

**Family Support Council Meeting
December 6th and 7th, 2024
Zoom Meeting – Pierre SD, Ramkota Hotel
Meeting Minutes**

Members present: In-Person: Ruth Conway, Krista Johnson, Janet Whiting, Carolee Little, Julie Flowers
Virtual: Peggy Waltner, Melissa Rickett, Carolee Little, Brittany Norin, Lindsey Hansen, Joshua Jones

Members absent: Tina Two Crow-Slow Bear, Jennifer Walker, Haley Coss

DHS Staff: Kade Anderson and Carrie Geppert

A&M Staff: Emily Ornstein and Ben Keschner

1. Call to Order and Roll Call

Janet called the meeting to order at 6:03 pm CT.

2. Approval of Agenda

Krista made a motion to approve the agenda and Julie seconded. Motion passed with a voice vote.

3. Approval of Minutes

Krista made a motion to approve the September minutes and Peggy seconded the motion. Motion passed with a voice vote.

4. Opening Round

Introductions were made from State staff and the Council Members as we had a new member join.

5. Appeals FAQ Overview

FAQ Document was shared with the council and the Division of Developmental Disabilities (DDD) requested feedback on the document.

DDD will post the FAQ document to the Boards and Commissions website.

<https://boardsandcommissions.sd.gov/Meetings.aspx?BoardID=40>

There were some grammatical things noted in the document. Concerns were also noted that the Cabinet Secretary could pass a verdict without having been at the hearing. Emily with A&M has a working copy of the document and DDD will take those for review to their legal team.

6. Family Support Waiver Amendment

Power point was presented by Carrie, Emily and Ben. The power point can be found on the Boards and Commissions website.

Comparability is waived to create specific services for people with Special Needs. Main goal is to keep children's and adults in the family home. There was a common theme for more "plain language" as a lot of the words used around describing waivers is very complex.

Emily from A&M talked through the pages about results from surveys, this information will also be shared with the Family Support Workgroup. Also Agency with Choice will be opened up to more providers, more vendors and not just Consumer Direct.

One key question A&M and DDD were asking was how to get more families involved in the waiver amendment process.

Lindsey H. thought that the Town Halls will help and is excited the department is looking for suggestions. Interest in “trained care providers” something between companion and personal care.

Melissa R. thought it would be beneficial to have family support coordinators solicit ideas directly from families.

Ruth made a motion to continue discussion until tomorrow morning and open up public comment. Carolee seconded, and motion passed with a voice vote.

7. **Public Comment**

T.B. was a former council member – commented that it is difficult to navigate the system, she suggested that DDD hire more “Carrie Gepperts”.

T.B. also suggested the Family Support Council post their contact information somewhere that is available to the public.

B.S. appreciated the plain language appeal FAQ document and has further suggestions based on her personal experience.

- she found that she could not email requests only regular mail
- All evidence had to be copied and 5 days before the hearing on paper – this is hard for a family member.
- felt a real power differential. DDD will even say it is an adversarial process.
- the process takes a lot of time – trials will be during the day.
- it wasn't clear to her that the initial recommendation was not accepted by the Secretary.

B.S. had a suggestion about the waiver to add individualized goods and services as a waiver category.

8. **Recess**

Went into recess at 8:06 PM CT.

9. **Recall to Order**

Janet called the meeting back to order at 8:32 AM CT.

7. Continued

Conversation continued around the upcoming waiver amendment.

Coordinators are a great point of contact for families and really should be one of their first contacts.

Texting out a survey, advertise as 1 to 2 questions and make it short. The ability to text updates and reminders would be beneficial as well.

Many families don't know what they need. Maybe see what others are doing or see what other States are doing.

Having someone help you find a care provider. Some coordinators help a lot with that process and others not as much. Consumer Direct does have plans to create this list but may be a few months. This would include a list of potential providers who have already had background checks completed.

The family workgroup is continuing to meet and new members are welcome. Starts Monday December 9th.

10. DDD Updates

- **Grievances and Appeals/ALJ** – There were 9 appeals for items. All 9 of them were for items that fall under SMAES. All were upheld. Some recently denied items have been blenders, hearth displays, and cuddle boxes.
- **SMART Data** – DDD went over information on the SMART data handouts. These are available on the Boards and Commissions website.
- **Waiting List** – the current data has 145 individuals on the waiting list. These individuals have went through screening to see if they would likely be eligible for the waiver but are not officially on the waiver. 19 individuals are waiting in the western part of the state, 2 in the central, 20 in the northeast and 104 in the southeast.
- **Agency with Choice** is progressing. It is almost complete, the majority of the work and transition have occurred. Roughly 800 individuals were transferred.
- **Service Overview Documents** – Reviewed and discussed Respite Care and Companion Care Overview documents. Made suggestions on ease of use and readability.
 - o Discussion occurred around what companion care goals could be – Independence can be difficult for those with profound physical disabilities.

