

Developmental Disabilities Advisory Committee

Meeting Notes

August 11, 2022

I. Call to order

MaryAnn Schiefen called to order the regular meetings of the DD Advisory Committee at 10:00 am on Thursday, August 11, 2022

II. Roll call

The following persons were present:

Advisory Members Present: Debbie Salomon, Linda Clemens, Lisa Pruitt, MaryAnn Schiefen, Dianne DeLair, Diane Focht, Peg Huss, Kristen Larsen, Mark Shriver, Stacy Bliss, Christina Zeleski, Dorothy Ackland, Jennifer Miller

Advisory Members Absent: Angela Willey, Michelle Summers, Cathy Martinez, Suzanne Wahlgren, Kizzie Vaughn

DHHS Staff: Tony Green, Tyla Watson, Aaron Smith

Meeting Attendees: Tonya Encalada Cruz, Lisa Rhodes, Amber Nore, Rick Larsen, Joe Valenti, Edison McDonald and Bailey w/ARC of Nebraska, Jennifer Hansen, Jennifer Quigley

III. Approval of Agenda

One change to the agenda. Edison McDonald has asked to present additional information on the Family Support waiver. This will be at 11:00 AM -11:30 AM. Dorothy Ackland moved to approve the agenda as amended. 2nd by Christina. Agenda approved.

IV. Approval of Minutes from June 2, 2022 meeting

Peg Huss made a motion to approve minutes, motion 2nd by Diane Focht. Kristen Larsen abstained from voting as she was not present at the last meeting. Minutes approved.

V. Public Comments:

- **Amber Nore, Mosaic:** Family Support Waiver 1) Recommends that we need more than \$10,000. While it's a good start, highly encourage additional or alternative funding for this waiver to increase the amount. 2) Please consider providers be able to contract day services, especially respite care.

- **Tonya Encalada Cruz:** Is here to figure out what is going on and to share how unrealistic and hard it is for parents trying to get support. Being a parent, when you have needs of your own, you wait for the information and learn all the information... and are still expected to attend all of these things and read more information, it is very frustrating. Feels trapped, "if I don't know I don't get the service". Some places don't want her to bring her kids, so she cannot attend the meetings. Needs services – speech/OT. More money should go to the right services. When you go to meetings, they make it so we can't make comments until the end of an 8 hour meeting. Feel

like it is made by design to make it impossible for parents. Tonya has a service coordinator (SC). Does not trust SC now.

- **Lisa Rhoades:** Duchenne muscular dystrophy is a progressive muscle weakening. Maverick isn't disabled enough to qualify for the waivers. His life expectancy is 30. How is he not disabled enough to qualify for services? Has to go to Denver every 6 months for care. What we need for Duchenne is help upon diagnosis. They can't wait. They have to wear leg splints. He has a power wheelchair. When son went to kindergarten he needed a scooter, had to pay \$2000 out of pocket for a pediatric chair. Needs van modifications. You pay someone \$1000 to come out and look at a vehicle to only tell you it won't work. You have to buy a specific vehicle. This does not include home modification. We had to move out of our house.

Committee member: Recommended they might want to contact the Shriners to see if there is anything else they might be able to help them.

Why is this something that we are just hearing about now? The SC asks "what do you need?" You do not know what to ask for. They just say, "It can be whatever you want it to look like." This is not helpful. Lane is on Comprehensive Waiver. Families need help, this isn't going away. Nurse comes weekly to give an infusion so slow the progression. Lack of resources for families. Service to help the quality of life for children.

