditional Individuals with Intellectual Disabilities and Developmental Disabilities Home and Community Based Waiver (DD HCBS Waiver) and Medicaid State Plan. This also includes technical assistance and further of development of services to be available within the waiver that allows individuals with intellectual disabilities to best be served within their community.

Meet the CDAC Members: Kim Hruby (Non-Voting Member)

My name is Kimberly Hruby. I am the Title V Maternal and Child Health Director and also serve as the Unit Director for Special Health Services (SHS), the Title V program for children and youth with special health care needs. My unit is located in the Public Health Division in the ND Department of Health and Human Services.

The overarching mission for SHS is to promote a system of care and services that improve the health and well-being of individuals with special health care needs and their families. SHS administers programs that provide care coordination and health benefits counseling to families. In doing so, the unit collaborates and refers families to various state-wide programs and resources, including those available through various waivers.

SHS currently offers gap-filling financial coverage for children and families with over 100 different medical conditions. A copy of our current conditions can be found on our portion of the HHS website at https://www.hhs.nd.gov/health/children/special-health-services/financial-coverage-program.

Meet the CDAC Members: Mary McCarvel-O'Connor (Non-Voting Member)

Mary McCarvel-O'Connor has 20+ years of experience working in special education. She is the Director of the Office of Specially Designed Services at the North Dakota Department of Public Instruction (NDDPI), formally known as the Office of Special Education. The NDDPI mission is to partner with schools and communities to provide a statewide system of excellent service and support to ensure a healthy school environment that fosters student success. The NDDPI Office of Specially Designed Services designs and implements policies and procedures for carrying out the requirements of the Individuals with Disabilities Education Act (IDEA) for students ages 3-21 and ensures compliance with those policies and procedures. Compliance is documented and ensured through monitoring, technical assistance, training, and dispute resolution processes.

Meet the CDAC Members: Kevin Miiller (Non-Voting Member)

My name is Kevin Miiller and my wife, Kathy, and I were selected by the State to be the facilitators for the Cross-Disability Advisory Council (CDAC). As the presiding officer of CDAC, I am excited about working with people with disabilities, parents of children with disabilities, service providers, teachers, employers, advocates and the State to solve problems and develop solutions that benefit the people of and state of North Dakota.

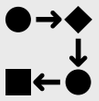
As an advisory council, CDAC provides the opportunity to give voice to those with lived experiences. CDAC strives to compile ideas which will improve the quality of life for families and people with disabilities as well as examine existing systems and develop recommendations for improvement. The initial biennium Council is specially designed to involve those who are innovators, uniquely qualified to represent children with disabilities and to draft recommendations based on their life situations.

Kevin (Mechanical Engineer, P.E. MBA) is the Founder of ITCB Consulting. ITCB specializes in leadership and management consulting: strategic planning, business-fixer, evaluation, facilitation, training and speaking.

Expanded Findings from the LMA Assessment

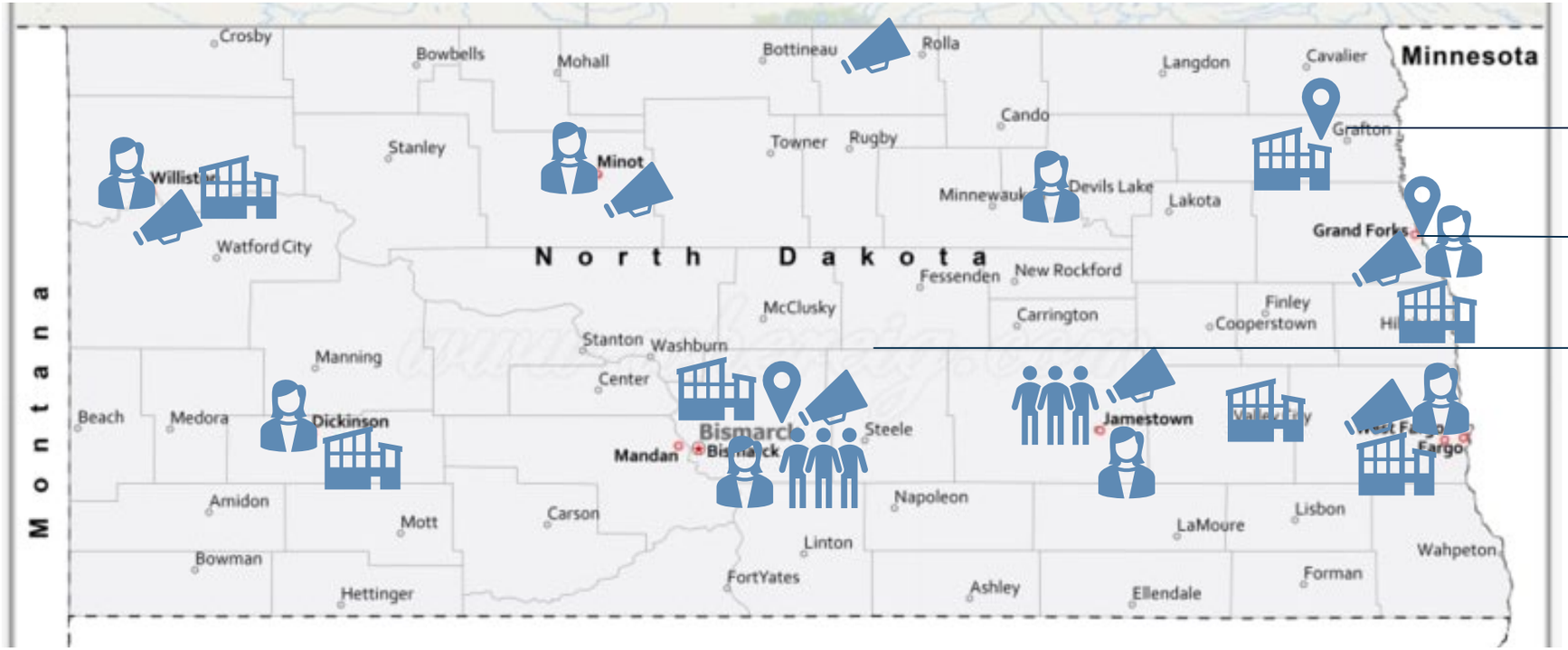
Gap Analysis

A&M conducted a gap analysis exploring North Dakota's various pathways to existing services and outlining current gaps in access; researched and analyzed peer states to compare service offerings; conducted a national scan of home and community-based services and waivers; and identified promising approaches used to modify or expand programs to address service access gaps.

	**State Staff**	• Interviews with 35+ employees • Developmental Disabilities Program Administrators Focus Group • 2 Developmental Disabilities Program Managers Focus Groups	• Bi-weekly Working Sessions • Intake Observation • Life Skills Training Center Site Visit
	**Stakeholders**	• Interviews with more than 40 advocates, including self-advocates and family members • 2 Autism Spectrum Disorder Taskforce Listening Sessions • 2 Autism Spectrum Disorder Advocacy Coalition Listening Sessions	• ND Association of Community Providers interview, survey, and listening session • Listening session for unaffiliated providers • Listening session with special education teachers and administrators • Attended Olmstead meeting
	**Document Review**	• Reviewed approximately 70 documents provided by HHS, including statute, regulations, waivers, policies, and process flows	• Reviewed relevant state and advocacy websites
	**Service & Waiver Review**	• Reviewed an array of ND services, including Aging, Autism Spectrum Disorder Voucher, Behavioral Health, Early Childhood, Early Intervention, Early & Periodic Screening, Detection, & Treatment, Home & Community-Based Services Waivers, Medicaid State Plan, Specialized Health Services, and Vocational Rehabilitation	• Conducted national scan of individual and family support waivers • Reviewed and interviewed select peer and promising practice states
	**Process Maps**	• Developed process maps of DDA intake and eligibility from birth until age 3; 3 years to adult	

Stakeholder Engagement

As part of the Gap Analysis, A&M conducted targeted stakeholder outreach to a variety of groups based across the State of North Dakota.



A&M On-Site Visits

Grafton: Visit to Life Skills and Transition Center

Grand Forks: Observation of intake and eligibility process

Bismarck: Discussions with self-advocates, presentation to State Legislature; working sessions with HHS

Interview with Self-advocate

Interview with Advocate/Family

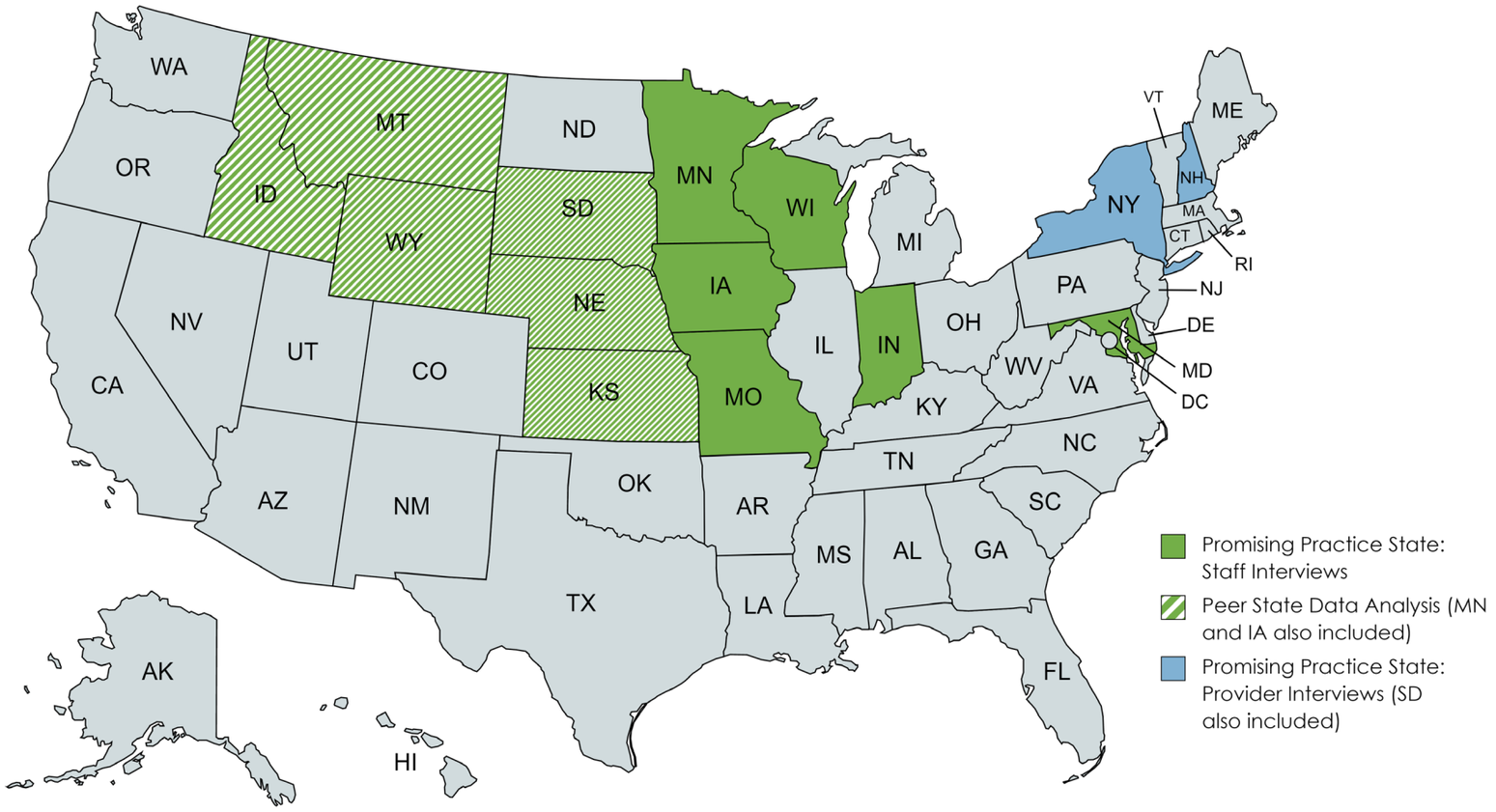
A&M On-site Visit

Interview/Listening Session With Case Worker

Interview with Provider

National Scan

A&M conducted a national scan to identify promising practice states. A&M also worked with HHS and LMA to identify peer states for benchmarking.



Promising Practice State Staff Interviews: Indiana, Iowa, Maryland, Minnesota, Missouri, New York, Wisconsin

Peer States Data Analysis: Iowa, Idaho, Kansas, Minnesota, Montana, Nebraska, South Dakota

Promising Practice State Provider Interviews: New Hampshire, New York, South Dakota

The Future of HCBS Waivers in North Dakota

North Dakota's HCBS waiver array will provide services based on level of need across the lifespan.

Waiver	Target Population	Summary	Waitlist	Age	Level of Care
Comprehensive Waiver- Intellectual & Developmental Disability. &/ Or Autism	High-needs and complex children and adults with intellectual and/ or developmental disabilities and autism	Use stakeholder engagement and the completed national scan of Individual and Family waivers to identify promising practices that may better support the target population and their families (for example: residential services that are an alternative to group homes, remote supports)	No	From birth with no maximum age	Modernized Level of Care (LOC) to match AAIDD, DSM-5, and ICD-11 definitions
Cross Disability IFS Waiver	Children aged 3 until age 18 (or 21) with mild to moderate support needs	Service array will include cost-effective community interventions that support children with disabilities and their families.	*For discussion*	Age 3 until age18/21	• New LOC for children aged 3 until age 5 that matches IDEA Part B • ICF and NF for 6+
HCBS Waiver	Seniors aged 65 with no maximum age limit, and individuals with physical and other disabilities aged 18 until age 64 years	No changes to existing waiver that provides adult day care, adult residential care, case management, homemaker, residential habilitation, respite care, supported employment, adult foster care, chore, community support service, community transition services, companionship service, emergency response, environmental modification, extended personal care, family personal care, home delivered meals, non-medical transportation, specialized equipment & supplies, supervision, and transitional living services	No	Seniors aged 65 with no maximum age limit PD: From age 18 until 64	No change-Nursing Facility LOC

* Currently ND Century Code 75-03-23-04 holds that if a person is found eligible for the DD waiver, they are not able to receive services through a different waiver. This section would need to be amended to allow the person to select the waiver that best fit their assessed needs.

Creating a Cross-Disability Children's Individual & Family Supports Waiver

A cross-disability children's Waiver would allow the State to provide services for children with support needs, regardless of disability category.

Target Population

- Children aged 3 until age18 (or 21) with mild to moderate support needs are served in the IFS waiver
- Those with higher support needs can be assessed for services through the IID/DD comprehensive waiver

Children from birth until age 3 would continue to be served by the IID/DD waiver

Level of Care

- Use an expansive LOC for children aged 3 until age 6, based upon children who are eligible for early intervention Part B Services
- For children ages 6 and above: use the new IID/DD LOC and other existing LOCs (Medically Fragile, Autism)

Services

- Build a service array that supports families; leverages the workforce; and facilitates success transition .
- Incentivize self-direction
- Understand existing utilization so that no one loses supports

Policy Decisions:

- Should there be an individual cost limit?
- If so, it is a hard cap or soft?
- Is there a need for tiered waivers with different levels of individual cost limits to help mitigate a potential waiting list?
- Is there an opportunity for county buy-in?

Appendix | Additional Access Recommendations from the LMA Assessment

Access: Front Door to Supports

People with disabilities, their families, advocates and providers all spoke about the need for more information to help navigate access to systems of supports. HHS staff collect and share referral information by region, but this is not systemized in a way that makes it easy to share.

PROPOSED SOLUTIONS	
TRANSACTIONAL	• Develop a referral folder to share with pediatricians, schools, other places that have regular contact with people with intellectual and/ or developmental disabilities, and Autism Spectrum Disorder to share information and referrals
OPERATIONAL	• Partner with Parent-to-Parent for family connections and networking • Expand First Link for consistent information and referrals • Cross-train intake staff and develop process for warm referrals • Provide mini-person-centered plan at intake connecting people to community-based services
TRANFORMATIONAL	• Continue efforts to build a No Wrong Door System for Long-Term Services & Supports: ○ One-Stop Coordinated System ○ Single standard process with common protocols and information exchange ○ Objective and neutral ○ Person-Centered ○ Use of Private & Public Programs ○ Seamless & Person Friendly

Access: Front Door to Supports

TRANSACTIONAL

- Develop a referral folder to share with pediatricians, schools, other places that have regular contact with people with ID/DD and/or ASD to share information and referrals

- Many people talked about the need to share referral information with diagnosing clinicians and with schools.
- Families are looking for easy access to information about community and government options for help.
- Resource folders are a low-tech and relatively low-cost way to share information in a way that meets people where they are-at doctors' offices, schools, health fairs, etc.
- A number of promising practice and peer states have developed and shared similar folders, including: Missouri, South Dakota, Oklahoma, Tennessee, Maryland, and the District of Columbia

Image Credit: https://supportstofamilies.org/lifecourse-showcase-opening-the-door-to-real-life-conversations-reframing-materials-gallery/

Access: Front Door to Supports

OPERATIONAL	• Partner with Parent-to-Parent to provide family connections and networking • Expand First Link beyond behavioral health for consistent information and referrals • Cross-train intake staff and develop process for warm referrals • Provide mini-person-centered plan at intake connecting people to community-based services

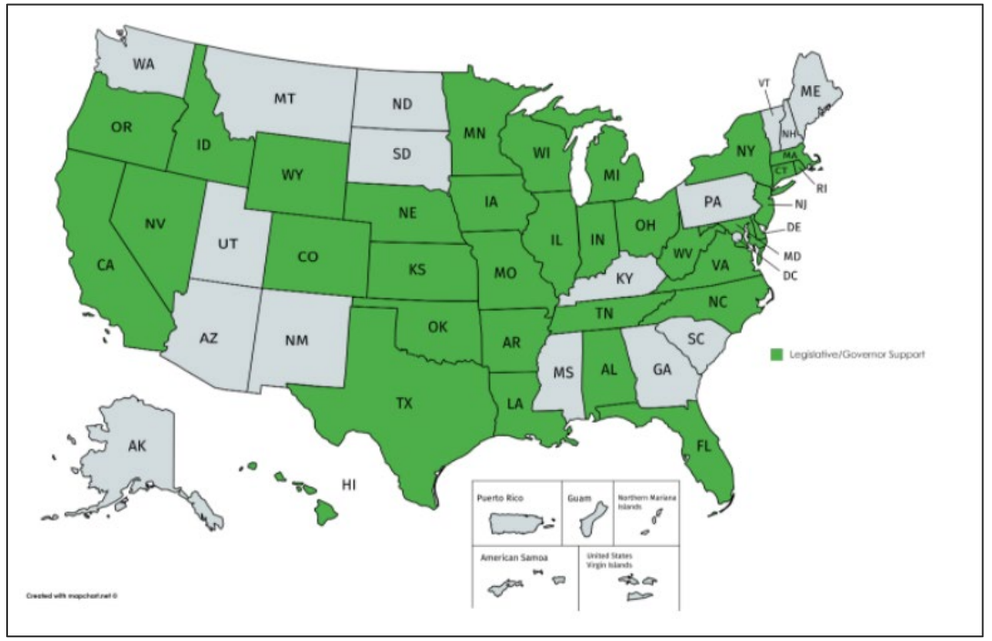
- We heard that people with disabilities and their families find the system difficult to navigate. Different eligibility criteria, forms, and places to apply make it complicated to know where to go for help. In addition to goods and services, families need help with (1) information and navigation; and (2) connecting and networking with peers.
- **Promising Practice**: Missouri and Texas partner with their Parent-to-Parent (P2P) to provide optional cross referrals at intake, so that families have help navigating their choices and learn about community-based (non-Medicaid) options for supports. (Consider a contractual arrangement to support Medicaid Administrative claiming for outreach, coordination, and referral.)
- DDPMs and advocacy organizations spoke about the importance of individualized, person-centered, and accurate referrals. Each independently were keeping referral lists. First Link already includes information on some autism and developmental disability services. Make this more robust and use this as the community source for referrals.
- People with disabilities and their families share a lot of personal information at intake and are sometimes cross-referred and must tell their entire story again. Include an optional referral authorization on the intake form and make it routine to ask for permission to share information gathered at intake and do a warm referral.
- There is a wait (times vary, based on whether or not there is a waiting list) between when eligible people apply for services and begin receiving them. Use person-centered planning skills and knowledge of community resources to create a mini person-centered plan that helps people and families get connect with integrated community-based supports at intake, so they can get non-eligibility-based support right away.

