

Developmental Disabilities Advisory Committee

Meeting Minutes

September 9, 2024

I. Call to order:

Lori Regier called to order the regular meetings of the DD Advisory Committee at 10:00 am on Monday, September 9, 2024. This meeting was a hybrid meeting via Zoom and at the Department of Health and Human Services, Conference Room 3R, 301 Centennial Mall South, Lincoln, NE.

II. Roll call:

The following persons were present:

Advisory Members Present: Dorothy Ackland, Stacy Bliss (Left at 11:00 AM), Mike Browne, Dianne DeLair, Jennifer Hansen, Kristen Larsen, Cris Petersen, Jennifer Miller, Lorie Regier, Debbie Salomon, Mark Shriver, Joe Valenti, Angie Willey, Suzanne Wahlgren (Arrived at 10:30 AM), Jennifer Miller (Arrived at 11:00 AM)

Advisory Members Absent: Cathy Martinez, Linda Clemens, Lisa Pruitt, Kizzie Vaughn

DHHS Staff: Tony Green, Tyla Watson, Jenn Clark, Kristen Smith, Colin Large

Meeting Presenters: Jackie George and Alisha Golec – Myers and Stauffers;

Other individuals present: Alana Schriver – Nebraska Association of Service Providers; Edison McDonald, Executive Director – ARC of Nebraska; Nikki Krause; Scott Lindbloom; Alaina Reinke; Grace Karloff

III. Approval of Agenda.

- Motion made by Mike Browne to change the agenda by moving Family Support Waiver update first and tabling the Committee meeting length and frequency discussion to the October meeting. Motion to change agenda and table committee length and frequency seconded by Dianne DeLair.
 - Roll call vote taken. All committee members present voted to approve agenda moving Family Support Waiver to the first agenda item and tabling the frequency discussion to the October meeting.

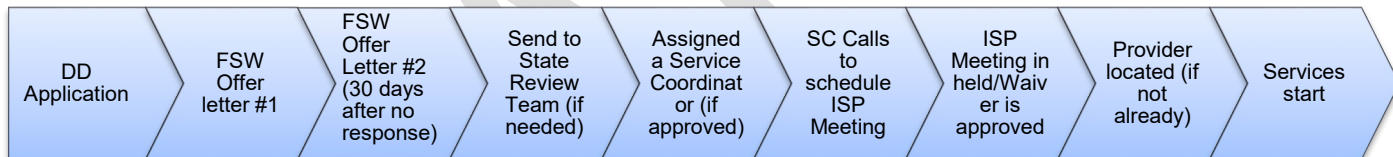
IV. Approval of Meeting Minutes:

Mike Browne moved to approve the June meeting minutes as presented, 2nd by Dorothy Ackland. Roll call vote taken, motion carried; minutes were approved as presented. Roll call vote taken. All committee members present voted to approval June meeting minutes as presented.

V. Family Support Waiver

- Offers made to children on the waitlist for Family Support Waiver is 850. Of those 850 offers (50 offers not included in the data as they were sent in the last two weeks):
 - 242 have not responded
 - 150 have declined

- 408 people have accepted Family Support waiver
 - 97 people are active services
 - 83 people pending in State Review Team
- Kristen Larsen read a letter to be added to the committee meeting record from Beth Plisek with the League of Human Dignity regarding barriers families face in accessing Family Support Waiver (FSW) (Attached)
- State Review Team- Feedback from Discussion:
 - Don't feel like people are getting timely services. State Review Team (SRT) has been the bane of our existence. Not sure where we are at in this process. Something needs to be done with SRT.
 - Submitted hundreds of pages of documentation to SRT and they said they need more information, but they don't.
 - The Katie Beckett keeps going back and forth between Medicaid and DDD about whether someone is approved.
 - Medicaid needs to be involved. Don't know if they are getting this feedback. They have to be involved in these kinds of meeting.
 - Hearing the problems are one thing. What are the action steps to handle these concerns?
 - Could an SRT advisor be assigned to help families with the process?
 - Committee asked to see a quick flow chart of how the process works:



- Department is currently working on creating short videos to help teach families what to expect. Examples of trainings include: Explain the SRT process, DD Eligibility process, & Meeting with your Service Coordinator.
- Department asked committee: What would be most helpful to hear from the Medicaid team: Presentation on the SRT process or a breakdown of where the specific cases are at in the process. Committee would like to be heard.
- **ACTION ITEM:** Committee to invite Medicaid staff to be present at future meeting to discuss State Review Team
- **ACTION ITEM:** Jennifer Hansen to send a presentation that was created re: Early and Periodic Screening, Diagnostic, and Treatment (EPDST) with committee members.
- Providers capacity:
 - 25 agency providers are currently set up as FSW providers.
 - 10 providers currently going through Maximus to become FSW provider.
 - Example of some of the current providers concerns per Alana Schriver:
 - Difference in services for Adults vs Kids and having them together. Can kids and adults be in the same space? Can they ride in the same vehicles? How can or can't the different ages interact? Do need to staff separate spaces?
 - Hourly rate currently around \$10. With staff being paid at least \$15 an hour, providers would need multiple kids to cover the cost of staff.