- **Joe Valenti:**
 1. Issues are typical of what we hear. The A&D Waiver change for kids, the criteria is tight and it made it challenging to parents.
 2. Would like to request that public comment time be available at the end of the meeting also as some of the things they want to discuss may have updates.
- Public Comment time Continued afternoon (see XI. Public Comments Continued)

VI. Quality Update – Aaron Smith & Jennifer Quigley

- Critical Incident Management Procedure (CIMP)
- DD waivers- currently in phase II of pilot.
- AD/TBI- currently in phase I of pilot.
- Mortality Review Committee (MRC)
 - Annual report should be public facing on our website prior to the next Advisory Committee.
- Quality Management Report
 - High level review of the annual report.
- Planning for FY 23-24
 - Human Legal Rights Committee (HLRC).
 - Planning starts October 2022. Tentative live date of Jan. 2023.
 - **ACTION ITEM:** Any recommendation by the committee of what our HLRC should focus on?
 - Quality On-site Provider Reviews - Planning starts February 2023.
- Provider Report cards

- Division is looking at starting up provider information or “report cards”
- **ACTION ITEM:** What would be some of the public facing topics the committee would like to see on the reports cards to better inform participants, families, and stakeholders of services to make better more informed decisions of care they receive?
 - Training for providers
 - Professional developmental
 - Staff wages for front line staff
 - How is reporting done for incidents?
 - Part of the HLRC – will have a professional.
 - More oversight for the on-site provider reviews.
- Discussion followed.

VII. Family Support Program: Presented by Edison McDonald

- POWERPOINT: Nebraska’s New Family Support Waiver (FSW)
- Committee’s role.
 - Once the department writes the waiver. Continuing to tell family to apply for the DD waiver.
 - Committee’s role is to be the intermediary voice. Hear the stories that families have to share.
 - Not just bringing public comments back but actively putting information back to the public.
 - Ask Questions
- Implementation timeline – Edison Recommends the committee encourage the department to be less scrupulous up front and move things forward. Should be asking how we speed up the timeline.
- **ACTION ITEM:** PowerPoint to be sent to the committee.
- Discussion followed.

VIII. Open Discussion/Committee Purpose

- Some Topics Discussed:
 - Service definitions.
 - Early Development Network vs DD service coordination.
 - Can we allow guardians or POA’s to be providers?
 - Committee directing the division more.
- Dorothy Ackland – is working on a pilot program for people that qualify for DD services but have too many resources. Dorothy is going to meet with some senators and would like the committee’s support.
 - The committee would need to have more information available for the people that get denied.
 - Discussion followed.
- Kristen Larsen: Shared copies of “Newline 2022”

IX. DHHS Division of Developmental Disabilities – Updates/Review of Action Items

a. Registry Update

- HANDOUT – Registry Statistics:

- 2,671 on Registry as of August 1, 2022.
- Discussion followed.

b. DD Court-Ordered Custody Act Update

- HANDOUT - DD Court-Ordered Custody Act Statistics;
- 45 Active DD COCA Cases;
 - 1 case closed since June 2022
 - 3 new cases since June 2022
- Discussion followed.

c. Waiver Update

- The Division is currently beginning work on a TBI renewal for implementation October 1, 2023.

d. Provider Rates

- Aged & Disabled Rate Modeling
 - Intent is to establish a rate model for services to the Aged and Disabled;
 - Contractor, Optumas has been secured for the project;
 - Communication sent out to all external partners (including independent Providers);
 - The Division will conduct Stakeholder engagement;
 - Discussion Followed

e. Deputy Director Position Update

- HANDOUT – Jenn Clark Announcement
- Discussion followed.

X. Family Support Waiver

- HANDOUT: Family Support Waiver – Milestone Timelines & Statute 68-1530 family support waiver.
- Discussion Followed.

XI. Public Comments Continued:

- **Joe Valenti:** With all of the changes and additions to the committee’s responsibilities. The committee may need a designated staff person to support the committee.
- **Edison McDonald:** Edison is looking at possibly submitted a legislative bill requesting that parents with children under the age of 18 be required on the committee.

XII. New Business:

MaryAnn has not reapplied for the committee. Her term is expiring. Will need to elect a new chairperson at the October Meeting.

XIII. Adjournment

MaryAnn adjourned the meeting at 2:00 PM.

Next Meetings:

Thursday, October 13, 2022

Conference Room P

5220 South 16th St

Lincoln, NE