APPENDIX F

# North Dakota Developmental Disabilities Study
## *Report & Oral Presentation*

June 2022

ALVAREZ & MARSAL
LEADERSHIP. ACTION. RESULTS.

# Table of Contents

# Table of Contents

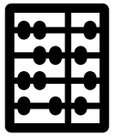
# Project Overview and A&M's Approach

## 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.

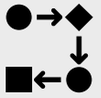
**Deliverables**

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

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

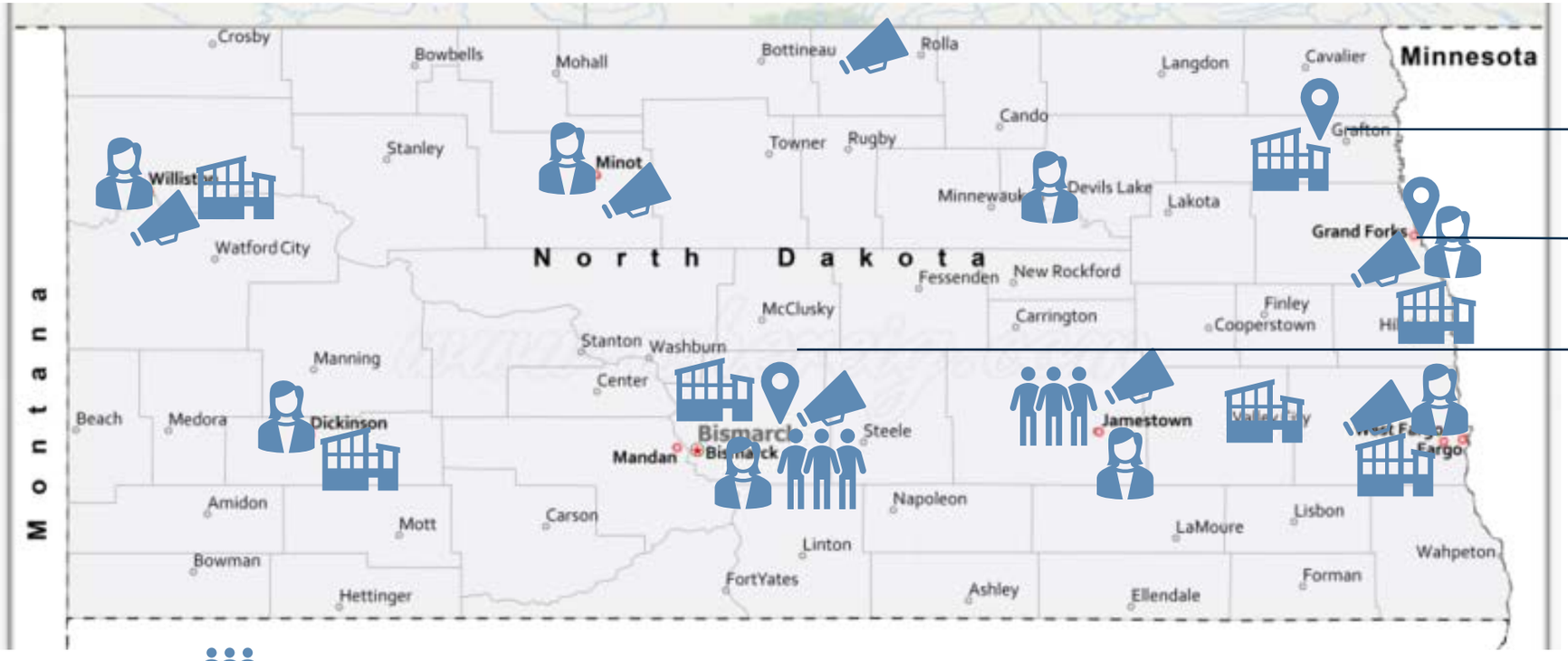
# Gap Analysis

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<br>• Developmental Disabilities Program Administrators Focus Group<br>• 2 Developmental Disabilities Program Managers Focus Groups | • Bi-weekly Working Sessions<br>• Intake Observation<br>• LSTC Site Visit |
|  | Stakeholders | • Interviews with more than 40 advocates, including self-advocates and family members<br>• 2 Autism Spectrum Disorder Taskforce Listening Sessions<br>• 2 Autism Spectrum Disorder Advocacy Coalition Listening Sessions | • ND Association of Community Providers interview, survey, and listening session<br>• Listening session for unaffiliated providers<br>• Listening session with special education teachers and administrators<br>• Attended Olmstead meeting |
|  | Document Review | • Reviewed approximately 70 documents provided by DHS, 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<br>• Reviewed and interviewed select peer and promising practice states |
|  | Process Maps | • Developed process maps of DDA intake and eligibility for 0 – 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 DHS

Interview with Self-advocate

Interview with Advocate/Family

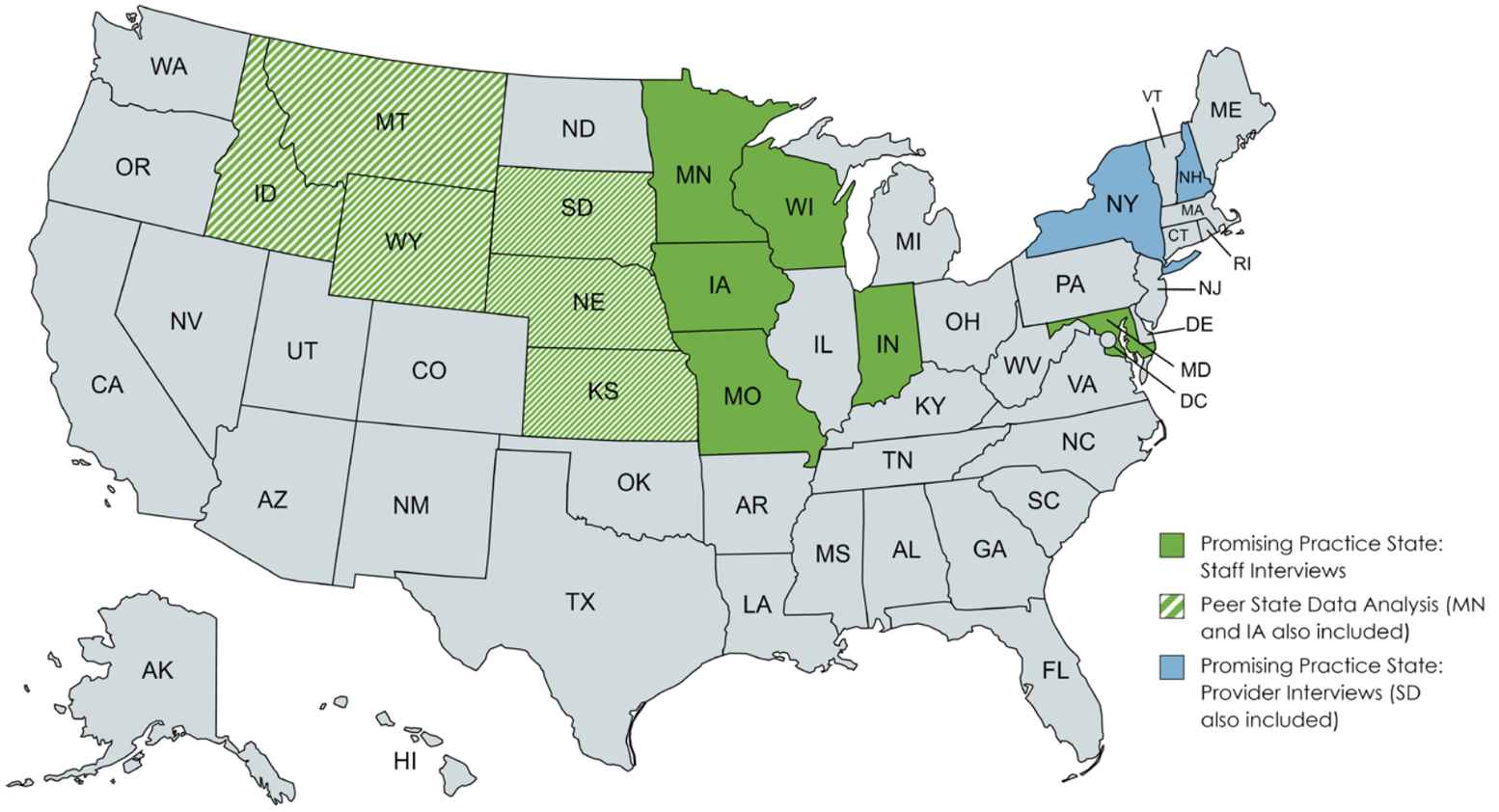
A&M On-site Visit

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 DHS and LMA to identify peer states for benchmarking.



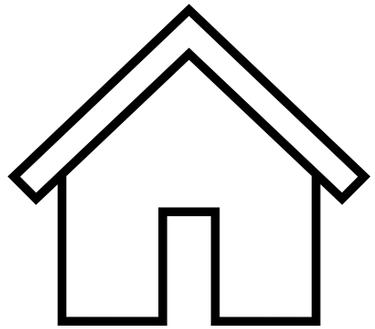

**Promising Practice State Staff Interviews:** Indiana, Iowa, Maryland, Minnesota, Missouri, New York, Wisconsin

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

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

# Understanding Home & Community Based Services (HCBS) Waivers

- Medicaid is the primary funder of long-term services and supports (LTSS) in the United States. It provides those services and supports either through institutional care (i.e., intermediate care facilities or nursing facilities) or home- and community-based services (HCBS).
- States develop home and community-based services waivers (HCBS Waivers) to meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting.
- States can offer a variety of unlimited services under an HCBS Waiver program, including medical services and non-medical services. Examples include service coordination, in home supports, respite, habilitation services, employment supports, and more.
- 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



**HCBS**

# Understanding Level of Care

- 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.
  - Waivers target a population of people in need of LTSS (for example: people with intellectual and developmental disabilities; people with autism; people with physical disabilities; seniors) and use functional eligibility criteria (LOC)
  - Eligibility for Medicaid HCBS waivers is directly linked to institutional level of care, because waivers are an alternative to institutionalization in facilities like Intermediate Care Facilities for Individuals with Intellectual Disabilities and Nursing Facilities
  - 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 people are getting the right amount of care, in the right environment.
  - People most in need have access to Long Term Services & Supports (LTSS)
  - Limited state resources are used to provide LTSS for that population of people
  - Those people have the opportunity to receive LTSS in the least restrictive environment that meets their needs

# 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.
- Case management may be provided by **family navigators**. Family navigators are specially trained in supporting families of children with disabilities. They coordinate services and supports for children with disabilities and their families to help the child achieve their goals. Among other things, they work directly with families, monitor progress, identify challenges, and connect the child to services.

# Table of Contents

# North Dakota's Home & Community-Based Waivers: Current State

North Dakota currently provides HCBS Waiver services for people with disabilities through five different waivers

| Waiver | Summary | Target Population | Age | Level of Care | Total Spend/ Year |
|---|---|---|---|---|---|
| ID/DD | Provides day habilitation, homemaker, independent habilitation, individual employment support, prevocational services, residential habilitation, extended home health care, adult foster care, behavioral consultation, community transition services, environmental modifications, equipment and supplies, family care option, in-home supports, infant development, parenting support, small group employment support for individuals with ID/DD ages 0 - no max age. | Individuals with ID/DD across the lifespan | 0-no max | Intermediate Care Facility (ICF) LOC | $268,528,805 |
| Autism Spectrum Disorder | Provides respite, service management, and assistive technology for individuals with autism ages 0 – 15yrs. | Children with Autism | 0-15 | Intermediate Care Facility (ICF) LOC + ASD Diagnosis | $1,935,363 |
| Medically Fragile | Provides institutional respite, program management or case management, dietary supplements, environmental modifications, equipment and supplies, in-home supports, individual and family counseling, and transportation for individuals who are medically fragile ages 3-17 . | Children who require medications, treatments, and other specialized care due to illness or congenital disorders | 3-17 | Nursing Facility LOC | $155,712 |

# North Dakota's Home & Community-Based Waivers: Current State

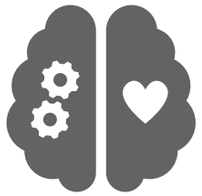
| Waiver | Summary | Target Population | Age | Level of Care | Total Spend/ Year |
|---|---|---|---|---|---|
| Children's Hospice | Provides case management, respite, hospice, skilled nursing, bereavement counseling, equipment and supplies, expressive therapy, palliative for medically fragile individuals ages 0 – 21 | Children in need of palliative care | 0-21 | Nursing Facility LOC | $964,960 |
| 1915(i) | North Dakota Medicaid 1915(i) Home and Community-based Behavioral Health Services are services to support eligible individuals with overcoming barriers in their social and physical environments that limit their ability to gain or maintain access to life in the greater community. Services include Care Coordination, Training & Supports for Unpaid Caregivers, Community Transitional Services, Benefits Planning, Non-Medical Transportation, Respite, Prevocational Training, Supported Education, Supported Employment, Housing Support Services, Family Peer Support, Peer Support (with services targeted to specific age ranges) | People with listed behavioral health conditions | 0 – No max | WHODAS to demonstrate functional limitations | Federal Budget Impact for 2021 (est.) $4,899,414 |

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

North Dakota's strong DD Waiver services, skilled DHS staff, and passionate advocate groups are all assets to the State

**The DD Waiver Programming**

- The 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 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

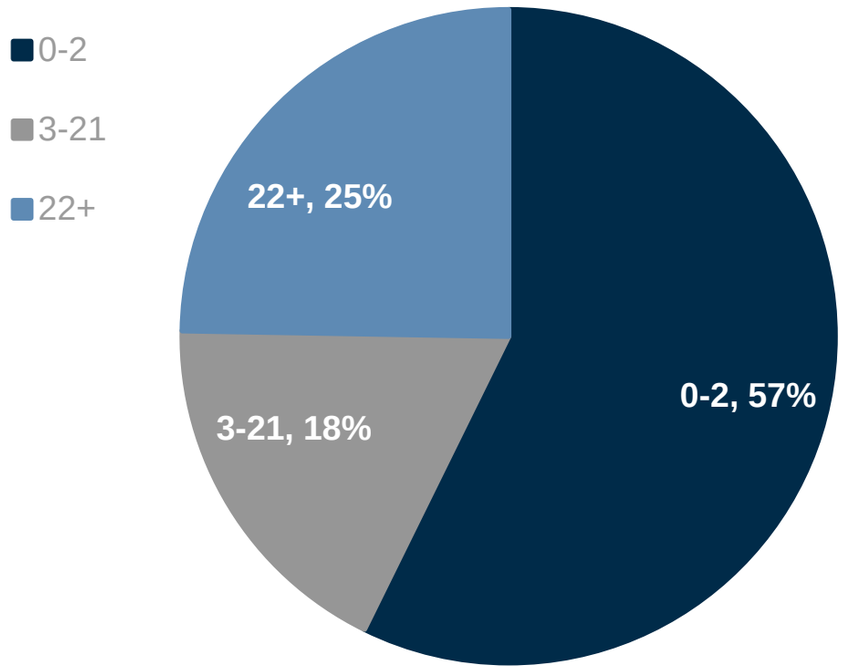
**Community Advocates**

- 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

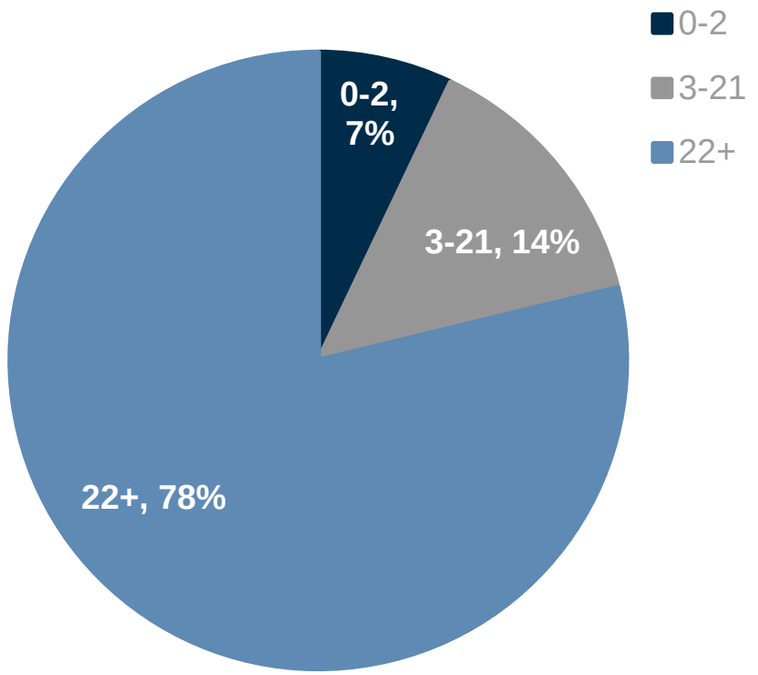
# North Dakota's Waivers: A Solid Foundation for Children Under Three

North Dakota's DD Waiver provides generous services to kids under three and delivers these supports in a highly cost-effective manner.