Access: Front Door to Supports

TRANFORMATIONAL

- Continue efforts to build a No Wrong Door System for Long-Term Services & Supports (LTSS)

- ND should continue to build a No Wrong Door (NWD) system infrastructure that includes outreach and awareness, streamlined access to public programs, person-centered counseling, and governance and administration.
- **Promising Practice**: to support access to LTSS is “ensuring leadership support for these practices.” Top performing states have cross-agency bodies, including their state Medicaid agency, aging system, developmental disability system, etc., that coordinate the state government’s work to develop a single NWD System for all people needing LTSS.
- NWD systems can provide return on investment through technology that streamlines communications and tracking. Virginia’s NWD system found “evidence it provides significant cost savings.”



Legislative/ Governor Support for No Wrong Door

Image Credit: Building A NWD System (acl.gov)

Access: Application

Families spoke of long waiting lists and costs (up to $2,000) to get assessments to establish eligibility for services. If they were not found eligible for a program, they had to start over at another government agency.

PROPOSED SOLUTIONS	
TRANSACTIONAL	
OPERATIONAL	• Contract with provider(s) and pay for required intake and eligibility assessments (eligible for federal match through administrative claiming)
TRANFORMATIONAL	• Continue efforts to build a No Wrong Door System for Long-Term Services & Supports (LTSS)

Access: Application

OPERATIONAL

- Contract with provider(s) and pay for required intake and eligibility assessments (eligible for federal match through administrative claiming)

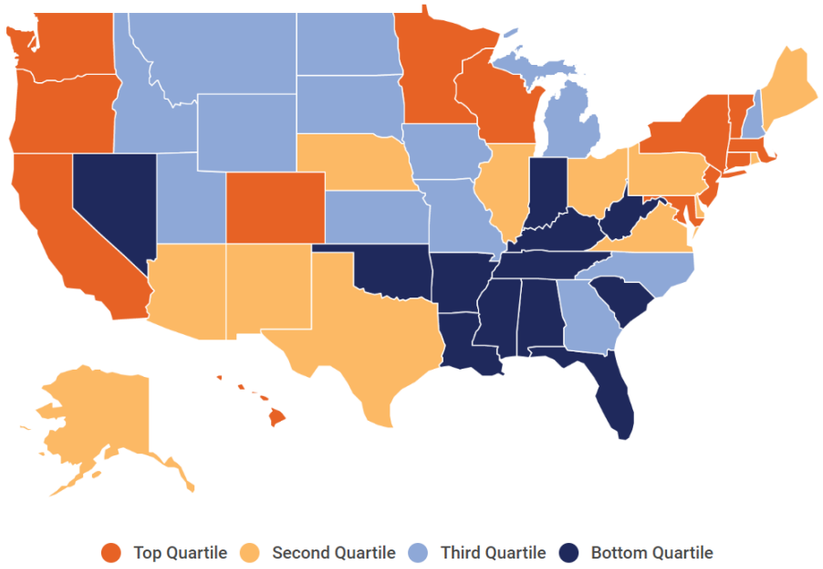
- A&M spoke with families who spent thousands of dollars to get an assessment to support their children's eligibility for services. We also heard from advocates about the long waiting lists that currently exist for people to get these assessments, especially in the more rural parts of the state. Lack of transportation further exacerbates access.
- Contracting with a clinician will help reduce expenses and wait times for people with disabilities and their families and bring a level of consistency to the application process. Additionally, having clinicians on contract will support DDA staff who are making eligibility determinations. (currently some regions have this assistance, but it is not uniform throughout the state.)
- Medicaid administrative claiming and reimbursement is available for eligibility determinations including those performed by skilled professional medical personnel, when authorized by the Center for Medicare & Medicaid Services, as part of the state plan.

Access: Application

TRANFORMATIONAL

- Continue efforts to build a No Wrong Door System for Long-Term Services & Supports (LTSS)

- One element of a No Wrong Door system is streamlined eligibility for public programs. People seeking access to LTSS would only need to complete one application for supports; said another way, people would only need to tell their story once. Then, they would be determined eligible for whichever programs for which they qualified and receive information and support to decide which were the right fit for their families.
- **Promising Practice**: Minnesota, which consistently ranks #1 in the *Advancing Action State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregiver*, uses an integrative communications strategy linking LTSS users. It permits the sharing of case management and health information among multiple agencies. This type of technology can help build efficiency and improve access to and across LTSS.



2020 State Scorecard Summary of LTSS System Performance across Dimensions

Image Credit: Advancing Action, 2020 Scorecard Report - State Rankings (longtermscorecard.org)

Access: Eligibility & Level of Care

Advocates and state staff recognize that there is an inconsistency in eligibility determinations across regions. Additionally, the current definition of developmental disability focuses on conceptual and practical adaptive deficits. More modern definitions also consider social adaptive deficits. Recognizing this category of limitation would open the door to services for people with Autism Spectrum Disorder.

PROPOSED SOLUTIONS	
TRANSACTIONAL	
OPERATIONAL	• Centralize eligibility determinations for the DDA • Align eligibility and level of care (LOC). Grandfather in current population of state-only people so that they do not lose eligibility
TRANFORMATIONAL	• Change eligibility from birth until age 6 to match IDEA Part B and Part C requirements • Update definition of developmental disability from the federal definition to match AAIDD definition. Continue to require that a person meet at least 3 functional limitations; require that the limitations cross two adaptive areas. Remove requirement for Active Treatment • Develop a cross-disability family support waiver for children to provide parity across services. • *Please see main deck for details regarding these recommendations*

Access: Eligibility for DDA

OPERATIONAL

- Centralize eligibility determinations for the DDA

- Advocates and state staff recognized that there are currently inconsistencies among regions-a sentiment A&M heard from several people was that a person could be found ineligible in one region, but eligible in another.
- A&M recommends keeping intake and application processes local, so that people are able to apply in person, in their community. Eligibility decisions should be centralized to add consistency to the process, with a team of dedicated decision-makers using a single set of policies, procedures, and practices. There may also be economy of scale, freeing up some time for DD Program Managers to further focus on their core work of supporting people and families.
- This hybrid approach would also help clarify the role of the DD Program Manager, placing them in a position to share information and advocate for the person, but not be part of the eligibility determination.

Access: Eligibility for DD

OPERATIONAL

- Align eligibility and level of care (LOC). Grandfather in current population of state-only people so that they do not lose eligibility

- Currently the DDA collects overlapping sets of initial eligibility information for adults to determine eligibility; that is, the Gollay Grid and the PAR collect similar information. Adopt a single eligibility tool that would govern access to DDA and determine level of care for adults.
- For people who are currently receiving state-only DDPM, consider grandfathering in their eligibility, so that they do not lose supports as a result of this change.

Access: Eligibility for DD

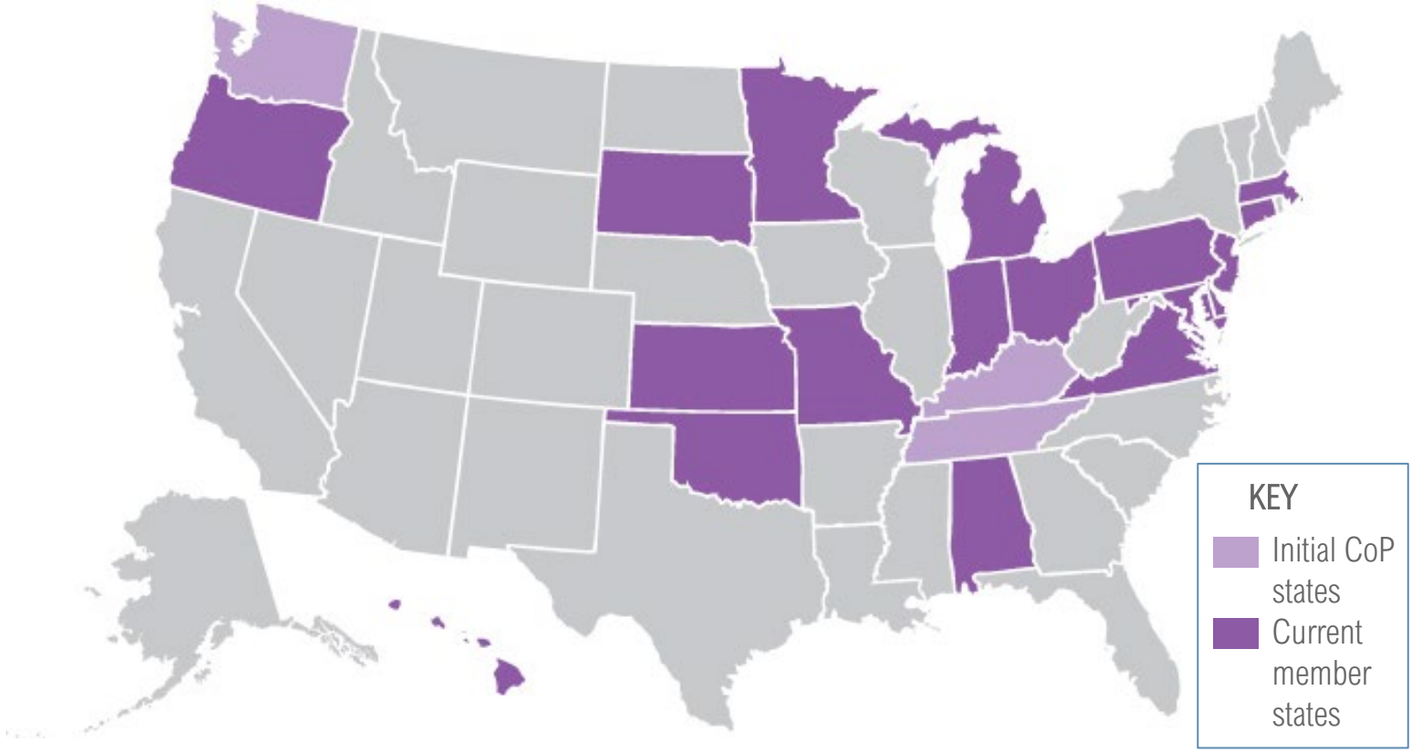
TRANFORMATIONAL

- Remove requirement that a person benefit from Active Treatment

- Remove the requirement for home and community-based services that a person would benefit from Active Treatment.
  - Active Treatment is a condition of participation for Intermediate Care Facilities for Individuals with Intellectual Disabilities.
  - It is the aggressive, consistent implementation of a program of specialized and generic training, treatment, health- and related services. In contrast, habilitation is the core of Medicaid HCBS waivers for IDD.
  - In promulgating the final rule which defined active treatment, the Centers for Medicare and Medicaid Services drew a distinction between habilitation and active treatment, finding that active treatment is broader, encompassing habilitation as well as "the whole range of services necessary for clients to achieve maximum possible independence."
  - The aggressive nature and consistent application of active treatment may be comparable to the habilitation provided in some intensive Medicaid HCBS settings; however, not everyone receiving Medicaid HCBS would require active treatment. People in need of less than daily supports, for example, would likely not meet Active Treatment criteria.

Develop a Supporting Families Community of Practice

Create a formal structure to routinely share and receive feedback with people with intellectual and developmental disabilities and autism, and their families. Developing a Community of Practice will allow North Dakota to partner with individuals and families and harness grassroots advocacy to support systems transformation. Joining the National Community of Practice, co-led by NASDDDS and UMKC-IHD, creates opportunities for ongoing information sharing and learning with peers, and technical assistance to support innovation.



The Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities exists to enhance and drive policy, practice, and system transformation to support people with intellectual/developmental disabilities within the context of their families and communities.

What began as a five-year grant (awarded by the Administration on Intellectual and Developmental Disabilities (AIDD) in October 2012), with six original state members has continued to expand. Teams are comprised of both public state agencies and grassroots stakeholders from each state, who are individually and collectively influencing and supporting sustainable transformation to support good lives for people with disabilities and their families.

Credit: The Community of Practice for Support Families of Individuals with Intellectual & Developmental Disabilities – A Collaboration Between NASDDDS and UMKC IHC, UCEDD (supportstofamilies.org)

Illustrative Areas for Potential Further Study

This study focused on existing pathways for people with intellectual disabilities, developmental disabilities, and autism, gaps, and recommendations on how to fill those gaps. There are correlating issues that are beyond the scope of this study that may be helpful to understand further. Some examples are listed below.

- **Rates**: This study did not address current rate adequacy and equity across programs. We did recommend cost reporting as part of implementation, so that rates for new services would be developed in a way that is data-driven and based upon actual provider experiences.
- **Regulatory Oversight:** State systems have a responsibility to oversee their provider network and assure quality, incident reporting, mortality review, and prevention of fraud, waste and abuse. How states implement this varies and there is a balance needed to assure health and safety without being unduly burdensome. This study did not review North Dakota's regulatory structure.
- **Private Insurance**: In 2018 the North Dakota Department of Insurance issued a bulletin requiring insurance companies to cover autism treatments with limits that are no more restrictive than the limits placed upon benefits for medical and surgical treatments by 2019. It may be helpful to research how private insurance companies are implementing this requirement.
- **Workforce**: Nationally, and here in North Dakota, there is a workforce crisis impacting the field and especially the availability of Direct Support Professionals. Understanding and planning for expansion will require consideration of how to leverage the current workforce, effectively incentivize people to join this workforce, and how to retain existing workers. (Please see Appendix Section on Workforce Challenges for more information).
- **Tribal Engagement:** A&M reached out to tribal leaders, but only connected with 2 Native American stakeholders. They spoke about lack of access to providers, difficulty with schools, and the need for culturally competent services. A&M recommends continuing these conversations and looking at ways to leverage the Indian Health Center 100% Medicaid match.
- **Educational System Capacity:** We heard that school systems have varying capacity to support children with the greatest needs, and also that in some instances, children are pulled from class time to do non-educational oriented clinical interventions like ABA.

Appendix | Access

Slide Excerpt from CDAC Meeting

Understanding the Current Paths to Access

What does accessing services look like today?

- The cross-disability waiver will include people who currently are served on three waivers:
  - IID/DD waiver
  - Autism waiver
  - Medically fragile waiver

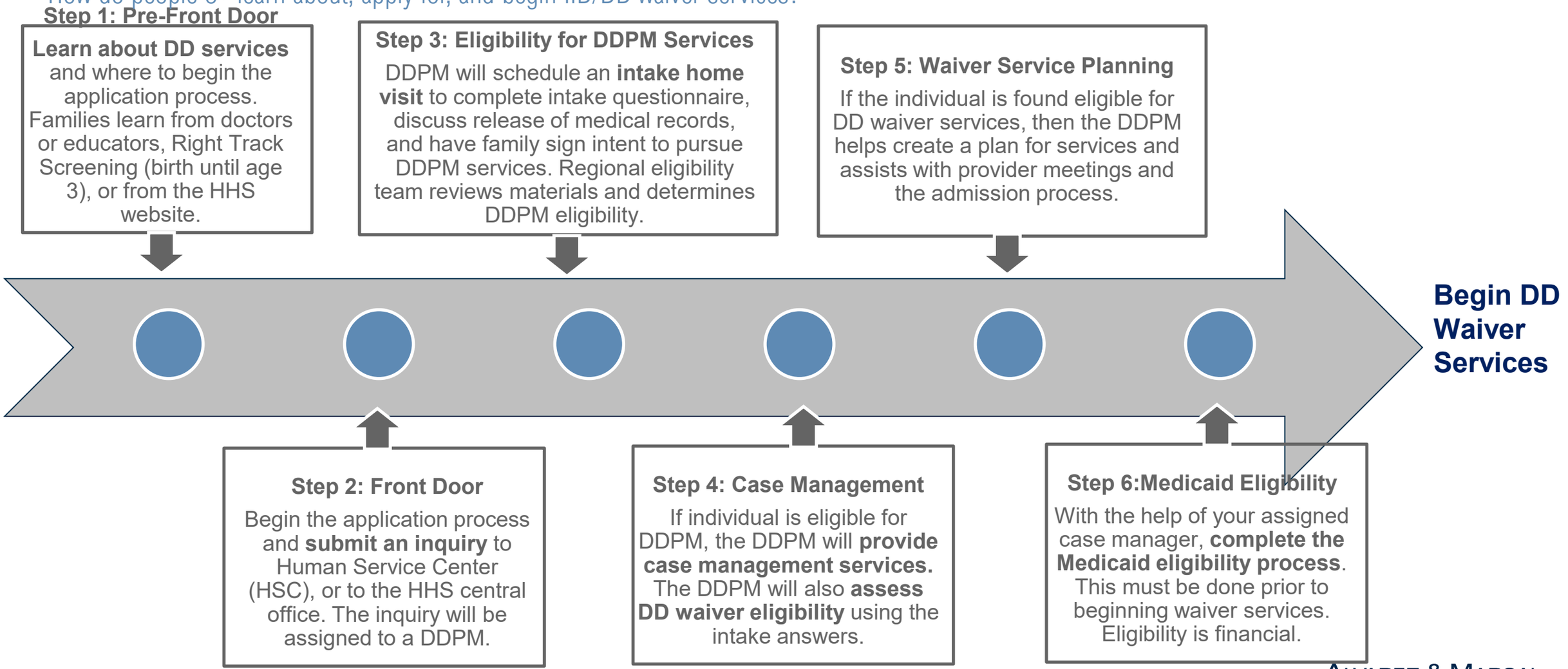
- Each of these three waivers has a different path to accessing services.

- Let's take a look at what the path to accessing services looks like in each waiver.