- Additional Discussion items :
 - Families need to be educated on what the Family Support Waiver can and can't do. My understanding of the purpose of the Family Support Waiver was that it was supposed to help make the kids more independent and to make things more inclusive. To help the kids be more integrated. To help them be as independent and self-sustaining as possible. Can funds be used for swimming lessons? No, but can be used for someone to take him to swimming lessons. I was surprised that this would not pay for that. I asked it is would pay for an equestrian camp, it didn't sound like it would. Navigating the Family Support Waiver, I am feeling lost and frustrated.
 - Service coordinators are used to working with adults. Could be get more training for the Service Coordinators? Can we block you-tube the SC said no however, my child is a child (16 years).

VI. interRAI Assessment Status Update and Reduce Reliance on Congregate Care Preliminary recommendations: Jackie George & Alisha Goleb, Meyers and Stauffer

- Handout: PowerPoint interRAI Assessment Status Update and Reduce Reliance on Congregate Care Preliminary recommendations
- interRAI Assessment State Update:
 - Currently piloting with a sample. They are looking at people on Comprehensive, Adult Day, and Family Support waivers. Those people on it and those coming onto the waivers.
 - We are expecting the results to be 95% valid. If the committee would like additional information on analytics, happy to present via email. No additional requests made at this time.
- Congregate Care - Myers and Stauffers requested committee feedback. Comments and Questions from Committee:
 - Debbie Salomon - Proposed Residential Service Array slide - Suggest Health Maintenance Activities also be under Shared Living
 - Dorothy Ackland - Concern is regarding the loss of services. Example: In schools if kids lose their accommodation because they are not doing well they can get it back. Do we have things in place to protect them in those situations, can they get their services back to what they were getting prior to the change? If you are doing well, you lose your supports. Response: Yes, Currently, teams can request an ICAP, this won't change with interRAI.
 - Dorothy Ackland - I know with one of the programs, you can have a higher level of care while someone is in crisis. Could we put that in shared living? Response: Exception funding is currently and will remain being a possibility to help with those that may need it.
 - Jennifer Hansen - It's not the use of the interRAI, but how it is implemented. There are some states that have lawsuits because of loss of budgets. We are hoping this won't be a negative change. We need to go in eyes wide open that this can cause negative change, we hope not.
 - Lorie Regier - Supported Family Living – Currently list “Reimbursed on a weekly rate” structure – that is completely different than what is in today. We would have to look at one person on week and another person another day. Would

suggest hourly. Response that piece of the recommendation came from provider feedback in the spring. Providers had expressed concern in situations when a provider travels out to a participant's home and when they arrive the person declined to participate. The provider is not paid if they do not participate, even if they drove all the way to provide the service. Will go back and review.

- Dorothy Ackland – When people choose independent providers, we should add a training on Abuse and Neglect, we really need to make sure that our people can advocate for themselves.

VII. Public Comments:

- **Scott Lindbloom**, Currently lives in Colorado. Former DD Advisory Committee. Scott worked with Adrian Smith & John Harms to get transportation set up for people in Western Nebraska. Scott would like ADA Transportation in all communities. Look at Tracy County. They used to have a door-to-door services and I got that changed. People ask why it can't be door to door. Should have put this in the waiver. I'm really concerned about people that live in western Nebraska. They do not have very good transportation in Western Nebraska. Scott used to be on the DD Advisory committee. The committee doesn't seem to understand how the DD waiver & ADA transportation works. Scottsbluff if doing a good job. Nebraska needs to expand transportation services.
- **Edison McDonald, ARC of Nebraska** – Sent the committee a copy of a letter. Very concerned with the failure to communicate and a solid written plan. See chaos in service coordination. Only 97 of 850 people are receiving services. This is extra concerning. Statute lays out the order of how service will be prioritized. The Department is unilaterally making decision about prioritization and ignoring the services. The Department is supposed to communicate any changes that will be made, 30 days out. I appreciate it does seem like this is beginning to happen. In HCBS Waiver, doesn't authorize any pause in services and that is what is happening. In Federal requirements, we are not following the law, which puts all of our Medicaid funding at risk. Within the Family Support Waiver, you only have 97 of 850 people, we are 6 months past the start of these services. There are so many others that are not being served. We are very timid on any changes. While a lot of these things seem like quality ideas, to go and introduce any changes to policy to an underfunded and unstable system is something we cannot support. I'm very glad for many of the questions have been asked to the committee and to see more of those answers in writing. If it is not in writing, Families cannot trust it.
- **Alana Schriver, National Association of Service Providers** – Providers are still experiencing staff shortages. Providers would like rates that support higher hiring wages, 150% percent of 2024 minimum wage (\$12) is \$18 - that's what we asked for this session and didn't get. In 2025 we need rates to support DSP hiring wages of \$22.50 to be at 150% of the \$15 Nebraska minimum wage. Rate would need to be tied to CPI, like minimum wage will be, after that. It is Direct Support Professional (DSP) appreciation week this week. Would like to give them more than just words of appreciation but to show them appreciation by giving better wages.