**Percent of Total DD Waiver Participants By Age Range**



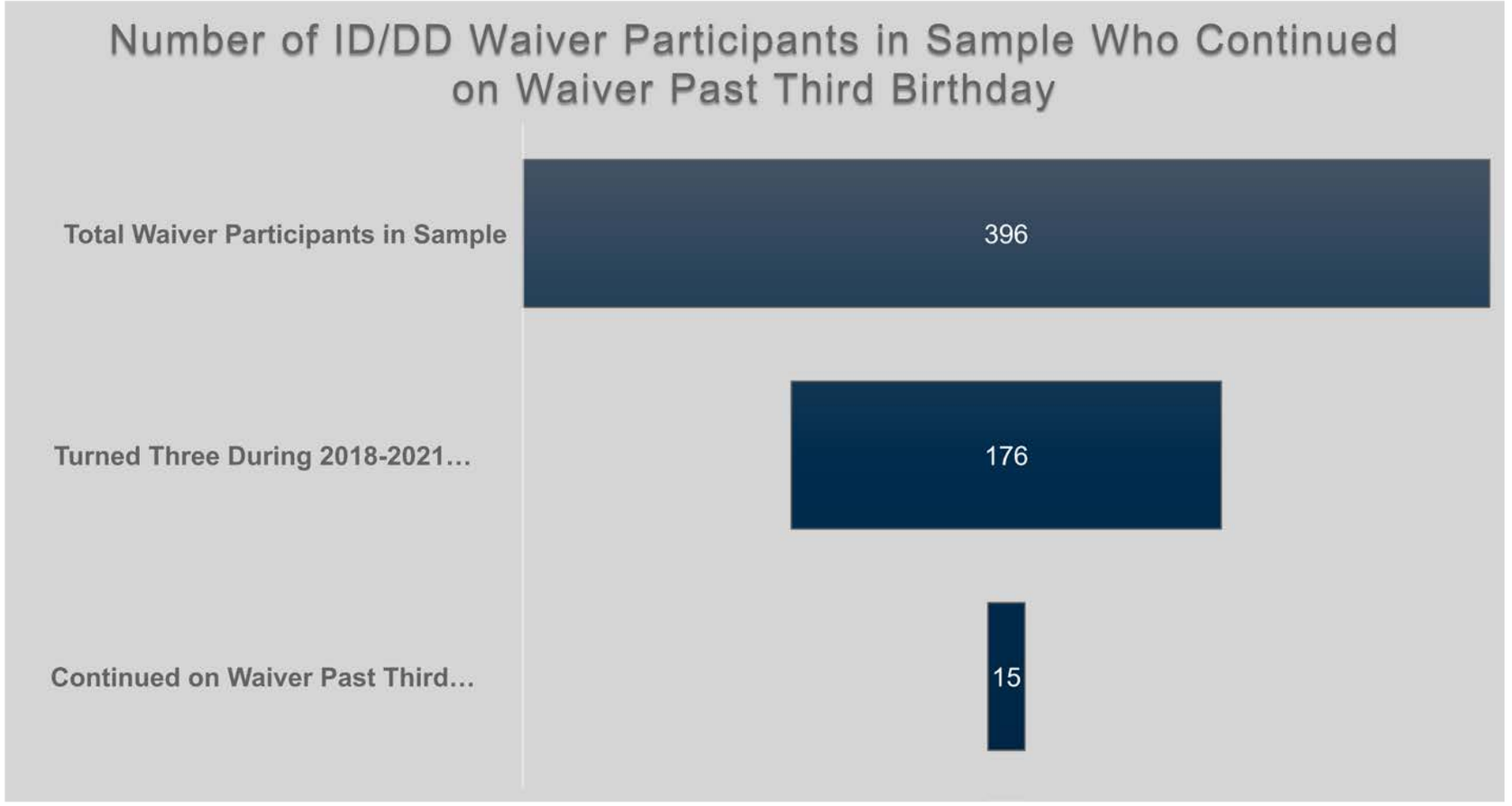

**Percent of Total DD Waiver Participant Spending By Age**




- Those aged 0-2 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

# The Opportunity: Improving The Experience for Young Children Ages 3-5

North Dakota's DD Waiver offers strong support for children under three; however, 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 DD Waiver regularly experiences significant year-to-year turnover, with around 800-900 people moving off yearly, many of whom are age three

# The Opportunity: A Need to Streamline Access to Services

North Dakota's waivers have different eligibility requirement and varying funding support, resulting in disparate access to services. There are also drop off points created both by the end of the 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* |
|---|---|---|---|---|---|---|
| ID/DD | 0-no max | ID, or DD and related condition | No | No limit | 6,830 | $37,624 |
| Autism Spectrum Disorder | 0-15 | ASD | Yes | No limit | 150 | $20,160 |
| Children's Hospice | 0-21 | Medically Fragile in need of palliative care | No | Highest monthly nursing facility rate allowed by DHS | 30 | $32,165 |
| Medically Fragile | 3-17 | Medically Fragile | Yes | $18,996 | 25 | $6,228 |

Differences in age coverage, diagnostic criteria, and slot availability drive inequity between children and adults with different categories of disability

**As projected in Appendix J of Waiver Application*

# Table of Contents

# 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 ages 0 through 2 and its robust DD Waiver programming to create a strong foundation for all people with disabilities through Home & Community Based Waiver services

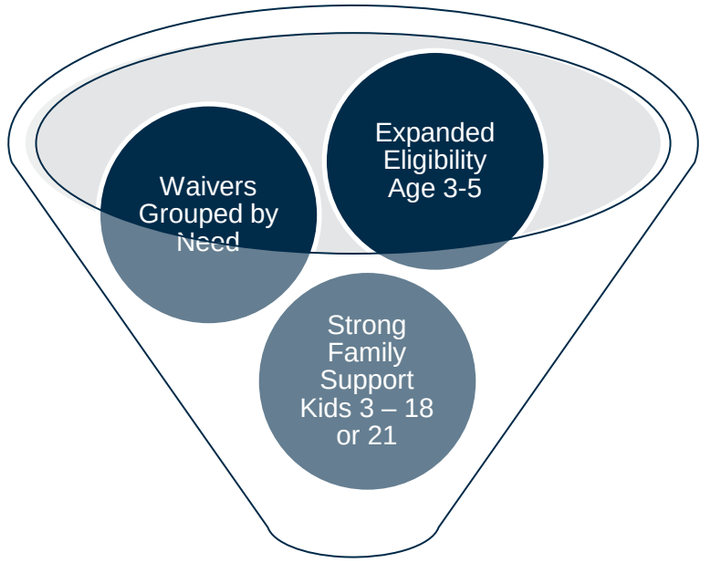
## The Vision

North Dakota can build on its legacy of exceptional support for children 0 through 2 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 people regardless of disability**

# Understanding the Types of Supports that Families Need

Often, conversations and planning around supports for people with disabilities and their families focus on goods and services, like in home supports and respite. People and families do need this kind of support. But they also need information, help navigating the service delivery systems, and opportunities to connect with others who have been in their shoes. These are described as the "three buckets" of supports that families need.

## Types of Supports

Research shows that while goods and services are critical to supporting people with disabilities and their families, they aren't sufficient. To truly meet the needs, the support array should include strategies around 3 buckets of support:

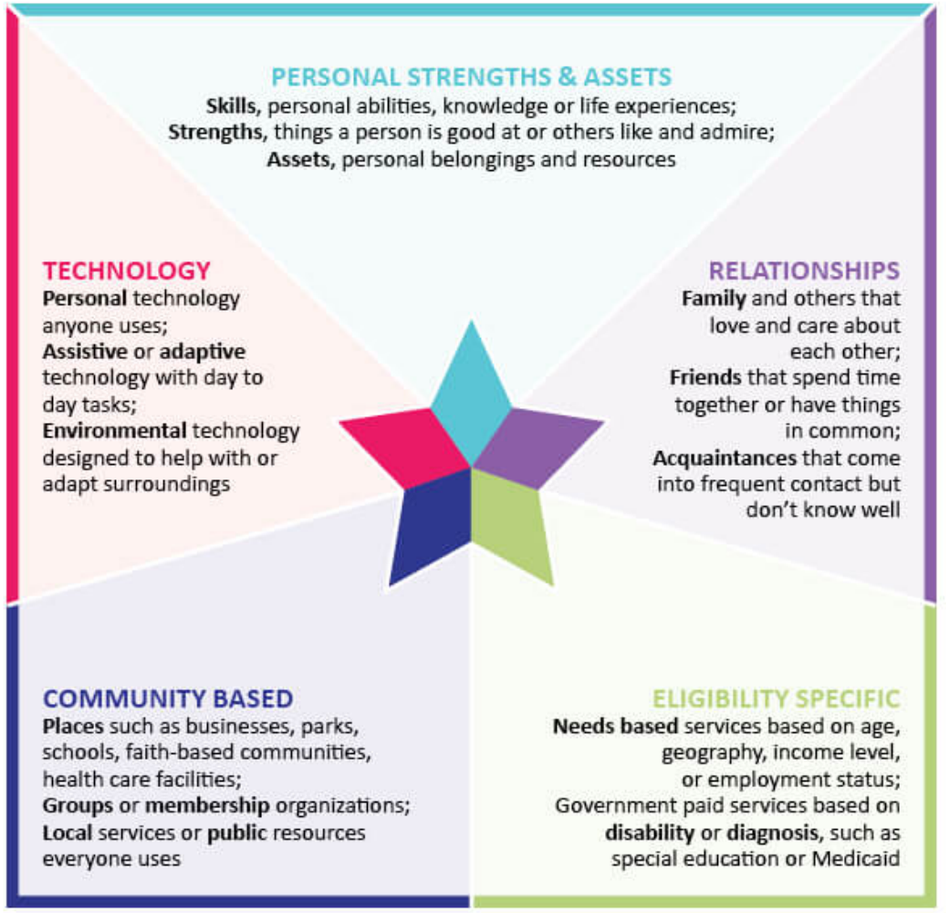
- **Discovery and Navigation:** helping people have the information and tools they need to navigate the system and community resources
- **Connecting and Networking:** making connections with peers who have been in your shoes and knowing who is out there
- **Goods and Services:** items or services you get from the waiver, the voucher, or from a private provider or shop

*Credit: https://www.lifecoursetools.com/lifecourse-library/lifecourse-framework/three-buckets-of-support/*

# Understanding Integrated Supports

People with disabilities and their families need access to a variety of supports to meet their day-to-day needs, support the achievement of long-term and short-term goals, solve problems, and enhance their quality of life.

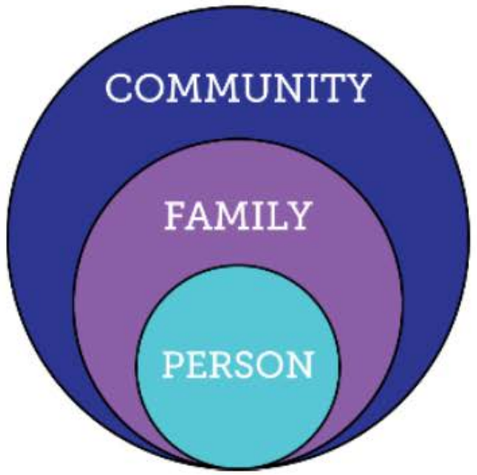
- Supports work best when they are integrated across an array of options, including those available to everyone in the community
- Focusing only on eligibility-based supports can unintentionally separate a person from their family and natural support system and can lead to segregation, loneliness, and 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 that are available to everyone
  - Technology
  - Eligibility based options that are publicly or privately funded




*Credit: Charting the LifeCourse Nexus (UMKC IHD)*

# Using Integrated Supports to Transform Systems

Eligibility-based services are an important part of supporting people, but they must be used tactically. Too many eligibility-based supports can unintentionally separate a person from their family and community; and they come at high financial and social costs. The goal is for people with disabilities and their families to have access to an array of integrated supports to achieve their envisioned good life.





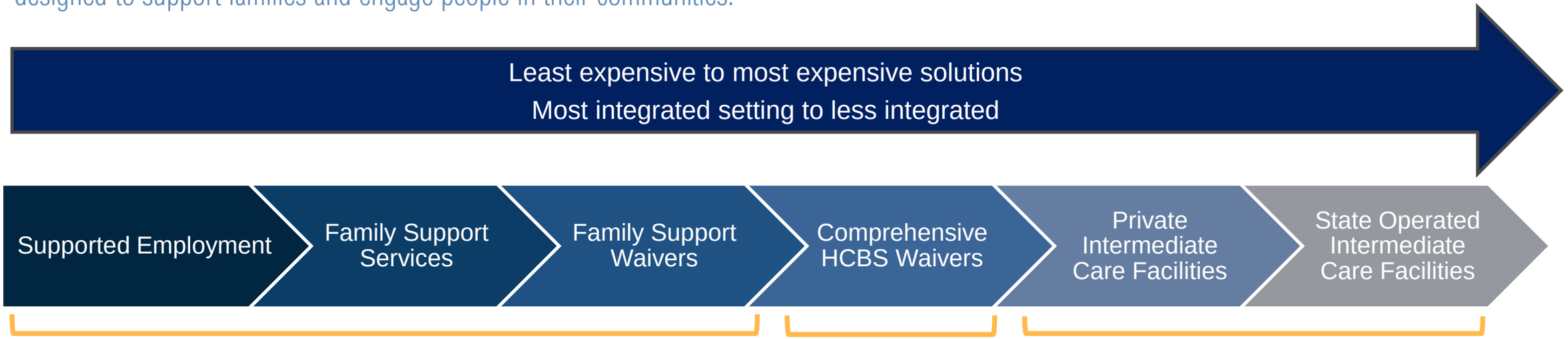

A&M's recommendations will focus on how North Dakota can develop an integrated system of supports for people with disabilities and their families that leverages their strengths, natural supports, communities, and technology.

NDCC § 25-01.2- 02 provides that *"all individuals with developmental disabilities have a right to appropriate treatment, services, and habilitation for those disabilities. Treatment, services, and habilitation for individuals with a developmental disability must be provided in the least restrictive appropriate setting."* Using integrated supports will help the state achieve this promise in a way that is cost effective and supports people in their own families and communities.

*Credit: Adapted from Putting People at the Center of the Practices (ndpanda.org)*

# Reducing Costs Over Time

The North Dakota DD System is already lean. Efficiency can be achieved by reducing reliance on Intermediate Care Facilities, the most expensive types of supports. Doing that in a way that is person-centered and not disruptive to people and families takes time. Begin by offering lower cost supports designed to support families and engage people in their communities.




With growing autism prevalence, demand for services is increasing. Meet the need by investing in lower cost, more inclusive services and supports that are person-centered, support families, and engage people in their communities.

Use comprehensive waivers only for people with the highest needs.

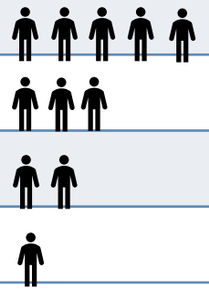
Once community capacity is established, consider rightsizing population of people using ICFs over time.

*Credit: Adapted from Human Services Research Institute, "Nudging the System"*

# Changing the Service Delivery System to Respond to Increasing Demand

Meeting the need will require shifting services to support more people to live at home with their families and be engaged with their communities.

| Service | Total Cost Per Person | People Served with $5M |
|---|---|---|
| Family Home | $25,072 | 200 |
| Host Home | $44,122 | 113 |
| Non-family HCBS | $70,133 | 71 |
| ICF/IID | $128,275 | 30 |



*Credit: "Re-evaluating current services – How many could we serve?," NASDDDS, citing Lakin, K.C. MSIS and NCI data, 2014.*

*For details on ND ICF/IID and HCBS Spending, please see the Appendix, Peer State Benchmarking*

- ND currently spends more than its peer states and the national average on supporting people in ICF/IIDs
- To serve people with autism and other developmental disabilities that are currently experiencing gaps, North Dakota will need to invest.
- Investing in family and community supports will help reduce new costs so that more people can be served.
- Using Medicaid HCBS will also provide federal match (currently 58%).