11. Overview of DD Services

Kade went through a power point about the different services offered through DDD. The power point is available on the Boards and Commissions website.

Julie discussed what it was like for her family to become a shared living provider. She stated that the training was fairly extensive and there is a lot of documentation that needs to occur. Julie shared that both her and her husband both still work and their son goes to Day Services with LifeQuest.

Toni shared about her Shared Living experience and she was just really appreciative to still being able to live with her mom and dad and loves living at home.

Discussion was had around how the provider is paid and what that looks like. DDD advised that there is a fee schedule that is publicly available on DSS's website that has all of the different rates. Rates are based on home size and ICAP score.

A question was asked on how many individuals were currently on Shared Living.

12. DD Council Updates

Jessica Lamb introduced herself as she is the new executive director of the DD Council. Jessica took over for Arlene Poncelet.

Some background on the DD Council is that it identifies needs of people in South Dakota. Advances public policy, builds capacity, conducts outreach, provides assistance, develop coalitions, and keep policy makers informed about the needs of individuals with intellectual and developmental disabilities.

The DD Council is in the middle of their State Plan and has 3 main focus areas. Community Supports and Services – working on a public information grant, Facebook page, working toward a website. Collaborate with the conference on Developmental Disabilities. Working with SD Parent Connection around older individuals. Dual Diagnoses – working on an assessment needs report about mental health for those with IDD. Also, mental health for caregivers and families. Advocacy – continuing with Partners in Policy Making, South Dakota Advocates for Change, USD Center for Disability also has a partnership with Native American Connections.

New plan is being developed for their next 5 year State Plan which is up for renewal in 2026.

Upcoming Events –

- Conferences August 26 and 27th – Disability Conference
- SD Special Ed Conference March 18th and 19th in Rapid City
- Early Childhood Conference on April 10th and 11th
- There is money available to assist families with travel expenses and registration expenses. \$350 limit in state and \$700 for out of state.
- In June there will be a vacancy on the DD Council.

The Department of Labor is attempting to change the sub-minimum wage rules around 14C certification. More information is located at www.regulations.com if anyone would like to give feedback on this issue. Also you can reach out to Jessica Lamb if you have any further questions.

13. Advisement from the Council to DDD

Ruth asked about the timeline for new members for this council. Kade said there is still one spot open but they are looking for applications from self-advocates.

Josh checked on Department Staff, acknowledging changes in the Division. Jaze was the waiver administrator and left the position to go to the Department of Social Services.

14. Setting the Agenda for Next Year's Council Meetings

Will keep current layout of meeting quarterly in 4 different locations around the state. Will keep the meetings being held on Friday night and Saturday morning.

March meeting will be February 28th and March 1st in Sioux Falls.

June meeting will be June 6th and 7th in Chamberlain.

September meeting will be September 5th and 6th in Rapid City.

December meeting will be December 5th and 6th in Pierre.

Julie made a motion to accept the meeting dates and Carolee seconded. Motion passed with a voice vote.

15. Share something you enjoyed from this meeting

Council members and State staff shared something they enjoyed from the meeting.

16. Public Comment

P. Shared that we need to be mindful of the fact that every situation is different. She revisited the idea that many kids will not be truly independent, but wants to focus on a good life for our kids and families.

M.K. is a family support coordinator – she is wondering about overnights with Respite Care especially for kids that sleep through the night. Further, she is thinking about the “regularly scheduled” wording for Respite Care. Also on the waiver amendment, could there be a part-time coordinator to help with the wait list problem.

17. Action Items

Items to discuss in future meetings:

- Discuss limits on how families can manage money and stay below that \$2000. Succession planning workshop? Maybe run the workshop through the Council first.
- Follow Up and Update on Waiver Amendment
- Part Time coordinator ideas follow up – what is the State doing to encourage or promote providers to be available.
- Legislative Session update on anything pertinent to the Council.

18. Adjourn

Krista made a motion to adjourn the meeting at 12:09 PM CT, Carolee seconded the motion. The motion passed with a voice vote.

X

Ruth Conway
Secretary