Slide Excerpt from CDAC Meeting

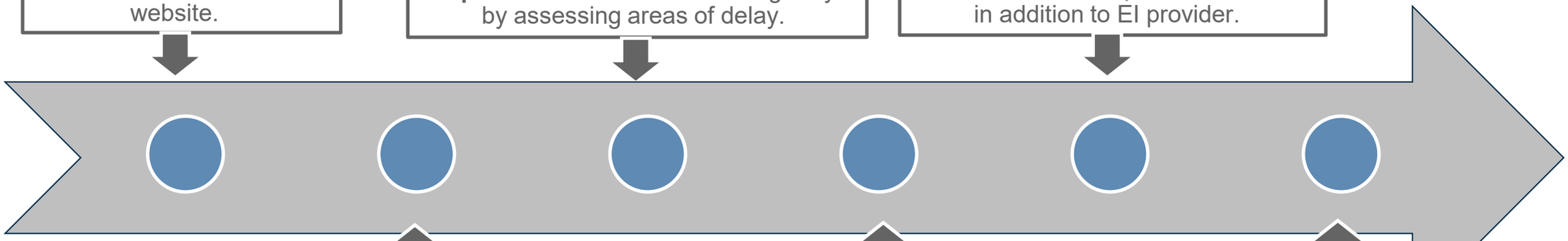
DD Waiver Access (3+): The Customer Journey to Services

How do people 3+ learn about, apply for, and begin IID/DD waiver services?



DD Waiver Access (birth until age 3): The Customer Journey to Services

Slide Excerpt from CDAC Meeting



Step 1: Pre-Front Door

Learn about DD services and where to begin the application process. Families learn from doctors or educators, Right Track Screening (birth until age 3), or from the HHS website.

Step 2: Front Door

Begin the application process and **submit an inquiry** to Human Service Center (HSC), or to the HHS central office. The inquiry will be assigned to a DDPM.

Step 3: Eligibility for DDPM Services

DDPM will schedule an **intake home visit** to complete intake questions, discuss release of medical info, and have family sign intent to pursue services. DDPM **connects family with EI provider** who assists with eligibility by assessing areas of delay.

Step 4: Case Management

If individual is eligible for DDPM, the DDPM will **provide case management services.** The DDPM will also **assess DD waiver eligibility** using the intake answers.

Step 5: Waiver Service Planning

If the individual is found eligible for DD waiver services, then the DDPM helps **create a plan for waiver services.** They will also help schedule provider meetings if the individual wants to pursue services in addition to EI provider.

Step 6: Medicaid Eligibility

With the help of your assigned case manager, **complete the Medicaid eligibility process**. This must be done prior to beginning waiver services. Eligibility is financial.

Begin DD Waiver Services

Slide Excerpt from CDAC Meeting

Autism (ASD) Waiver Access: The Customer Journey to Services

How do people learn about, apply for, and begin ASD waiver services?

Step 1: Pre-Front Door

Learn about ASD services and where to begin the application process. Many families learn from doctors or educators, or from online website materials.

Step 2: Front Door

Begin the application process by submitting a completed 2-page application to HHS, Kathy Barchenger. This application is available online.

Step 3: Eligibility Process

Complete a questionnaire called the Vineland 3. HHS will then score the answers and use the results to determine ASD waiver eligibility. HHS will send decision and scores via letter

Step 4: Case Management

HHS will connect waiver eligible individuals with case managers. Case managers will help the family **create a person-centered plan** that includes a plan for services.

Step 5: Medicaid Eligibility

With the help of your assigned case manager, **complete the Medicaid eligibility process**. This must be done prior to beginning waiver services. Eligibility is financial.

Begin ASD Waiver Services

Slide Excerpt from CDAC Meeting

Medically Fragile (MF) Waiver Access: The Customer Journey to Services

How do people learn about, apply for, and begin MF waiver services?

Step 1: Pre-Front Door

Learn about MF services and where to begin the application process. Many families learn from doctors or educators, or from online website materials.

Step 2: Front Door

Begin the application process by submitting a completed 1-page application to HHS, Kathy Barchenger. This application is available online.

Step 3: Level of Care

Complete an intake phone call with Kat Barchenger from HHS. During this call, HHS will fill out level of care determination forms and validate findings with department nursing staff.

Step 4: Level of Need

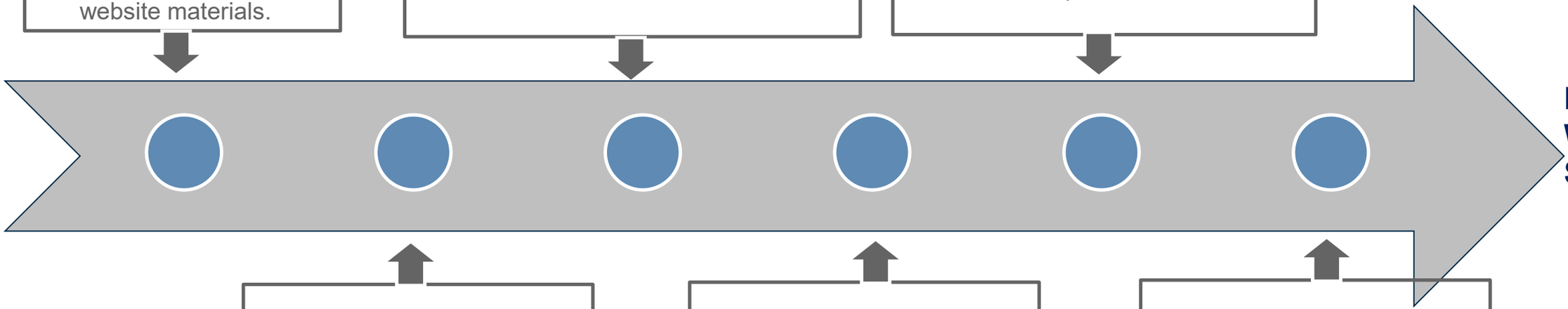
Submit information on needs, including a paragraph on family experiences, and a form completed by a doctor. Families have 30 days to complete this process.

Step 5: Case Management

HHS will connect waiver eligible individuals with case managers. Case managers will help the family **create a person-centered plan** that includes a plan for services.

Step 6:Medicaid Eligibility

With the help of your assigned case manager, **complete the Medicaid eligibility process**. This must be done prior to beginning waiver services. Eligibility is financial.



Begin MF Waiver Services

Slide Excerpt from CDAC Meeting

Comparing the Customer Journey to Services

Process Step	ASD Waiver	MF Waiver	DD Waiver
Pre-application: Where do most families learn about services?	• Doctors, schools, HHS website	• Doctors, schools, HHS website	• Doctors, schools, HHS website • Right Track Screening (if birth until age 3)
Start Application Process: Who is the point of contact to begin the application process?	• HHS (Kat Barchenger)	• HHS (Kat Barchenger)	• Human Service Center DDPM (locations across 8 regions)
Submit Written Application: What materials does a family need to submit at the beginning of the application process?	• 2-page written application	• 1-page written application	• No written application • Family will sign intent to pursue services during initial home visit (see description of visit below)
Complete Intake Call: Is there an intake call or home visit that a family must complete during the application process?	• No formal intake call	• Formal intake call where HHS (Kat) collects information to complete LOC	• Intake visit where DDPM visits home and collects information for DDPM and DD waiver eligibility
Additional Forms: Are there any other forms the family is responsible for completing?	• Vineland: the family must submit a completed Vineland 3 form (HHS will score this form as part of eligibility)	• Paragraph on family viewpoint • Level of need form filled out by family doctor within 30 days	• No additional requirements • DDPM is responsible for completing and scoring eligibility forms based on intake conversation
Case Management: How does the family create a plan and begin to receive waiver services?	• Kat connects the family with a private agency case managers who helps create a person-centered plan and complete Medicaid financial eligibility	• Kat connects the family with a DDPM who helps create person-centered plan and complete the Medicaid financial eligibility process	• Family continues working with the DDPM who conducted intake visit. DDPM helps them create person-centered plan and Medicaid eligibility

Creating a Cross-Disability Children's Individual & Family Supports Waiver

A cross - disability children's Waiver would allow the State to provide services for children with support needs, regardless of disability category.

Target Population

- Children aged **3 until age 18 (or 21)** with mild to moderate support needs are served in the Individual and family support (IFS) waiver.
- Those with higher support needs can be assessed for services through the IID/DD comprehensive waiver.

Children from birth until age 3 will continue to be served by the IID/DD waiver.

Level of Care

- Use an expansive LOC for children aged 3 until age 6, based on eligibility for early intervention Part B Services.
- For children ages 6 and above, use the new IID/DD LOC and other existing LOCs (Medically Fragile, Autism).

Services

- Build a service array that supports families, leverages the workforce, and facilitates success transition.
- Incentivize self-direction.
- Understand existing utilization so that no one loses support.

Policy Decisions:

- Should there be an individual cost limit?
- If so, is it a hard cap or soft cap?
- Is there a need for tiered waivers with different levels of individual cost limits to help mitigate a potential waiting list?
- Is there an opportunity for county buy-in?

Promising Practice Cross-Disability State Waiver Approaches: New York

New York operates a cross-disability children's waiver that provides services for a variety of populations.

Waiver Names	Target Populations	Age Limits	Level of Care	Self Direction	Maximum Participants	Spend per Person	Total Annual Spend
New York							
NY Children's Waiver (4125.R06.00)	• Physically Disabled • Disabled (Other) • HIV/AIDS • Brain Injury • Medically Fragile • Technology Dependent • ID/DD • Autism • SED	• SED: From birth until age 8 • All Others: From birth until age 20	• Hospital as defined in 42 CFR §440.10 • Inpatient psychiatric facility for individuals aged 21 and under as provided in 42 CFR §440.160 • Nursing Facility • ICF	No	17,379	$3.7K	$64.0M
Provides community habilitation, day habilitation, prevocational services, respite, supported employment, adaptive and assistive technology, caregiver/family advocacy and support services, environmental modifications, non-medical transportation, palliative care-expressive therapy, palliative care-counseling and support service, palliative care-massage therapy, palliative care-pain and symptom management, and vehicle modification services							

Additional Notes on NY's Cross-Disability Children's Waiver

- Designed for children who do not need intensive life long LTSS (those children would be served in the IID/DD comprehensive waiver)
- All children on this waiver also receive health home services for care coordination
- Helpful for children with dual diagnoses to receive coordinated care
- Challenging for case managers and providers to serve a cross-disability population well; seeing some providers who will serve only a target population
- Workforce is especially challenging in rural areas; working on remote supports and telemedicine to mitigate

Source: Interview with Jodi Saitowitz

Promising Practice Cross-Disability State Waiver Approaches: Wisconsin

Wisconsin operates two cross-disability waivers-one for children, and one for adults.

Waiver Names	Target Populations	Age Limits	Level of Care	Self Direction	Maximum Participants	Spend per Person	Total Annual Spend
Wisconsin							
WI Children's Long-Term Support Waiver Program (0414.R04.00)	• Physically Disabled • Disabled (Other) • Autism • ID/ DD • SED	From birth until age 21	• Nursing Facility • ICF/IID	Yes	22,092	$11.2K	$247.6M
WI Family Care Waiver (0367.R04.00)	• Aged • Physically Disabled • Disabled (Other) • ID/DD	• Aged: 65+ • Physically disabled: Aged 18 until age 64 • IDD: 18+ • Other: 18+	• Nursing Facility • ICF/IID	Yes	71,840	$28.7K	$2.1B

Children's Services: Provides adult family home, assistive technology, child care services, children's foster care, communication assistance for community inclusion, community integration services, community/competitive integrated employment (individual), community/competitive integrated employment (small group), counseling and therapeutic services, daily living skills training, day services, discovery and career planning, empowerment and self-determination supports, family/unpaid caregiver supports and services, financial management services, grief and bereavement counseling, health and wellness, home modifications, housing support services, mentoring, participant and family-directed goods and services, participant and family-directed broker services, personal emergency response system, personal supports, relocation services, respite, safety planning and prevention, specialized medical and therapeutic supplies, support and service coordination, transportation, vehicle modifications, and virtual equipment and supports services

Adult Services: Provides adult day care, case management, daily living skills training, day habilitation, prevocational, respite, supported employment-individual employment support, consumer directed supports broker, financial management services, adaptive aids, adult residential care (1-2 bed adult family homes), adult residential care (3-4 bed adult family homes), adult residential care (community-based residential facilities), adult residential care (residential care apartment complexes), assistive technology/communication aids, consultative clinical and therapeutic services for caregivers, consumer education/training, counseling and therapeutic resources, environmental accessibility adaptations (home modifications), home delivered meals, housing counseling, personal emergency response system, relocation services, self-directed personal care, skilled nursing services RN/LPN, specialized medical equipment and supplies, supported employment (small group employment support), supportive home care, training services for unpaid caregivers, specialized transportation (community transportation), specialized transportation (other transportation), vocational futures planning and support services

Definitions: Early Intervention Part C & Part B

From Assessment

	Early Intervention Program IDEA-Part C	Early Childhood Special Education Services IDEA-Part B
Age of Child	Birth to age 2	Ages 3 - 5
Eligibility Criteria	Infant and toddler services may be provided to children if there is evidence of a developmental delay or risk of developmental delay. Young children who have a high risk of becoming developmentally delayed, or are developmentally delayed, may receive program management services and be considered for services to meet specific needs. “High Risk” means a child who has a diagnosed physical or mental condition and has a high probability of becoming developmentally delayed or who, based on informed clinical opinion and documented by evaluation data, has a high probability of becoming developmentally delayed. “Developmentally delayed” is defined as performing 25 percent below age norms in two or more of the following areas: • cognitive development • gross motor development • fine motor development • sensory processing • communication development (receptive or expressive) • social or emotional development • adaptive development; Or who is performing at 50 percent below age norms in one of the following areas: • cognitive development • physical development (including vision and hearing) • communication development (including receptive and expressive) • social or emotional development • adaptive development	Based on results from the initial evaluation process, eligibility for early childhood special education services may be determined in the following categories: • Autism • Deaf-blindness • Deafness • Hearing-impairment • Other health impairment • Orthopedic impairment • Speech or language impairment • Visually impaired including blindness • Traumatic brain injury • Intellectual disability • Emotional disturbance • Specific learning disability For younger children (up to age 9) in North Dakota, a “Non-Categorical Delay” (NCD) eligibility option may be used when a disability is not clearly identified, but delays are evident.

Intellectual or Developmental Disability Definitions (1 of 2)

From Assessment

	North Dakota	AAIDD
Intellectual or Developmental Disability Definition **Recommendation**: 1. Recognize adaptive social deficits 2. Require substantial functional limitations in 3 or more major life activities, that cross at least 2 of the 3 domains: conceptual, social, and practical	The term "developmental disability" means a severe, chronic disability of a person which: A. is attributable to a mental or physical impairment or combination of mental and physical impairments; B. is manifested before the person attains age twenty-two; C. is likely to continue indefinitely; D. results in **substantial functional limitations in three or more of the following areas of major life activity**: [SEE BELOW] E. reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are of lifelong or extended duration and are individually planned and coordinated.	Intellectual disability is a disability characterized by **significant limitations in** both intellectual functioning and in **adaptive behavior**, which covers many everyday social and practical skills. This disability originates before the age of 18. Intellectual functioning-also called intelligence-refers to general mental capacity, such as learning, reasoning, problem solving, and so on. One way to measure intellectual functioning is an IQ test. Generally, an IQ test score of around 70 or as high as 75 indicates a limitation in intellectual functioning.
Adaptive Deficit: Conceptual	Receptive and expressive language Learning Self-direction	Conceptual skills-language and literacy; money, time, and number concepts; and self-direction.
Adaptive Deficit: Social		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.
Adaptive Deficit: Practical	Self-care Mobility Capacity of independent living, and Economic self-sufficiency	Practical skills-activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

Intellectual or Developmental Disability Definitions (2 of 2)

From Assessment

	DSM-5	ICD-11
Intellectual or Developmental Disability Definition	Intellectual disability involves impairments of general mental abilities **that impact adaptive functioning in three domains, or areas.** These domains determine how well an individual copes with everyday tasks. While intellectual disability does not have a specific age requirement, an individual's symptoms must begin during the developmental period and are diagnosed based on the severity of deficits in adaptive functioning.	Neurodevelopmental disorders are behavioral and cognitive disorders that arise during the developmental period that involve significant difficulties in the acquisition and execution of **specific intellectual, motor, or social functions.** Although behavioral and cognitive deficits are present in many mental and behavioral disorders that can arise during the developmental period (e.g., Schizophrenia, Bipolar disorder), only disorders whose core features are neurodevelopmental are included in this grouping. The presumptive etiology for neurodevelopmental disorders is complex, and in many individual cases is unknown.
Adaptive Deficit: Conceptual	The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.	Conceptual skills are related to the application of knowledge (e.g., reading, writing, calculating, solving problems, decision-making) and communication
Adaptive Deficit: Social	The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.	Social skills are those related to managing interpersonal interactions, relationships, social responsibility, following rules, obeying laws as well as avoiding victimization.
Adaptive Deficit: Practical	The practical domain centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.	Practical skills are those related to activities such as self-care, health and safety, occupational skills, recreation, use of money, transportation, and use of home appliances and devices.

Intellectual or Developmental Disability Definitions (1 of 5)

From Assessment

	AAIDD	DSM-5
Intellectual or Developmental Disability Definition	Intellectual disability is a disability characterized by **significant limitations in** both intellectual functioning and in **adaptive behavior**, which covers many everyday social and practical skills. This disability originates before the age of 18. Intellectual functioning-also called intelligence-refers to general mental capacity, such as learning, reasoning, problem solving, and so on. One way to measure intellectual functioning is an IQ test. Generally, an IQ test score of around 70 or as high as 75 indicates a limitation in intellectual functioning.	Intellectual disability involves impairments of general mental abilities **that impact adaptive functioning in three domains, or areas.** These domains determine how well an individual copes with everyday tasks. While intellectual disability does not have a specific age requirement, an individual's symptoms must begin during the developmental period and are diagnosed based on the severity of deficits in adaptive functioning.
Adaptive Deficit: Conceptual	Conceptual skills-language and literacy; money, time, and number concepts; and self-direction.	The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
Adaptive Deficit: Social	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.	The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
Adaptive Deficit: Practical	Practical skills-activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.	The practical domain centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.