# Modernizing the HCBS Waiver System: The Proposed Future State

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

## Current State

ID/DD Waiver

ASD Waiver

Medically Fragile Waiver

## Future State

**Updated, Comprehensive ID/DD Waiver**

- Modernizes Level of Care (LOC) to match AAIDD, DSM-5, and ICD-11 definitions
- Services designed for high-needs and complex people with Intellectual Disabilities, Developmental Disabilities and / or Autism
- Serves children and adults with Intellectual Disabilities, Developmental Disabilities and / or Autism

**Children's Cross Disability IFS Waiver**

- New LOC for children ages 3-5 that matches IDEA Part B
- Incentivize self-direction
- Uses family navigators to support person-centered planning
- Service array will include cost-effective community interventions that support children with disabilities and their families
- *For discussion, should this go to age 18 or age 21?*

*Note: A&M recommends leaving the Children's Hospice waiver separate. This is a limited and targeted population with special needs that is currently being served in that waiver.*

# Proposed Changes to the Comprehensive ID/DD Waiver

Changes to Level of Care will allow the state to narrowly open the door for children and adults with autism, while keeping a strong focus on people with intellectual and developmental disabilities

## What Changes?

| | Current State | Future State |
|---|---|---|
| **Level of Care** | • The I/DD Waiver LOC is based on the federal definition<br>• This definition can make it more difficult for individuals with ASD to qualify, while making it easier for individuals with PD to qualify | • **Amending the LOC** will enable the State to better target children and adults who best fit comprehensive ID/DD services models |
| **Services** | • Day habilitation, homemaker, independent habilitation, individual employment support, prevocational services, residential habilitation, extended home health care, adult foster care, behavioral consultation, community transition services, environmental modifications, equipment and supplies, family care option, in-home supports, infant development, parenting support, small group employment support | • **Service Array**: Use stakeholder engagement and the research done 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; innovative ways to leverage workforce; supports for transition-age youth) |

### What Stays the Same?

- The ID/DD Waiver will continue to serve individuals throughout the entire lifespan
- The LOC for children under 3 will remain the same, and qualifying individuals 0-3 will continue to be served on this waiver
- The ID/DD waiver will continue to provide a rich array of services and supports needed to support children and adults in the community

# Modernizing the DD Definition to Recognize Adaptive Social Deficits

| | |
|---|---|
| FUTURE STATE | • Update definition of developmental disability to match AAIDD, DSM-5, & ICD-11 definition.<br>• Continue to require that a person meet at least 3 functional limitations.<br>• Add requirement that functional limitations cross two adaptive areas. |

- North Dakota currently uses the federal definition of developmental disability from the Developmental Disabilities Assistance and Bill of Rights Act of 2000 as part of determining eligibility for services. The definition aligns major life activities with adaptive deficits that are conceptual: receptive and expressive language, learning, and self-direction; and practical: self-care, mobility, capacity of independent living, and economic self-sufficiency.
- The AAIDD, DSM-5, and ICD-11 definitions also consider adaptive deficits in social functioning. Examples include: 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.
- A&M recommends **modernizing the statutory definition of developmental disability and**, accordingly, level of care, to align with these more modern definitions, **requiring significant functional limitations in two of the following three areas of adaptive functioning: conceptual, social, and practical**.
- Examples of peer states that use all three categories of adaptive deficits include: Nebraska, Iowa, Kansas, and South Dakota.

# Intellectual or Developmental Disability Definitions (1 of 2)

| Intellectual or Developmental Disability Definition | North Dakota | AAIDD |
|---|---|---|
| **Recommendation**:<br>1. Recognize adaptive social deficits<br>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:<br>A. is attributable to a mental or physical impairment or combination of mental and physical impairments;<br>B. is manifested before the person attains age twenty-two;<br>C. is likely to continue indefinitely;<br>D. results in **substantial functional limitations in three or more of the following areas of major life activity**: [SEE BELOW]<br>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.<br><br>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<br>Learning<br>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<br>Mobility<br>Capacity of independent living, and<br>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)

| | 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. |

*See Appendix, Intellectual & Developmental Disabilities Definitions, for peer state examples.*

# 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 ages 3-18 (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 ID/DD comprehensive waiver

Children ages 0 through 3 would continue to be served by the ID/DD waiver

## Level of Care

- Use an expansive LOC for children 3 through 6 years old, based upon children who are eligible for early intervention Part B Services
- For children ages 6 and above: use the new ID/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?

# Person-Centered Planning & Case Management

Person-centered planning and case management is a critical part of providing supports for people with disabilities and their families and is required by the Centers for Medicare and Medicaid Services. Expansion will require shoring up the current system and seeking innovative solutions to meet the need.

## Current State

- At the core of home and community-based supports is a case manager (also called a program manager or service coordinator) who supports the person and their family to set goals, get connected with services in the community and through the waiver to help them achieve those goals, stay healthy and safe, and understand and mitigate risks.

- The case manager works with the person to develop and implement an individualized person-centered plan, at least annually, and more frequently based upon changes in the person's needs and preferences. They connect the person with providers, monitor to assure quality supports, and do annual assessments for level of care. A case manager is also the person many people call when they have questions and need help navigating the system.

- Currently, by regulation, North Dakota has a 1:60 ratio for developmental disabilities case management, and services are provided by state staff, called Program Managers. To meet the required ratio, the Department is using temporary employees. This creates risk of overturn, disrupting continuity of relationships and knowledge-base for people and their families. For employees, there is an inequity in that temporary employees are doing the same job as their peers with less benefits.

# Person-Centered Planning & Case Management

## Recommendations

- A&M recommends re-examining the current caseload ratio to understand whether it is sufficient, given the changing nature of the community-based services. The caseload was established when people were receiving residential and day services in larger congregate settings. As North Dakota continues to support people to live in smaller settings and more individualized day services, including employment, it is more challenging for service coordinators to meet each person's individualized needs. A&M recommends reviewing current duties to determine whether there are administrative functions that could be carved from case managers' jobs and done by administrative support to create leverage

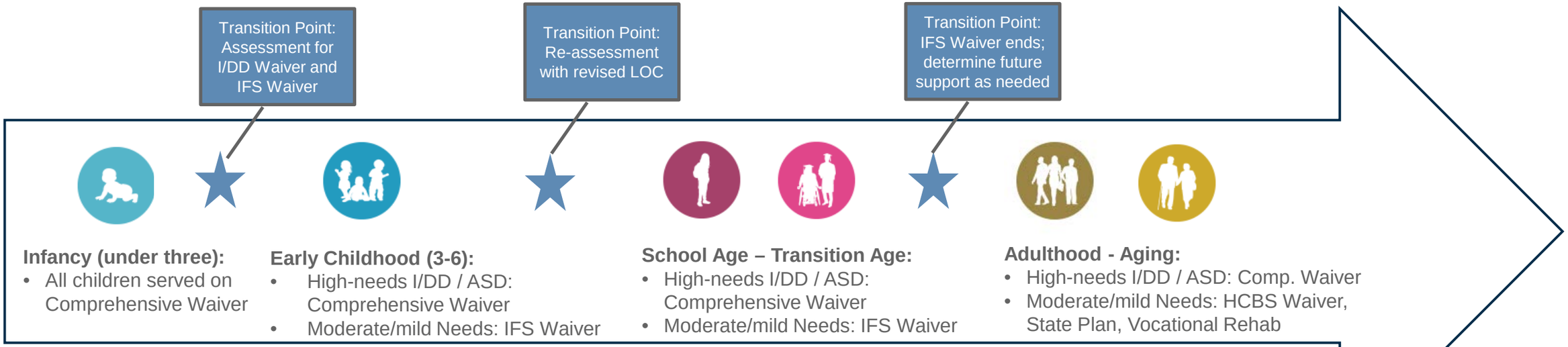
- For the Cross Disability Individual and Family Support waiver, A&M recommends using family navigators instead of traditional case managers. These are people, often family members themselves of people with disabilities, who are highly knowledgeable of the service delivery systems and the community. They may have different educational backgrounds and requirements than case managers. This will allow the state to tap into a wider workforce net of non-traditional case managers for expansion, while providing the connection and navigation support that families need. Family navigators could be state employees, contractors, or providers (but must not also provide other services to the person to avoid conflict of interest). A&M also recommends a smaller caseload ratio for family navigators to ensure that they have the time to provide the family with this more intensive support.



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

# The Future of ND Waivers: Providing Integrated Support Across the Lifespan

The current state of multiple diagnostic-based waivers leads to disparate services and creates gaps in service, including at age 15 when the ASD Waiver ends. The proposed future state would streamline waivers based on needs and align age eligibility to ensure continuous, integrated support.




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

IFS Waiver: Provides services to children ages 3-18 (or 21) with mild to moderate support needs

HCBS Waiver: Serves individuals with physical and other disabilities ages 18-64 years, and seniors 65+

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

# Providing Supports Across the Lifespan

- Infancy: People have different needs across the lifespan and require different kinds of support. What happens in one life stage will impact the rest. Providing strong early intervention can change a child's developmental path and improve outcomes for children and their families. The Comprehensive waiver would continue to provide these supports for children from infancy through age 3. Children would continue to be reassessed to understand their need prior to turning 3 years old.

- Early Childhood: Some children will continue to require supports once early intervention ends. Children with intellectual and developmental disabilities, and autism with the highest needs, would continue to receive supports through the Comprehensive waiver. Children ages 3 through 6 with mild to moderate needs would be supported through the Cross Disability Individual and Family Supports waiver.

- School Age: Level of care is reassessed prior to the child turning age 6. Children with intellectual disabilities, developmental disabilities, autism, and those that are medically fragile, who meet level of care, would continue to receive supports through the Cross Disability Individual and Family Supports waiver.

- Transition Age:  At this life stage, children are beginning to transition to young adulthood and preparing for adult life and employment. Many children with disabilities will continue to need supports through this transition. The Cross Disability Individual and Family Supports waiver will need to include a service array that supports this, including community integration and supported employment. This is also time to begin planning well for what happens when services through the waiver end.

- Adulthood: At adulthood, some people will continue to require supports. For those with the most significant needs, the Comprehensive waiver will be available for people with intellectual and developmental disabilities, and autism. The HCBS waiver will continue to support adults with physical disabilities. Services like State Plan Medicaid and Vocational Rehabilitation will also continue to provide important supports.

- Aging: People at retirement age also have different needs and preferences than other adults. Service arrays should support integrated retirement options.

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

# 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 | 0-no max | Modernized Level of Care (LOC) to match AAIDD, DSM-5, and ICD-11 definitions |
| Cross Disability IFS Waiver | Children ages 3-18 (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* | 3-18 / 21 | • New LOC for children ages 3-5 that matches IDEA Part B<br>• ICF and NF for 6+ |
| HCBS Waiver | Seniors 65 to no max age, and individuals with physical and other disabilities ages 18-64 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 65 – no max<br>PD: 18 – 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.

# Understanding & Managing Costs of Expansion (1 of 2)

Services expansion requires investment. There are several options to expand in a way that is planned and meets budgetary constraints/ funds availability. These can be used individually or combined to reach the state's goal in a way that is reasonable and targeted.

## Participants

- States choose the maximum number of people that are served in this kind of HCBS waiver.
- Limit the number of children that can be served in the waiver each year

## Individual Cost

- Set a maximum cost per person
- This can be a hard cap or soft cap, which would give additional flexibility to respond to individual needs of people served by the waiver

## Service Array

- Limit the service array
- Review past service utilization and spend by population to project new costs/ year for expansion

- Additionally, there are people with disabilities now who are in correctional facilities, homeless shelters, and foster care; or who have declared bankruptcy due to medical debt
- A strong HCBS program will help mitigate those costs

# Understanding & Managing Costs of Expansion (2 of 2)

The fiscal impact of expansion includes services through the Medicaid State Plan and waiver, case management, and program administration.

- Services exist within a system of supports:
  - People are connected with services through case managers
  - Providers are licensed and monitored to assure quality
  - There is state reporting to the Centers for Medicare and Medicaid services, as well as other national data sets
  - Inter and intra agency collaboration, coordination, and agreements are needed to help people get the supports they need, across systems
  - Continuous quality improvement requires dedicated time for innovation planning
  - There are fiscal controls and systems to provide payment
  - Ongoing stakeholder engagement is needed to ensure that the system is meeting people's needs and providing the right balance of provider oversight and autonomy

- Expansion will require not only expanding who gets services and the service array, but also expansion of the state staff who support the system.

# Projecting North Dakota's Costs

A&M projected costs of the recommendations where possible, but the ultimate cost of DD and ASD service modernization efforts depends on State policy decisions.

## Understanding Current Costs

Current costs provide a directionally correct understanding of how North Dakota's DD and ASD program expenses are structured.

- The total Medicaid cost of a Waiver slot includes both the HCBS Waiver Services, as well as the cost of State Medicaid Plan services that an individual accesses
- A&M utilized Medicaid claims data from a random, 400-person sample from 2018-2021 to help estimate both total Medicaid cost of a Waiver participant, as well as costs before and after Waiver enrollment (if applicable).
- In some cases, provider shortages can suppress utilization. This means that individuals may have a need for greater services (spending) than is reflected in current data.
- To control for under-utilization, and to reduce any sampling error, A&M also included the State's projected Waiver expenditures in the cost ranges for current spending.

## Calculating Future Costs

The cost of modernizing North Dakota's DD and ASD programs is composed of both ongoing and one-time expenses.

**Ongoing service-delivery fees:** These ongoing expenses include the cost of broadening the DD Waiver LOC, the cost of expanding services for kids 3-5, and the cost of clearing the waiting lists. **These costs will be heavily influenced by the State's policy decisions including caps, services, and slots.** The State will need to make these decisions to begin zeroing in on a reliable cost estimate for the total ongoing expenses.

**One-time system innovation costs**: North Dakota will need to invest heavily in the process of redesigning their system thoughtfully over several years, likely seeking help from national experts along the way. A&M recommends that the State looks to leverage federal innovation money currently available to States through ARPA funding.

# Projected Cost of Adding Someone to the DD Waiver, By Age

A&M utilized claims data from the 400-participant sample to calculate the average total Medicaid spending among DD Waiver participants, by age group.

*Note: Average total cost across all age ranges in the sample was $41,727. Comparatively, the 2020 federal reporting average was $46,921.*

| Age | Average Cost of HCBS + State Plan Medicaid / New Waiver Slot Annually* | Federal Contribution** | North Dakota's Cost |
|---|---|---|---|
| 0-2 | $10,717 | $5,525 | $5,192 |
| 3-5 | $15,783 | $8,136 | $7,647 |
| 6-12 | $23,691 | $12,213 | $11,478 |
| 13-17 | $23,467 | $12,097 | $11,370 |
| 18-21 | $30,258 | $15,598 | $14,660 |
| 22+ | $76,961 | $39,674 | $37,288 |

*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.*
***2023 Federal Matching Percentage for North Dakota is 51.55%*

# Expanding I/DD Waiver Eligibility for Children Under Six

A&M utilized service costs for the 0-2 and 3-5 group to estimate the cost of expanding waiver eligibility for children under six.

## Cost of Expanding DD Waiver Eligibility for Kids Through Age Six

*Inclusive of DD Waiver specific costs and general Medicaid spending (but not including Administrative Costs)*

| Expansion Year | Additional DD Waiver Participants Served | Estimated Annual Medicaid Cost / Participant * | Estimated Total Cost per Expansion Year | North Dakota's Share of Costs (48.45%) |
|---|---|---|---|---|
| Year One | 538 | $10,717 - $15,783 | $5,765,735 - $8,491,518 | $2,793,499 - $4,114,140 |
| Year Two | 1,076 | $10,717 - $15,783 | $11,520,754 – $16, 967.252 | $5,581,805 - $8,220,633 |
| Year Three | 1614 | $10,717 - $15,783 | $17,297,206 - $25,474,553 | $8,380,496 - $12,342,421* |

*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.*

# Building on the Strengths of the Current Autism Voucher Program

The Autism Voucher serves several important roles today but could be improved in parallel with the Waiver reform to ensure balanced ASD services for all.

## ASD Voucher Strengths

**The ASD Voucher Program provides three core benefits as it exists today:**

1. **No Waitlist:** The ASD Voucher allows individuals to receive services immediately without going through the ASD Waiver waitlist process.
2. **Expanded Eligibility***: The Voucher allows the State to use general funds to offer ASD services to individuals who otherwise would not be eligible through Medicaid.
3. **Flexibility:** The Voucher allows families to purchase goods and services that fit their unique needs, including options such as fidget toys or karate lessons.

## ASD System Changes

**The ASD Voucher could be improved, alongside the Waivers, to better meet the needs of all kids with ASD:**

1. **No Waiver Waitlist:** Fund the Children's IFS Waiver sufficiently to ensure no waitlist for any ASD services, not just the Voucher.
2. **Revise Voucher Eligibility*:** Require a Medicaid denial to ensure ASDV funds are targeted to those who need them most, and that federal money is maximized wherever possible.
3. **Add Waiver Flexibility**: Add more flexibility to the Waiver through Individual Goods and Services (IDGS) to ensure families don't have to choose between Medicaid and their children's unique support needs.

**Eligibility: The ASD Voucher includes individuals at 200% of the FPL and below. In comparison, eligibility for CHIP (a Medicaid program which provides coverage for children) includes those at 175% of the FPL and below.*

# Autism Voucher Program Recommendations

Unlike Waiver funds, Autism Voucher Funds are not matched by the federal government; it is therefore essential that ND ensures maximum effectiveness of these funds. Recommendations are aimed at maximizing federal financial participation, learning from the Voucher experience, and ensuring people do not lose supports.

## Current State

The ASD Voucher Program is not meeting its full potential to provide services for families who would otherwise not be eligible, as many of the current participants could be served through Medicaid. Serving Medicaid eligible individuals through ASDV means the State cannot claim the 50% federal match, which would help serve more individuals.

## Next Steps

(1) Add sufficient slots to the ASD Waiver for eligible people currently on the Voucher and projected new participants.
(2) Make the Voucher a program of last resort. Require current recipients and new applicants to apply for Medicaid and waiver services.
(3) Align ASD Waiver and Voucher services

## Medium Term

(1) In the children's waiver, develop a robust individually directed goods and services program that builds upon learnings from the Voucher.
(2) Align ASD Voucher services with the new children's waiver.
(3) Continue to require that all Medicaid eligible people use the waiver.

