



North Dakota
Cross Disability
Advisory Council

MAR 14, 2024

**CROSS-DISABILITY
ADVISORY COUNCIL**

ROLL CALL



MINUTES



FUTURE MEETING DATES

- **Apr 11th - Thursday**
- **May 9th - Thursday**

9:30am to 4:00pm

Please plan to come in person for the May meeting!





AGENDA

- I. Action Items and Points of Business
- II. Review of February Discussion: Services and Transition Supports
- III. Feedback from the Public Meetings
- IV. Defining Quality: How will we Know the Waiver is Working Well?
- V. Complaints, Grievances, Appeals
- VI. Looking at the Big Picture: Prioritizing Limited Funds
- VII. Preview of Next Session: Prioritization 2.0, Beginning to Review the Report

Review of February's Discussion: Services and Transitions

The CDAC's Purpose

Plain Language Purpose

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

This initially includes:

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

Core areas for advisory input (as defined in statute)

Access

How people can apply to the waiver

Services

What supports people need

Case Management

What supports from CM are helpful?

Quality

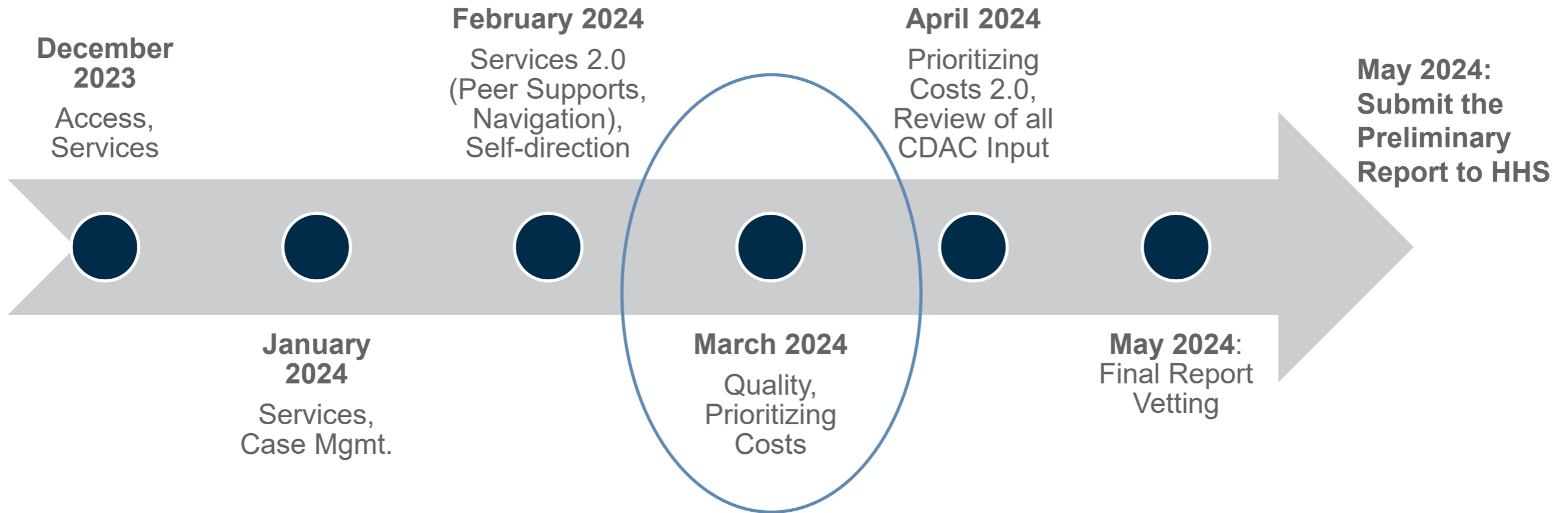
What does quality look like?



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

Timeline Overview of the CDAC Engagement Process

CDAC will meet monthly from December 2023 – May 2024 to provide input regarding the design of the new cross-disability waiver

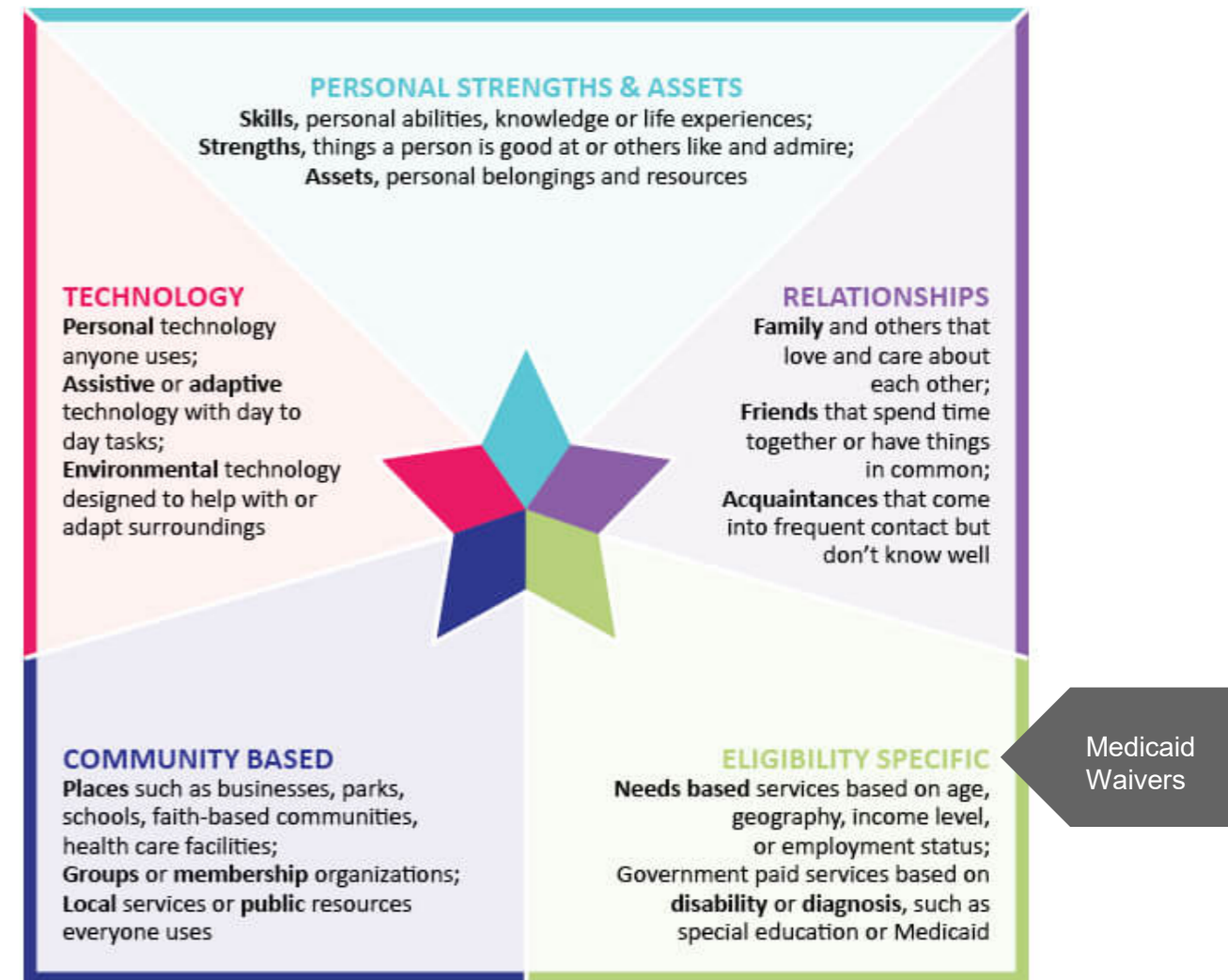


Note that CDAC will continue to meet quarterly following submission of the May 2024 report