Intellectual or Developmental Disability Definitions (2 of 5)

From Assessment

	ICD-11	North Dakota
Intellectual or Developmental Disability Definition	Neurodevelopmental disorders are behavioral and cognitive disorders that arise during the developmental period that involve significant difficulties in the acquisition and execution of **specific intellectual, motor, or social functions.** Although behavioral and cognitive deficits are present in many mental and behavioral disorders that can arise during the developmental period (e.g., Schizophrenia, Bipolar disorder), only disorders whose core features are neurodevelopmental are included in this grouping. The presumptive etiology for neurodevelopmental disorders is complex, and in many individual cases is unknown.	The term "developmental disability" means a severe, chronic disability of a person which: A. is attributable to a mental or physical impairment or combination of mental and physical impairments; B. is manifested before the person attains age twenty-two; C. is likely to continue indefinitely; D. results in **substantial functional limitations in three or more of the following areas of major life activity**: [SEE BELOW] E. reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are of lifelong or extended duration and are individually planned and coordinated.
Adaptive Deficit: Conceptual	Conceptual skills are related to the application of knowledge (e.g., reading, writing, calculating, solving problems, decision-making) and communication	(2) receptive and expressive language (3) learning (5) self-direction
Adaptive Deficit: Social	Social skills are those related to managing interpersonal interactions, relationships, social responsibility, following rules, obeying laws as well as avoiding victimization.	
Adaptive Deficit: Practical	Practical skills are those related to activities such as self-care, health and safety, occupational skills, recreation, use of money, transportation, and use of home appliances and devices.	(1) self-care (4) mobility (6) capacity of independent living, and (7) economic self-sufficiency

Intellectual or Developmental Disability Definitions (3 of 5)

From Assessment

	Nebraska
Intellectual or Developmental Disability Definition	Developmental disability shall mean a severe, chronic disability, including an intellectual disability, other than mental illness, which: (1) Is attributable to a mental or physical impairment unless the impairment is solely attributable to a severe emotional disturbance or persistent mental illness; (2) Is manifested before the age of twenty-two years; (3) Is likely to continue indefinitely; (4) Results in **substantial functional limitations in one of each of the following areas of adaptive functioning** [SEE BELOW] and (5) Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. An individual from birth through the age of nine years inclusive who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the major life activities described in subdivision (4) of this section if the individual, without services and support, has a high probability of meeting those criteria later in life.
Adaptive Deficit: Conceptual	(a) Conceptual skills, including language, literacy, money, time, number concepts, and self-direction
Adaptive Deficit: Social	(b) Social skills, including interpersonal skills, social responsibility, self-esteem, gullibility, wariness, social problem solving, and the ability to follow laws and rules and to avoid being victimized
Adaptive Deficit: Practical	(c) Practical skills, including activities of daily living, personal care, occupational skills, healthcare, mobility, and the capacity for independent living

Intellectual or Developmental Disability Definitions (4 of 5)

From Assessment

	Kansas	Iowa
Intellectual or Developmental Disability Definition	Intellectual disability is defined as having substantial limitations in present functioning that is manifested during the period from birth to age 18 years and is characterized by significantly subaverage intellectual functioning existing concurrently with deficits in adaptive behavior including related **limitations in two or more of the following applicable adaptive skill areas** [SEE BELOW]	Intellectual disability is defined as: a diagnosis of intellectual disability (intellectual developmental disorder), global developmental delay, or unspecified intellectual disability (intellectual developmental disorder) which shall be made only when the onset of the person's condition was during the developmental period and shall be based on an assessment of the person's intellectual functioning and level of adaptive skills. The diagnosis shall be made in accordance with the criteria provided in the DSM-5. For LOC: The person has a diagnosis of **intellectual disability made in accordance with the criteria provided in the current version of the Diagnostic and Statistical Manual** of Mental Disorders published by the American Psychiatric Association; **or has a related condition as defined in 42 CFR 435.1009; and needs assistance in at least three of the following major life areas:** [SEE BELOW]
Adaptive Deficit: Conceptual	Communication, self-direction, functional academics	Academic skills
Adaptive Deficit: Social	Social skills, community use, leisure	Social/community skills, behavior
Adaptive Deficit: Practical	Self-care, home living, health and safety, work	Mobility, musculoskeletal skills, activities of daily living, domestic skills, toileting, eating skills, vision, hearing or speech or both, gross/fine motor skills, sensory-taste, smell, tactile, health care, vocational skills

Intellectual or Developmental Disability Definitions (5 of 5)

From Assessment

	South Dakota
Intellectual or Developmental Disability Definition	(1) The individual has a severe, chronic disability attributable to intellectual disability, cerebral palsy, epilepsy, head injury, brain disease, autism, or another condition which is closely related to intellectual disability and requires treatment or services similar to those required for individuals with intellectual disabilities. To be closely related to intellectual disability, a condition must cause impairment of general intellectual functioning or adaptive behavior similar to that of intellectual disability; (2) The disability manifested itself before the individual reached the age of 22; and (3) The disability is likely to continue indefinitely. An individual is in need of ICF/IID services if the Inventory for Client and Agency Planning (ICAP) completed under § 67:54:03:05 shows that the individual has a **substantial functional limitation in three or more of the following functional areas**:
Adaptive Deficit: Conceptual	(2) Receptive and expressive language--communication involving verbal and nonverbal behavior that enables a person to understand others and to express ideas and information to others; (3) Learning/general cognitive competence--the ability to acquire new behaviors, perceptions, and information and to apply the experiences to new situations; (5) Self-direction--the management of one's social and personal life; the ability to make decisions affecting and protecting one's self-interests;
Adaptive Deficit: Social	(5) Self-direction--the management of one's social and personal life; the ability to make decisions affecting and protecting one's self-interests; (intentionally repeated, since this criteria may be applied in both conceptual and social)
Adaptive Deficit: Practical	(1) Self-care--the daily activities enabling a person to meet basic life needs for food, hygiene, and appearance; (4) Mobility--the ability to use fine or gross motor skills to move from one place to another with or without mechanical aids; (6) Capacity for independent living--based on age, the ability to live without extraordinary assistance; and (7) Economic self-sufficiency--the maintenance of financial support.

Example of an Updated Definition: District of Columbia

In 2022, DC updated their definition to include developmental disabilities, with a focus on including adults with autism

- D.C. Official Code § 7-761.03(7A) and 7-1301.04(15A), and as amended by the Developmental Disability Eligibility Reform Amendment Act of 2022, means a person that is diagnosed before 22 years of age with an **intellectual disability as set forth in the Diagnostic and Statistical Manual of Mental Disorders** published by the American Psychiatric Association.
- In addition, eligibility for services **is expanded to people with a developmental disability** as defined in D.C. Official Code §§ 7-761.02(3A) and 7-1301.03(8D), and as amended by the Developmental Disability Eligibility Reform Amendment Act of 2022, means
  - a severe and chronic disability of a person that is attributable to a mental or physical impairment, other than the sole diagnosis of mental illness, or to a combination of mental and physical impairments;
  - is manifested before 22 years of age;
  - is likely to continue indefinitely;
  - results in substantial functional limitations in 3 or more of the following areas of major life activity: self-care; understanding and use of language; functional academics; social skills; mobility; self-direction; capacity for independent living; or health and safety; and
  - reflects the person'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 person-centered, planned, and coordinated.

Medically Fragile Waiver Eligibility (1 of 2)

CDAC members have recommended that being on the Social Security Compassionate Care list should be sufficient to meet level of care for the Cross Disability Children's waiver. A&M conducted a national scan of Medically Fragile children's waiver and did not find a comparable level of care. Two states, Florida and Utah, reference Social Security disability criteria, but children still must show accompanying functional limitations such that they meet level of care. Therefore, A&M disagrees with this recommendation.

State	Eligibility Criteria
AK	Nursing Facility level of care assessed by the State of Alaska Nursing Facility Assessment form for Children; Detailed descriptions of medical needs are not documented in the waiver's level of care description.
CA	This waiver's eligibility criteria include a list of medical device dependencies and conditions such as peritoneal dialysis, tube feeding, and stage 3 or greater pressure sores.
CO	Institutional level of care required. Additional medical details are not outlined.
FL	At Risk of Hospitalization level of Care is required. The individual must also be determined disabled using criteria established by the Social Security Administration.
GA	A medical evaluation is included as part of level of care. Some of the areas of assessment include cardio-pulmonary status, urogenital, neurological and the Integument system. The mobility status, nutritional, bowel integrity and behavioral status must be evaluated.
KS	Kansas uses the Medical Assistive Technology level of care tool to assess eligibility. Other specifications of medical conditions are not included.
KY	Individuals are eligible if they meet nursing facility level of care and are ventilator-dependent for 12 hours or more daily.
MD	Maryland describes different medical conditions or needs that are required to meet chronic hospital level of care, such as ventilator assistance, tracheostomy participants, surgical drains, or intensive language pathology needs.

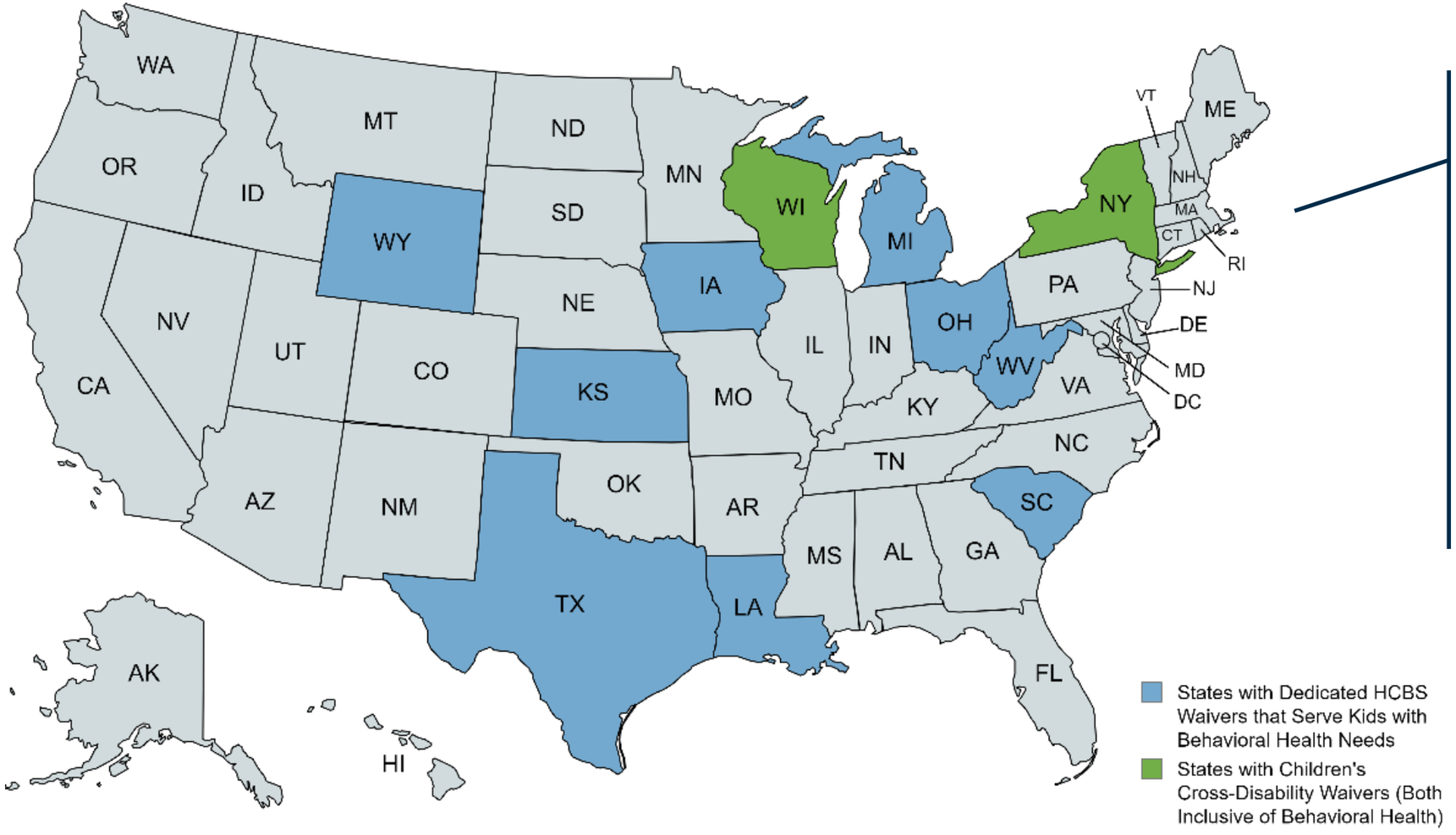
References the SSA criteria

Medically Fragile Waiver Eligibility (2 of 2)

State	Eligibility Criteria
NC	Requires individuals to meet HCBS nursing facility level of care, which is characterized by specifical medical needs, including ambulation training, drug administration via tube, and gastronomy feedings.
NM	Requires Intermediate Care Facility. Criteria include nutritional status, toileting, hygiene, etc.
OR	Requires hospital level of care to be met. The instrument measures the frequency and intensity of the care needed in the following: Skin/Physical Management; Metabolic: GI/Feeding; Neurological; Urinary/Kidney; Respiratory; and Vascular.
SC	Requires Hospital level of care. Criteria include an evaluation of an applicant/participant's dependency on medications; hospitalizations; emergency room visits; skilled nursing level needs; physical, occupational, and speech therapy needs; and specialty care physician needs.
TX	The applicant/member must demonstrate a medical condition of sufficient seriousness that the applicant's/member's needs exceed the routine care which may be given by an untrained person and requires licensed nurses' supervision, assessment, planning, and intervention. The applicant/member must also require medical or nursing services that are ordered by a physician; are dependent upon the applicant's/member's documented medical conditions; require the skills of a registered or licensed vocational nurse; are provided either by or under the supervision of a licensed nurse in an institutional setting; and are required on a regular basis.
UT	Two of the following criteria must be met: (a) Due to diagnosed medical conditions, the applicant requires substantial physical assistance with daily living activities above the level of verbal prompting, supervising, or setting up; (b) The attending physician has determined that the applicant's level of dysfunction in orientation to person, place, or time requires nursing facility care or equivalent care provided through a Medicaid Home and Community-Based waiver program; or (c) The medical condition and intensity of services indicate that the care needs of the applicant cannot be safely met in a less structured setting, or without the services and supports of a Medicaid Home and Community-Based Waiver program. A disability determination by the Social Security Administration or the Medical Review Board must also be made.

References the SSA criteria

National Landscape of HCBS Waivers for Children's Behavioral Health



National Outlook:

- Nine states have HCBS waivers for children's behavioral health.
- Both states with cross - disability children's waivers include behavioral health.

SED Waiver Approaches (1 of 3)

In addition to a gap for children with developmental disabilities, there is a gap for children with severe emotional disturbance (SED). Ten states provide waiver services specifically for children with SED offering a mix of services including respite, parent training and support, independent living skills, and more. These services align with what families have identified as most needed for the Cross-Disability Children's Waiver.

Waiver Names	Target Populations	Age Limits	Level of Care	Self Direction	Maximum Participants	Waiver Spend per Person	Total Annual Spend
Iowa							
IA Children's Mental Health Waiver (0819.R02.00)	• Serious Emotional Disturbance	From birth until age 17	Inpatient psychiatric facility for individuals aged 21 and under, as provided in 42 CFR §440.160	No	1,860	$9K	$16.8M
Provides family and community support service, respite, environmental modifications and adaptive devices, and in-home family therapy.							
Kansas							
KS Serious Emotional Disturbance (SED) Waiver (0320.R05.00)	• Serious Emotional Disturbance	Aged 4 until age 18	Inpatient psychiatric facility for individuals aged 21 and under, as provided in 42 CFR §440.160	No	4,900	$1.7K	$8.4M
Provides attendant care, independent living/skills building, short-term respite care, parent support and training, professional resource family care, and wraparound facilitation services.							
Louisiana							
LA Coordinated System of Care (CSoC) Severely Emotionally Disturbed (SED) Children's Waiver (0889.R02.00)	• Mental Illness • Serious Emotional Disturbance	• Mental Illness: Aged 18 until age 20 • SED: Aged 5 until age 17	• Hospital as defined in 42 CFR §440.10 • Inpatient psychiatric facility for individuals aged 21 and under, as provided in 42 CFR §440.160 • Nursing Facility	No	5,557	$3.2K	$18.0M
Provides independent living/skills building, parent support and training, short-term respite, and youth support and training services.							

SED Waiver Approaches (2 of 3)

Waiver Names	Target Populations	Age Limits	Level of Care	Self Direction	Maximum Participants	Waiver Spend per Person	Total Annual Spend
Michigan							
MI Waiver for Children with Serious Emotional Disturbances (0438.R03.00)	• Serious Emotional Disturbance	From birth until age 21	Inpatient psychiatric facility for individuals aged 21 and under as, provided in 42 CFR §440.160	Yes	969	14.6K	$14.2M
Provides respite, fiscal intermediary, child therapeutic foster care, community living supports, family home care training, family support and training, home care training (non-family), overnight health and safety support, therapeutic activities, therapeutic overnight camp, and wraparound services.							
Ohio							
OH OhioRISE Waiver (2226.R00.00)	• Serious Emotional Disturbance	From birth until age 20	Inpatient psychiatric facility for individuals aged 21 and under as, provided in 42 CFR §440.16,0	Yes	1,235	$3.2K	$4.0M
Provides out-of-home respite, transitional services and supports, and secondary flex fund services.							
South Carolina							
SC Palmetto Coordinated System of Care for Children (PCSC) Home and Community Based Waiver (1686.R00.00)	• Serious Emotional Disturbance	From birth until age 21	Inpatient psychiatric facility for individuals aged 21 and under as, provided in 42 CFR §440.160	Yes	360	$12.0K	$4.3M
Provides high-fidelity wraparound, respite, and individual directed goods and services.							

SED Waiver Approaches (3 of 3)

Waiver Names	Target Populations	Age Limits	Level of Care	Self Direction	Maximum Participants	Waiver Spend per Person	Total Annual Spend
Texas							
TX Youth Empowerment Services (YES) Waiver (0657.R03.00)	• Serious Emotional Disturbance	Aged 3 until age 18	Inpatient psychiatric facility for individuals aged 21 and under as, provided in 42 CFR §440.160	No	3,591	$5.0K	$17.7M
Provides respite, supported employment, adaptive aids and supports, community living supports, employment assistance, family supports, minor home modifications, non-medical transportation, paraprofessional services, specialized therapies, supportive family-based alternatives, and transitional services.							
West Virginia							
WV Children with Serious Emotional Disorder (1646.R01.00)	• Mental Illness • Serious Emotional Disturbance	• Mental Illness: Aged 18 until age 21 • SED: Aged 3 until age 17	Inpatient psychiatric facility for individuals aged 21 and under as, provided in 42 CFR §440.160	No	2,000	$102.6K	$205.2M
Wyoming							
WY Children's Mental Health Waiver (0451.R03.00)	• Mental Illness • Serious Emotional Disturbance	• Mental Illness: Aged 18 until age 21 • SED: Aged 4 Until age 17	Inpatient psychiatric facility for individuals aged 21 and under as, provided in 42 CFR §440.160	No	135	$796	$107,534
Provides youth and family training and support services.							

Appendix: Peer and Promising State Service Examples

Family Skill Development Services

Idaho | Iowa | Kansas | Minnesota | Montana | Nebraska | South Dakota | Wyoming

Behavior Consultation/ Crisis Management

ID Adult Developmental Disabilities Waiver (0076.R07.00)

- Provides direct consultation and clinical evaluation of individuals experiencing a crisis
- This service may be used for providing training and staff development related to the needs of an individual

Family Training and Support

MT Montana Big Sky (0148.R06.00)

- Provides training and emotional support to families with children with disabilities
- Types of support include general training about the child's disability, providing education about developmental stages, identifying resources to help manage stress, and working alongside the family and the case manager to advocate for the family's needs

Psychological Evaluation/ Counseling and Consultation Services

MT Home and Community-Based Waiver for Individuals with Developmental Disabilities (0208.R07.00)

- This service includes counseling for primary care givers when their needs are related to problems dealing with the individual with a disability

Parent Support and Training (Peer-to-Peer)

KS Autism Waiver (0476.R03.00)

- Provides training and support to family members to encourage family participation in the treatment process
- Supports are meant to help families improve their abilities to provide a safe and supportive environment
- Trainings are meant to be tailored to a child's diagnosis and specific needs
- This also includes training related to different waiver or grant requirements

Caregiver Training and Support

MT Home and Community-Based Waiver for Individuals with Developmental Disabilities (0208.R07.00)

- Provides training and support services for people who provide unpaid training, companionship, or supervision to waiver recipients.
- Training includes coaching to learn skills to participate in the community

Family and Community Support Services

IA Children's Mental Health Waiver (0819.R02.00)

- This service is focused on the practical application of skills and interventions that will allow the family and the child to function more appropriately
- This includes helping the child and the family identify and implement various coping strategies to support community engagement

Note that this research is currently in progress; more updates will be shared in future working sessions

Example of Peer Provider Qualifications for Parent Training

Several states, including the District of Columbia, allow peers to provide parent training-is responsive to parents' request for more peer-to-peer support, helps bring in a new kind of workers into the workforce, and often costs less than a clinical professional.