## Long Term

Study the population of people who remain on the ASD Voucher (do not qualify for Medicaid) to understand this population and explore any gaps in the system that need to be addressed in order to better serve these and other similar individuals moving forward.

# Projected Cost of Clearing the ASD/MF Waiver Waiting Lists

A&M examined the sample of 400 DD Waiver participants and calculated the average total Medicaid spend during an individual's DD Waiver enrollment period

| | Autism Waiver | Medically Fragile Waiver |
|---|---|---|
| Size of current waitlist | 58 | 9 |
| Total Average Additional Cost of HCBS + State Plan Medicaid / New Waiver Slot Annually Based on Sample Data* | $2,447 | $12,621 |
| Overall Projected Cost / Slot According to Appendix J | $21,645 | $8,005 |
| **Total Cost for Clearing Waitlist** | **$141,930 - $1,255,391** | **$72,042 - $113,598** |

**$213,972 - $1,368,989**
Total Estimated Cost to Clear ASD and MF Waiver Waiting Lists

48.45%
North Dakota's share of costs after Federal matching funds are applied

**$103,669 - $663,275**
**North Dakota's Cost to Clear Waiting Lists***

**Figures are rounded to nearest dollar. Assumes average LOS and Waiver Costs remain constant; annual figure based on waitlist numbers as of June 2022. Cost does not include Medicaid Administrative costs.*

# Autism Spectrum Disorder Task Force (1 of 2)

Build upon the foundation of the Taskforce to develop and inform a cross-disability advisory council.

- Transformational systems change happens when **people with disabilities and their families are truly involved in policy making** so that they influence planning, policy, implementation, research, and revision of the practices that affect them.
- Modernizing the system to support children and their families, across disabilities, requires new ways of collaborating and thinking.
- Just as the system will become cross-disability, so too should the advisory body:
    - Design, recruit, and support a **cross-disability advisory committee** to refine these recommendations, vet an implementation roadmap, and share feedback on design.
    - The new body should **be majority people with disabilities and their families.** They are the context experts on the systems that support them.
        - **Ensure diversity in disability** (for example, representation by people with autism and their families; people with intellectual and developmental disabilities and their families; etc.) as well as **regional and other diversity**
        - Remaining positions are for traditional subject matter content experts.
        - State agencies participate in a non-voting role. The lead state agency should also help facilitate the meeting, providing logistical support to the group.
        - Promising practice states include Ohio, Indiana, and the District of Columbia.

# Autism Spectrum Disorder Task Force (2 of 2)

- **The Autism Spectrum Disorder Task Force would serve as an important input to the cross-disability advisory council.**
- They should have a seat at the table, with a representative serving on both groups as a liaison to share information, experiences, perspectives and ideas from all taskforce members, to create opportunities for double loop learning.
    - To be most effective, redesign the task force to change the composition so that the majority of members are people with autism and their families; state agencies participate in a non-voting role and to support facilitation and logistics
    - Clarify their purpose to advise on the service delivery redesign
    - Sunset the task force once this is achieved and stabilized
- Consider whether there are other needed or existing task forces that could be transformed to support the system modernization and be a liaison to the cross-disability advisory council; or others that are needed.

# Table of Contents

# ARPA Funding Opportunities

Service transformation requires resources. States need support from national experts to help redesign their systems. The American Rescue Plan Act provides a unique **one-time opportunity to support investment in Home & Community Based Services infrastructure**. There is also funding available to support building a sustainable workforce.

**1. Enhanced FMAP for Home and Community Based Services**

**CMS announced extension of the spending deadlines until 3/31/2025 – and states can request further extensions**

- Temporary 10 percentage point increase to the federal medical assistance percentage (FMAP) that can be invested as a catalyst to the transformation / modernization of systems to deliver high-quality, cost-effective, person-centered services for Medicaid beneficiaries
- Workforce investment / development would be an allowable use of these funds

**2. State and Local Fiscal Recovery Funds (available through 12/31/2024)**

- Negative Economic Impacts
  - Assistance to small business and non-profits in the form of loans or grants to mitigate financial hardship such as declines in revenue or impact of periods of business closure, includes **costs to retain employees and job training to address negative economic or public health impacts** experienced due to a worker's occupation or level of training
- Premium Pay
  - **Additional support to those who have and will bear the greatest health risks** because of their in-person service in critical infrastructure sectors who regularly perform in-person work, interact with others at work, or physically handle items handled by others. Funds can be used **retroactively back to January 27, 2020**. Prioritizes lower-income workers

# Roadmap

Implementing these recommendations will bring sustainable and systemic change, but it is a significant lift. It will take time (spanning across biennia), FTEs, and funding.

## Phase 1

1. Level of Care Reform
   - National review of best practice tools
   - Stakeholder engagement
   - Piloting along with current system to determine population impact
   - Determine new tool and LOC
2. Implementation Planning
   - Development of a detailed roadmap and project plan that sequences tasks, builds out timelines, IT systems impacts, and assigns responsible parties
   - Stand up Project Management Office with a governance structure, for regular reporting, guidance, and risk escalation and mitigation
3. Stakeholder Engagement
   - Develop Cross-Disability Advisory Council to inform LOC Reform and Implementation Planning
   - Structured statewide stakeholder engagement through information sharing and innovation sessions to create opportunities for double loop learning.

## Phase 2

1. Waiver Redesign
   - National review of best and promising practices to support individuals and families
   - Stakeholder engagement
   - Determine service array, tiered approach, cost limitations
   - Cost reporting as a foundation for rates
   - Draft, vet and submit waiver applications; negotiate with CMS
2. Implementation Planning
   - Leverage PMO and governance structure from Phase 1 to continue to build out the detailed roadmap and project plan.
   - Continue regular reporting and risk mitigation
3. Stakeholder Engagement
   - Work closely with Cross-Disability Advisory Council to advise on redesign efforts.
   - Continue structured statewide stakeholder engagement through information sharing and innovation sessions

## Phase 3

1. Future State: No Wrong Door
   - Move beyond waiver redesign to HHS redesign
     - 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
2. Implementation Planning
3. Stakeholder Engagement

*Phases 2 & 3 will be influenced by the learning from the work in the prior phase. The phases may happen consecutively, or, with sufficient resources, could be overlapping.*

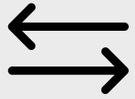
# Appendix

- Additional Recommendations
- ID/DD Program Services & Costs
- Peer State Benchmarking
- Autism Waivers
- Individual & Family Support Waivers
- Intellectual & Developmental Disability Definitions
- Early Intervention Definitions
- Individual Directed Goods & Services Definitions
- Workforce Challenges
- Autism Spectrum Disorder Taskforce
- Acronyms
- Sources

# Additional Recommendations

# 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. DHS 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<br>• Expand First Link for consistent information and referrals<br>• Cross-train intake staff and develop process for warm referrals<br>• 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:<br>o One-Stop Coordinated System<br>o Single standard process with common protocols and information exchange<br>o Objective and neutral<br>o Person-Centered<br>o Use of Private & Public Programs<br>o 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<br>• Expand First Link beyond behavioral health for consistent information and referrals<br>• Cross-train intake staff and develop process for warm referrals<br>• Provide mini-person-centered plan at intake connecting people to community-based services |

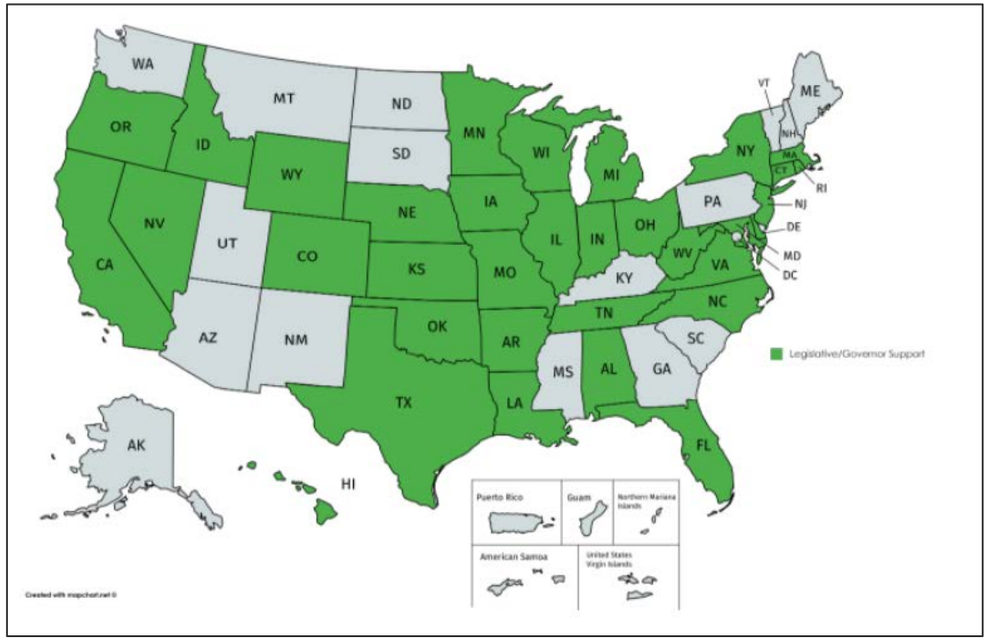
- We heard that people with disabilities and their families find the system difficult to navigate. Different eligibility criteria, forms, and places to apply make it complicated to know where to go for help. In addition to goods and services, families need help with (1) information and navigation; and (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)

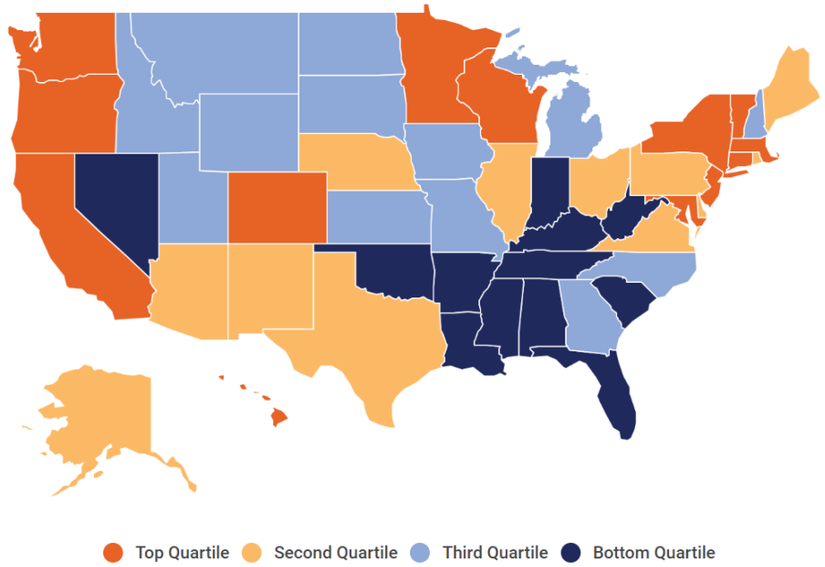
- A&M spoke with families who spent thousands of dollars to get an assessment to support their children's eligibility for services. We also heard from advocates about the long waiting lists that currently exist for people to get these assessments, especially in the more rural parts of the state. Lack 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<br>• 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 for ages 0 through 6 to match IDEA Part B and Part C requirements<br>• 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<br>• Develop a cross-disability family support waiver for children to provide parity across services.<br>• *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

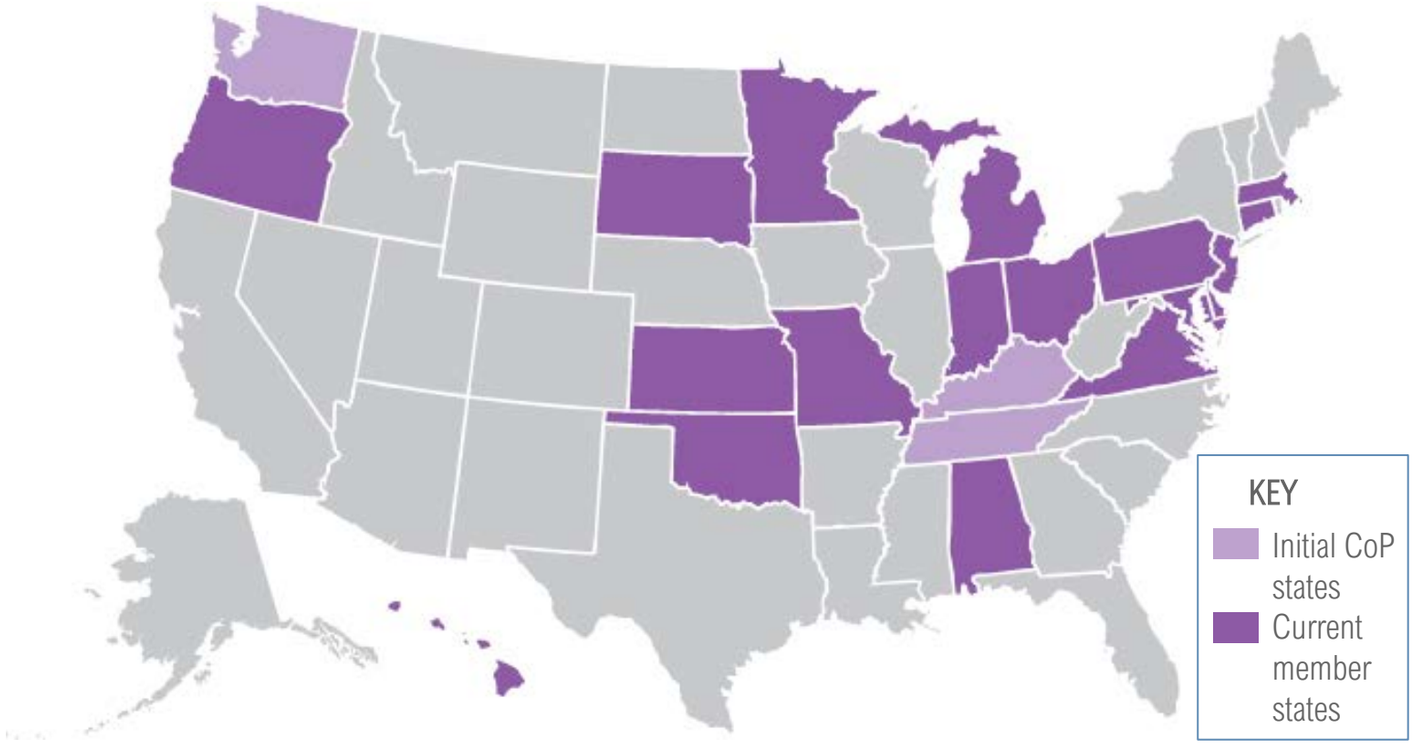
**TRANFORMATIONAL**

- 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.)

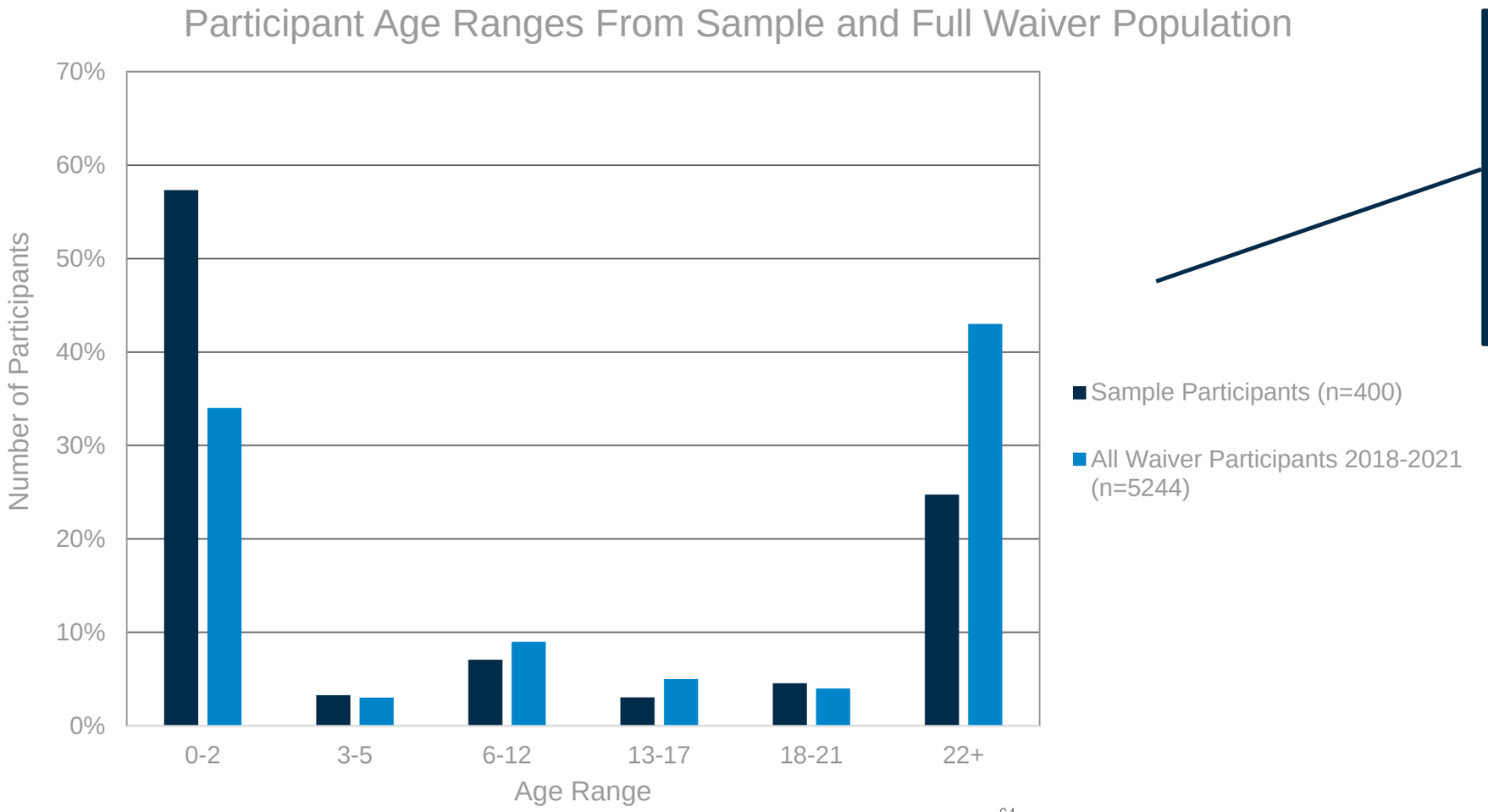
- **Tribal Engagement:** A&M reached out to tribal leaders, but only connected with 2 Native American stakeholders. They spoke about lack of access to providers, difficulty with schools, and the need for culturally competent services. A&M recommends continuing these conversations and looking at ways 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.