Our Framework for Discussing Services

CDAC has been brainstorming the types of integrated supports people need across every life domain

- CDAC has been talking about services using the **integrated supports** framework (see integrated supports star, right)
- Supports work best when they are integrated across an array of options, including both eligibility-based supports and natural supports available in the community
- We have previously asked people to think about different types of supports people need to live a good quality life
- To help ensure we thought about all areas of life, we used the idea of **life domains** to organize our thoughts
- Life domains include daily life & employment, community living, healthy living, safety & security, social & spirituality, safety & security, and family support (respite)



Integrated Supports Stars – Advocacy

- Over the next several slides we have pasted the integrated supports stars CDAC has worked on
- We know these will be too small to read in the slides – we will share a paper copy for those in the room, and an online photo in the virtual meeting
- We have also emailed the document with these stars to the group in advance



Integrated Supports Stars – Community Living and Daily Life and Employment



Integrated Supports Stars – Family Supports and Healthy Living




Integrated Supports Stars – Safety and Security and Social and Spirituality



Life Trajectory for Transition Planning – Turning 6 / Starting School


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



LIFE TRAJECTORY | EXPLORING

Turning 6 / Starting School

- >Enough paras to support children
- >Emphasize general student first, special education student second
- >Opportunity to prep and see school building
- >Meet and greet with teachers before school
- >Training for teachers on how to support
- >Single school point of contact
- >Bus / transit training
- >IEP advocacy
- >IEP / Transition meetings with preschool and grade school support teams
- >Explain "jargon" in meetings
- >Accessible classroom - tables for wheelchairs, inclusion in group work spots
- >Social skills stories
- >Educate children about expectations for activities like recess/music/gym
- >Access to supportive tech
- >Inclusive after school care, inclusive social opportunities like clubs
- >Creative partnerships for therapy services




Vision for What I Want

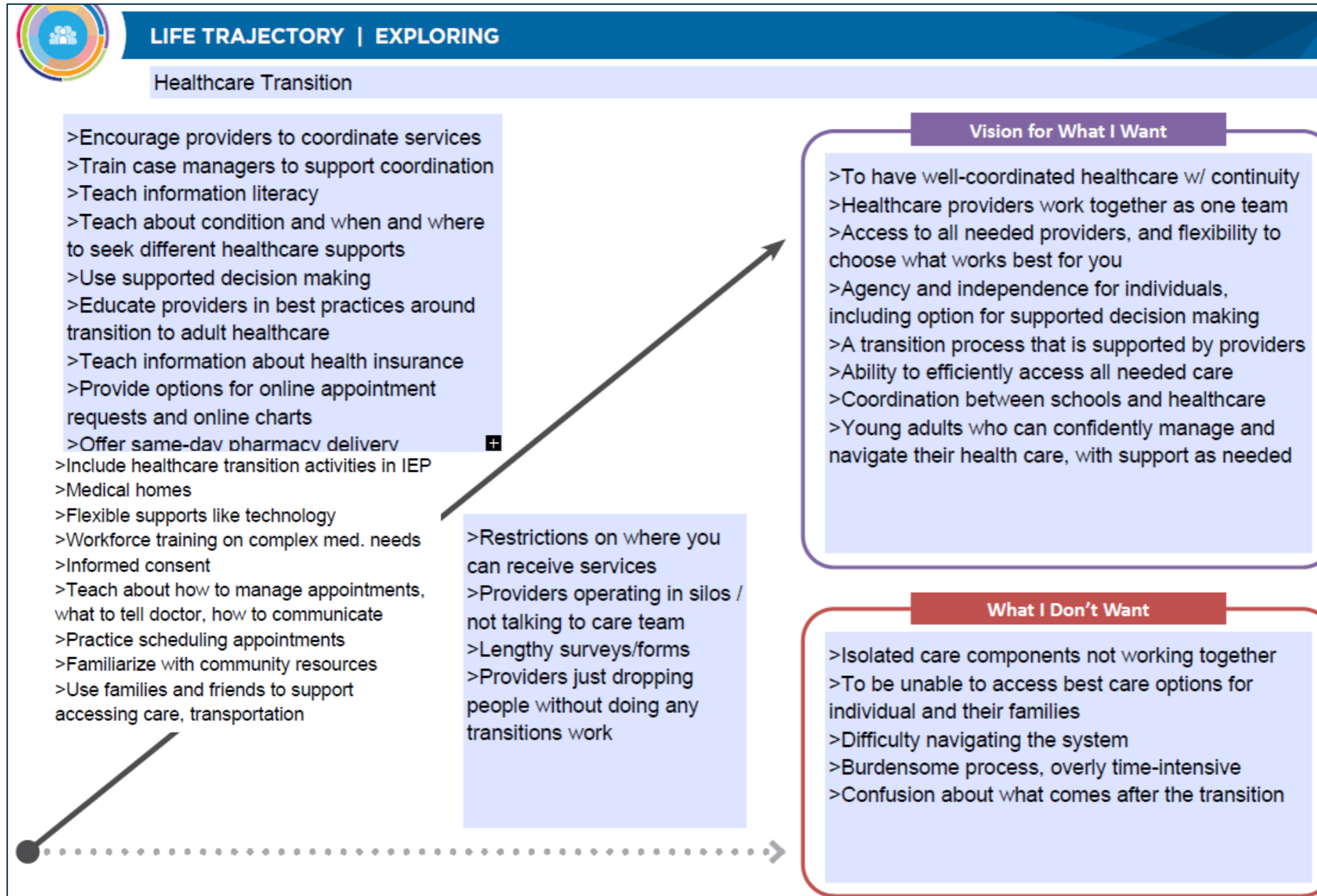
- >Inclusion with peers / entire class
- >Feeling ready and supported to start school
- >Flexibility to meet student needs
- >Making sure students can have fun!
- >Ability to stay in school for a full day
- >Opportunity to build comfort with consistent adults and environments
- >Team approach with student, educators, and family members part of the process