Example of Individual Provider Qualifications

For individual employees, the following requirements apply:

- Lived experience as a family member of a person with intellectual disabilities;
- Demonstrated history of advocacy either for themselves or their family members;
- Documentation that each employee is 18 years of age or older;
- Documentation that each employee was found acceptable by the individual;
- A high school diploma or GED;
- Annual documentation from a physician or other official that the employee is free from communicable disease as confirmed by an annual PPD skin test;
- COVID vaccination; and
- Record of a criminal background check.

Source: DC People with Intellectual and Developmental Disabilities (IDD) Waiver (0307.R05.00) | Medicaid

Connecticut Peer Support Services

Connecticut offers peer support services for the waiver participant.

Peer Support Services Definition:

Peer support includes face-to-face interactions including Face Time or comparable technology(such as IPAD, IPHONE) in accordance with HIPAA requirements, that are designed to promote ongoing engagement of waiver participants towards the participant's personal goals. All peer support will promote the individuals strengths and abilities to continue improving socialization, self-advocacy, development of natural supports, and maintenance of community living skills. Peer support also includes communication and coordination with medical providers including behavioral health services providers and/or others in support of the participant. Service can be provided in the participants home, at their job or community. **Example of Activities: How to manage the participants home, manage self-direction of supports, How to find a job or maintain a job, How to advance in chosen career, how to access the community and build community supports**

Limitations:

Peer Support interventions will exclude activities that are duplicative of any other waiver service. Peer Support is limited to 2 hours per week and over a six month time period. Prior approval is needed to extend beyond the six months and should be documented in the individual plan.

Projections:

- # Users/Total Waiver Participants: 1/4500
- Unit: 15 minutes
- Average Units/User: 76
- Average Cost/ Unit: $8.79
- Total Projected Cost/Year: $668.04

Staff Qualifications:

- Be at least 21 years old;
- Possess at least a high school diploma or GED;
- Minimum 2 years of personal experience,
- Other qualifications as determined by the participant

Source: CT Individual and Family Support Waiver (0426.R04.00)

Promising Practice: Health Care Navigation & Coordination

- **Is there a need for navigation services to support for family caregivers?**
  - Challenges for parents of medically complex children
  - Potentially exacerbated by private nursing duty shortages

- **Benefits**:
  - Enhances independent living skills and navigation of community resources
  - Improves overall health, safety, and wellbeing
  - Promotes safe and effective hospital diversion and/or discharge planning
  - Provides training and supervision of family and service providers
  - Builds capacity of family caregivers and DSPs for monitoring and response
  - Provides continuity of care through workforce/staffing turnover

- **Considerations**:
  - Limited to additional and non-duplicative services not covered under state plan, EPSDT or waiver services
    - Is this covered by EPSDT in North Dakota? Example: Indiana excludes children up to age 21 because "*all medically necessary wellness coordination services for children under age 21 are covered in the state plan benefit pursuant to the EPSDT benefit.*"
    - Compare Wisconsin (in their children's waiver), Pennsylvania, Missouri, which provide various approaches
  - Cannot replace or perform core functions of case management
  - Nurse delegation and supervision
  - Coordination with skilled nursing
  - These are relatively new services, with the examples we shared all added to waivers in 2022

Wisconsin Health & Wellness

Slide Excerpt from CDAC Meeting

Wisconsin offers Health and Wellness to support a child's access and inclusion in health and wellness activities within their community.

Health and Wellness Service Definition:

Health and Wellness services **focus on healthy habits thereby preventing or delaying higher cost institutional care** and include:

a) **Healthy Lifestyles-**Participants can take classes, lessons, events, or other educational opportunities, such as health and wellness web and mobile applications, to address issues regarding living with a disability and having a healthy lifestyle, including nutrition, physical activity, and sensory regulation. This increases the capacity of the participant to self-advocate, navigate community resources and improve overall health and socialization skills. These skills keep participants in the community and out of an institution.

b) **Non-traditional/alternative medicine and wellness**, such as yoga, meditation, mindfulness, sound healing, Traditional African Based Holistic Services, Ayurveda, Chinese or Oriental medicine, Reiki, Tai Chi, Native American healers (treatments may include prayer, dance, ceremony and song, plant medicines and foods, participation in sweat lodges, and the use of meaningful symbols of healing, such as the medicine wheel and/or other sacred objects), and spiritual counseling.

c) **Sexuality Education and Parenting Training for Participants**-intended to provide a proactive educational program about the values and critical thinking skills needed to form and maintain meaningful relationships, healthy sexuality, and sexual expression and train and support participants who are also parents.

Limitations*: Any service that could be furnished under the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit, which provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid, or the Medicaid State Plan services. In addition, the waiver is the payer of last resort and coordination of benefits (COB) must occur with private health insurance, special education services funded under the Individuals with Disabilities Education Act (IDEA), or vocational rehabilitation services funded under section 110, as amended in 2014, of the Rehabilitation Act of 1973 (29 U.S.C. 730).*

Projections:
- # Users: 1602/22092
- Unit: Days and Hours
- Average Units/User: Days-27.26; Hours-13.64
- Average Cost/Unit: Days-$95.73; Hours-$47.87
- Total Projected Cost/Year: $776,427.16

Staff Qualifications:
- Any persons appropriately qualified as approved by the State and as related to the unique service being provided to the child

**added 1/1/22*

Source: WI Children's Long-Term Support Waiver Program (0414.R04.00) | Medicaid

Missouri Health Assessment & Coordination

Slide Excerpt from CDAC Meeting

Missouri offers Health Assessment and Coordination as a telemedicine care coordination service to provide physician driven right-on-time health assessment.

Health Assessment and Coordination Service Definition:

The Health Assessment & Coordination **telemedicine services** are designed to coordinate care with local emergency departments, urgent cares, and primary care physicians to enable real time support, consultation and coordination on health issues and **to assist individuals, families and support providers to understand presenting health symptoms and to identify the most appropriate next steps**. The service is consultative in nature related specifically to the presence of an intellectual disability and seeks to provide disability-specific advice on when best to seek additional or in-person medical treatment. This service is a supportive service that can occur while the person is in their home to help **assess the need for medical attention**.

The service includes support and consultation to families and direct support professionals (DSPs) otherwise unavailable in any other service. This component of the service seeks to **build the capacity of families and DSPs** (who do not possess medical credentials) to better understand the best approaches for supporting the individual depending on their symptom presentation. This service is available 24 hours a day, 7 days a week and includes immediate **evaluations, video-assisted examinations, treatment plans and discussion and coordination with individuals and/or caregivers by professionals with extensive specialized expertise supporting individuals with I/DD**. If a hospital visit is clinically necessary, this service allows the HAC provider to communicate with the emergency department directly, ensuring advance preparation for the ED and decreasing the chances of admission. This service works in close contact with but does not duplicate any of the functions of case management.

***Limitations**: The services are limited to additional services not otherwise covered under the state plan, including EPSDT, but consistent with waiver objectives of avoiding institutionalization.*

Projections:
- # Users: 814/9196
- Unit: month
- Average Units/User: 12.0
- Average Cost/Unit: $31.03

Total Projected Cost/Year: $3,109,020.60

Staff Qualifications:
- Physician (MD/DO)

*Added 7/1/2022

Source: MO Developmental Disabilities (DD) Comprehensive Waiver (0178.R07.00) | Medicaid

Pennsylvania Family Medical Support Assistance

Pennsylvania offers Family Medical Support Assistance which includes two components of direct and indirect service.

Family Medical Support Assistance Service Definition:

The Family Medical Support Assistance service assists with management of services in the participant's private home related to the medical needs of participants with a Needs Group 3 or 4 who use medically necessary technology and require nursing. This is a **direct and indirect service that does not involve direct care**.

Providers are required to render the following two components of the service.

1. **Family support assistant** - The family support assistant provides **assistance to participants and their families with scheduling and communication between and among unpaid supports and paid services** such as skilled nursing services, home health services, medical services, and behavioral health services in the participant's home including: coordinating/scheduling medical and behavioral health appointments; assisting with medical visits; mitigating concerns; assisting with discharge processes and home care and treatment; communication with insurance providers to facilitate understanding of coverage; assisting in obtaining medication, supplies, and equipment; identifying barriers to accessing effective and necessary medical services and supports and collaboration with service team plan members to reduce barriers; providing training and consultative assistance on implementation of non-medical aspects of the service plan
2. **Nursing Oversight** – Nursing oversight is completed by a licensed nurse within the scope of the state's Nurse Practice Act

***Limitations**: The family support assistant may provide Family Medical Support Assistance to no more than 8 participants for this or any other service. A licensed nurse may provide Family Medical Support Assistance to no more than 16 participants for this or any other service. Family Medical Support Assistance is available to participants who live in private homes. This service is not available to participants who receive Life Sharing, Supported Living or Residential Habilitation services.*

Projections:
- # Users: 30/19181
- Unit: 15 minute
- Average Units/User: 1920
- Average Cost/Unit: $18.41
- Total Projected Cost/Year: $1,413,888

Staff Qualifications:
- Family support assistant-college degree(s) with defined years of experience
- Nursing oversight-RN/LPN

*added 6/1/22

Source: Application for 1915(c) HCBS Waiver: PA.0147.R06.15 - Jun 01, 2022 (as of Jun 01, 2022)

New York Prevocational Services

New York offers prevocational services to youth to help prepare the individuals for employment.

Prevocational Services Definition:

Prevocational Services are individually designed to prepare a youth (age 14 or older) to engage in paid work, volunteer work or career exploration. Prevocational Services are not job-specific, but rather are geared toward facilitating success in any work environment for youth whose disabilities do not permit them access to other prevocational services. In addition, Prevocational Services assist with facilitating appropriate work habits, acceptable job behaviors, and learning job production requirements. Prevocational Services may include volunteer work, such as learning and training activities that prepare a person for entry into the paid workforce.

Prevocational Services should enable each participant to attain the highest level of work in the most integrated setting and with the job matched to the participant's interests, strengths, priorities, abilities, and capabilities.

Examples include, but are not limited to:

- Ability to communicate effectively with supervisors, co-workers and customers;
- Generally accepted community workplace conduct and dress;
- Ability to follow directions;
- Ability to attend to and complete tasks;
- Punctuality and attendance;
- Mobility training;
- Career planning;
- Proper use of job-related equipment and general workplace safety.
- Appropriate behaviors in and outside the workplace;
- Workplace problem solving skills and strategies;

Prevocational Services include activities that are not primarily directed at teaching skills to perform a particular job, but at underlying habilitative goals (e.g., attention span, motor skills, interpersonal relations with co-workers and supervisors) that are associated with building skills necessary to perform work and optimally to perform competitive, integrated employment.

- Resume writing, interview techniques, role play and job application completion.
- Exploring career options, facilitating appropriate work habits, acceptable job behaviors, and learning job production requirements • Assisting in identifying community service opportunities that could lead to paid employment
- Helping the youth to connect their educational plans to future career/vocational goals
- Helping youth to complete college, technical school or other applications to continue formal education/training
- Helping youth to apply for financial aid or scholarship opportunities

***Limitations**: Prevocational services will not be provided to an HCBS participant if: (i) Special education and related services that are otherwise available to the individual through a local educational agency, under the provisions of the Individuals with Disabilities Education Act (IDEA). (ii) Vocational rehabilitation services that are otherwise available to the individual through a program funded under section 110 of the Rehabilitation Act of 1973 (Access VR). (iii) Vocational services that are provided in facility-based work settings that are not integrated settings in the general community workforce. Prevocational services are limited to 2 hours a day.*

Projections:

- # Users/Total Waiver Participants: Approx. 600/17379
- Unit: 15 minutes
- Average Units/User: 100
- Average Cost/Unit: Approx. $23
- Total Projected Cost/Year: $1428092.16

Staff Qualifications:

- Minimum qualifications of an Associate's degree with one year human service experience. Direct service workers must have background checks.

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Source: New York Children's Waiver

New York Supported Employment Services

New York offers Supported Employment services to youth to provide on-the-job assistance to young people in competitive employment settings.

Supported Employment Services Definition:

Supported Employment services are individually designed to prepare youth with disabilities (age 14 or older) to engage in paid work. Supported Employment services provide assistance to participants with disabilities as they perform in a work setting. The outcome of this service is sustained paid employment at or above the minimum wage in an integrated setting in the general workforce, in a job that meets personal and career goals.

Supported employment services are individualized and may include any combination of the following services:

- vocational/job-related discovery or assessı
- person-centered employment planning
- job placement
- job development
- negotiation with prospective employers
- job analysis
- job carving
- training and systematic instruction
- job coaching
- benefits support
- training and planning
- Transportation
- career advancement services
- Other workplace support services

Supported employment services may be provided in a variety of settings, particularly work sites.

Supported employment is provided **through individual face-to-face intervention.**

***Limitations**: Supported Employment service will not be provided to an HCBS participant if:*

(i) Special education and related services that is otherwise available to the individual through a local educational agency, under the provisions of the Individuals with Disabilities Education Act (IDEA).

(ii) Vocational rehabilitation services that are otherwise available to the individual through a program funded under section 110 of the Rehabilitation Act of 1973.

(iii) Supported employment does not include facility based, or other similar types of vocational services furnished in specialized facilities that are not a part of the general workplace.

(iv) Supported employment does not include payment for supervision, training, support and adaptations typically available to other workers without disabilities filling similar positions in the business.

(v) Supported employment does not include volunteer work. Such volunteer learning and un-paid training activities that prepare a person for entry into the paid workforce are addressed through pre-vocational services.

Medicaid funding cannot be claimed for incentive payments, subsidies, or unrelated vocational training expenses. Supported employment is limited to 3 hours per day.

Projections:

- # Users/Total Waiver Participants: 54/17379
- Unit: 15 minutes
- Average Units/User: $38.59
- Average Cost/Unit: $26.24
- Total Projected Cost/Year: $54680.49

Staff Qualifications:

- Minimum qualifications of an Associate's degree with one year human service experience. Direct service workers must have background checks.

Source: New York Children's Waiver

Oregon Employment Path Services

Oregon offers Employment Path services to youth to help the individual develop job skills before employment.

Employment Path Services Definition:

Employment Path Services provide learning and work experiences, including volunteer opportunities, where the individual can develop general, non-job-task-specific strengths and skills that contribute to employ ability in paid employment in integrated community settings. Employment path may also include benefits supports, training, and planning. Services are expected to occur over a defined period of time. The optimal and expected outcome of this service is sustained paid employment and work experience leading to further career development and individual integrated employment.

Services are intended to develop and teach general skills to improve an individual's ability to communicate effectively with supervisors, co-workers and customers; understanding of generally accepted community workplace conduct and dress; ability to follow directions; ability to attend to tasks; workplace problem solving skills and strategies; understanding of general workplace safety.

The services are provided to individuals who are expected to be able to join the general work force with the assistance of supported employment services.

These services and supports should be designed to support successful employment outcomes consistent with the individual's personal and career goals.

The presumption in considering these services is that all individuals eligible for services under this waiver are capable of working in an integrated employment setting and earning at least minimum wage. As a component part of this service, employment service providers should be helping individuals identify and pursue career advancement opportunities that will move them toward individual integrated employment at competitive wage (with individual supported employment services as necessary Discovery/Career Exploration services are detailed more fully and are billed separately under the Service Title: Discovery/Career Exploration Services contained in this waiver.

Limitations:

An individual may receive any combination of Small Group Employment Services, and Employment Path Services, the total of which (including any Supported Employment - Individual Employment services received) shall be in compliance with Oregon Labor Laws.

Projections:

- # Users/Total Waiver Participants: 2/154
- Unit: Hours
- Average Units/User: 200
- Average Cost/Unit: 26.01
- Total Projected Cost/Year: $10404.00

Staff Qualifications:

- A state certification is required

Source: OR Behavioral (ICF/IDD) Model Waiver (40194.R04.00)

Tennessee Intermittent Employment and Community Integration Wrap Around Services

Tennessee offers Wrap Around services to help individuals engage in both employment and community integration activities.

Wraparound Services Definition:

These supports are expressly designed to support waiver participants in engaging in integrated community participation and integrated community employment when sustained, all-day participation in these opportunities outside the home is not possible for the individual due to intermittent needs related to personal care (where this care requires certain environments and/or equipment to perform, which is not otherwise available to the individual in any integrated community setting), personal assistance with preparing and eating a meal, and/or regaining stamina (physical and mental readiness and/or motivation for integrated community participation and/or employment occurring later on the same day).

This service is also expressly designed to avoid the need for people to attend a facility-based day service setting in order to have these intermittent needs met, and to enable people with these needs to use their home as the base from which they routinely access their neighborhood and broader community**. On each day this service is delivered, the service includes supports and supervision that are appropriate and necessary to enable a waiver participant, who has engaged in integrated employment and/or community participation earlier in the day, to engage in additional integrated employment and/or community participation later in the day.**

This service may be delivered by the waiver participant's residential provider or by the waiver participant's chosen provider of other non-residential habilitation services occurring on the same day (or one of these providers if more than one is providing services to the waiver participant in a given day) in order to ensure seamless continuity of supports for a waiver participant being supported with community participation and/or integrated employment.

Limitations:

Non-residential habilitation services (Supported Employment-Individual Employment Supports (except as noted below); Supported Employment-Small Group Employment Supports; Community Participation Supports; Intermittent Employment and Community Integration Wrap-Around Supports; Facility-Based Day Supports) and either the Residential Special Needs Adjustment-Homebound or the Non-Residential Homebound Support Service, when combined, may involve no more than 5,832 quarter hour units/year and no more than 240 quarter hour units in a fourteen day billing period.

A waiver participant may receive this service up to four (4) hours on same day that at least two (2) hours of Supported Employment (Individual and/or Small Group) and/or Community Participation Supports are also provided (or the waiver participants spends at least two (2) hours working in the community and/or participating in the community without staff support because the staff support is not necessary).

Intermittent Employment and Community Integration Wrap-Around Supports shall not be provided during the same time period that the person is receiving Personal Assistance Services, Respite Services, or services under a 504 Plan or Individual Education Program (IEP), is being homeschooled, or any combination thereof, or as a substitute for education services which are available pursuant to the Individual with Disabilities Education Act (IDEA), but which the person or his/her legal representative has elected to forego.

Projections:

- # Users/Total Waiver Participants: 3444/4648
- Unit: 15 minutes
- Average Units/User: 1858.48
- Average Cost/Unit: Days-$3.38
- Total Projected Cost/Year: $21634045.31

Staff Qualifications:

- Be 18 years of age or older
- Have a high school diploma or GED
- Have a minimum of six months of paid or volunteer experience in working with people with physical disabilities and/or older adults

Source: TN Statewide Home and Community Based Services Waiver (0128.R06.00) | Medicaid

Wisconsin Community Integration Services

Wisconsin offers Community Integration services provide coordination supports to a child and family to engage in community settings.