VIII. Elimination of the waitlist – Committee comments to the Division

- Mike Browne:
 - Family Support Waiver – the full process – we never received a baseline of how the system works. If someone would have laid it out, they would have noticed an SRT process issue in advance. Not seeing a full plan in a comprehensive way is not how you roll out a plan.
 - What happens with this waitlist program if we go through with all of this and at the end we don't like the plan.
 - How would I understand the questions if I don't understand how it fits into everything. The Department is asking the committee to give feedback and advice into elements that is going to affect our most vulnerable citizens.
 - When are we going to see a written formal comprehensive plan, including the budget, changes to the waivers, changes with Medicaid. I've never in my business career seen a major shift, that a complete plan wasn't laid out in advance. We seem to be doing pieces and parts.
 - Committee would like to see the entire scope of the plan from start to finish.
- Jennifer Hansen: September to December is supposed to be Phase 2 including public comment. Are we going to see those things before they go do public comment? Department Response: the PowerPoint handout Related Policy Changes on today's meeting agenda is part of the department showing the committee possible changes prior to go to public comment.
- Joe Valenti:
 - If the announcement to Eliminate the waitlist would not have happened when it did, would any of these discussions still be happening. You would still be going the congregate care and interRAI. What was so wrong with what we were doing? I don't know if the goal to eliminate the waitlist is achievable and realistic. If it is not realistic then this is all for not. Department's response: ICAP was part of rate study many years ago before COVID. This has nothing to do with Elimination of the Waitlist, this would be happening regardless.
 - I feel like I would be doing a dis-service without seeing the totality of the program and plan. I think that we can do it, but I think there is a mentality that this is the way we have always done it. It sets up all kinds of alarms for people that have been working through the system over the years.
- **ACTION ITEM:** Committee request the Department provide the committee with a comprehensive written plan on Elimination of the waitlist to be delivered for discussion at the October meeting.

IX. Adjournment: Committee meeting ended at 12:50 PM

Next Meeting:
Wednesday, October 9, 2024
Conference Room P
5220 South 16th St
Lincoln, NE

From: Beth Plisek <[b\[REDACTED\]@gmail.com](mailto:b[REDACTED]@gmail.com)>

Sent: Thursday, September 5, 2024 4:33:17 PM

To: Larsen, Kristen <Kristen.Larsen@nebraska.gov>; Ward, Rachel <Rachel.Ward@nebraska.gov>

Subject: Subject: Urgent: Barriers to Accessing Family Support Waiver for Families Not Eligible for SSI

To whom it may concern,

I hope this message finds you well. I am writing to bring attention to the significant barriers that families face in accessing the Family Support Waiver, particularly in cases where they are not eligible for Supplemental Security Income (SSI). This situation is becoming increasingly concerning and is impacting many families in our community. Currently, families who do not qualify for SSI are required to submit a Medicaid application, even if their income exceeds the Medicaid eligibility threshold. This process can be cumbersome and often leads to denials based solely on income, particularly if the application is not caught and addressed in time by Kathie Arens. Once a denial occurs, families are directed to the SRT team, which evaluates cases under criteria similar to SSI. Unfortunately, this process can take an extended period, ranging from a month to potentially a year or more. As I understand it, the SRT team currently has 82 cases in queue. This backlog is particularly problematic for families who do not have significant health barriers, as the focus seems to be primarily on those with intellectual disabilities and developmental disabilities. This situation is causing significant delays and frustration for families who are in urgent need of support. The requirements and processes in place not only complicate access to necessary services but also place undue stress on families who are already facing challenges. I urge you to consider reviewing these barriers and exploring potential solutions that would facilitate a more efficient process for families seeking the Family Support Waiver. It is crucial that we address these issues to ensure that all families have timely access to the support they need. Thank you for your attention to this matter. I look forward to your response and hope we can work together to improve the situation for our community.