What I Don't Want

- >Isolation from peers
- >Not respecting individual
- >Low expectations
- >Families who aren't included / don't understand the process, ex: IEPs
- >Expulsion / suspension of young children
- >Shortened school days for my child



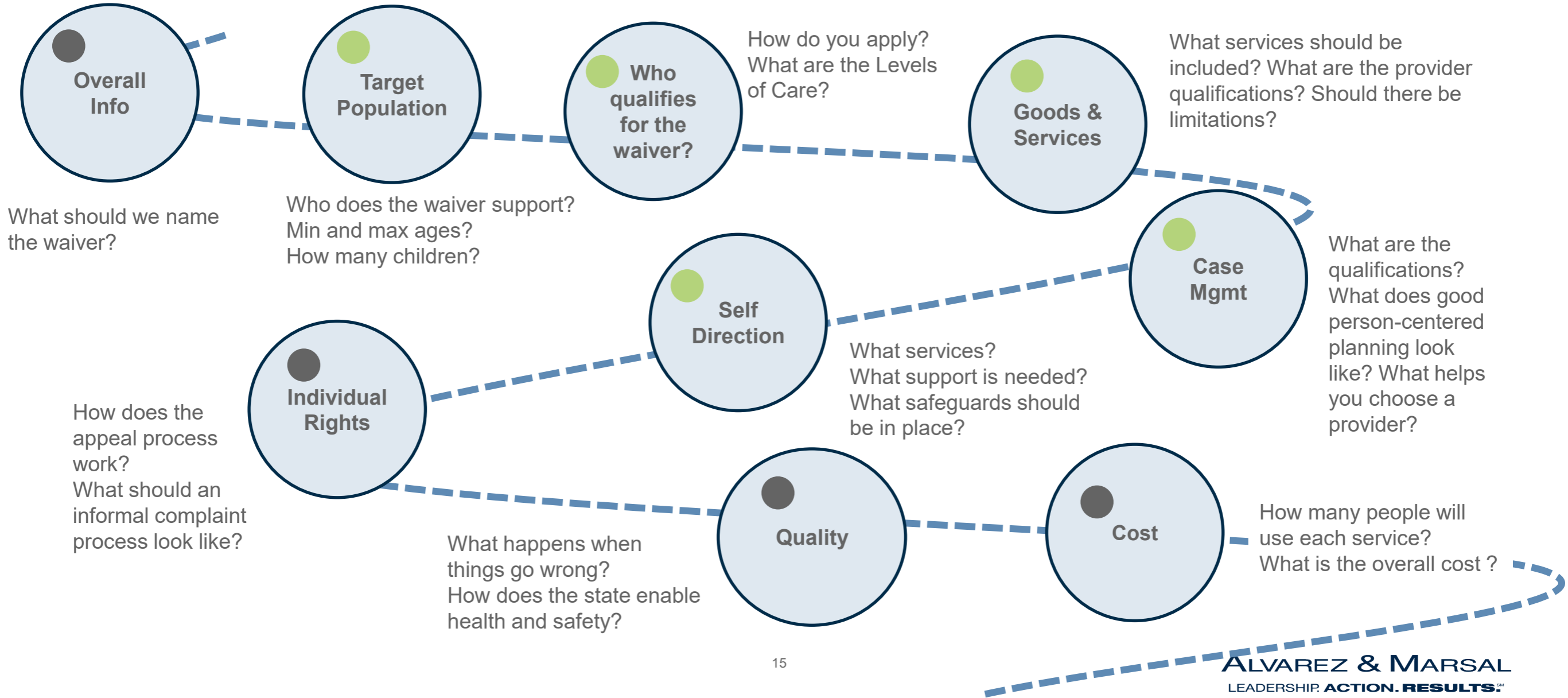
Life Trajectory for Transition Planning – Medical Transition to Adulthood



How the CDAC Helps: Advising on HCBS Design Elements

- Complete
- Delayed
- On Track
- Not Started

To create the Cross Disability Children’s waiver, ND will need to submit an application to the Centers for Medicare and Medicaid Services. The CDAC advises the state on what to include in that application. We are on time and on track to complete this work.



Feedback from the Public Meetings

Public Comment: Key Themes (1 of 2)

Public attendees at the listening sessions provided recommendations on the new cross-disability waiver, and on broader system opportunities to serve children more effectively. **Common themes from participant feedback included the following:**

Target Population

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

Access

- People are concerned about **the cliff that happens at age 3:**
 - Families may not understand the process, and waiting lists for assessments are long
 - Stopping services could lead to regression
- Multiple families shared that the **waiting time to receive assessments is lengthy** and may result in children losing services at 3
- Participants felt that the **system is challenging to navigate**, and there is a need for more online information
- Participants raised the issue that **Medicaid is too challenging for children with disabilities to access** and offered suggestions:
 - Expanding Early Intervention criteria
 - Instituting a Katie Beckett waiver

Quality

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

Public Comment: Key Themes (2 of 2)

Case Management

- Participants shared positive stories of how **case managers have helped** them
- People noted that receiving **case management only without services is an administrative burden** for families and not helpful
- Attendees shared feedback about **additional support that would be helpful from case managers**, including:
 - Information on services and resources in their area
 - Anticipatory guidance to navigate the eligibility changes at age 3
- Participants asked questions about who would provide **case management on the new waiver**, and provided feedback that they felt state case managers were better positioned to provide consistent and responsive support coordination
- Members expressed that case managers should be able to **substitute lived experience for a 4-year degree**

Services

- Participants shared that it would be helpful to have **more services to support behavioral health needs**, and that these services should also be included on the cross-disability waiver
- A behavioral analyst shared the recommendation that **additional behavioral analytic treatment** would be beneficial across other types of disabilities, a recommendation several participants agreed with
- Families shared that **workforce** can impact their ability to access services, especially in rural areas
- Attendees suggested **expanding options for self-direction** and provided input on opportunities to improve the program, including:
 - A liaison for families
 - Additional training resources for families
 - More training for DD case managers to support families