Community Integration Services Definition:

Community Integration Services is built upon current wrap-around service delivery models and includes services and supports that are identified by the child/parent and the multidisciplinary team as necessary to support the child and family within a community setting based on their strengths and needs. Community Integration Services programs benefits families with children who have multiple and complex mental health and/or behavioral concerns, and are involved in multiple services and service systems, by providing intensive care coordination, in addition to Support and Service Coordination and by a provider who is not the Support and Service Coordinator.

Community Integration Services works well for participants who would benefit from a single point of contact for multiple waiver services and service systems and a consistent approach across services and systems.

The child or youth, their parent, and the multidisciplinary team identify services and supports, based on the child and family's strengths and needs, that are necessary for the child or youth and family to move seamlessly through all community environments, and prevent out-of-home placement. **The Community Integration Services team coordinator is required to facilitate coordination of the multidisciplinary team and the child's or youth's integration into their community.**

Typical waiver services that the Community Integration Services team coordinator may provide and/or coordinate include: daily living skills, mentoring, parent education and training, community integration activities and behavior interventions, safety planning and prevention, development and nurturing of natural supports, transportation and respite services.

Community Integration Services is for the coordination of these supports. The supports being coordinated should be billed under their respective service codes. The outcome of this program is to assist, empower and build upon the strengths of the child and family or order that the child can be fully integrated into the community.

Limitations:

The minimum service requirements are that the Community Integration Services coordinator shall convene quarterly team reviews.

Community Integration providers shall complete a written report every six months or sooner if the child's condition changes. This report shall be provided to the SSC.

Projections:

- # Users/Total Waiver Participants: Approx 600/18492
- Unit: Hours (Days not documented in this presentation)
- Average Units/User: Approx. 140
- Average Cost/Unit: Approx. $60
- Total Projected Cost/Year: $521607

Staff Qualifications:

- At least two years of experience

Source: WI Children's Long-Term Support Waiver Program (0414.R04.00)

Colorado Homemaker Services

Colorado offers homemaker services in a participant's primary residence to help with household tasks that require assistance due to the participant's disability.

Homemaker Services Definition:

Services that consist of the performance of basic household tasks within the participant's primary residence (i.e., cleaning, laundry, or household care) including maintenance which are related to the participant's disability and provided by a qualified homemaker, when the parent or primary caretaker is unable to manage the home and care for the participant in the home. **This assistance must be due to the participant's disability that results in additional household tasks and increases the parent/caregiver's ability to provide care needed by the participant.**

This assistance may take the form of hands-on assistance (actually performing a task for the participant) or cuing to prompt the participant to perform a task. Enhanced Homemaker Services provided by a qualified homemaker that consist of the same household tasks as described under Basic Homemaker services with the addition of either habilitation or extraordinary cleaning.

Habilitation includes direct training and instruction to the participant, which is more than basic cuing to prompt the participant to perform a task. Habilitation shall include a training program with specific objectives and anticipated outcomes. There may be some amount of incidental basic homemaker services that is provided in combination with enhanced homemaker services, however, the primary intent must be to provide habilitative services to increase independence of the participant. Habilitation may include some hands-on assistance (actually performing a task for the participant) or cuing to prompt the participant to perform a task, only when such support is incidental to the habilitative services being provided and the primary duties must be to provide habilitative services to increase independence of the participant.

Enhanced Homemaker services also include the need for extraordinary cleaning as a result of the participant's behavioral or medical needs.

Limitations:

Parents of the individual receiving services by virtue of blood or adoption, may be employed by a Program Approved Service Agency to provide Homemaker services. Parents employed by an agency shall meet the same experience and qualification standards required of all agency employees. There is a 2,080 annual unit cap for parents to provide this service.

Projections:

- # Users/Total Waiver Participants: Approx 400/2243
- Unit: 15 min
- Average Units/User: Approx 400 to 800
- Average Cost/Unit: Days-Approx $4-$7
- Total Projected Cost/Year: $2627034.16

Staff Qualifications:

- Direct Care Staff: Be at least 18 years of age, have the ability to communicate effectively, complete required forms and reports, and follow verbal and written instructions.
- Have the ability to provide services in accordance with a Service Plan.
- Have completed minimum training based on State training guidelines.
- Have necessary ability to perform the required job tasks and have the interpersonal skills needed to effectively interact with persons with developmental disabilities.

Source: CO Children's Extensive Support (CES) Waiver (4180.R05.00)

Pennsylvania Homemaker/Chore Services

Pennsylvania offers homemaker services to people who live in private homes to assist in situations when there is no caregiver (or alternative) who can complete the needed work.

Homemaker Services Definition:

Homemaker/Chore services are provided to participants who live in private homes.

Homemaker services enable the participant or the family member(s) or friend(s) with whom the participant resides to maintain their primary private home. Homemaker Services include cleaning and laundry, meal preparation, and other general household care. Homemaker services also include infection control measures and intensive cleaning such as cleaning medical equipment and disinfecting the home.

Chore services consist of services needed to maintain the home in a clean, sanitary, and safe condition. Chore services consist of **heavy** household activities such as washing floors, windows, and walls; tacking down loose rugs and tiles; moving heavy items of furniture in order to provide safe access and egress; ice, snow, and/or leaf removal; and yard maintenance. In the case of rental property, the responsibility of the landlord, pursuant to the lease agreement, will be examined prior to any authorization of service

Homemaker/Chore services can only be provided in the following situations when there is no other relative, caregiver, landlord, community/volunteer agency, provider agency staff, or third-party payer that is capable of or responsible for the provision:

1. When a participant and household members are temporarily unable to perform Homemaker/Chore functions covered under the service definition.

2. When a participant or household member is permanently unable to perform the Homemaker/Chore functions.

The service plan team is responsible for determining whether a person is temporarily or permanently unable to perform the Homemaker/Chore functions. The service plan team's determination must be documented in the service plan. Participants authorized to receive Homemaker/Chore services may not be authorized to receive the following services as Homemaker/Chore tasks are built into the rates for these services: Life Sharing or Supported Living. This service must be delivered in Pennsylvania.

Limitations:

Homemaker/Chore services are limited to 40 hours per participant per fiscal year when the participant or family member(s) or unpaid caregiver(s) with whom the participant resides is temporarily unable to perform the homemaker/chore functions. A person is considered temporarily unable when the condition or situation that prevents the person from performing the homemaker/chore functions is expected to improve. There is no limit when the participant lives independently or with family members or unpaid caregivers who are permanently unable to perform the homemaker/chore functions. A person is considered permanently unable when the condition or situation that prevents them from performing the homemaker/chore functions is not expected to improve. The service plan team is responsible to determine whether a person is temporarily or permanently unable to perform the homemaker/chore functions. The service plan team's determination should be documented in the service plan.

Projections:

- # Users/Total Waiver Participants: 77/6000
- Unit: Hours
- Average Units/ User: 40
- Average Cost/ Unit: Days- $16.73
- Total Projected Cost/Year: $51528.40

Staff Qualifications:

- Be at least 18 years of age

Source: PA Community Living Waiver (1486.R01.02)

Appendix: Self-Direction

Components of an Information & Assistance Service

Information

- Person-centered planning and how it is applied
- The range and scope of individual choices and options
- The process for changing the plan of care and individual budget
- The grievance process
- Risks and responsibilities of self-direction
- Freedom of choice of providers
- Individual rights
- The reassessment and review schedules
- Other subjects pertinent to the person and/or family in managing and directing services

Assistance

- Defining goals, needs and preferences
- Identifying and accessing services, supports and resources
- Practical skills training (e.g., hiring, managing and terminating workers, problem solving, conflict resolution)
- Development of risk management agreements
- Development of an emergency backup plan
- Recognizing and reporting critical events
- Independent advocacy, to assist in filing grievances and complaints when necessary
- Other areas related to managing services and supports

Information & Assistance Models

Information & Assistance can be offered through Service Coordination, a waiver service, a vendor Financial Management Service & Support Broker, or any combination thereof. States take different approaches to the model.

States have taken different approaches to offering participants in self-direction programs the Information & Assistance they need to be successful.

Options include:

- The **Case Manager** provides Information & Assistance, along with their typical responsibilities
- There is a specific **waiver service** for Information & Assistance.
  - Agency model: For example, the provider may be a Support Broker agency or a Center for Independent Living.
  - Individual/independent model: anyone who meets the provider qualifications for the service
- **Contracted** Information & Assistance as part of the Scope of Work of the Financial Management Services (FMS)
- States may **combine** these options

There is a range in provider requirement around the skills and experience required to provide I&A support:

- Minimal initial training with little or no ongoing training
- Some states allow lived experience in lieu of professional training
- Professional credentials and offer rigorous opportunities for further training

Examples of Role Definitions: Pennsylvania

Pennsylvania provides Supports Coordination and Supports Broker as a waiver service. Part of the expectation of the case management service is that it provides information and assistance. In addition, PA provides a financial management service through administrative activity that includes a requirement for information and assistance.

Supports Coordinator	Support Broker	Vendor FMS
• Provides ODP materials on self-direction and a basic overview of the participant-directed options, the differences, and responsibilities associated with each option during the planning process, annual service plan review meetings, and upon request. • Provides participants with support and assistance to make the decision to exercise participant direction authority, and refers participants to other resources (e.g., FMS, supports brokers) as necessary. • Also supports the participant with designating a surrogate and transition activities when needed.	• Designed to assist participants or their designated surrogate with employer-related functions in order to be successful in self-directing some or all of the participant's needed services.	• The FMS provides, in addition to fiscal management services, orientation, functional training, and enrollment, and informational materials.

Roles and Responsibilities: State Examples

- **Connecticut**: “There are two choices 1) a DDS participant can have a DDS case manager and an Independent Support Broker or 2) a DDS specialized case manager. Duplication is avoided by having very clear roles and responsibilities”
- **Maryland**: Support Broker services are offered as an optional service to participants who enroll in the Self-Directed Services Model. Support Broker services are designed to assist participants (or their designated representative) with the human resources employer-related functions necessary for successful self-direction. Participants will receive case management services through a Coordinator of Community Services (CCS), who assists participants in developing a Person-Centered Plan, which identifies individual health and safety needs and supports that can meet those needs. The CCS is also responsible for conducting monitoring and follow-up to assess the quality-of-service implementation.
- **Massachusetts**: Most waivers have a Targeted Case Manager, who among other things, teaches participants how to be employers. The Autism Waiver has an Autism Support Broker, who assists the legal representative of the participant in arranging for, directing, and managing waiver services.
- **Missouri**: Support coordinators are responsible for monitoring health and safety, ensuring individuals stay within budgeted allocations, and ensuring that required documentation is created and maintained. Additionally, the support coordinator is responsible in informing individuals of the option to self-direct. A Support Broker is an option for individuals who need additional Information & Assistance in managing and directing their employees.
- **Ohio**: Service and Supports Administrator helps participants to select a Support Broker.
- **Wisconsin**: The Support and Service Coordinator introduces and explains PDS. Participant and Family-Direction Broker Services are offered as an optional service to participants and families who elect to direct their own services. Participant and Family-Direction Broker Services help the participant and the family in meeting their participant and family-direction responsibilities.

Innovative Approaches to Information & Assistance: Alabama (1 of 3)

Alabama offers Family Empowerment and Systems Navigation Counseling and Peer Specialist Services, in part to support self-direction.

Family Empowerment and Systems Navigation Counseling Service Definition:

Family Empowerment and Systems Navigation Counseling matches the involved family members (e.g., support/caregivers; legal guardians) of an individual with intellectual disabilities with a local professional or similar reputable adult with broad knowledge of the variety of programs and local community resources that are available to an individual with intellectual disabilities and his/her family. The Family Empowerment Counseling and Systems Navigation Service is intended to be a time-limited service that involves assessment of the individual's situation (including needs, goals), assessment of the family's specific goals and needs for information, assistance, and referral to address the individual and family's situation. The service further includes, researching as needed, and sharing of the identified information, connecting the family with assistance, and making referrals as appropriate. The goal of the service is to empower the family with the information, connections and referrals they need, and to work with the family to increase their skills in problem-solving and leveraging available programs and community resources, including Support Coordination. This service is also intended, through temporary peer supervision, to facilitate an opportunity for interested family members, who have received this service, to become providers of this service themselves in order to grow the network of providers of this service over time.

Projections:

- **# Users**: 253/1097 people using the service
- **Milestone**
- **Average Cost/Unit**: $1717
- **Total Projected Cost/Year:** $434,401

Innovative Approaches to Information & Assistance: Alabama (2 of 3)

Peer Specialist Services Service Definition (1 of 2):

A service that assists a person to develop and utilize skills and knowledge for self-determination in one or more of the following areas:

- Directing the person-centered planning (PCP) process;
- Understanding and considering self-direction;
- Understanding and considering individualized integrated employment/self-employment; and
- Understanding and considering independent and supported living community living options.

The service is provided on a time-limited basis, determined by the person's individual need, by a peer with intellectual or developmental disabilities who has experience matched to the focus areas, needs and goals of the person receiving this service: has successfully directed their own Person-Centered Planning process; has self-directed their own services; has successfully obtained individualized integrated employment at a competitive wage; and/or utilizes independent/supported living options.

A qualified Peer Specialist service provider understands and empathizes with the person while working to empower the person, supporting three critical areas important for enhancing self-esteem and self-determination:

- The human need for connections, social supports and allies;
- Overcoming the disabling power of learned helplessness, low expectations, and the stigma of labels; and
- Supporting self-advocacy, informed choice and dignity of risk in decision making.

Innovative Approaches to Information & Assistance: Alabama (3 of 3)

Peer Specialist Services Service Definition (2 of 2):

The Peer Specialist service provider offers:

- Education and training on the principles of self-determination, informed decision making and informed risk-taking;
- One-on-one training, information and targeted support to encourage and support the person to lead their own Person-Centered Planning process, pursue self-direction, seek individualized, integrated competitive employment and/or pursue independent living/supported living options in the community;
- Education on self-direction, including best practices recruiting, hiring, and supervising staff;
- Planning support and support for exercising self-determination and using self-advocacy skills in regard to pursuing individualized, integrated competitive employment;
- Planning support and support for exercising self-determination and using self-advocacy skills in regard to pursuing independent/supported living opportunities, including selection of place to live and, if needed or desired, housemates; and,
- Assistance with identifying opportunities for increasing natural allies a person has to rely on, including opportunities for the development of valued social relationships, and expanding unpaid sources of support in addition to, or reduce reliance on, paid services.

Projections:

- **# Users:** 106/1097 people using the service
- **Unit:** Cost
- **Average Units/User:** 127
- **Average Cost/Unit:** $500
- **Total Projected Cost/Year:** $53,000

Innovative Approaches to Information & Assistance: Connecticut

In addition to a waiver Support Broker service, CT also offers Information & Assistance through peer supports.

Peer Supports Service Definition:

Peer support includes face-to-face interactions including FaceTime or comparable technology (such as iPad, iPhone) that are designed to promote ongoing engagement of waiver participants towards the participant's personal goals. All peer support will promote the individual's strengths and abilities to continue improving socialization, self-advocacy, development of natural supports, and maintenance of community living skills. Peer support also includes communication and coordination with medical providers, including behavioral health services providers and/or others in support of the participant.

Service can be provided in the participant's home, at their job, or community. Example of Activities: How to manage the participants home, manage self-direction of supports, How to find a job or maintain a job, How to advance in chosen career, How to access the community and build community supports.

Projections:

- **# Users:** 31/5700 people using the service
- **Unit:** 15 min
- **Average Units/User: 2920**
- **Average Cost/Unit:** $7.07
- **Total Projected Cost/Year:** $639,976

Promising Practices | Individual Directed Goods & Services

- **Consider a flexible, capped, "individual directed goods and services" offering** that would meet a person's assessed need, as identified in their Individual Support Plan, and would do at least one of the following (for example): decrease the need for other Medicaid services, promote or maintain community inclusion, promote independence, increase the person's health or safety at home, develop or maintain personal, social, physical or work-related skills, etc.

- **CMS Technical Guidance**
  - **Core Service Definition**: Individual Directed Goods and Services are services, equipment or supplies not otherwise provided through this waiver or through the Medicaid state plan that address an identified need in the service plan (including improving and maintaining the participant's opportunities for full membership in the community) and meet the following requirements: the item or service would decrease the need for other Medicaid services; AND/OR promote inclusion in the community; AND/OR increase the participant's safety in the home environment; AND, the participant does not have the funds to purchase the item or service or the item or service is not available through another source. Individual Directed Goods and Services are purchased from the participant-directed budget. Experimental or prohibited treatments are excluded. Individual Directed Goods and Services must be documented in the service plan.
  - **Guidance:**
    - The coverage of this service permits a state to authorize the purchase of goods and services that are not otherwise offered in the waiver or the state plan.
    - The coverage of this service is limited to waivers that incorporate the Budget Authority participant direction opportunity.
    - Goods and services purchased under this coverage may not circumvent other restrictions on the claiming of FFP for waiver services, including the prohibition against claiming for the costs of room and board.
    - The specific goods and services that are purchased under this coverage must be documented in the service plan.
    - The goods and services that are purchased under this coverage must be clearly linked to an assessed participant need established in the service plan

Source: Instructions Technical Guide and Review Criteria (cms.gov)

Individual Directed Goods & Services Definitions (1 of 5)

Connecticut Individual Directed Goods and Services

A. Equipment or supplies that will provide direct benefit to the individual and support specific outcomes identified in the Individual Plan. The service, equipment or supply must address one of the following: reduce the reliance of the individual on other paid supports, be directly related to the health and/or safety of the individual in his/her home, contribute to a therapeutic goal, enhance the individual's ability to be integrated into the community, or provide resources to expand self-advocacy skills and knowledge.
B. The service or good may be delivered in the individual's home, at work, vocational or retirement location, or in the community. Experimental and prohibited treatments are excluded.
C. This service is only available for individuals who self-direct his/her own supports; DDS applies consistent guidelines in respect to the appropriateness of the services or items to be approved in this service definition.
D. This service may not duplicate any Medicaid State Plan service. All services or items are pre-approved by DDS. Costs and rates are negotiable.
E. Examples include cleaning services, homemaker services, specialized clothing for work, public speaking and self-advocacy training, and specialized therapies not covered by Title19.
F. The region is responsible for reviewing services and supports in an individual's budget that exceed $2000. **Prior approval is required for all items over $2000** or not one of the approved items in e above.

Restrictions and Expenses not allowed a. Vacations Cost for travel, lodging, food, and entertainment. b. Clothing Cost for personal clothing that is not related to the person's disability c. Alcohol Any alcoholic beverage or fees to access establishments that serve alcohol. d. Room and Board Recurring expenses Any utilities, food, and other housing costs. e. Gratuities f. Experimental Treatments g. Fines h. Debts i. Activity costs that exceed the allowance in these guidelines. j. Legal fees or Advocate fees k. Donations and Contributions l. Cost for items or services that are of general utility to the members of a household. m. Any cost that does not provide a direct support or remedial benefit to the participant. n. Costs for items or services that are available to the participant form private insurance or Title 19. o. Use of funds from a prior budget period is not allowed.

Individual Directed Goods & Services Definitions (2 of 5)

Maryland Individual and Family Directed Goods and Services (IFDGS)

A. IFDGS are services, equipment, or supplies that enable the participant to maintain or increase independence and promote opportunities for the participant to live in and be included in the community, relate to a participant's need or goal identified in the participant's Person-Centered Plan, and are not available under the Waiver program or Maryland Medicaid Program.