# ID/DD Program Services and Costs

# Developmental Disability Waiver: Who Does North Dakota Serve?*

North Dakota's DD Waiver serves individuals from birth through death. Most participants fall into the age ranges 0-2, or 22+




**Across both the sample and full population:**

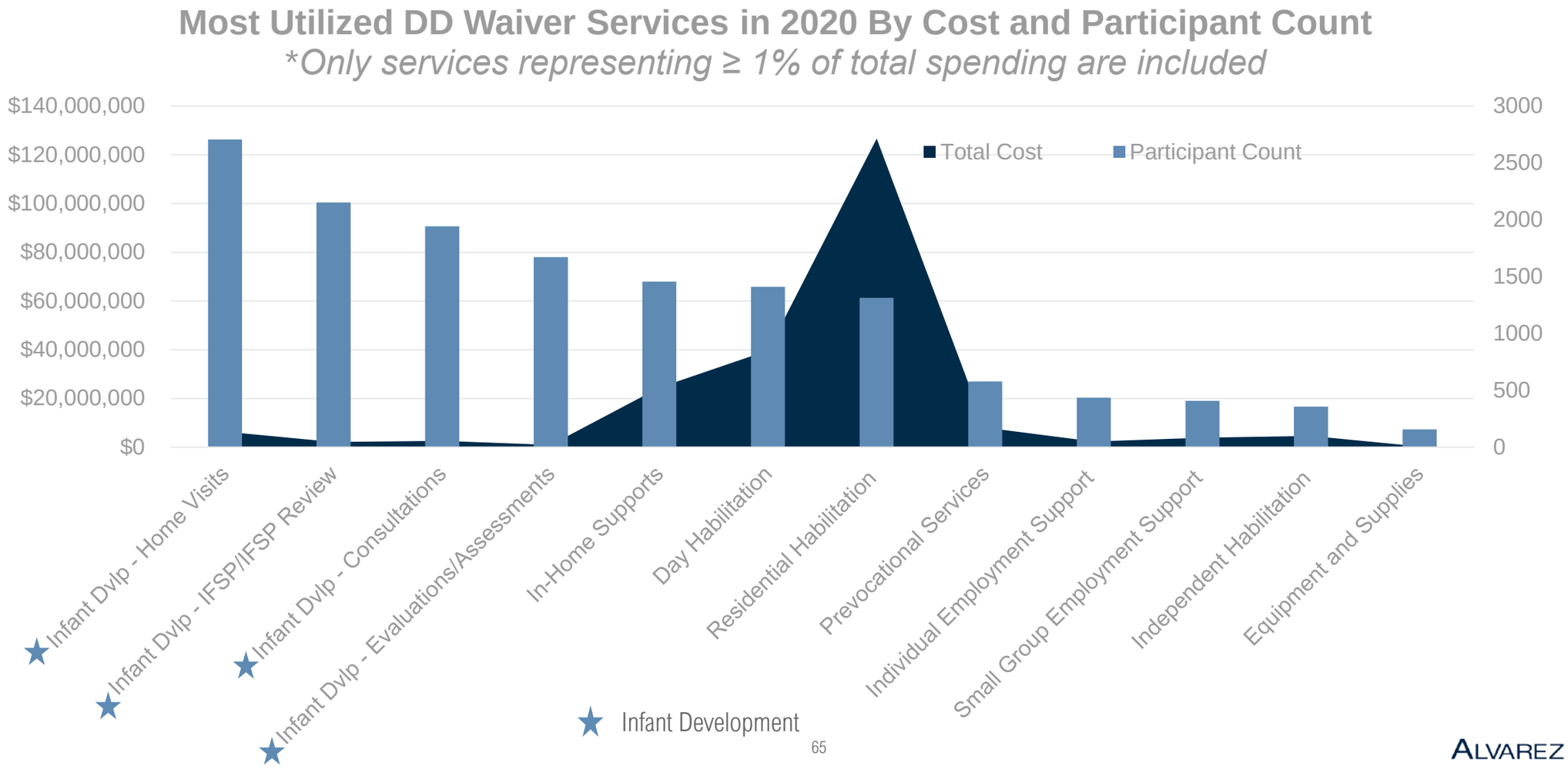
- People aged 0-2 and 22+ represent the two largest groups of individuals served
- Participants 3-21 only make up around 20% of the total



**Sample data in these slides is pulled from a random 400-person sample of DD Waiver participant Medicaid claims, 2018-2021*

# Developmental Disability Waiver: What Waiver Services Do Participants Use?

A&M analyzed State reports to the Centers for Medicare and Medicaid Services to assess the most utilized services by cost and participant counts



# Cost of Adding Someone to the DD Waiver, By Age*

A&M calculated the true cost of adding someone to the waiver, by age, using the four years of sample claims. This figure differs from the earlier slides as it includes an estimate of what this population spends on Medicaid when not enrolled on the Waiver. This number is subtracted from the total Medicaid spending when on the Waiver.

| Age | Average Yearly Medicaid State Plan Costs If Not on DD Waiver | Average Yearly State Plan & HCBS Medicaid Costs on DD Waiver* | Average Additional Cost of Waiver Slot Over One Year, Assuming 281 LOS (50% of cost would be paid by Federal match) | Participant Count |
|---|---|---|---|---|
| 0-2 | $2,725 | $10,866 | $8,140 | 221 |
| 3-5 | $11,206 | $16,003 | $4,796.45 | 10 |
| 6-12 | $18,394 | $24,020 | $5,626 | 12 |
| 13-17 | $0 | $23,793 | $23,793 | 3 |
| 22+ | $29,222 | $76,961 | $47,739 | 16 |
| All | $6,859 | $29,829 | $22,970 | 269 |

*

*Figures rounded to nearest dollar.*
**Assumes average LOS of 281 days continues*
***Due to limited sample size, we did not include ages 18-21 in these calculations*

# Average Cost of Adding Someone to the DD Waiver Across All Ages

A&M calculated a weighted average based on the distribution of ages across the full 2018-2021 waiver population. This differs from the earlier figure as it includes an estimate of what this population spends on Medicaid when not enrolled on the Waiver. This number is subtracted from the total Medicaid spending on the Waiver.

| Age | Average Cost of HCBS + State Plan Medicaid / new Slot Annually* | % Sample Population | % Total Waiver Population |
|---|---|---|---|
| 0-2 | $8,140 | 57% | 34% |
| 3-5 | $4,796 | 3% | 3% |
| 6-12 | $5,626 | 7% | 9% |
| 13-17 | $23,793 | 3% | 5% |
| 18-21 | **$23,793 - $47,739 | 5% | 4% |
| 22+ | $47,739 | 25% | 43% |

**Average Additional Cost of One Waiver Slot Over A Year;**

- Calculated across sample: $18,838 - 22,970
- Weighted to match age distribution of the total waiver population : $26,087 - $27,045
- Federal Matching for North Dakota is 51.55% of spending
- **Average yearly State cost per additional DD Waiver slot: $12,639 - $13,103**

*Figures rounded to the nearest dollar.*

**Assumes average LOS of 281 days continues*

***Due to limited sample size, we used neighboring age groups as a proxy for this age range*

*

# Developmental Disability Program Management Costs

North Dakota provides case management services through regionally-based DD Program Managers. This service is provided to qualifying individuals including both DD Waiver participants (funded through Medicaid), and individuals with I/DD who are not on the Waiver (funded through State Funds).

| Funding Source | Description | State Fund | Federal Fund | Total |
|---|---|---|---|---|
| **Medicaid** | Traditional DD Waiver Admin | 2,365,478.93 | 3,220,982.98 | 5,586,461.91 |
| **Medicaid** | Non-Waiver MA Admin – All HSCs | 486,054.58 | 628,042.19 | 1,114,096.77 |
| **State Funded Project** | DD Services | 2,333,338.14 | N/A | 2,333,338.14 |
| **Grand Total** | | 5,184,871.65 | 3,849,025.17 | 9,033,896.82 |

# Cost Considerations for HCBS Waiver Redesign

A variety of costs would potentially be included in the proposed HCBS Waiver redesign/expansion, depending on State decisions

## Common Cost Elements

- HCBS Waiver-specific services (see appendix for examples of common DD Waiver services)
- Medicaid State Plan spending
- Potential for rate changes / inflation of all Medicaid-related costs over time
- Case management staff / family navigators
- Administrative staffing at DHS
- One-time investment in additional FTEs/contractor support to design and implement new system

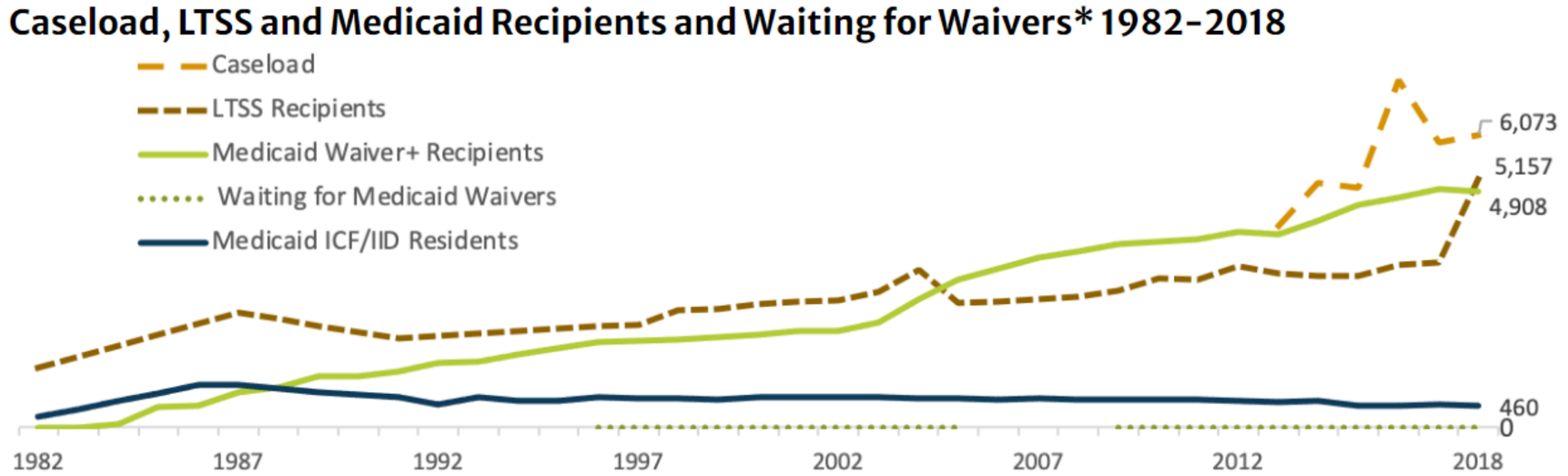
→ **General I/DD Waiver Revision**
- Changes to service array may result in minimal cost added, with emphasis on cost-effective services
- Changes to LOC may result in more individuals with ASD qualifying for the I/DD Waiver – the new LOC would need to be selected to identify this cost

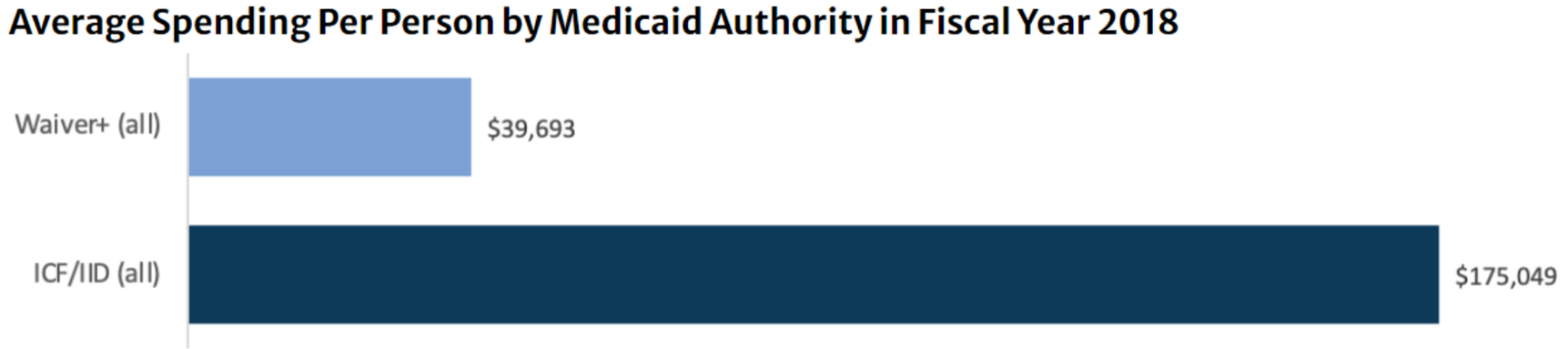
→ **Service Expansion for Ages 3-5**
- If LOC fully opened to match the under three eligibility, the State would spend $8-$12 million on Medicaid-related costs
- LOC for this group could be more narrowly targeted than the under three group to reduce this cost

→ **New IFS Waiver**
- If the new IFS Waiver is designed to meet the full demonstrated need of the ASD and MF waitlists, then the State will need to spend an additional $100-$600 thousand based on waitlists

# Peer State Benchmarking

# North Dakota Residential Information Systems Project (RISP) State Profile




Citation: FY 2018 RISP State Profiles | North Dakota | State Profiles (umn.edu)



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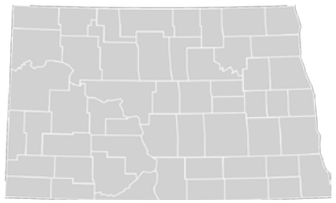
LEADERSHIP. ACTION. RESULTS.

# Where do People with Developmental Disabilities Receive Services?

A&M examined the living arrangements of individuals receiving LTSS from the State IDD Agency in 2018, both in ND and nationally.