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

Quality: Opening Round

Share YOUR experiences / knowledge about quality

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



Join at Menti.com | use code: 4297 8434

Some Thoughts on Quality

Quotes to get us thinking about quality

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

– John F. Kennedy

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

-Cathy Ficker Terril

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

— Maya Angelou

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

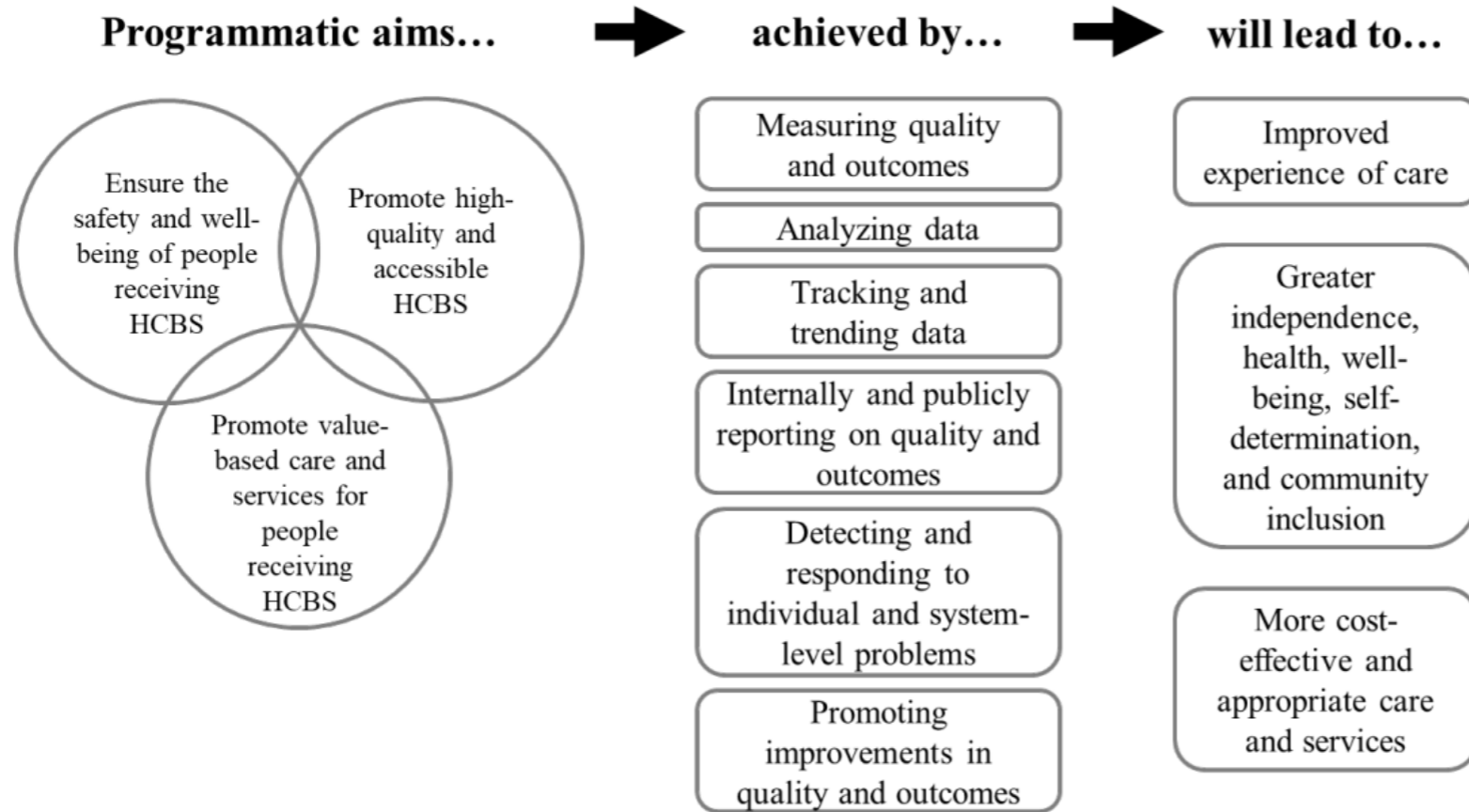
– Michael Smull

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

- Dr. Sheli Reynolds,

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

HCBS Quality Framework



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

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

What do we mean when we talk about “quality”?

- When we talk about quality, we are talking about how well a waiver program works
- During today’s session, we will discuss aspects of quality including:
 - How to define what a well-functioning program looks like
 - Ways to measure success of a program
 - Safeguards for protecting health and welfare of participants
- The Department of Health & Human Services will have to outline quality measures and protections for the new cross-disability waiver. **CDAC will play an important role by:**
 - Sharing ideas for what a makes a program good, and how we can measure these things
 - Suggesting possible protections to ensure health and safety for children and families



Thinking About Personal Outcomes

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

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

Personal Outcomes & the Life Domains

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

On the wall and on the jamboards, you will see the life domains. We are going to ask you to think about each life domain and share an **example** of a personal outcome that might fit in each.



Daily Life & Employment

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



Community Living

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



Healthy Living

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



Safety & Security

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



Social & Spirituality

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



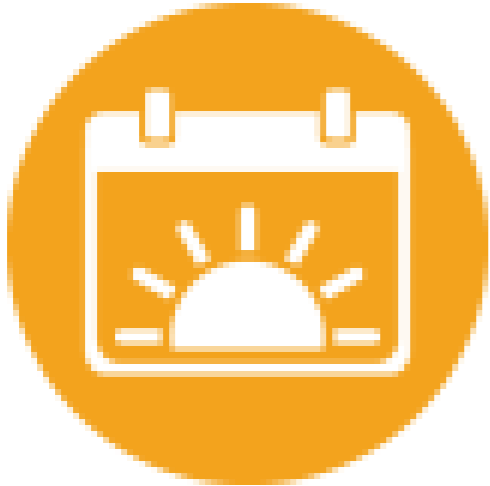
Advocacy & Engagement

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

Public members, we welcome your participation! Please mark your responses as public.

Personal Outcomes & the Life Domains: Daily Life and Employment

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



What are some ideas you have about personal outcomes?

Here is one to get you started:

- Youth have opportunities to do after school activities that include people with and without disabilities

Brainstorming Quality Outcomes

This activity will help highlight what is important to CDAC members when they think about quality.

Group Activity!



- **For those in person:** We have written each of the six life domains on a sheet of paper around the room. At each, spend a couple of minutes thinking about examples of personal outcomes that are important to your family.



- **For those joining virtually:** We have created an online whiteboarding space where you can add ideas across each of the six personal outcomes.
 - Visit the link in the chat to start
 - Begin at the first slide. Each slide is one dimension. Click between slides by using the arrows on the bottom.
 - We will spend a couple of minutes on dimension. Add your ideas on a virtual sticky note.
- Public attendees are welcome to participate, in-person or virtually; we simply ask that you label (public) on your feedback
- We will come back together as a group and share out thoughts when we have rotated through every station

Example: Missouri's Approaches to Quality Outcome Data (1 of 2)

Stakeholder Engagement

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

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

Example Talking Points for *Daily Life* Outcomes:

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

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

Example: Missouri's Approaches to Quality Outcome Data (2 of 2)



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

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

TALKING POINTS:

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



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

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

TALKING POINTS:

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

Complaints, Grievances, Appeals

When Things Go Wrong

If you are not satisfied with a Medicaid decision made by the ND HHS, you have the right to appeal

To File an Appeal:

1. An appeal can be filed verbally over the phone, or in written format by email, fax or mail.
2. A request to appeal must be filed no later than 30 days from the date the notice of action is mailed.
3. You can use [SFN 162: Request for Hearing](#) to file the appeal but it is not required.
4. You are not required to sign [SFN 162: Request for Hearing](#) to submit the appeal request.
5. If you do not use [SFN 162: Request for Hearing](#), please provide your name, contact information, and program decision or error that you are appealing.



