

CROSS-DISABILITIES ADVISORY COUNCIL

Hybrid Meeting

Wednesday, February 21, 2024

9:30 a.m. – 3:39 p.m.

Cross-Disability Advisory Council voting members present: Colette Fleck, Heather Larson, Toby Lunstad, Katynka Morrisette, Stephanie Nelson, Erin Peterson, Vicki Peterson, Moe Swanson, Carmen Troutman, Trevor Vannett, Emily Vieweg, Heidi Wilhelm

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

Guests present: Erin Leveton, Kathy Miiller, Jillian Salmon, Wanda Seiler

WELCOME and ADMINISTRATIVE MATTERS

The meeting was called to order at 9:30.

APPROVAL OF CDAC DECEMBER MINUTES

Kevin Miiller opened the floor for discussion on the January. “ND-CDAC Minutes 22JAN24 DRAFT”

Corrections: Heather Larson, Toby Lunstad names removed from voting on Charter Modifications and December minutes

Motion: It was moved by Emily Vieweg and seconded by Heidi Wilhelm to approve the January CDAC minutes with voting corrections.

Vote (Yes): Colette Fleck, Heather Larson, Toby Lunstad, Stephanie Nelson, Erin Peterson, Vicki Peterson, Moe Swanson, Carmen Troutman, Emily Vieweg, Heidi Wilhelm

Vote (No): none

Motion carried

GENERAL BUSINESS

- Future Meeting Dates: March 14th, April 11th, May 9th
- Two public input sessions were held on February 15th. That feedback will be shared with CDAC in March

Feedback on Target Population

- Members discussed the role of the compassionate care list in qualifying for Medicaid programs
 - Members initially expressed that the list should be used as qualification for the waiver; however, after further discussion members clarified that this list should be used as the basis for helping kids qualify for general Medicaid and not necessarily the waiver

Feedback on Services

- Members reviewed the integrated supports stars for each life domain, with feedback from past sessions captured a dedicated star for each life domain (community living, safety and security, healthy living, social and spirituality, daily life, advocacy and engagement)
- Members reviewed and added new ideas for each star. See example of one such completed star:



- Members discussed additional needs / gaps including:
 - Relationships, and the need for social skill building
 - Community acceptance
 - Transportation
- Several members shared the importance of networking and connecting with peers
- It is important to have the right supports in place for self-advocacy, including:
 - Training for kids and families
 - Options in addition to online
 - Transportation
 - Staff support
- It is important to plan for safety in not only homes, but communities. One member shared a story about the danger of staying in hotels with kids who elope.
- Members discussed peer supports that would be helpful for parents / families:
 - A member talked about their experience in WI as part of a group for parents of children with disabilities, and expressed that this type of group was very helpful
 - One parent shared how helpful Family Voices trainings and support groups are
 - CDAC representatives from Family Voices discussed their offerings including trainings, and said they are not able to reach as many people as they would want due to challenges like transportation and awareness of resources
 - A member shared areas they want more training and support with, including how to talk to their child about transition topics, and how to ask clinicians the right questions
- A member shared their experience that the current supplies service isn't working well for them due to challenges including needing multiple bids, approved vendors, and paperwork
- One member discussed concerns that day rehab doesn't allow for people to make their own plans and is a poor fit for individuals with physical disabilities

Feedback on Life Transitions

- Members shared that it is important to think about and plan for life transitions early
 - One member shared that Got Transition is a helpful resource for this
- Members discussed what is important when planning for employment. Highlights included:
 - Having employment goals in IEPs
 - Exposing children to options, through things like exploring interests and job shadowing
 - Educating employers, communities, on things like customized employment
 - Individualizing options for people – “why is everyone cleaning?”
 - Coordinating across special education, public instruction, and vocational rehab
- A member shared best practices from their experiences in special education, including offering lots of prep for job related skills and activities, and integrating these activities with the community. One example shared was the students’ bi-weekly radio show featured on the news.
- Members discussed how to plan for transitions using two examples: 1) healthcare transitions and 2) Turning 6 / starting school. Responses are summarized below:



LIFE TRAJECTORY | EXPLORING

Healthcare Transition

- >Encourage providers to coordinate services
- >Train case managers to support coordination
- >Teach information literacy
- >Teach about condition and when and where to seek different healthcare supports
- >Use supported decision making
- >Educate providers in best practices around transition to adult healthcare
- >Teach information about health insurance
- >Provide options for online appointment requests and online charts
- >Offer same-day pharmacy delivery

- >Include healthcare transition activities in IEP
- >Medical homes
- >Flexible supports like technology
- >Workforce training on complex med. needs
- >Informed consent
- >Teach about how to manage appointments, what to tell doctor, how to communicate
- >Practice scheduling appointments
- >Familiarize with community resources
- >Use families and friends to support accessing care, transportation

- >Restrictions on where you can receive services
- >Providers operating in silos / not talking to care team
- >Lengthy surveys/forms
- >Providers just dropping people without doing any transitions work

Vision for What I Want

- >To have well-coordinated healthcare w/ continuity
- >Healthcare providers work together as one team
- >Access to all needed providers, and flexibility to choose what works best for you
- >Agency and independence for individuals, including option for supported decision making
- >A transition process that is supported by providers
- >Ability to efficiently access all needed care
- >Coordination between schools and healthcare
- >Young adults who can confidently manage and navigate their health care, with support as needed

What I Don't Want

- >Isolated care components not working together
- >To be unable to access best care options for individual and their families
- >Difficulty navigating the system
- >Burdensome process, overly time-intensive
- >Confusion about what comes after the transition



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
- >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

- >"Baby talk"
- >Challenges working with school leaders
- >Unclear communication between teachers / parents
- >Segregated programs
- >Too much support
- >Removing children from familiar environments where they have success

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

Feedback on Self-Direction

- Member feedback on self-direction:



- Members shared their potential concerns with self-direction, including:
 - Difficulty getting paid
 - Risk of having to go back on provider waitlist if switching off self-direction
 - Challenges hiring new staff
 - Concerns over responsibility of W2, liability, etc
- Members also shared the benefits those who self-direct can experience, including:
 - Options for individualized training to match unique needs
 - Increased flexibility
 - More choice in staffing
- Several members expressed that they would like to be able to combine self-direction and provider staffing options
 - One member expressed that more information would be needed about this option including how the balance of hours would work
 - *Note that this authority is currently proposed and under review with CMS*
- Some members who have self-directed shared that they have been able to balance the challenges and benefited from the options, while some others who have not self-directed shared this option would not work for them due to the complexity / time concerns.
- Members expressed interest in support brokers to provide assistance

ADJOURNMENT

The meeting was adjourned at 3:39 p.m.