5,157 North Dakotans receiving LTSS from the State IDD Agency in 2018

83%
Lived in own home, family setting, or a foster/host home

7.1%
Lived in group setting ≤ 6 people

9.9%
Lived in group settings of 7+ people

1. Home, Family, or Foster/Group Home
2. Group setting, 7+ people
3. Group setting, ≤6 people

1,308,659 Americans receiving LTSS from State IDD Agencies in 2018

77.1%
Lived in own home, family setting, or a foster/host home

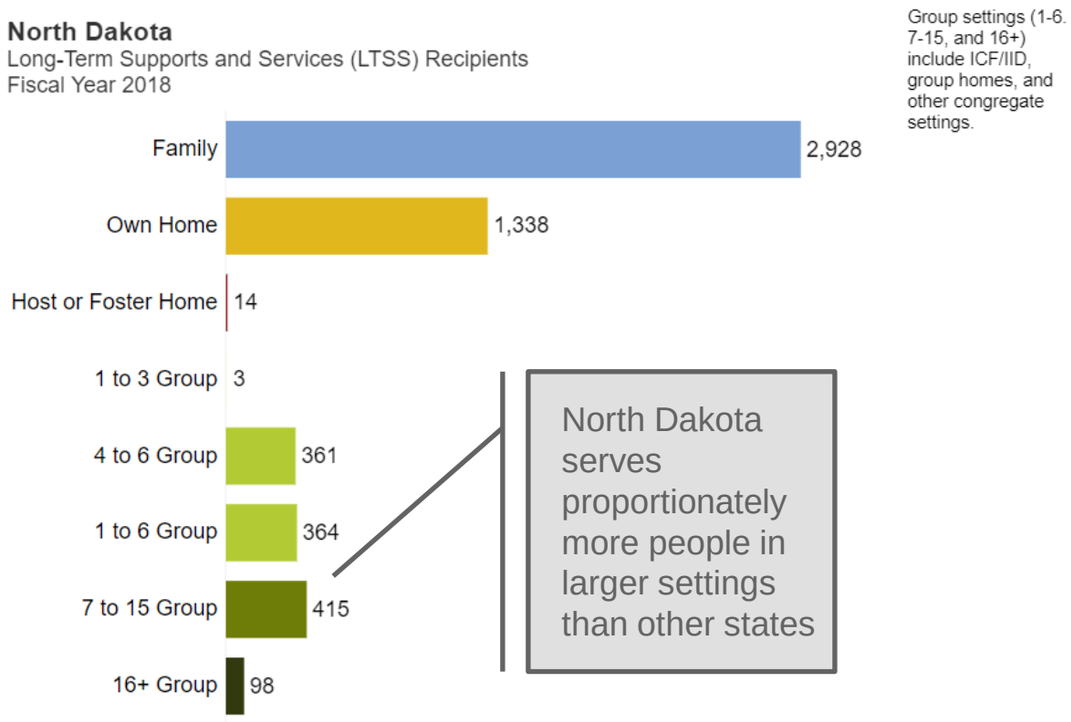
15.8%
Lived in group setting ≤ 6 people

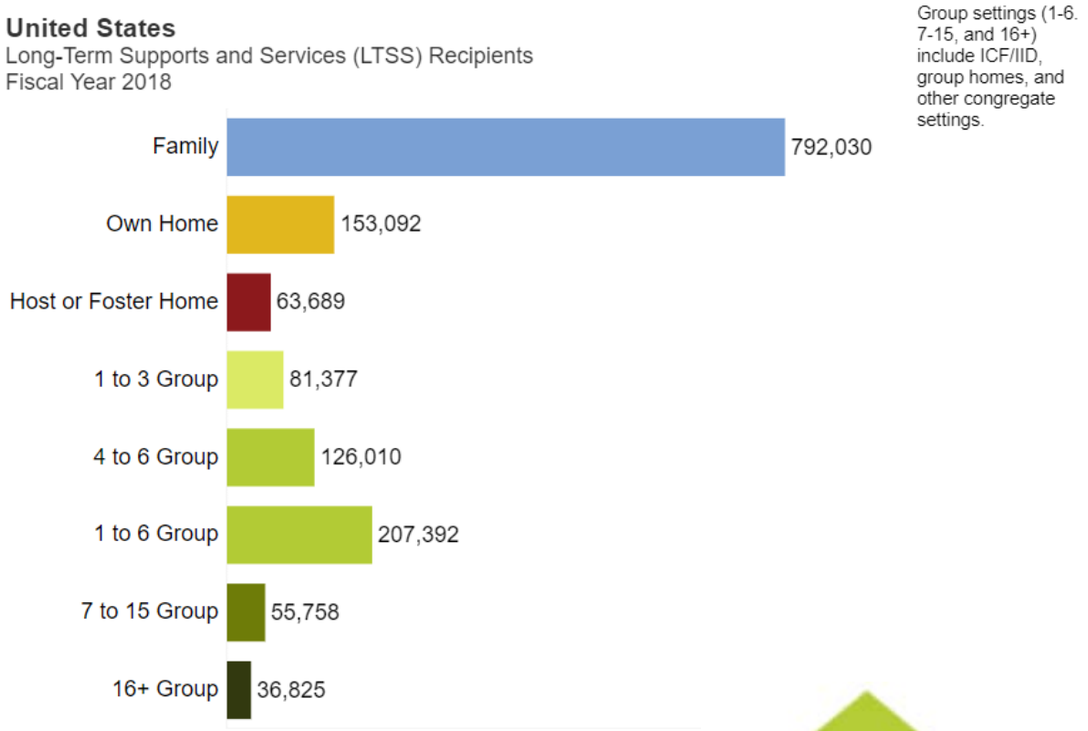
7.1%
Lived in group settings of 7+ people

1. Home, Family, or Foster/Group Home
2. Group setting, ≤6 people
3. Group setting, 7+ people

*Citation: Residential Information Systems Project. (2021). Living Arrangements of LTSS Recipients by Fiscal Year Over Time. University of Minnesota. https://risp.umn.edu/viz/living-arrangements/living-arrangements-of-ltss-recipients-by-fiscal-year-over-time

# Where People with ID/DD Who Receive Long Term Services & Supports Live

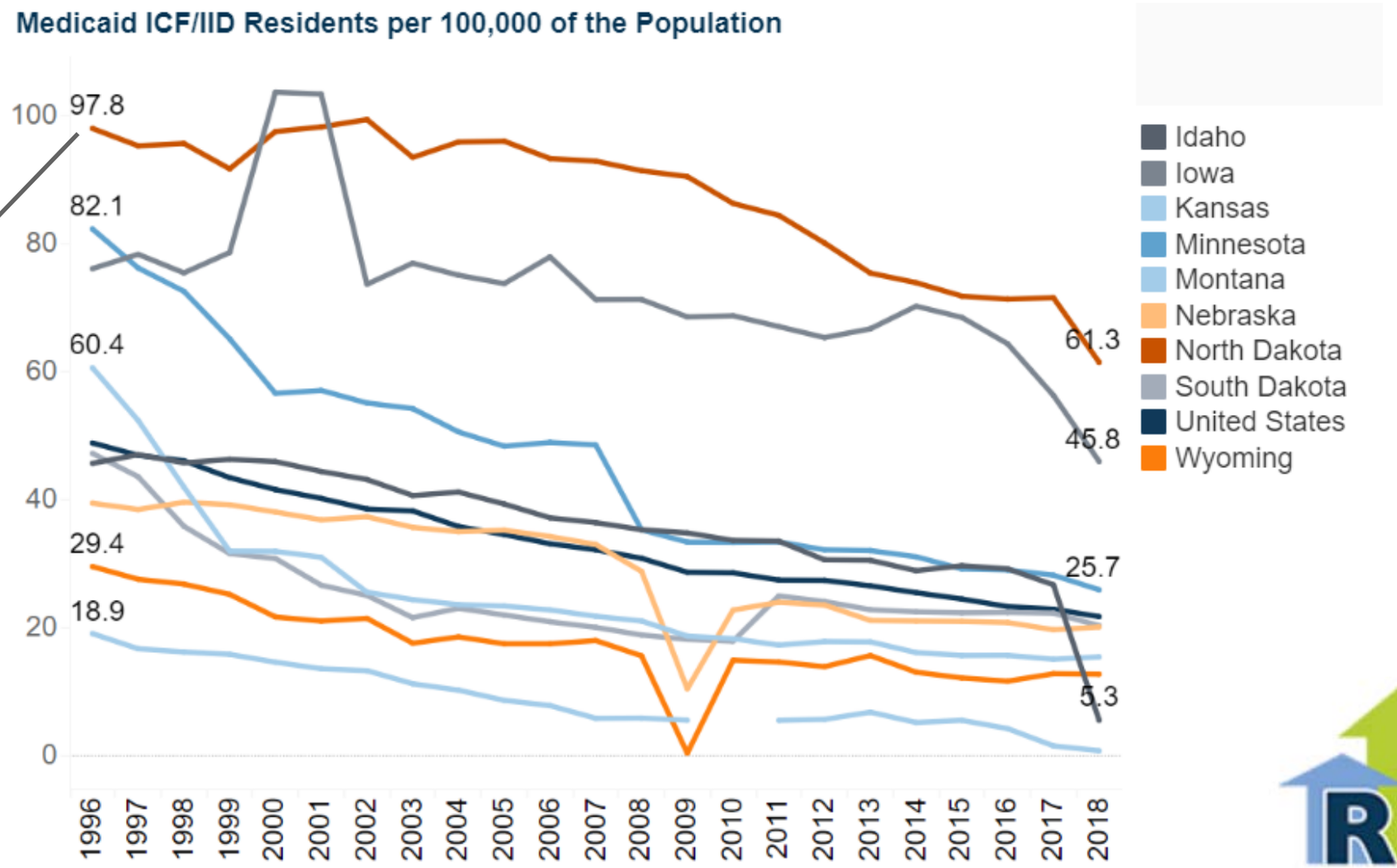



Citation: Residential Information Systems Project. (2021). *Long-Term Supports and Services (LTSS) Recipients by Setting Type and Year*. University of Minnesota. https://risp.umn.edu/viz/living-arrangements/ltss-recipientss-by-setting-type-and-year

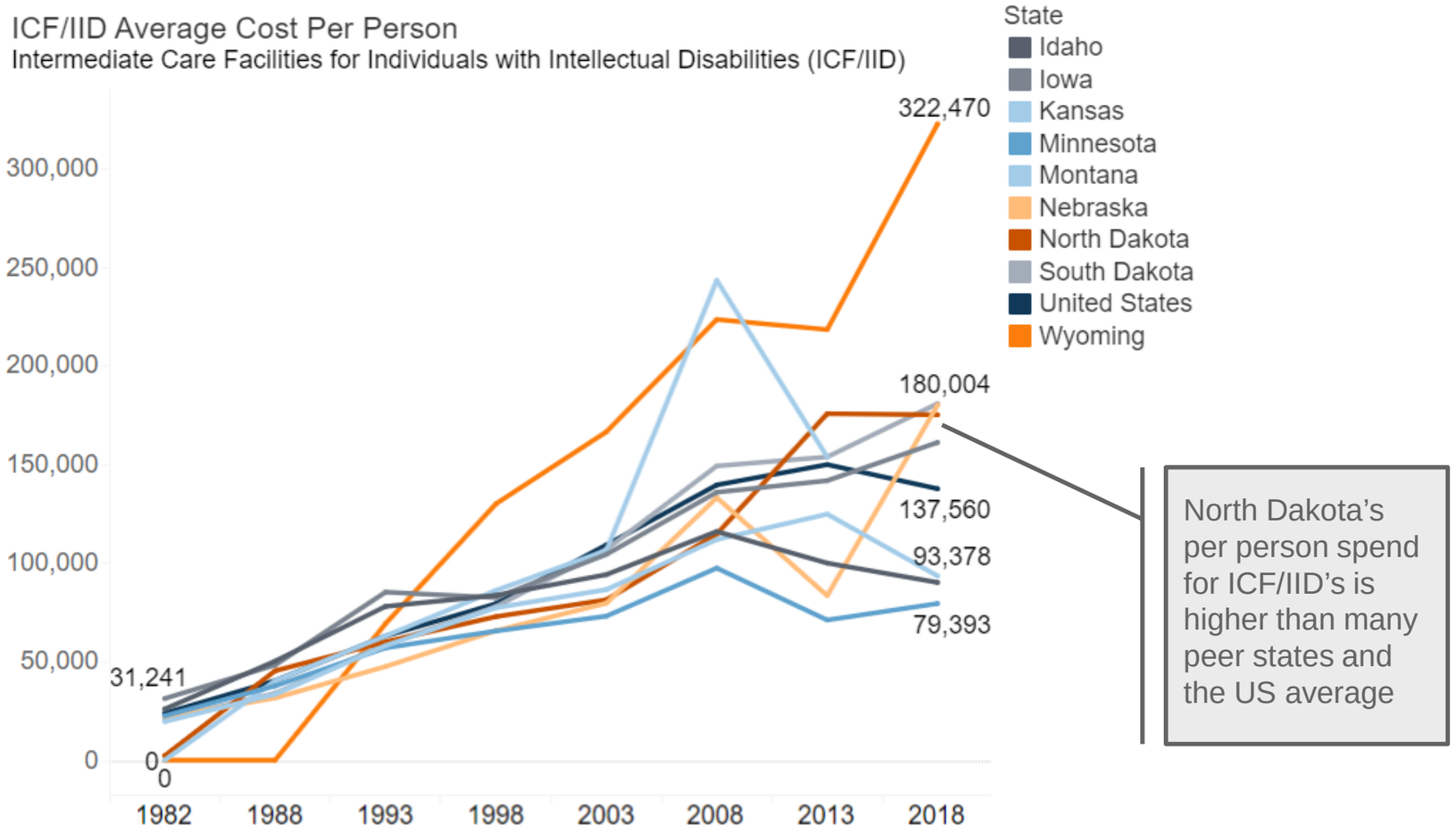
# Peer States: ICF/IID Residents

North Dakota serves more people in ICF/IIDs than peer states




Citation: Residential Information Systems Project. (2021). *ICF/IID Residents*. University of Minnesota. https://risp.umn.edu/viz/medicaid-icf-iid/icf-iid-residents

# Peer States: ICF/IID Spend

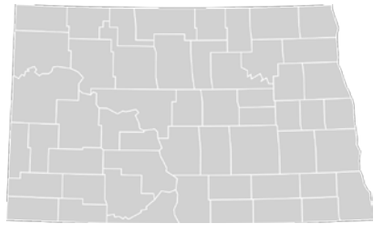



North Dakota's per person spend for ICF/IID's is higher than many peer states and the US average

Citation: Residential Information Systems Project. (2021). *Compare States ICF/IID Average Cost Per Person*. University of Minnesota. https://risp.umn.edu/viz/medicaid-icf-iid/compare-states-icf-iid-average-cost-per-person

# What Does it Cost To Serve People with Developmental Disabilities in Different Settings?

In both North Dakota and across the country, it costs less per person to serve someone with I/DD on a DD waiver than in an Intermediate Care Facility (ICF)



Waiver Cost Per Person (2018): $39,693

ICF Cost Per Person (2018): $175,049

5,157 North Dakotans receiving LTSS from the State IDD Agency (2018)

Waiver Cost Per Person (2018): $47,835

ICF Cost Per Person (2018): $137,560

1,308,659 Americans receiving LTSS from State IDD Agencies (2018)

| State | ICF Spend as % of Total IDD $ | Waiver Spend as % of Total IDD $ |
|---|---|---|
| North Dakota | 29% | 71% |
| United States | 19% | 81% |

*North Dakota's share of DD spending in institutions is significantly higher than national figures, indicating there is an opportunity to invest in the home and community-based settings supported by the DD Waiver.

*See Appendix, Peer State Benchmarking, for more detailed analysis of ICF and waiver spending.*

*Citation: Residential Information Systems Project. (2021). Living Arrangements of LTSS Recipients by Fiscal Year Over Time. University of Minnesota. https://risp.umn.edu/viz/living-arrangements/living-arrangements-of-ltss-recipients-by-fiscal-year-over-time

# Peer States: ICF/IID Spend Comparison

| | Total People Living in ICFs | % of People Living in ICFs | Total ICF Spend | % ICF Spend | Total People Served | Total Spend |
|---|---|---|---|---|---|---|
| North Dakota | 460 | 7.57% | $80,522,540 | 29.25% | 5,157 | $275,335,784 |
| Nebraska | 382 | 6.59% | $68,761,528 | 18.73% | 5800 | $367,058,908 |
| Montana | N/A | N/A | N/A | 0.00% | 2746 | $113,619,580 |
| Idaho | 73 | 0.88% | $6,574,599 | 2.52% | 8327 | $260,486,457 |
| Wyoming | 72 | 3.01% | $23,217,840 | 19.18% | 2394 | $121,046,256 |
| Minnesota | 1,441 | 4.22% | $114,405,313 | 6.86% | 34161 | $1,668,719,713 |
| Kansas | 430 | 4.50% | $41,086,500 | 7.29% | 9554 | $563,481,120 |
| Iowa | 1,440 | 7.77% | $231,887,520 | 28.78% | 18522 | $805,652,614 |
| South Dakota | 176 | 4.41% | $31,807,072 | 21.52% | 3,990 | $147,774,447 |
| National | 70,046 | 5.35% | $9,635,527,760 | 18.64% | 1,308,659 | $51,685,458,530 |

# Peer States: HCBS Waiver & ICF/IDD Spend Comparison

| | Waiver Spend | % Waiver Spend | ICF Spend | % ICF Spend | Total Spend |
|---|---|---|---|---|---|
| North Dakota | $194,813,244 | 70.75% | $80,522,540 | 29.25% | $275,335,784 |
| Nebraska | $298,297,380 | 81.27% | $80,522,540 | 18.73% | $367,058,908 |
| Montana | $113,619,580 | 100.00% | N/A | 0.00% | $113,619,580 |
| Idaho | $253,911,858 | 97.48% | $6,574,599 | 2.52% | $260,486,457 |
| Wyoming | $97,828,416 | 80.82% | $23,217,840 | 19.18% | $121,046,256 |
| Minnesota | $1,554,314,400 | 93.14% | $114,405,313 | 6.86% | $1,668,719,713 |
| Kansas | $522,394,620 | 92.71% | $41,086,500 | 7.29% | $563,481,120 |
| Iowa | $573,765,094 | 71.22% | $231,887,520 | 28.78% | $805,652,614 |
| South Dakota | $115,967,375 | 78.48% | $31,807,072 | 21.52% | $147,774,447 |
| National | $42,049,930,770 | 81.36% | $9,635,527,760 | 18.64% | $51,685,458,530 |