SUBMIT ONLINE

Submit an appeal request online.

Go

CDAC Experiences with Appeals

We know that no system is perfect. If you are not satisfied, what would help?

For Discussion:

- Do any members have experience with complaining or appealing to the HHS that they are comfortable sharing? What worked about that experience? What was hard?
- Do you understand the appeals process now?
 - If yes, how did you learn about it?
 - If no, what would help you learn?
- Systems must have a formal appeals process. They can also have informal complaint processes, grievance systems, and more. What would you recommend for the Cross Disability Children's Waiver?

Looking at the Big Picture: Prioritizing Limited Funding

Reminder: How Medicaid Waivers Work



Medicaid funds long-term services and supports (LTSS)

- Medicaid is the primary funder of LTSS in the United States
- Medicaid provides LTSS through both:
 - institutional care (i.e., intermediate care or nursing facilities), or
 - home and community-based services (HCBS).



HCBS waivers provide LTSS in community-based settings

- States develop home and community-based services waivers (HCBS Waivers) to meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting



HCBS Waivers offer medical and non-medical services

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



HCBS programs must meet federal program guidelines

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

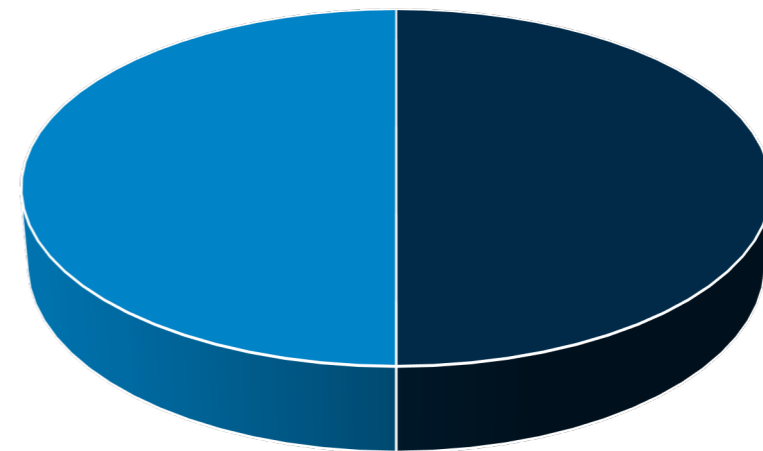
Understanding Waiver Spending

Mapping waiver spend per person is critical for the State to budget successfully.

Waiver Spending 101

- When someone is eligible for a Medicaid HCBS waiver, such as the Medically Fragile Waiver, they are eligible for both waiver specific services (ex: dietary supplements) and general Medicaid State Plan services (ex: therapies)
- To understand the impact of including someone on the waiver, states must calculate both the cost of providing waiver services to an individual, and the cost of providing Medicaid State Plan services to an individual
- We do not expect anyone to be an expert in waiver spending! We are including this information as additional context for those that may find this helpful when thinking about prioritizing limited funds

**Total Medicaid Spending,
per Waiver Participant**
(illustrative; not proportional)



- Waiver Services
- Medicaid State Plan Services

Waiver Services Funding: Current Projections for ASD and MF Waivers

Summary of Funds North Dakota is Currently Projected to Spend Across Children’s Waivers in the 2023-2024 Waiver Year.

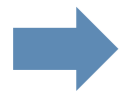
| Waiver | Age | Diagnostic Criteria | Individual Cost Limit | Projected Yearly Participants | Projected Average Cost / Participant for Waiver Services | Projected Total Annual Cost for Waiver Services |
|----------------------------|------------|---------------------|-----------------------|-------------------------------|--|---|
| Autism Spectrum Disorder | 0-15 | ASD | No limit | 345 | \$22,242.93 | \$7,673,812.08 |
| Medically Fragile | 3-17 | Medically Fragile | \$25,300 | 50 | \$6,882.27 | \$324,397.64 |
| ASD and MF Combined | N/A | N/A | N/A | 395 | \$20,298.54 (weighted) | \$8,017,924.35 |

-  **Rough Baseline Estimate of Spending on Waiver Services:**
- Total: ~\$8 million
 - Participants: ~400 participants
 - Average: Approximately \$20k/participant

Total Medicaid Funding Projections For Waiver Participants: ASD and MF Waivers

Total Funds North Dakota is Projected to Spend Across Participants in the 2023-2024 Waiver Year, Including General Medicaid.

| Waiver | Slots | Average Cost of Waiver Services / Participant | Average Cost of Medicaid State Plan Services | Average Annual Cost of State Plan + Waiver Services | Total annual cost of all Medicaid services (State Plan and Waiver Services) |
|----------------------------|------------|---|--|---|---|
| Autism Spectrum Disorder | 345 | \$22,242.93 | \$10,075.00 | \$32,317.93 | \$11,149,685.85 |
| Medically Fragile | 50 | \$6,882.27 | \$30,752.00 | \$37,634.27 | \$1,881,713.50 |
| ASD and MF Combined | 395 | \$20,298.54 (weighted) | \$12,692.34 (weighted) | \$32,990.88 (weighted) | \$13,031,399.35 |

