

Iowa Developmental Disabilities Council Meeting Minutes July 14, 2022

Council Member Attendees: Hugh Kelly, Kristen Aller, Mike Vratsinas, Alecia Balduf, Jean Willard, Judy Warth, Brady Werger, Kitty Hedderich, Paula Motsinger, Steve Steveson, Carol Cross, Mark Smith, Eric Evans, Roxanne Cogil, Rob Roozeboom, Scott Lyon, Amber Gale, Julie Bergeson, Brittney Funston, Mike Hoenig, George Thompson

Council Staff: Brooke Lovelace, Bill Kallestad, and Lindsay Hommer

Council Members Absent: Tiffany Poage

Members of the Public: Connie Fanselow, Morgan Casey, Lisa Yunek, John McCalley, Josh (Brady's support staff)

Call to Order:

Council Chair Werger called the Iowa Developmental Disabilities Council (DD Council) meeting to order on July 14, 2022, at 10:30 AM. A quorum was established.

Welcome and Introductions:

All meeting attendees introduced themselves. Michael Hoenig and George Thompson are newly appointed members.

Agenda Item/Approval of Minutes and Agenda:

Balduf motioned to approve the minutes from the May 12, 2022 meeting, Kelly seconded. Motion passed. Hoening motioned to approve the agenda, seconded by Aller. Motion passed.

Executive Committee (EC) report:

Actions and Recommendations since May Meeting: The Iowa DD Council is under the umbrella of Health and Human Services as of July 1, 2022. This is a merger of the Department of Human Services and the Department of Public Health.

Budget Review: June 2022 Spending chart was reviewed. We have spent all of our 2020 funds. 2021 funds need to be spent by the end of September, 2022. Lovelace stated that some of the 2021 funds will be spent on Make Your Mark! Conference and some of the funding will not be spent. Lovelace stated we will have to approve the budget for 2023 in September. Lovelace stated that we can only spend 30% of our appropriation on administrative duties, everything else must be spent on state plan projects.

Creating change with and for persons with developmental disabilities so they can live, work, learn and play in the community of their choosing.

Center for Disabilities and Development Ambassador Project: Lovelace stated that the University Centers for Excellence on Developmental Disabilities (UCEDD) Community Ambassador Project has funds remaining from the previous year. A no cost extension was requested for \$50,000 to be carried over to the next year. UCEDD would like to do a speakers bureau in which they will market the ambassadors and they will ask the ambassadors to reach out to community organizations on their own and do speaking events. They're also going to train the ambassadors to be peer mentors to persons living in a facility or have transitioned out. They would also like to create a social forum to do interacting and mentoring virtually and get ambassadors more involved on a legislative level. One way to get involved legislatively would be to come and participate in a capitol advocacy day. Lovelace submitted the no-cost extension request yesterday to the federal government and it was approved yesterday. Executive committee (EC) motioned for this to pass. Vratsinas seconded. Hoenig, Warth, and Willard abstained from voting. Motion passed.

Bylaws and Bylaws committee: EC met today and there will be another meeting of the EC to make changes to the bylaws. Pre-pandemic, we were not able to meet virtually or by phone. Attendance was required in person. Once the pandemic happened, meetings were able to be held via Zoom. In our bylaws it states that meetings must be held in person and this needs updated in our bylaws. Two years ago, the EC gave the Executive Director discretion to spend \$1,000 – \$20,000 without having to go to the EC. This needs updated in the bylaws. At 8:30 AM today we were notified that the new members were appointed. We would like to change the bylaws to state that if people have applied for a second term and not yet been reappointed, we will act as if they are council members and can vote during meetings. Lovelace stated that the EC will suggest those changes, the council then has 30 days to review and the full council will vote on these changes during the September 8, 2022 meeting.

State Plan Work Plan Review: Lovelace shared the workplan with the Council. Lovelace stated the state plan was not approved by the federal government in February. The state plan was updated and resubmitted in June. The federal government will not review the plan until after August 15 for approval. Thompson asked what changes they were looking for. Lovelace stated they wanted us to be more specific and language needed to be changed. We had to put "developmental" before the word "disabilities" in the plan. They also want us to do more work supporting an advocacy movement that is led by people with disabilities. We made changes to the targeted disparity goal to target youth in rural areas.

