

CROSS-DISABILITIES ADVISORY COUNCIL

Hybrid Meeting

Monday, January 22, 2024

9:30 a.m. – 3:00 p.m.

Cross-Disability Advisory Council voting members present: Colette Fleck, Susan Karpyak, Katynka Morrissette, Stephanie Nelson, Magan Paulson, Erin Peterson, Vicki Peterson, Magan Sande, Moe Swanson, Carmen Troutman, Trevor Vannett, Emily Vieweg, Heidi Wilhelm

Cross-Disability Advisory Council non-voting members present: Jackie Adusumilli, Kathy Barchenger, Kevin Miiller

Guests present: Erin Leveton, Kathy Miiller, Jillian Salmon

WELCOME and ADMINISTRATIVE MATTERS

The meeting was called to order at 9:33.

APPROVAL OF CDAC CHARTER MODIFICATION

Kevin Miiller opened the floor for discussion on the CDAC charter. "ND-CDAC Charter DRAFT 10JAN24"

Motion: It was moved by Katynka Morrissette and seconded by Emily Vieweg to approve the CDAC charter modification.

Vote (Yes): Colette Fleck, Susan Karpyak, Katynka Morrissette, Stephanie Nelson, Magan Paulson, Erin Peterson, Vicki Peterson, Moe Swanson, Carmen Troutman, Emily Vieweg, Heidi Wilhelm

Vote (No): none

Motion carried

APPROVAL OF CDAC DECEMBER MINUTES

Kevin Miiller opened the floor for discussion on the December. "ND-CDAC Minutes 13DEC23 DRAFT"

Motion: It was moved by Emily Vieweg and seconded by Vicki Peterson to approve the December CDAC minutes.

Vote (Yes): Colette Fleck, Susan Karpyak, Katynka Morrissette, Stephanie Nelson, Magan Paulson, Erin Peterson, Vicki Peterson, Moe Swanson, Carmen Troutman, Emily Vieweg, Heidi Wilhelm

Vote (No): none

Motion carried

AGE LIMIT DISUSSION

- Shared Transitions, North Dakota Century Code, Medicaid and Special Education Policies for ages 18, 21, 26
- "The cross - disability advisory council shall participate with and provide feedback to the department regarding the implementation, planning, and design of the cross-disability children's waiver"
- CDAC Children's Waiver should not go up to age 26

HOSPICE INCLUSION DISUSSION

- Current Hospice Waiver: Protected Funds, No Wait List, Small Numbers, Highly Spcific
- Cross-Disability Waiver: ??? Funding, Potential Wait List, Larger Population Impacted, Transition Preparation
- Discussion about keeping the hospice waiver separate from the Cross-Disability Children's Waiver

FEEDBACK ON TARGET POPULATION

- Members continued the discussion on the appropriate waiver age range and shared various relevant transitions, including health insurance, Special Education, and Medicaid Expansion
- There is a desire to align with schools and look specifically at school-related transitions, including the timelines of finishing school at 18/19, or continuation of Special Ed services through age 21
- Members revisited the Hospice Waiver discussion and agreed that the services are highly specific and operate in unique ways (mix of State Plan and waiver)
- Members raised the need to support transitions for children who may move off the Hospice Waiver to the Cross-Disability Children's Waiver
- It is critical to think about transition planning across and between all waivers

- The Early Intervention program is well-regarded, but many families fall off all services after 3 – there is a need to expand services for young kids after three who currently lose all services
- Members shared that there are lots of children who should be receiving services who aren't currently, including those with physical disabilities and behavioral health issues

FEEDBACK ON ACCESS

- Members expressed strong support for online options that would help families understand if they were likely to qualify for waiver services, including a potential online screening tool
 - These online options would also help families who don't want to share traumatic stories repeatedly and need a place to start
- Some families may be hesitant to reach out or be embarrassed, so doctors should be prepared to conduct preventative screening for things like speech delays and refer families if appropriate
- It would be helpful to have a system road map available to families that explains waiver processes including:
 - What the waiver application process looks like
 - How the appeals process works (step by step guide)
- More online information about services would be helpful, including FAQs, videos, and training
- Members shared that it will be important to think about simplifying the process as much as possible so that their aren't delays or backlogs for waiver eligibility

FEEDBACK ON SERVICES

- Members have used a variety of waiver services including PCA support, nutritional support, in home support services, early intervention, and respite care
- There is not full awareness of what services are currently available among CDAC members
- Members expressed that workforce challenges make it hard to access some services, but being able to hire people they know for some services (ex: PCA) has helped address this issue
- Securing providers in rural areas is especially challenging given length of driving time required, and the fact that rates don't include reimbursement for transportation time
- It is difficult to keep staff due to challenges with agency requirements / lack of flexibility
- Members suggested that it would be beneficial to have the ability to mix agency providers with self-directed providers within a service to help with staffing challenges
- Members discussed that the previous family subsidy program was extremely helpful in supporting travel for out of town therapy and services not available locally
- Members shared an interest in the following additions / changes to existing services for the future state Cross-Disability waiver:
 - Family counseling (add)
 - Tube feeding support (add)
 - Transportation (increase)
 - Respite (increase)
 - Experienced parent navigators (add)

Feedback on Case Management

- Members reiterated that there are case manager shortages in certain parts of the state
- It would be helpful to explore whether case management requirements can be more flexible to address shortages, including substituting lived experience for degrees
- Members suggested family members may also help address acute shortages in rural areas.
- A member shared that some families have had challenges with case managers and may feel more comfortable with other family members who have lived experience
- Members shared ideas about what good case management looks like:



- Members highlighted that case managers have two key functions, internal and external:
 - Internal: Manage programs within DHHS and the waiver
 - External: Facilitate community living, connect families to supports, protect health
- Members shared that they want case managers who can help advocate for them, understand their needs, and explain what’s available for them regarding services and hours
- Members discussed life transitions as a key area where more support is needed. They shared examples of important transitions including:
 - Moving into adult healthcare
 - Transitioning off a children’s waiver
 - Preparing for life after parents
- Case managers can be really helpful in this process by identifying resources, ideas, and solutions

ADJOURNMENT

The meeting was adjourned at 3:01 p.m.