# Peer States: HCBS Waiver Spend Comparison

| | Total People on Waiver | % of People on Waiver | Total Waiver Spend | % Waiver Spend | Total People Served | Total Spend |
|---|---|---|---|---|---|---|
| North Dakota | 4,908 | 80.82% | $194,813,244 | 70.75% | 5,157 | $275,335,784 |
| Nebraska | 4,666 | 80.45% | $298,297,380 | 81.27% | 5800 | $367,058,908 |
| Montana | 2,740 | 99.78% | $113,619,580 | 100.00% | 2746 | $113,619,580 |
| Idaho | 8,234 | 98.88% | $253,911,858 | 97.48% | 8327 | $260,486,457 |
| Wyoming | 2,394 | 100.00% | $97,828,416 | 80.82% | 2394 | $121,046,256 |
| Minnesota | 21,792 | 63.79% | $1,554,314,400 | 93.14% | 34161 | $1,668,719,713 |
| Kansas | 9,124 | 95.50% | $522,394,620 | 92.71% | 9554 | $563,481,120 |
| Iowa | 13,214 | 71.34% | $573,765,094 | 71.22% | 18522 | $805,652,614 |
| South Dakota | 3,625 | 90.85% | $115,967,375 | 78.48% | 3,990 | $147,774,447 |
| National | 879,062 | 67.17% | $42,049,930,770 | 81.36% | 1,308,659 | $51,685,458,530 |

# Early & Periodic Screening Detection & Treatment (EPSDT) Benchmarking

| | Screening Ratio * | Participant Ratio** | Average |
|---|---|---|---|
| Iowa | 0.87 | 0.61 | 0.74 |
| National | 0.79 | 0.60 | 0.70 |
| Idaho | 0.81 | 0.58 | 0.70 |
| Kansas | 0.72 | 0.55 | 0.64 |
| Wyoming | 0.7 | 0.52 | 0.61 |
| Minnesota | 0.67 | 0.53 | 0.60 |
| Nebraska | 0.72 | 0.48 | 0.60 |
| North Dakota | 0.59 | 0.48 | 0.54 |
| South Dakota | 0.69 | 0.38 | 0.54 |
| Montana | 0.59 | 0.42 | 0.51 |

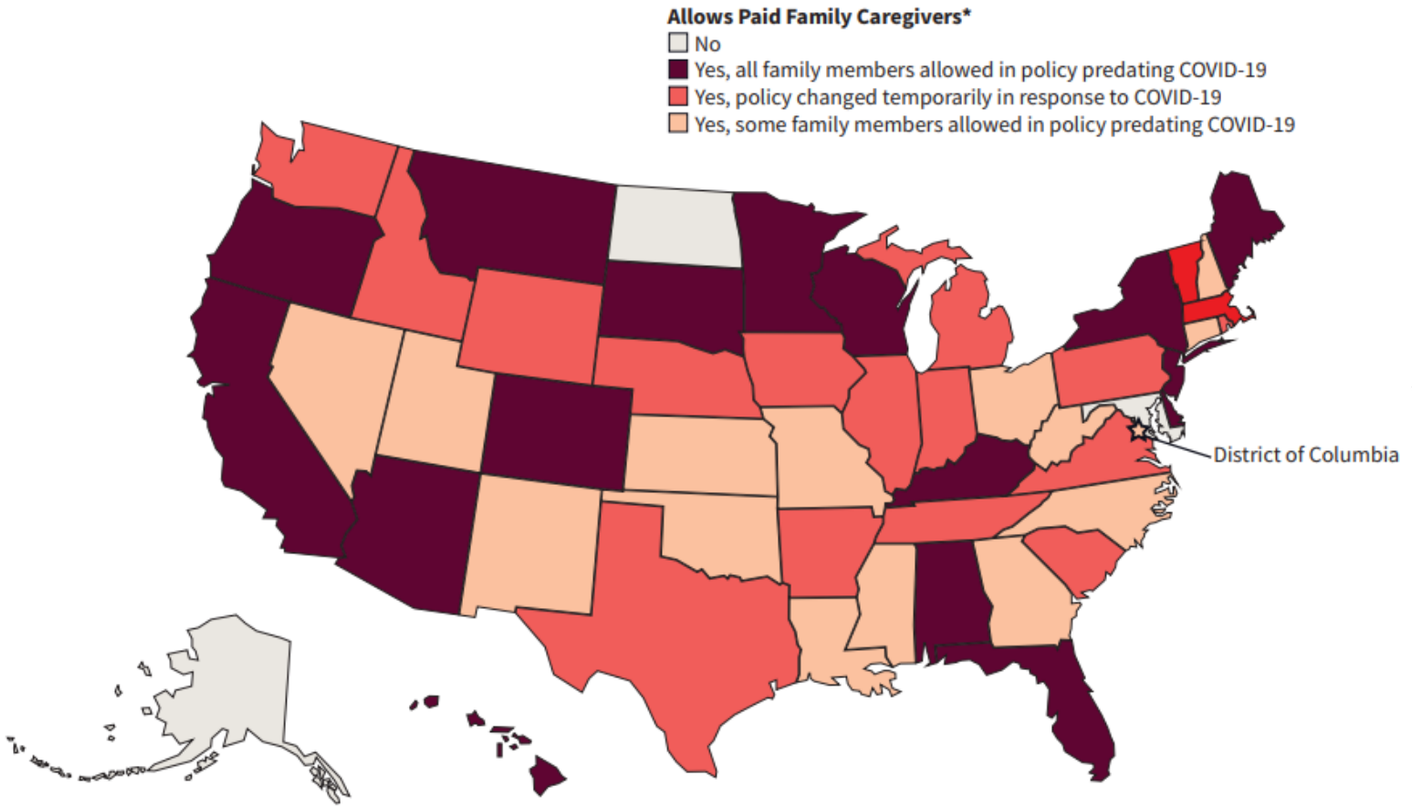
- Stakeholder interviews raised concerns that EPSDT was not robust in North Dakota.
- Benchmarking indicates that North Dakota is in the bottom tier of peer states and below the national average for EPSDT screening and participation
- A&M understands that there is currently a study of the EPSDT program underway
- The Department is currently working on revamping the program to provide more outreach services to members and providers to increase EPSDT screening participation

** Expected number of screenings / total screens received*
*** Total eligible who should receive at least one initial or periodic screen / total receiving*

# Understanding Self Direction

- Self-direction is a model of long-term care service delivery that helps people of all ages, with all types of disabilities, maintain their independence at home.
- When a person self-directs, they decide *how*, *when*, and *from whom* their services and supports will be delivered. People may choose to hire friends, family, or neighbors to provide services.
- Although federal Medicaid law allows family members to provide these supports through self-direction, prior to the pandemic, more than half of self-directed HCBS programs restricted this. 15 states began allowing family members to be hired during the pandemic. See next slide for more information.
- This is different than the traditional model, in which a person receives services from a provider agency. The agency selects the staff who will provide the supports and trains them. In self-direction, the person hires and trains their staff, as well as setting their schedule.
- Self-direction is based on the principle that people with disabilities know their needs best and are in the best position to plan and manage their own services.
- More than 1 million people in the United States self-direct their long-term services and supports. In North Dakota, people currently have an opportunity to self-direct services through the ID/DD waiver, the Medically Fragile waiver, and Veteran's Directed Care.

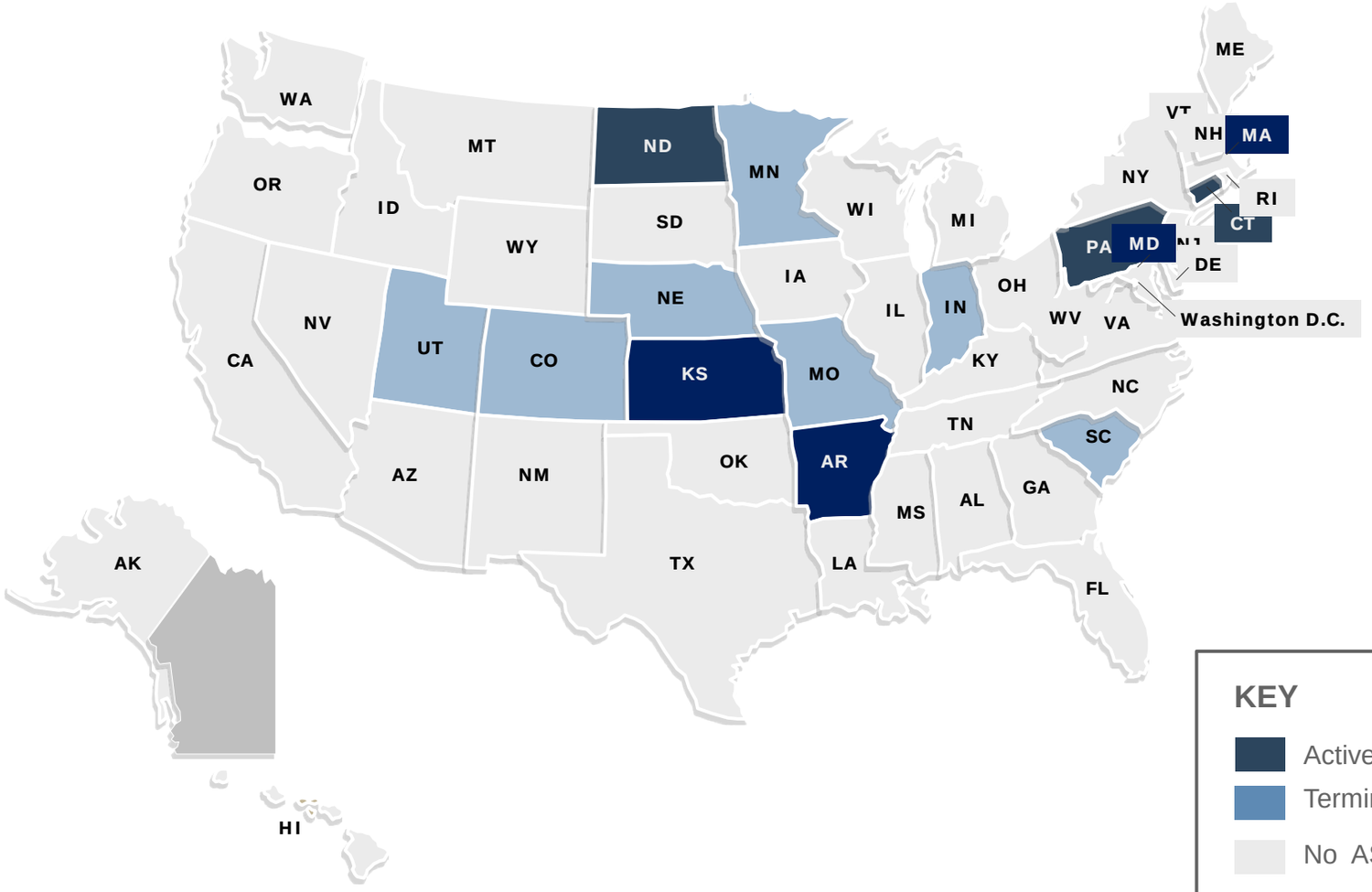
# State Policies Allowing Paid Family Caregiving in Self Directed Programs




- This map looks at self-directed programs for adults ages 65+ and adults with physical disabilities
- Data is from November 2020
- Sources: AARP Public Policy Institute, 2020 Long-Term Services and Supports Scorecard; CMS, Emergency Preparedness and Response for HCBS 1915(c) Waivers.

# Autism Waivers

# National Status of Autism Waivers




- North Dakota is one of seven states that currently has a standalone autism waiver.
- Many states serve people with autism through their family support and comprehensive waivers, rather than a standalone waiver.
- Anecdotally, some states have terminated their autism waiver after adding ABA therapy to their Medicaid state plan.

# Comparison of Autism Waivers (2 of 2)

| State | Services | Age | Individual Cost Limit | Participants/ Year | Average Spend/ Year | Total Spend/ Year |
|---|---|---|---|---|---|---|
| Massachusetts | Provides community integration, expanded habilitation/education, homemaker, respite, assistive technology, behavioral supports and consultation, family training, home delivered meals, home modifications and adaptations, individual goods and services, and vehicle modification. | 0 – 8 | No cost limit | 410 | $12,326 | $5,053,735 |
| North Dakota | Provides respite, service management, and assistive technology service. | 0 – 15 | No cost limit | 150 | $21,258 | $3,188,753 |
| Pennsylvania | Provides day habilitation, residential habilitation, respite, supported employment, supports coordination, therapies, assistive technology, career planning, community transition services, family support, home modifications, nutritional consultation, small group employment, specialized skill development, temporary supplemental services, transportation, and vehicle modification. | 21 – No max | No cost limit | 754 | $66,143 | $49,872,010 |

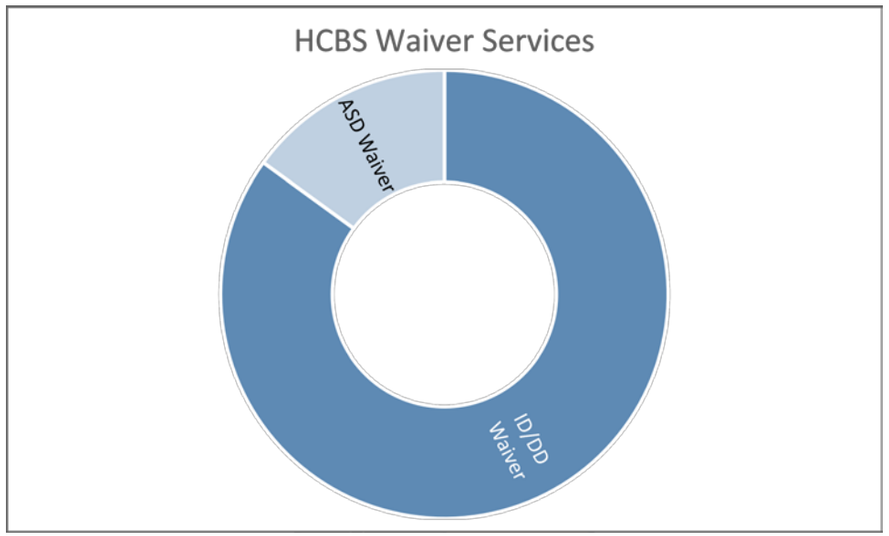
*Figures rounded to nearest dollar.*

# North Dakota Waiver Comparison

There are significant disparities in level of supports that a person can receive, depending on whether they are receiving services from the Autism or the Developmental Disabilities waiver.

### ND Autism Spectrum Disorder (ASD) Birth through Fifteen

Provides respite, service management, and assistive technology services for individuals with autism **ages 0 to 15 years**.



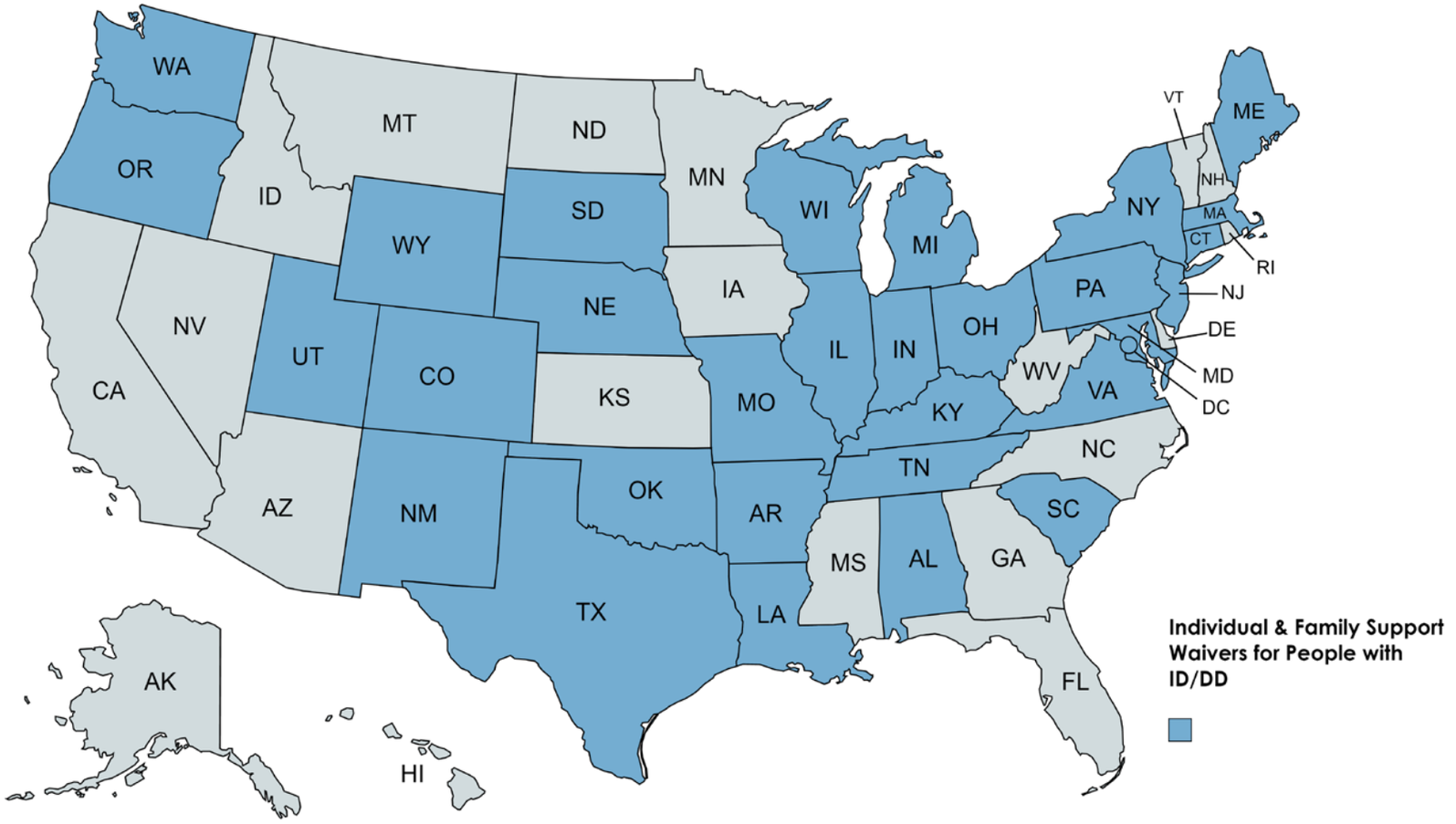

### ND Traditional Intellectual Disabilities and Developmental Disabilities HCBS Waiver

Provides day habilitation, homemaker, independent habilitation, individual employment support, prevocational services, residential habilitation, extended home health care, adult foster care, behavioral consultation, community transition services, environmental modifications, equipment and supplies, family care option, in-home supports, infant development, parenting support, and small group employment support services for individuals with intellectual disabilities and developmental disabilities **ages 0 to no max age**.