Sincerely,

Beth Libra

Watson, Tyla

Subject: Concerns Regarding Comprehensive Waiver and Wait List

From: Edison McDonald <edison@arc-nebraska.org>

Sent: Monday, July 8, 2024 3:10 PM

Subject: Concerns Regarding Comprehensive Waiver and Wait List



Friend --

I just sent this to DHHS and other state leaders, as it's time for us to get more clarity regarding these issues. I hope these questions can support your advocacy and provide us all more clarity as we look to address the Waiting List and other pressing issues.

Dear Nebraska DHHS Leadership,

I am writing to express our deep concerns regarding the actions being taken by Nebraska DHHS in relation to the plan to "Eliminate the Wait List." The lack of clarity in the details and inadequate communication has led to significant confusion among stakeholders. Furthermore, we are troubled by actions that appear to contradict DHHS assurances, potentially harming individuals with disabilities and their families. These actions also appear to place us in violation of Nebraska statutes, our Medicaid Waiver, and federal law.

1) Nebraska is currently out of compliance with Nebraska Revised Statute 83-1216 (2), which mandates that "The department shall provide directly or by contract service coordination to Nebraska residents found to be eligible for specialized services." This statute specifies a mandatory requirement, not discretionary. By halting new Comprehensive Waiver offers, as communicated during the Department's Town Hall on May 8th, Nebraska is in clear violation of this statutory obligation.

2) Nebraska DHHS has consistently disregarded Nebraska Revised Statute 83-1212.01 (5), which stipulates that "The department shall inform the advisory committee of proposed systemic changes to services for persons with developmental disabilities at least thirty days prior to implementation." This provision ensures that the advisory committee and members of the community have adequate time to respond to proposed changes. Despite our repeated reminders to DHHS and committee members, this statutory requirement has been routinely ignored. This mechanism is crucial for ensuring that individuals with disabilities and their families have meaningful input into decisions affecting their lives.

3) There are multiple instances of violations of our Comprehensive Developmental Disabilities Waiver as outlined in the Application for 1915(c) HCBS Waiver: NE.4154.R07.00 - Mar 01, 2022. This document delineates our service framework, and nowhere within its 319 pages does it authorize a "pause" or "temporary stop" in services.

4) Given the violations mentioned above, Nebraska also appears to be in violation of 42 U.S.C. 1396n, which governs the operation of Medicaid Waivers and ensures compliance with federal requirements.

5) We are also unclear as to the compliance with LB 1412 which states "It is the intent of the Legislature that all unutilized or unspent funds appropriated to Program 424, inclusive of, General Funds will be distributed at the end of each fiscal year in this order: To service providers for the needs of persons with developmental disabilities under subdivision (4)(f) of section 83-1216."

We have not heard of any clear action that these funds will be utilized as was listed in LB 1412. The unused funds are designated to go specifically to provide for those who fall under 83-1216 (4) (f), which is Priority 6 (otherwise known as the waiting list). With over \$93 million in that fund last year we expect these funds should be significant enough to handle almost all of the Waiting List without other systemic changes. Therefore, we would like clarity as to how much of these funds remain. With that clarity, we are also looking for a clear division as to what American Rescue Plan Act dollars were used for versus state general funds.

6) All of this is further troubling given the information that Nebraska DHHS has only enrolled 12 families into the Family Support Waiver (per the Governors Developmental Disability Advisory Meeting on June 17) and thus seems to violate Nebraska Revised Statute 68-1530. This has been paired with stories of DHHS staff indicating that the offer letters families received were not real, incorrect information, a burdensome application process that has slowed even the most savvy of families, and other stories of poor implementation by DHHS.

It is imperative that DHHS takes immediate steps to rectify these violations and uphold the rights and protections guaranteed under state and federal law. We urge you to engage in transparent and collaborative dialogue with stakeholders, including the advisory committee, to address these concerns promptly and ensure that individuals with developmental disabilities continue to receive the supports and services they are entitled to under the law.

Thank you for your attention to this matter. We look forward to your prompt action and resolution. To ensure clarity we would appreciate a response in writing from DHHS.

Sincerely,

Edison McDonald

Executive Director

The Arc of Nebraska

CC:

Governor Pillen

Nebraska Legislature

Nebraska Attorney General Hilgers

Nebraska Developmental Disabilities Governors Advisory Committee

Edison McDonald

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This email was sent to tony.green@nebraska.gov. To stop receiving emails, [click here](#). You can also keep up with Edison McDonald on [Twitter](#).

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