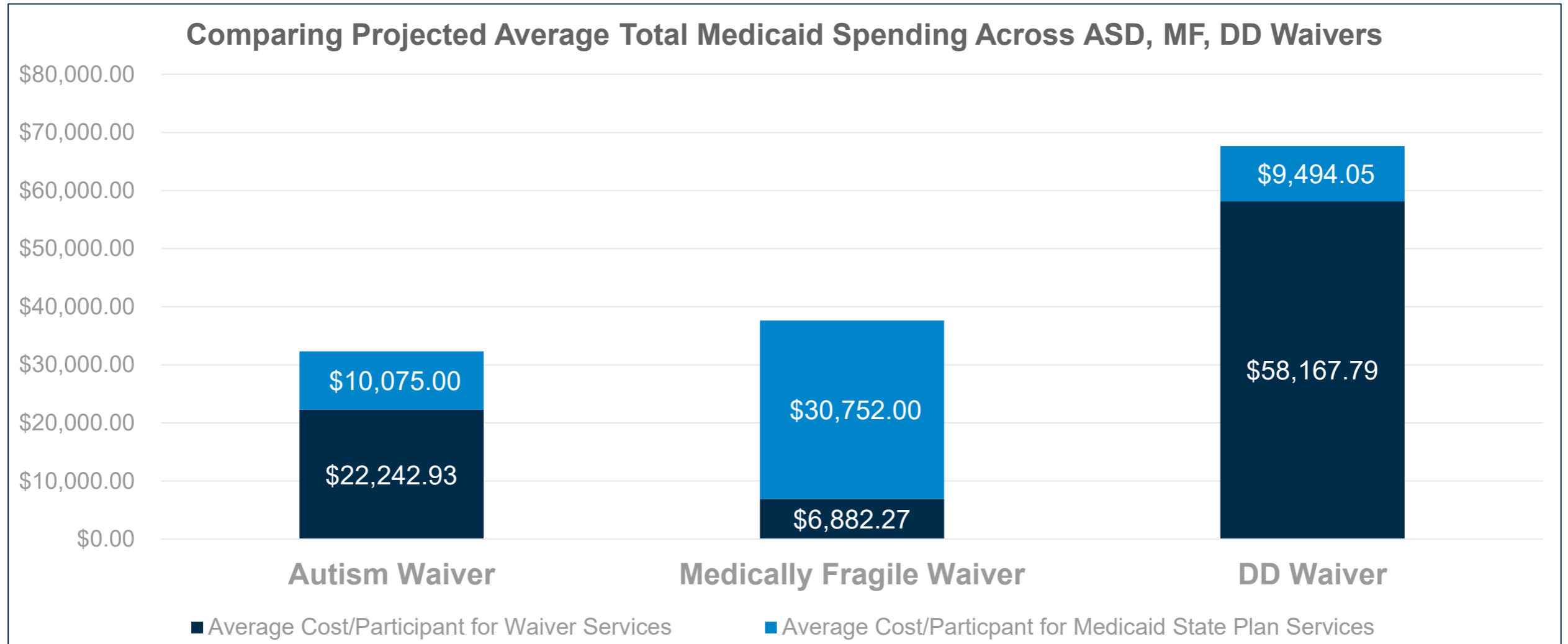


Rough Baseline Estimate of Total Medicaid Spending on Waiver Participants:

- Total: ~\$13 million
- Participants: ~400 participants
- Average: Approximately \$33k/participant

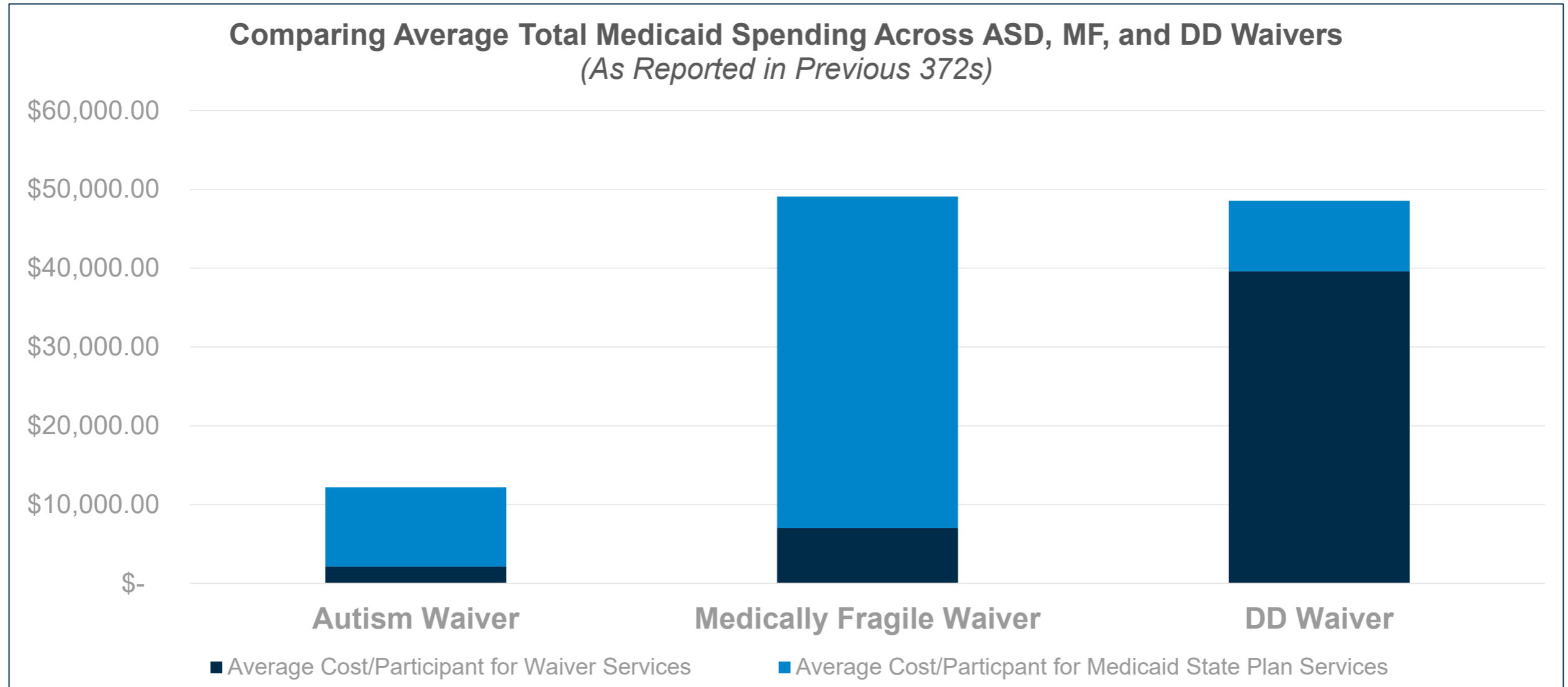
Comparing Total Medicaid Funding Projections: ASD, MF and DD Waiver

Total Funds North Dakota is Projected to Spend Across Participants in the 2023-2024 Waiver Year, Including General Medicaid.



Comparing Actual Medicaid Expenditures: ASD, MF and DD Waiver

Note that this data is from during peak COVID, which may explain why ASD waiver service utilization is lower than projected. Challenges finding workforce, especially in the areas of respite, may also contribute to underutilization of waiver services.



Mapping CDAC Feedback to Potential New Services

Below are some of the key, recurring CDAC themes that have been shared by the group, mapped out to potential waiver services. Note that we have broken out transition-related supports into its own slide, on the next slide.

| CDAC Input | Existing Service? | Potential New Service(s)? |
|--|---|---|
| Families benefit from access to therapies such as OT, PT and Speech | Offered through Medicaid State Plan | N/A |
| Families need nutritional supports for kids with complex medical needs | Offered through dietary supports service on MF waiver | N/A – will carry over onto cross-disability waiver |
| Families need more support for complex care coordination | No | Complex medical care coordination |
| Kids need peers who can help support community integration | No | Peer support (kids) |
| Families are seeking help with chores like cooking and laundry so that they can focus on taking care of their children | No | Home / chore support |
| Families need help navigating self-direction | No | Support broker (help navigating self-direction) |
| Families are asking for in home nursing services, like med checks | Offered through Medicaid State Plan | N/A |
| Transportation services are not sufficient | Medical transportation is currently offered through the State Plan | Consider including transportation as part of habilitation / integration services |
| Play therapy and music therapy are valuable | No | Music / play therapy |
| Families need a break and want respite | Offered through current waivers, continue exploring workforce support options | N/A |
| Families need support and training, especially to help children navigate life changes successfully | Varied, to a degree across waivers | Additional peer supports and parent training for family members |
| Families need help paying for medical supplies such as feeding tubes, attachments, and catheters | Offered through Medicaid State Plan, though CDAC members have shared opportunities for improvement to this offering | N/A |

Mapping CDAC Feedback to Potential New Services: Transition Supports

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

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

Prioritizing Services: What's Most Important?