B. IFDGS are services, equipment, or supplies for self-directing participants that: 1. Relate to a need or goal identified in the Person-Centered Plan; 2. Maintain or increase independence; 3. Promote opportunities for community living and inclusion; and 4. Are not available under a waiver service or State Plan services.

C. IFDGS includes dedicated funding up to $500 that participants may choose to use for costs associated with staff recruitment and advertisement efforts such as developing and printing flyers and using staffing registries.

D. IFDGS decrease the need for Medicaid services, increase community integration, increase the participant's safety in the home, or support the family in the continued provision of care to the participant.

E. The goods and services only include: 1. Fitness memberships; 2. Fitness items that can be purchased at most retail stores; 3. Toothbrushes or electric toothbrushes; 4. Weight loss program services other than food; 5. Dental services recommended by a licensed dentist and not covered by health insurance; 6. Nutritional consultation and supplements recommended by a professional licensed in the relevant field; and 7. Other goods and services that meet the service requirements under A. through D.

F. Experimental or prohibited goods and treatments are excluded.

G. IFDGS do not include services, goods, or items: 1. That have no benefit to the participant; 2. Otherwise covered by the waiver or the Medicaid State Plan Services; 3. Additional units or costs beyond the maximum allowable for any waiver service or Medicaid State Plan, with the exception of a second wheelchair; 4. Co-payment for medical services, over-the-counter medications, or homeopathic services; 5. Items used solely for entertainment or recreational purposes, such as televisions, video recorders, game stations, DVD player, and monthly cable fees; 6. Monthly telephone fees; 7. Room & board, including deposits, rent, and mortgage expenses and payments; 8. Food; 9. Utility charges; 10. Fees associated with telecommunications; 11. Tobacco products, alcohol, marijuana, or illegal drugs; 12. Vacation expenses; 13. Insurance; vehicle maintenance or any other transportation- related expenses; 14. Tickets and related cost to attend recreational events; 15. Personal trainers; spa treatments; 16. Goods or services with costs that significantly exceed community norms for the same or similar good or service; 17. Tuition including post-secondary credit and noncredit courses; educational services otherwise available through a program funded under the Individuals with Disabilities Education Act (IDEA), including private tuition, Applied Behavior Analysis (ABA) in schools, school supplies, tutors, and home schooling activities and supplies; 18. Staff bonuses and housing subsidies; 19. Subscriptions; 20. Training provided to paid caregivers; 21. Services in hospitals; 22. Costs of travel, meals, and overnight lodging for staff, families, and natural support network members to attend a training event or conference; 23. Service animals and associated costs; or 24. Therapeutic interventions to maintain or improve function including art, music, dance, and therapeutic swimming or horseback riding with recommendation from a licensed professional in the relevant field.

- IFDGS are **limited to $5,500 per year from the total self-directed budget** of which $500 is dedicated to support staff recruitment efforts such as developing and printing flyers and using staffing registries.

Individual Directed Goods & Services Definitions (3 of 5)

Missouri Individual Directed Goods and Services

Individual Directed Goods and Services (IDS) refers to a service, support, or good that enhances the individuals' opportunities to achieve outcomes related to full membership in the community. Each service, support or good selected must meet each of the following eight criteria::

1. The service, support or good is designed to meet the individual's safety needs, community membership and also advances the desired outcomes in his/her Individual Support Plan (ISP);
2. The service, support or good must increase independence, substitute for human assistance;
3. The service, support, or good must reduce the need for a Medicaid waiver service;
4. The service, support or good must have documented outcomes in the ISP;
5. The service, support or good is not prohibited by Federal and State statutes and regulations;
6. The service, support or good is not available through another source and the person does not have the funds to purchase it;
7. The service, support or good will be acquired based upon anticipated use and most cost-effective method (rental, lease, and/or purchase); and
8. The service, support or good must not be experimental or prohibited

Costs are **limited to $3,000 per annual support plan year**, per individual.

Individual Directed Goods & Services Definitions (4 of 5)

Ohio Participant-Directed Goods and Services

Participant-Directed Goods and Services means Services, equipment, or supplies not otherwise provided through the self-empowered life funding waiver or through the Medicaid state plan that address a need identified in the individual service plan and meet all of the following requirements:

(a) The services, equipment, or supplies are required to assist the individual with achieving one of more of the following outcomes: (i) Decrease the need for other Medicaid home and community-based services; (ii) Promote inclusion in the community; (iii) Increase the individual's safety in his or her home.; (iv) Increase the individual's independence; (v) Improve cognitive, social, or behavioral functions; or (vi) Develop or maintain personal, social, or physical skills.

(b) The individual does not have funds to purchase the services, equipment, or supplies, and they are not available through another source.

(c) The services, equipment, or supplies are required to ensure the health and welfare of the individual.

(d) The services, equipment, or supplies are the least costly alternative that reasonably meets the individual's assessed need as evidenced through the county board's established cost comparison process. The services, equipment, or supplies are for the direct medical or remedial benefit of the individual.

Excluded: (a) Experimental treatments; (b) Items used solely for entertainment or recreational purposes; (c) Tobacco products or alcohol; (d) Items considered by the federal food and drug administration as experimental or investigational; (e) New equipment or supplies or repair of previously approved equipment or supplies that have been damaged as a result of confirmed misuse, abuse, or negligence; (f) Equipment, supplies, and devices of the same type for the same individual, unless there is a documented change in the individual's condition that warrants the replacement; (g) Home modifications that are of general utility or that add to the total square footage of the home; or (h) Items that are illegal or otherwise prohibited through federal or state regulations.

Individual Directed Goods & Services Definitions (5 of 5)

Pennsylvania Participant-Directed Goods and Services

Participant-Directed Goods and Services are services, equipment or supplies not otherwise provided through other services offered in this waiver, the Medicaid State Plan, or a responsible third-party.

Participant-Directed Goods and Services must address an identified need in the participant's service plan and must achieve one or more of the following objectives:

- Decrease the need for other Medicaid services.
- Promote or maintain inclusion in the community.
- Promote the independence of the participant.
- Increase the participant's health and safety in the home environment.
- Develop or maintain personal, social, physical or work-related skills.
- Items and services must be used primarily for the benefit of the participant.

Participant-directed Goods and Services may not be used for any of the following:

- Personal items and services not related to the participant's intellectual disability or autism;
- Experimental or prohibited treatments;
- Entertainment activities, including vacation expenses, lottery tickets, alcoholic beverages, tobacco/nicotine products, movie tickets, televisions and related equipment, and other items as determined by the Department; or
- Expenses related to routine daily living, including groceries, rent or mortgage payments, utility payments, home maintenance, gifts, pets (excluding service animals), and other items as determined by the Department.
- Items and services that are excluded from receiving Federal Financial Participation, including but not limited to room and board payments which include the purchase of furnishings and services provided while a participant is an inpatient of a hospital, nursing facility, or ICF/ID.

Participant-directed Goods and Services are **limited to $2,000 per participant per fiscal year**.

Appendix: Assistive Technology

Assistive Technology | State Medicaid & CHIP Telehealth Toolkit

Center for Medicare and Medicaid Services (CMS) published a new toolkit this month to support states to increasing their use of telehealth.

- Telehealth is a delivery modality, not a service.
- Federal laws and regulations do not specifically address telehealth delivery methods or criteria. As a result, states have a great deal of flexibility in designing the parameters of service delivery using telehealth.
- States generally have the option to determine what types of covered services may be delivered via telehealth, what types of practitioners or providers may deliver covered services via telehealth, and what payment parameters will support telehealth-such as whether payment is the same for services delivered in-person and via telehealth, and alignment within and across fee - for - service and managed care delivery systems.
- Policy considerations around using telehealth to expand access to care include:
    - Whether the service can be delivered effectively though telehealth and if the efficacy could vary across populations, such as individuals with access to different modalities and technologies;
    - Whether providers can complete the components of the visit that could not be done via telehealth in a follow-up visit;
    - Privacy and consent laws and policies;
    - Alignment of service delivery via telehealth across services provided under different authorities (e.g., waiver and state plan services) best serves their beneficiaries;
    - Review services for the possibility of authorizing service delivery via telehealth; states can expand coverage of services delivered via telehealth to additional classes of services or particular services that are underutilized;
    - Consider allowing services to be delivered via telehealth statewide or in regions where increased access to providers is needed most.

Assistive Technology | Center for Medicare and Medicaid Services (CMS) Examples of State Best Practices for Using Telehealth to Deliver Services to People with Disabilities

Promising practices in telehealth.

State	Strategy
Arizona	Used ARPA-HCBS funds to make time-limited payments to incentivize providers to create new remote / telehealth delivery models for services for individuals with disabilities that **support independence, community integration, and employment, while mitigating social isolation.**
Colorado	In its Supported Living Services 1915(c) HCBS waiver for adults (18+) with a developmental disability, Colorado allows several services to be provided using telehealth. For example, the waiver includes **Homemaker services that allow for assistance with general household tasks** (e.g., meal preparation and routine household care) **provided by staff at a remote location**. These staff engage with the individual to respond to the individual's health, safety, and other needs through technology/devices with the capability of live two - way communication. The individual's interaction with support staff may be scheduled, on-demand, or in response to an alert from a device in the technology - integrated system.
Idaho	Idaho allows **developmental therapy and community crisis supports** in its 1915(i) State Plan HCBS Benefit for Adults with Developmental Disabilities to be provided virtually (e.g., real - time telephonic or audiovisual). In these instances, the services are required to be safely and effectively delivered via virtual methods, fully meet the service definitions when provided via virtual methods and be appropriate to meet the individual's needs as identified in the person-centered service plan, in addition to other assurances and information related to telehealth service delivery. Idaho also required that providers provide and document at least one in-person contact with an individual every twelve months (Scheduled to end May 2024).
New York	New York's "Crisis Services for Individuals with Intellectual and/or Developmental Disabilities" (CSIDD) **helps stabilize individuals with intellectual and/or developmental disabilities (I/DD) who have significant behavioral or mental health needs**. Services are provided using specially trained behavior support professionals to build skills and de-escalate behaviors. CSIDD can be provided using audio-only or any two-way, real-time communication technology that meets state, federal, and HIPAA rules requirements.

Appendix: Case Management

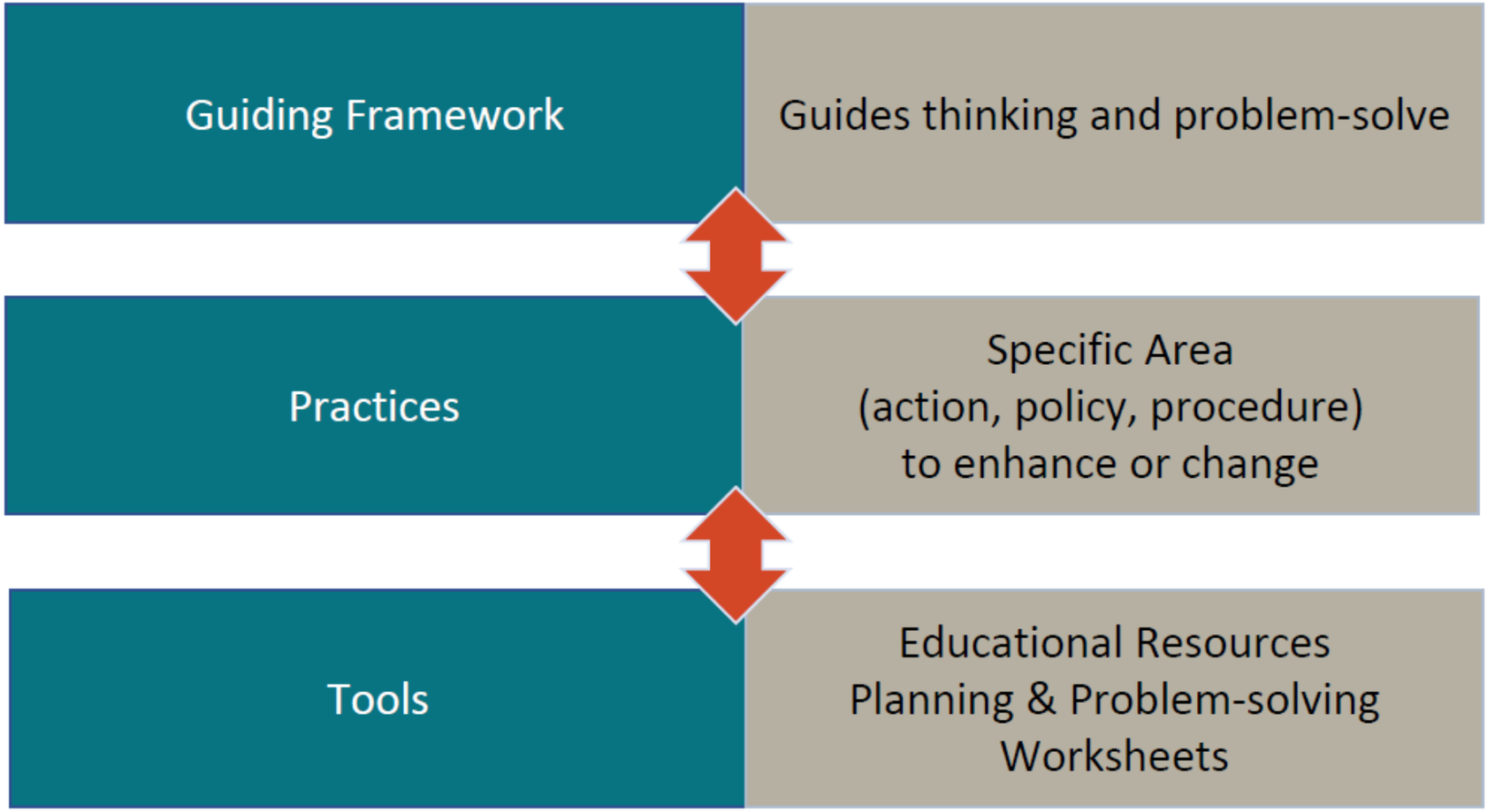
What is Charting the LifeCourse

Created to help individuals and families of all abilities and all ages:

- *develop a vision for a good life*
- *think about what they need to know and do*
- *identify how to find or develop supports*
- *discover what it takes to live the lives they want to live*

Source: Putting People at the Center of the Practices, North Dakota HHS (National Center for Advancing Person Centered Practices Webinar)

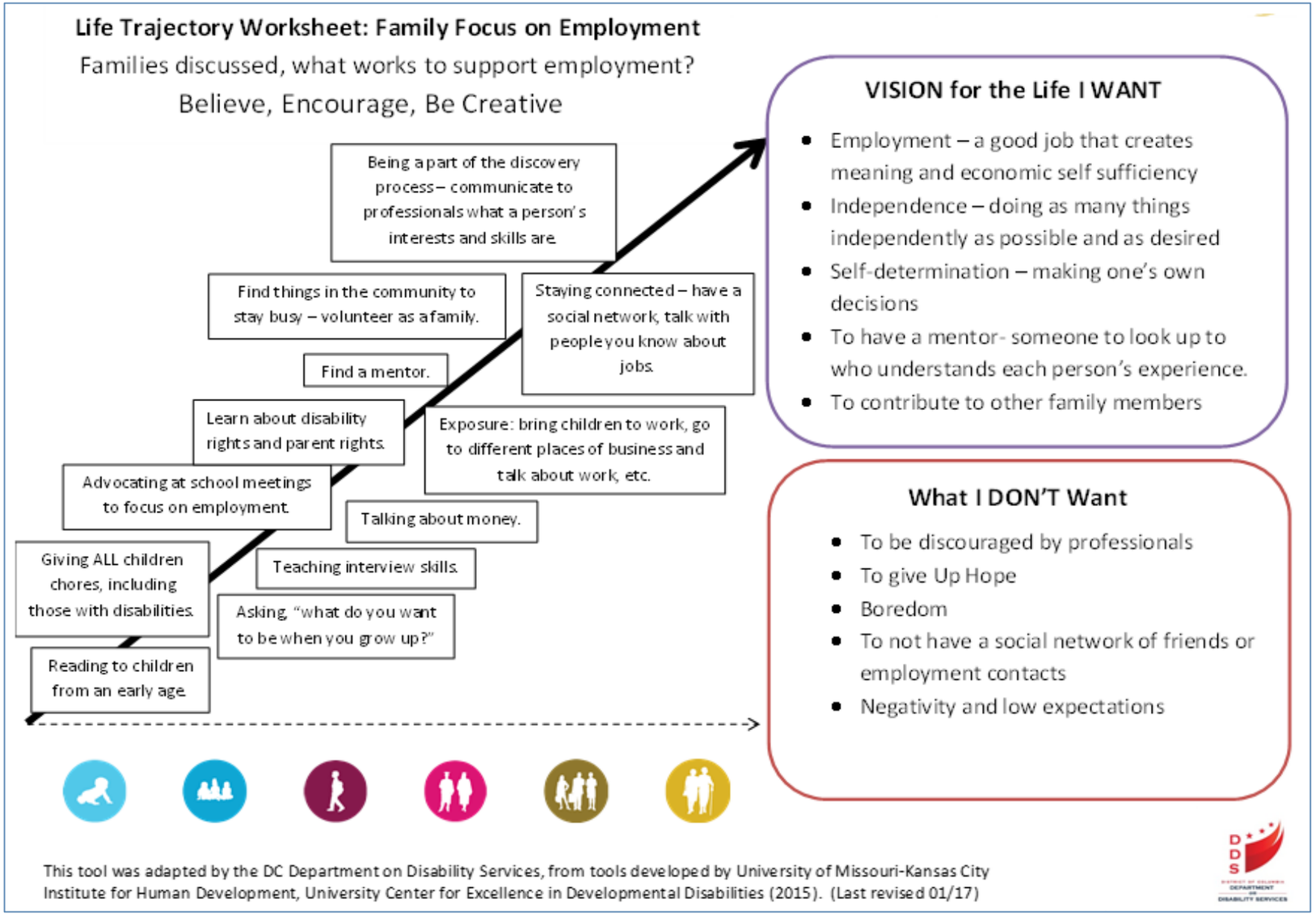
What is Charting the LifeCourse



Source: Putting People at the Center of the Practices, North Dakota HHS (National Center for Advancing Person Centered Practices Webinar)

Slide Excerpt from CDAC Meeting

Planning for Life Transitions: What Does a Successful Transition Look Like for Families?



- We know this may be hard to see. We are passing out copies in person, and have pasted a full-size image of the document in the chat
- This example shows how some families are thinking about and planning for transitions around employment
- This includes ways that families plan throughout an individual's lifespan, starting from an early age
- What resonates with you? What would you add or change about this vision?

Appendix | Defining Quality: How Will We Know if the Waiver is Working Well?