# Individual & Family Support Waivers

# National Status of Individual & Family Support Waivers for People with ID/DD/ASD

More than half of all states have Individual and Family Supports Waivers for people with Intellectual & Developmental Disabilities and/ or Autism Spectrum Disorder.



# Intellectual & Developmental Disability Definitions

# Intellectual or Developmental Disability Definitions (1 of 5)

| | 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.<br><br>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)

| | 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:<br>A. is attributable to a mental or physical impairment or combination of mental and physical impairments;<br>B. is manifested before the person attains age twenty-two;<br>C. is likely to continue indefinitely;<br>D. results in **substantial functional limitations in three or more of the following areas of major life activity**: [SEE BELOW]<br>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<br>(3) learning<br>(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<br>(4) mobility<br>(6) capacity of independent living, and<br>(7) economic self-sufficiency |

# Intellectual or Developmental Disability Definitions (3 of 5)

| | Nebraska |
|---|---|
| Intellectual or Developmental Disability Definition | Developmental disability shall mean a severe, chronic disability, including an intellectual disability, other than mental illness, which:<br>(1) Is attributable to a mental or physical impairment unless the impairment is solely attributable to a severe emotional disturbance or persistent mental illness;<br>(2) Is manifested before the age of twenty-two years;<br>(3) Is likely to continue indefinitely;<br>(4) Results in **substantial functional limitations in one of each of the following areas of adaptive functioning** [SEE BELOW] and<br>(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.<br><br>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)

| | 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:<br>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.<br><br>For LOC:<br>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)

| | 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;<br>(2) The disability manifested itself before the individual reached the age of 22; and<br>(3) The disability is likely to continue indefinitely.<br><br>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;<br>(3) Learning/general cognitive competence -- the ability to acquire new behaviors, perceptions, and information and to apply the experiences to new situations;<br>(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;<br>(4) Mobility -- the ability to use fine or gross motor skills to move from one place to another with or without mechanical aids;<br>(6) Capacity for independent living -- based on age, the ability to live without extraordinary assistance; and<br>(7) Economic self-sufficiency -- the maintenance of financial support. |

# Early Intervention Definitions

# Definitions: Early Intervention Part C & Part B

| | 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.<br><br>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.<br><br>"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.<br><br>"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<br><br>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. |

# Individual Directed Goods & Services Definitions

# 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**.

# Workforce Challenges

# Direct Support Worker Workforce Challenge

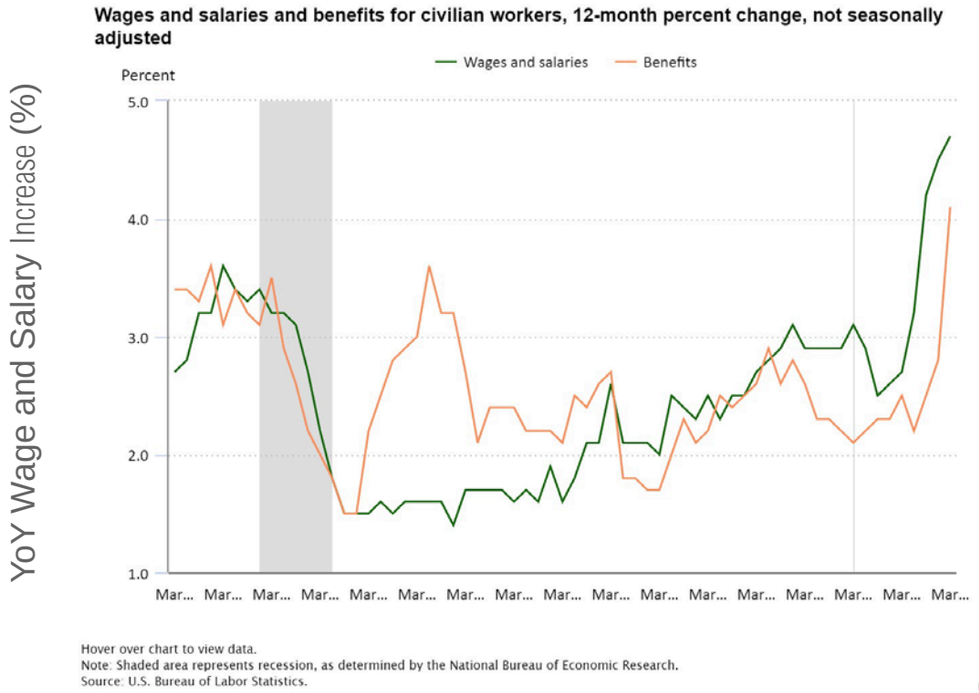
The longstanding Direct Support Professional (DSP) workforce crisis has been exacerbated by the COVID-19 pandemic and increased wages in multiple sectors. A&M surveyed ND providers, who rated this as the toughest problem they are currently facing. People with disabilities and families also shared the impact of the workforce crisis on their lives – with people unable to get the supports they need.

**Workforce shortages are one of the most significant issues facing LTSS systems.**

- With a pre-pandemic full-time vacancy rate of 8% and part-time rate of 11%, combined with a turnover rate of 43%, ID/DD services are in crisis.[1]
- Likewise, for aging and disability service providers, nearly 90% of LTC facilities are reporting staffing shortages.[2]

In addition to raising serious concerns about quality of services and the safety of people with ID/DD, this comes at a significant cost

- A federal report estimates the costs of this turnover to be approximately **$2.3B annually**.
- Updated for inflation, turnover costs roughly **$5,400/ DSP**.[3]




**Wages and salaries** increased 4.7% percent for the 12-month period ending in March 2022 (all civilian sectors). Data is year over year, March 2006 – March 2022.[4]

Sources: 1 - National Core Indicators, Staff Stability Survey; America's Direct Support Workforce Crisis and Direct Support Workforce and COVID-19 National Report: 6 Month Follow-Up; 2 -State of the Long Term Care Industry; 3 - The Staffing Struggle is Real; 4 - Employment Cost Index (BLS March 2022);



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# Sustainable Solutions to the DSP Workforce Crisis (1 of 2)

Raising DSP salaries and supporting workforce development is critical, but not sufficient. Sustainable solutions require transformational changes to Developmental Disabilities systems. Solving the crisis will take a variety of cross-workforce solutions: tapping non-traditional workers; developing career ladders; and providing ongoing training and support.

**DSP E-Badges**

- The NADSP's E-badge Academy© is built on the principle that DSPs assist people with intellectual and developmental disabilities in achieving their personal outcomes through the confluence of three critical interventions: Knowledge, Skills & Values
- The E-Badge Academy provides opportunity for DSPs to demonstrate that they have an up-to-date and relevant skill set, highlight their professional achievements, and document the value that they bring in partnership with the people they support

**Career Ladders**

- Career ladders not only create professional career paths and enhance the status of DSPs, they also improve workers' skills and the quality and safety of supports
- Career ladders help with both attracting and retaining the workforce. They offer the opportunity for ongoing training and development and competency-based improved pay

**DSP Academy**

- The DSP Academy is an innovative training program developed through evidence-base practices that certifies people with and without disabilities to work as DSPs
- It creates opportunity at the crossroad between two critical issues facing the field: the workforce shortage of DSPs and the high unemployment rates for people with disabilities.  In 2020, only 18% of people with disabilities were employed, compared to 66% of people without disabilities

Sources: eBadge Academy; Career Ladders

# Sustainable Solutions to the DSP Workforce Crisis (2 of 2)

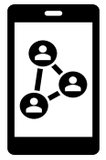
**Supporting Families**

- All people exist and have reciprocal roles within a family system, as defined by the person. The entire family, individually and as a whole, needs support to ensure they all are able to successfully live their good life. Supporting families means that more people with developmental disabilities will be able to live in their homes, surrounded by people who love and care for each other
- Supports must be integrated so that people with developmental disabilities can achieve their envisioned good life. These include those that are publicly or privately funded and based upon eligibility; community supports that are available to anyone; relationship-based supports; technology; and the personal strengths and assets of the individual and their family

**Employment First**

- Competitive integrated employment of people with disabilities increases opportunities for meaningful days and inclusion, while reducing a person's need for paid day supports. States must align policies, service delivery practices, and reimbursement structures to commit to integrated employment as the priority option for publicly-financed day services for youth and adults with significant disabilities

**Technology First**



- The COVID-19 pandemic has shown us that even people with the most significant disabilities can benefit from technology and that services can be delivered differently. Services like remote supports and assistive technology can help people with disabilities improve their quality of life and experience more independence and personal freedom, while decreasing the need for paid staff

Sources: DSP Academy; Persons with a Disability: Labor Force Characteristics Summary (bls.gov); Technology First; Charting the LifeCourse Nexus

# Autism Spectrum Disorder Taskforce

# What We Heard: Autism Spectrum Disorder Task Force

Below are common themes we heard from interviews and listening sessions with ASDTF members

| Working: Build Upon | Opportunity |
|---|---|
| **Membership**: Dedicated members with experience; member with ASD brings valuable perspective; new members are bringing new energy and ideas, | **Membership**: Need for new diverse voices at the table; more members with ASD. |
| **Purpose**: Members find having a single-issue task force valuable given the rising population of people with ASD and lack of system of support, | **Purpose**: Members are not clear on their mandate or how to contribute. There is no charter. State recommends an umbrella Task Force on ID/DD/ASD system of care that single issue groups could participate in/ advise as a subcommittee. |
| **Agenda**: Members are given the opportunity to contribute to the agenda. Guest speakers are helpful. Members can request education on specific issues. | **Agenda**: Chairwoman develops the agenda and it is often focused on ASD & voucher services. Members are interested in also hearing about other ASD : Life Skills Transition Center, Vocational Rehabilitation, Indian Health etc. Although members may contribute to the agenda, they feel uncertain doing so, given that the Chairwoman works for the DHS. |
| **Facilitation**: Chairwoman is knowledgeable and a skilled facilitator. Relationships are mending after the state suggested ending the Task Force without first consulting members. | **Facilitation**: Having a state employee as chair of the Task Force creates a “power over” dynamic. Members recommend someone in a supportive function who is a liaison to the committee. State agrees that having a neutral party to facilitate would be helpful. |
| **Action**: There is a history of the Task Force doing data collection and surveys, and interest in doing this again. New members bring momentum. | **Action**: Task Force is more discussion-based than action-oriented. Members often do not take action outside of meetings. |

# Peer States: Autism Spectrum Disorder Task Force (1 of 2)

Among identified peer states, only Iowa & Minnesota has an active Autism Spectrum Disorder Task Force (ASDTF). Other states have used time limited task forces to advise to the state on needs and recommend strategy for supporting people with autism.

| Peer States | Status of Autism Spectrum Disorder Task Force or Council |
|---|---|
| North Dakota | **Active** Autism Spectrum Disorder Task Force (ASDTF) |
| Idaho | No ASDTF |
| Iowa | **Active** 13-member Autism Council within the Department of Education. Responsibilities include offering advice, consultation, and recommendations to the Governor and the Iowa legislature regarding matters concerning the Autism Spectrum Disorder (ASD) population. The mission of the Council is to identify the needs of and make recommendations for improving and enhancing the lives of individuals and families living with ASD. The vision of this group is that individuals and families living with ASD have a comprehensive coordinated system for diagnosis, treatment, and support so that individuals grow to live productive, integrated lives in communities they choose. |
| Kansas | **Kansas Autism Task Force sunsetted in 2018**, after developing a report that included goals, challenges and proposed recommendations, including expanding the number of children served under the autism waiver and a health insurance mandate for autism. |
| Minnesota | **ASDTF sunsetted in 2015**, after developing a statewide strategic plan on improving awareness, early diagnosis, and intervention and on ensuring delivery of treatment and services for individuals diagnosed with an autism spectrum disorder, including the coordination and accessibility of cost-effective treatments and services throughout the individual's lifetime. |
| | In **2018, the legislature established an Autism Council** to provide a consensus-driven venue to review and propose improved autism spectrum policy and program priorities to benefit the lives of individuals with autism and their families. Special focus issues will be education, housing, employment, workforce needs, services, and community integration. |

# Peer States: Autism Spectrum Disorder Task Force (2 of 2)

| Peer States | Status of Autism Spectrum Disorder Task Force or Council |
|---|---|
| Montana | **Autism Task Force sunsetted in 2008**, after advising on whether the state should move forward with a Medicaid waiver for autism, how the waiver should be focused, and a strategy to provide services for adults with autism. |
| Nebraska | No ASDTF |
| South Dakota | **No ASDTF.** The SD Department of Labor and Regulation and Department of Human Services did contract to develop an autism study in 2014. |
| Wyoming | No ASDTF |

# Acronyms

# Acronyms (1 of 3)

| | |
|---|---|
| A&M | Alvarez & Marsal |
| AAIDD | American Association on Intellectual & Developmental Disabilities |
| ABA | Applied Behavioral Analysis |
| AIDD | Administration on Developmental Disabilities |
| ARPA | American Rescue Plan Act |
| ASD | Autism Spectrum Disorder |
| ASDTF | Autism Spectrum Disorder Task Force |
| ASDV | Autism Spectrum Disorder Voucher |
| CDC | Center for Disease Control |
| CHIP | Children's Health Insurance Program |
| CMS | Center for Medicare & Medicaid Services |
| DD | Developmental Disability |
| DDA | Developmental Disability Administration |
| DDPM | Developmental Disability Program Manager/ Management |
| DHS | Department of Human Services |
| DSM-5 | Diagnostic Statistical Manual of Mental Disorders, Fifth Edition |
| DSP | Direct Support Professional |
| EPSDT | Early & Periodic Screening Detection & Treatment |
| FMAP | Federal Medical Assistance Percentage |
| FPL | Federal Poverty Level |

# Acronyms (2 of 3)

| | |
|---|---|
| HCBS | Home & Community Based Services |
| HHS | Health & Human Services |
| ICAP | Inventory for Client & Agency Planning |
| ICD-11 | International Classification of Diseases, 11th Revision |
| ICF | Intermediate Care Facility |
| ICF/IID | Intermediate Care Facility for Individuals with Intellectual Disabilities |
| ID/DD | Intellectual Disabilities/ Developmental Disabilities |
| IDD | Intellectual & Developmental Disability |
| IDEA | Individuals with Disabilities Education Act |
| IDGS | Individually Directed Goods & Services |
| IFDGS | Individual & Family Directed Goods & Services |
| IFS | Individual & Family Support |
| LMA | Legislative Management Agency |
| LOC | Level of Care |
| LOS | Length of Stay |
| LSTC | Life Skills Transition Center |
| LTC | Long Term Care |
| LTSS | Long Term Services & Supports |
| MF | Medically Fragile |
| NADSP | National Association of Direct Support Professionals |

# Acronyms (3 of 3)

| | |
|---|---|
| NASDDDS | National Association of State Directors of Developmental Disability Services |
| NCD | Non-Categorical Delay |
| ND | North Dakota |
| NDCC | North Dakota Century Code |
| NF | Nursing Facility |
| NHIS | National Health Interview Survey |
| NIH | National Institute of Health |
| NWD | No Wrong Door |
| P2P | Parent-to-Parent |
| PAR | Progress Assessment Review |
| PD | Physical Disability |
| PMO | Project Management Office |
| RISP | Residential Information Systems Project |
| UCEDD | University Center on Excellence in Developmental Disabilities |
| UMKC-IHD | University of Missouri Kansas City - Institute for Human Development |
| US | United States |

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