During this activity, we will ask CDAC members to review some of the services we've talked about and vote on which ones they consider to be the most important.

Group Activity!



- We've talked about a lot of new potential services to add. Let's think about what's most important from that list. This will help us prioritize funding for what matters most for families.
- **For those in person:** We have hung up papers with the names of potential new services around the room. Each person has been given a sheet with five green dots. Use your dots to vote on which types of services you think are most important.



- **For those joining virtually:** We have created an online poll that asks you to select the five services you feel are most important to consider adding. We will email the link to CDAC members.
- Public attendees are welcome to participate; if you would like to participate, please share your email in the chat. We will share a separate poll for members of the public.
- We will come back together as a group and share out thoughts in 10 minutes

Looking at the Whole Waiver: Where Should ND Prioritize Investment of Funds?

As a group, we've talked about many ways that the new waiver can serve as an important investment for children with disabilities. In a world where funding may be limited, we want to hear what's most important to you all. After the "status quo" of current waiver participants and services is established in the new waiver, how should we apply any additional funding?

Let's first discuss the below areas, and then we will do a group activity to learn how people might spend the waiver budget.

Adding New Waiver Services

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

Making it Easier for People to Qualify

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

Expanding Access for Kids 3-5

Lowering the barrier to qualify for this age range would make it easier for kids to stay on the waiver after 3.

Ensuring No Waiver Waiting Lists

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

How Would You Budget Funds for the Waiver?

During this activity, we will ask CDAC members to imagine they are budgeting funds for the new waiver. This activity is meant to spark high-level conversation and is of course considered “directional” rather than exact.

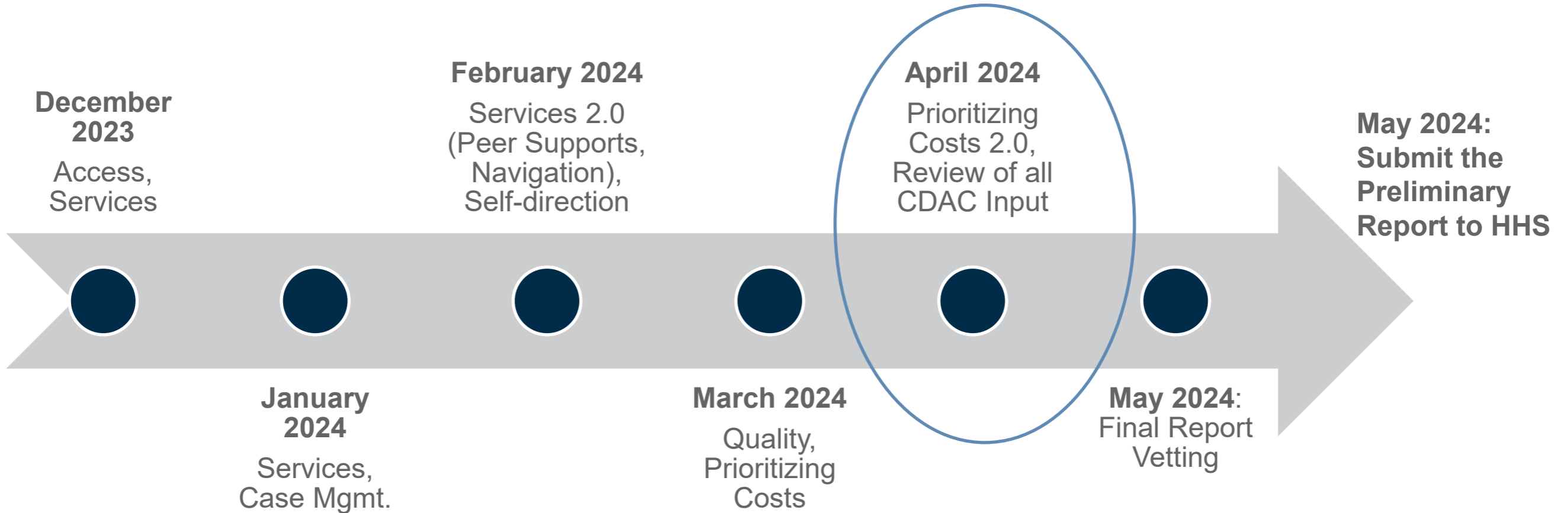
Group Activity!



- **Let’s imagine you have \$100 to invest in the new waiver, once the baseline programs and populations are established from combining the Medically Fragile and ASD waivers. How would you invest these additional funds?**
- **For those in person:** Each green dot represents \$10 in funding. Place your dots on the sheet(s) of papers around the room where you would invest new funds. Please only use 10 total!
- **For those joining virtually:** We have created an online poll that asks you to allocate \$100 across these areas. We will email this link to CDAC members.
- Public attendees are welcome to participate; if you would like to participate, please share your email in the chat. We will share a separate poll for members of the public.
- We will come back together as a group and share out thoughts in 10 minutes

Thank You & Look Ahead

We are almost there! Thank you for all of your hard work. Next month we will go over all the feedback we heard and do some more prioritizing.



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

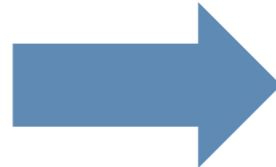
Appendix

Our Goal: Creating a New Cross-Disability Children's Waiver

ND 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



Future State

Updated, Comprehensive ID/DD Waiver

- Services designed for high-needs and complex people (children and adults) with Intellectual Disabilities, Developmental Disabilities and / or Autism .
- *Note that children 0-3 will continue to be served on this waiver .*
- Modernized Level of Care (Phase Two)

ASD Waiver

Medically Fragile
Waiver



New Children's Cross Disability Waiver

- Services designed for children with mild to moderate support needs living in the community
- New LOC for children ages 3-5 that matches IDEA Part B
- Modernized Level of Care for children 6+ (uses ID/DD LOC, Phase Two)
- Targeted to children ages 3-18 or 3-21, not a lifespan waiver
- ***CDAC input is critical to waiver design and implementation***