HCBS Waiver Assurances (1 of 3)

1. Administrative Authority (Quality Improvement: Appendix A) Assurance: The Medicaid agency retains ultimate administrative authority and responsibility for the operation of the waiver program by exercising oversight of the performance of waiver functions by other state and local/regional non-state agencies (if appropriate) and contracted entities.
2. Level of Care (LOC) (Quality Improvement: Appendix B) Assurance: The state demonstrates that it implements the processes and instrument(s) specified in its approved waiver for evaluating/re-evaluating and applicant's/waiver participant's level of care consistent with care provided in a hospital, NF, or ICF/IID.
   - An evaluation for LOC is provided to all applicants for whom there is reasonable indication that services may be needed in the future.
   - The processes and instruments described in the approved waiver are applied appropriately and according to the approved description to determine participant LOC.
3. Qualified Providers (Quality Improvement: Appendix C) Assurance: The State demonstrates that it has designed and implemented an adequate system for assuring that all waiver services are provided by qualified providers.
   - The state verifies that providers initially and continually meet required licensure and/or certification standards and adhere to other standards prior to their furnishing waiver services.
   - The state monitors non-licensed/non-certified providers to assure adherence to waiver requirements.
   - The state implements its policies and procedures for verifying that provider training is conducted in accordance with state requirements and the approved waiver.

HCBS Waiver Assurances (2 of 3)

4. Service Plan (Quality Improvement: Appendix D) Assurance: The State demonstrates it has designed and implemented an effective system for reviewing the adequacy of service plans for the waiver participants.
   - Service plans address all participants' assessed needs (including health and safety risk factors) and personal goals, either by waiver services or through other means.
   - Service plans are updated/revised at least annually or when warranted by changes in the waiver participant's needs.
   - Services are delivered in accordance with the service plan, including in the type, scope, amount, duration, and frequency specified in the service plan.
   - Participants are afforded choice between/among waiver services and providers.
5. Health and Welfare (Quality Improvement: Appendix G) Assurance: The State demonstrates it has designed and implemented an effective system for assuring waiver participant health and welfare. • The State demonstrates on an ongoing basis that it identifies, addresses and seeks to prevent instances of abuse, neglect, exploitation and unexplained death. • The State demonstrates that an incident management system is in place that effectively resolves those incidents and prevents further similar incidents to the extent possible. • State policies and procedures for the use or prohibition of restrictive interventions (including restraints and seclusion) are followed. • The State establishes overall health care standards and monitors those standards based on the responsibility of the service provider as stated in the approved waiver.

HCBS Waiver Assurances (3 of 3)

6. Financial Accountability (Quality Improvement: Appendix I) Assurance: The State must demonstrate that it has designed and implemented an adequate system for insuring financial accountability of the waiver program.
   - The State provides evidence that claims are coded and paid for in accordance with the reimbursement methodology specified in the approved waiver and only for services rendered.
   - The State provides evidence that rates remain consistent with the approved rate methodology throughout the five-year waiver cycle.

Source: Instructions Technical Guide and Review Criteria (cms.gov)

State Example: Washington DC's Approach to Quality Outcomes (1 of 2)

DC uses Person-Centered and Organizational Outcomes and Domains in its Provider Certification Review.

Person Centered Outcomes

- **Rights & Dignity:**
  - People have the same rights and protections as others in the community.
  - People are treated with respect and dignity.
- **Safety and Security:**
  - People are safe from abuse, neglect and injury.
  - People live and work in safe environments.
  - People's funds are secure and used appropriately.
- **Health**
  - People are supported to have the best possible health and health care services.
  - People's medications are prescribed and administered appropriately.
- **Choice and Decision Making**
  - People make life choices.
- **Community Inclusion**
  - People use integrated community services and participate in everyday community activities.
- **Relationships**
  - People maintain connections with family members/guardians.
  - People gain/maintain friendships and relationships.
- **Service Planning and Delivery**:
  - Services are provided according to people's Individual Support Plans.
  - Services maximize people's autonomy and independence.
- **Satisfaction**
  - People are satisfied with their living arrangements and supports.
  - People are satisfied with their job or day program and supports.

Organizational Outcomes

- **Provider Capabilities**
  - The provider has systems to protect individual rights.
  - The provider has a system to respond to emergencies and risk prevention.
  - The provider ensures that staff possess the needed skills, competencies and qualifications to support people.
  - The provider has a system to improve Provider Certification results over time.
  - The provider has a system to ensure that people have the opportunity to develop and maintain skills in their home and community.
  - The provider will ensure people are safe and receive continuity of services when receiving respite services.

State Example: Washington DC's Approach to Quality Outcomes (2 of 2)

This is DC's new provider Provider Certification Review process, which covers all day and employment services and includes Person-Centered measures.

DDS HCBS Waiver Provider Application → **Medicaid Waiver Provider Application** → **New Provider Certification** → **Annual Provider Certification + HCBS Settings**

Starts with the Operating Agency

Examples of Qualified Provider Requirements

- Staff qualifications for key personnel
- Business license and organizational documents
- Financial audit
- Certificate of good standing
- Quality assurance and improvement plan
- $1M in liability insurance
- COOP for residential providers
- Policies and procedures
- Documentation templates

Prior to Service Delivery

- The 2 DD HCBS waivers have their own Medicaid provider application (and there is also a separate application for the EPD waiver)
- Provider must fulfill mandatory requirements and received a pre-approval notice from DC DDA before initiating this application.
- Cannot begin providing service until the provider has a Medicaid approval notice, Provider Agreement that authorizes billing under the waiver, and an NPI

60 days after Service begins

- One-time 60-day PCR is completed using a modified PCR tool.
- **Person centered** reviews that are conducted for a sample of individuals in each service
- **Organizational review** to establish if systems are in place to support people in a provider's service(s).
- Any indicators that are not met require a corrective action by the provider.

Within 6 mo. of starting service

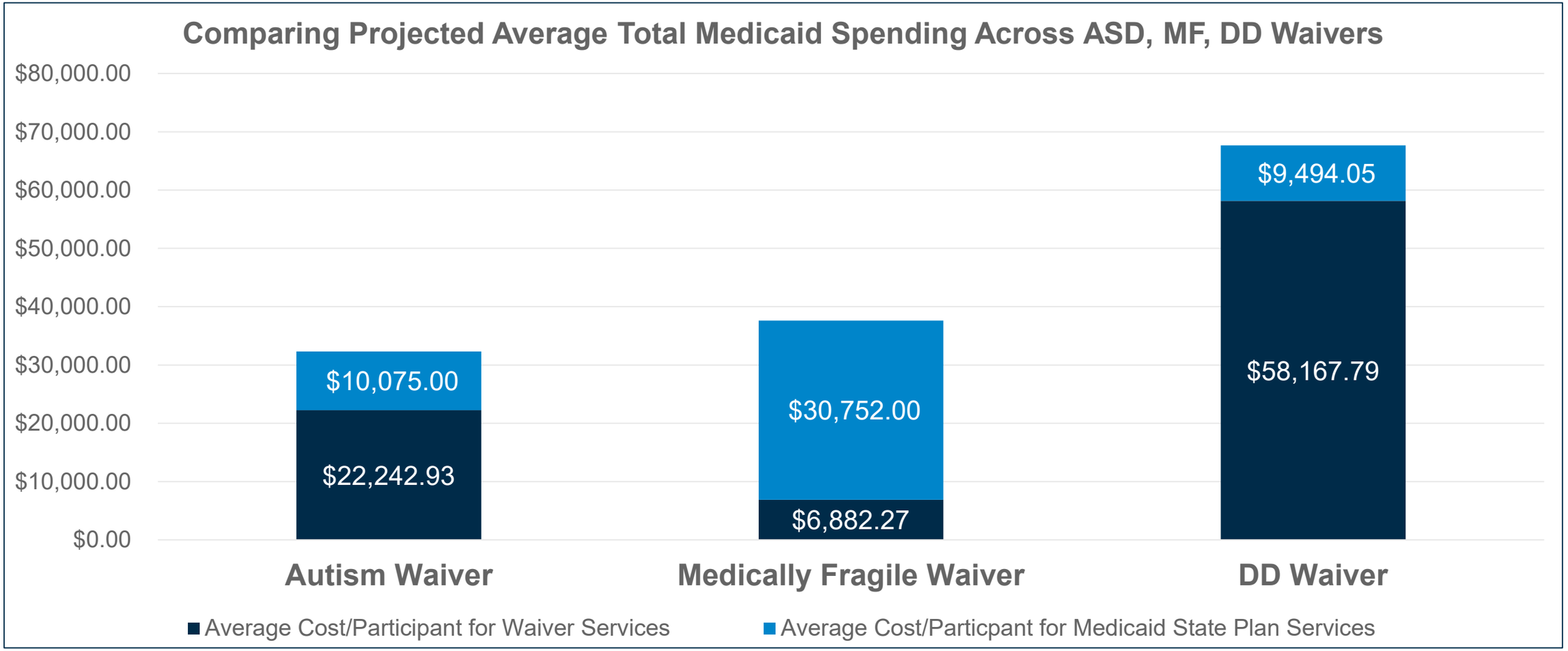
- **Person centered reviews** that are conducted for a sample of individuals in each service
- **Organizational review** to establish if systems are in place to support people in a provider's service(s).
- **Satisfaction component**
- **HCBS Assessment f**or all services that are part of the HCBS setting requirements
- **Environmental component** on provider operated homes/facilities also are conducted.
- Any indicators that are not met require a corrective action by the provider.

Fiscal Implications

Comparing Total Medicaid Funding Projections: ASD, MF and DD Waiver

Slide Excerpt from CDAC Meeting

Total Funds North Dakota is Projected to Spend Across Participants in the 2023-2024 Waiver Year, Including General Medicaid.



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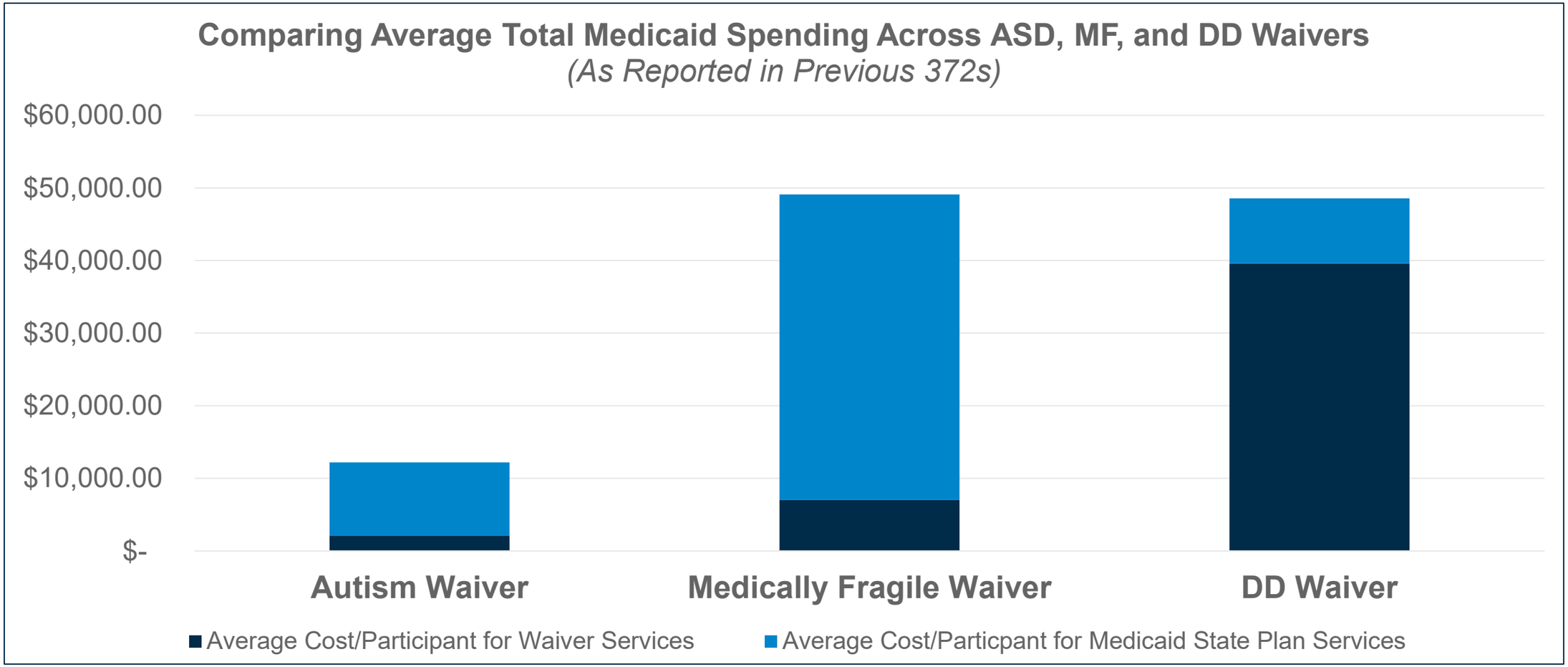
Comparing Actual Medicaid Expenditures: ASD, MF and DD Waiver

Slide Excerpt from CDAC Meeting

Note that this data is from during peak COVID, which may explain why ASD waiver service utilization is lower than projected. Challenges finding workforce, especially in the areas of respite, may also contribute to underutilization of waiver services.



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Waiver Funding By Service: Autism Spectrum Disorder

Which waiver services are people on the ASD Waiver projected to utilize the most?

Service Name	Projected Participants	Projected Average Cost	Projected Total Cost
Respite, agency	60	$ 14,784.00	$ 887,040.00
Respite, self-directed	32	$ 11,942.40	$ 382,156.80
Service Management	344	$ 17,841.80	$ 6,137,579.52
Assistive Technology	96	$ 1,730.00	$ 166,080.00
Community Connector	86	$ 1,150.00	$ 98,900.00
Remote Monitoring	2	$ 1,027.88	$ 2,055.76
SUM	**N/A**	**N/A**	**$ 7,673,812.08**

Waiver Funding By Service: Medically Fragile

Which waiver services are people on the ASD Waiver projected to utilize the most?

Service Name	Projected Participants	Projected Average Cost	Projected Total Cost
Institutional Respite	4	$ 2,739.66	$ 10,958.64
Program Management	50	$ 514.32	$ 25,716.00
Dietary Supplements	4	$ 1,146.10	$ 4,584.40
Environmental Modification	4	$ 4,274.26	$ 17,097.04
Equipment and Supplies	10	$ 2,836.90	$ 28,369.00
In-Home Supports	34	$ 6,825.60	$ 232,070.40
Individual and Family Counseling	2	$ 573.60	$ 1,147.20
Transportation	4	$ 1,113.74	$ 4,454.96
SUM	**N/A**	**N/A**	**$ 324,397.64**

(OPTION A) Serving Kids with Behavioral Health Needs: A National Scan

Several states serve kids with behavioral health needs using a dedicated waiver for this population; A&M utilized the states in blue as the best models for estimating expenditures. See next slide for further details on selection methodology.

State	Criteria	Waiver Slots	State Population Under 25	Percent of Pop. Under 25 Served on Waiver	Reason for Exclusion
Iowa	**SED**	**1,860**	**1,020,800**	**0.182%**	**N/A**
Kansas	SED	4,900	981,900	0.499%	Outlier with regards to percentage under 25 served-significantly higher.
Louisiana	MI, SED	5,557	1,485,100	0.374%	Includes broader level of need than SED.
Michigan	**SED**	**969**	**3,069,400**	**0.032%**	**N/A**
Ohio	**SED**	**1,235**	**3,619,900**	**0.034%**	**N/A**
South Carolina	**SED**	**360**	**1,585,600**	**0.023%**	**N/A**
Texas	**SED**	**3,591**	**10,545,200**	**0.034%**	**N/A**
West Virginia	MI, SED	2,000	507,200	0.394%	Includes broader level of need than SED.
Wyoming	MI, SED	135	179,300	0.075%	Includes broader level of need than SED.

(OPTION A) Methodology for Selecting Model States and Estimating ND's Costs

To estimate costs of serving kids with behavioral health needs, A&M selected for best fit comparison states.

- Of the nine states with waivers dedicated to children's behavioral health:
  - Three waivers include both kids with serious emotional disturbance (SED) and kids with mental illness
  - Six waivers include only kids with SED

- A&M focused only on states that served SED populations exclusively, as this is a higher level of need more appropriate to the narrower scope we are recommending in North Dakota

- Although these types of waivers serve children through varying ages (most commonly 18 or 21), we utilized census data on state population under 25 as a proxy to understand directionally how much of the youth population states are serving in their children's behavioral health waivers

- When examining waiver slots as a percentage of the population under 25, A&M identified Kansas as a significant outlier, serving more than double the percentage of the next week

- Our final sample included: IA, KS, MI, OH, SC, and TX. We averaged the percentage in each state and projected North Dakota's waiver slots and cost according to adjusted population

(OPTION A) Projecting North Dakota's Cost to Include Kids with Behavioral Health Needs

A&M utilized national data on serving kids with behavioral health needs to estimate North Dakota's potential costs, adjusted for population size. The below projections are based on average costs across comparison states, with a projected range in parenthesis.

Participants

- **Slots:** 155 *(58-463)*
- **Percent under 25 served:** .061% *(.023%-.182%)*

Individual Cost

- **Avg. waiver services / person:** $8,300 *($3,200-$14,600)*
- **Avg. total Medicaid / person:** $27,100 ($13,400-$60,422)

Cumulative Cost

- **Total waiver services cost for 155 slots at $8,300:** $1.3 million *($184k-$6.8million)*
- **Total costs for 155 slots: $4.2 million** *($775k-$30.0 million)*
- *Additional costs for Case Management, Therap, and FMS not included in this range (see main deck for full costs)*

Total Medicaid Spending for ID/DD Waiver Participants, Estimated by Age

Based on claims data analysis from a 400-participant sample of DD Waiver participants, calculated by age group.

Age	Total annual Medicaid (State Plan and Waiver Services)
0-2	$10,717
3-5	**$15,783**
6-12	**$23,691**
13-17	**$23,467**
18-21	**$30,258**
22+	$76,961

Potentially eligible for cross-disability waiver

- Average total spending across all age ranges in sample: $41,727
- Average total spending across population n potentially eligible for new waiver (3-21): **$23,300 of spending**

Figures are rounded to the nearest dollar.
Cost includes State Plan & DD waiver service costs. It does not include Medicaid Administrative costs, including case management.
**Assumes average LOS of 281 days continues; assumes costs remain constant. This figure does not account for the fact that some amount of Medicaid State Plan spending may occur for individuals prior to and regardless of Waiver Enrollment.*

Projecting DD Waiver Spending By Age, Based on Historical Data

Based on analysis of historical waiver claims data

Potentially eligible for cross-disability waiver

Age	Total annual Medicaid (State Plan and Waiver Services)*	Percent of Waiver Population, 2018-2021	Projected Slots**	Projected Total Cost
0-2	$10,717	34%	2,322	$24,884,874
3-5	$15,783	3%	205	**$3,235,515**
6-12	$23,691	9%	615	**$14,569,965**
13-17	$23,467	5%	342	**$8,025,714**
18-21	$30,258	4%	273	**$8,260,434**
22+	$76,961	43%	2937	$226,034,457

Potentially Eligible Population Currently Served on DD Waiver (ages 3-21)

- 18% of DD Waiver
- $~34 million in total annual funding
- Represents 12% of claims analysis spending, and about 7% of the projected waiver spending (as reported in Appendix J for WY5),

Figures are rounded to the nearest dollar.
Cost includes State Plan & DD waiver service costs. It does not include Medicaid Administrative costs, including case management.
**Assumes average LOS of 281 days continues; assumes costs remain constant.*
***Utilizing Appendix J Waiver projections for 2023-2024 of 6830 total participants, and waiver population data from 2018-21*