We Are Currently In Phase One – Designing the Waiver

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

- Outline service array that includes community-based interventions to help families and their children
- Build strong support for service navigation, person-centered planning, and self-direction
- Combine existing ASD / MFW / IDD Level of Care for children during waiver launch to ensure continuity
- For children 3-5: Include expanded eligibility to address “cliff” that happens when children turn 3



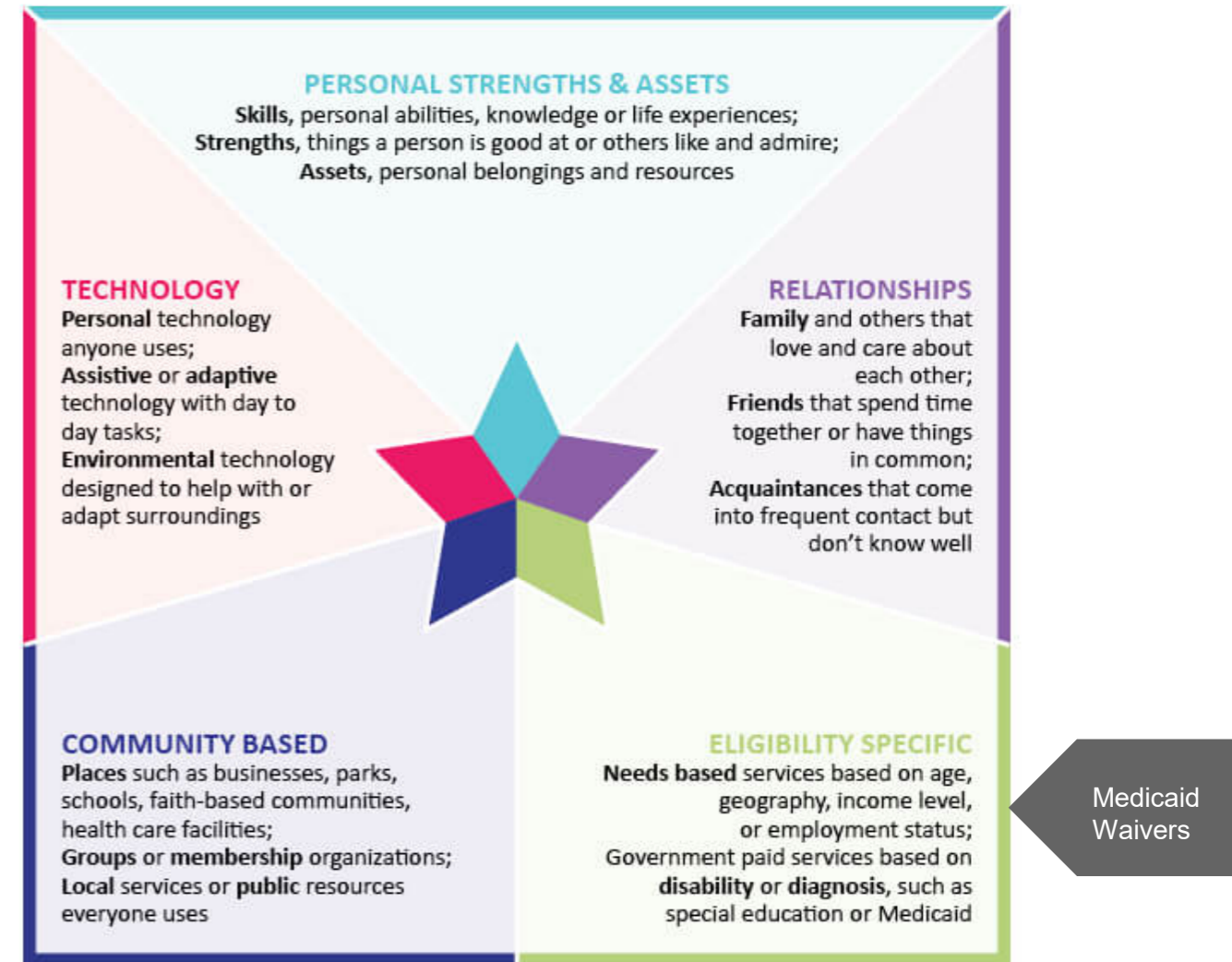
Phase 2: Refine LOC Across Waivers, Including New CDW and Existing I/DD Waiver

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

Understanding Integrated Supports

The New Waiver Will be Focused on Integrated Supports

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



Understanding Life Domains

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



Daily Life & Employment

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



Community Living

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



Healthy Living

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



Safety & Security

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



Social & Spirituality

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



Advocacy & Engagement

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

Life Stages

Every life stage is connected, and what happens in each, affects all the stages to come. The life experiences in each stage build upon one another and prepare a person for the future life stages.



Prenatal/Infancy

From conception through the earliest years of life or babyhood.



Early Childhood

The time in a child's life before they begin school full time.



School Age

The years from kindergarten through middle school.



Transition to Adulthood

Moving from childhood to young adulthood and from school to adult life.



Adulthood

Period of time after we transition from school years through the time we begin entering our golden years.



Aging

The golden years are when we begin to slow down and experience many age-related changes.

Waiver Funding By Service: Autism Spectrum Disorder

What waiver services are people on the ASD Waiver projected to utilize the most?

| Service Name | Projected Participants | Projected Average Cost | Projected Total Cost |
|------------------------|------------------------|------------------------|------------------------|
| Respite, agency | 60 | \$ 14,784.00 | \$ 887,040.00 |
| Respite, self-directed | 32 | \$ 11,942.40 | \$ 382,156.80 |
| Service Management | 344 | \$ 17,841.80 | \$ 6,137,579.52 |
| Assitive Technology | 96 | \$ 1,730.00 | \$ 166,080.00 |
| Community Connector | 86 | \$ 1,150.00 | \$ 98,900.00 |
| Remote Monitoring | 2 | \$ 1,027.88 | \$ 2,055.76 |
| SUM | N/A | N/A | \$ 7,673,812.08 |

Waiver Funding By Service: Medically Fragile

What waiver services are people on the ASD Waiver projected to utilize the most?

| Service Name | Projected Participants | Projected Average Cost | Projected Total Cost |
|----------------------------------|------------------------|------------------------|----------------------|
| Institutional Respite | 4 | \$ 2,739.66 | \$ 10,958.64 |
| Program Management | 50 | \$ 514.32 | \$ 25,716.00 |
| Dietary Supplements | 4 | \$ 1,146.10 | \$ 4,584.40 |
| Environmental Modification | 4 | \$ 4,274.26 | \$ 17,097.04 |
| Equipment and Supplies | 10 | \$ 2,836.90 | \$ 28,369.00 |
| In-Home Supports | 34 | \$ 6,825.60 | \$ 232,070.40 |
| Individual and Family Counseling | 2 | \$ 573.60 | \$ 1,147.20 |
| Transportation | 4 | \$ 1,113.74 | \$ 4,454.96 |
| SUM | N/A | N/A | \$ 324,397.64 |