Council Member Recruitment: Lovelace stated that Balduf, Hedderich, Roozeboom, Kelly, Werger were all reappointed. Thompson and Hoenig are new members that were appointed. Also, Kevin Harris and Matt Conaway are new members that were appointed. Hoenig stated that the Talent Bank needs to do work on their accessibility efforts. Hoenig had to get someone else to assist him as it was not very compatible with his screen reader. Lovelace stated she has been in contact with Monica Stone and this was to be addressed. She will contact Monica Stone again about this. Lovelace stated the brain injury

Creating change with and for persons with developmental disabilities so they can live, work, learn and play in the community of their choosing.

council did a video on how to use the Talent Bank and maybe we could do something similar to that. Lovelace stated it would be great if we could videotape a self-advocate filling out the application.

Other topics for discussion: None

Policy Updates:

Bill Kallestad – Kallestad stated there has been some success this year at the legislature for people with disabilities. Kallestad shared a PowerPoint. Some of the items to be celebrated that the legislature passed: More money for direct support staff wages, more people with intellectual disabilities will be served, more money for vocational rehabilitation, children with disabilities will have equal access to special education. Almost \$30 million in new money to make it easier for people to live, work, and be involved in their community, access to mental health services was improved, people with disabilities and their families spoke to legislators, and efforts to make voting more difficult were stopped. Some of the bills that did not pass were: scholarships for college aged students with disabilities who attend an alternative post-secondary transition program, a bill that would have required insurers to pay for children's hearing aids, voters with disabilities would have been allowed to request to vote via an electronic absentee ballot, and balancing the rights of landlords and renters who have service animals. One out of every three legislators will not return to the capitol next year so there will be a lot of new legislators. Some of the reasons for new legislators are: retirements, some are running for a different office, and a few were put into the same district as other legislators so they will now have to run against each other. Our legislative committee is starting to meet with regularity. The group last month and discussed keeping our current priorities which are the workforce shortage, the waiting lists, and accessibility. We will use the same three priorities but we will have new stories that reference our priorities. Our voting material has been updated and we have been collaborating with the Secretary of State's office to enhance the voting experience of people with disabilities. We are going to be putting voter grants out that are for groups that are led by people with disabilities. We are working with Roozeboom and Funston in NW Iowa to have an advocacy group there and we are working with Kelly in Sigourney.

Kallestad served as a mentor and a coach for a fellowship program that Drake University is doing. Kallestad's mentee is Callixte and is he from Rawanda and he has a disability.

We have monthly chats, weekly video Capitol chats, weekly written reports, quarterly infoNET mailers, and our editorial board.

Aller asked what ARPA stands for. Motsinger stated that it means American Rescue Plan Act and is a grant that is used for provide services for people in the community with disabilities. Aller asked what the November elections are for. Kallestad stated that it is for state senators, representatives, governor, and federal legislators up for re-election. Hoenig asked if there can be some more direction to get people to their candidate pages and forums. Kallestad stated that he has received questions from people about who their candidates are. We have links to the Secretary of State's page and it will show who is running

Creating change with and for persons with developmental disabilities so they can live, work, learn and play in the community of their choosing.

in your district. Lovelace stated we will be sending specific questions to the people running for the governor's office and federal positions and will share those responses.

There have been updates to the voting legislation and the laws and Kallestad stated he does not see this stopping. We have summarized our thoughts with a position statement. Kallestad did a presentation with the county auditors some of the feedback was that we should promote curbside voting and since the days have been lessened to request absentee ballots, especially in rural Iowa, receiving ballots late has been a new issue. Also, it should be noted that there are fewer drop boxes now. Each year more people with disabilities are voting. Six out of ten Americans with Disabilities vote. We need to educate our lawmakers about the voting challenges for people with disabilities. Voting should be easier for people with disabilities and not harder. We need trained polling workers, accessible voting locations, and an easier voting system that works for all Iowans. Lovelace stated that people commenting on our state plan asked that the DD Council do more of these statements. We would like the Council's feedback on how we should distribute these statements. We could do press releases, have Council members share within their network, and we will share with our network. Warth asked if Capture Management could create something infographic that would be eye-catching. Warth suggested Community Rehabilitation Programs (CRP) post our statement and post at election offices. Funston stated that her father is the news director for a radio station and she could get the statement to him to do a story on. Willard stated that this could be a press release. Motsinger stated she could share on their Medicaid social media. Funston stated she is on the board of Governance Board for the Mental Health and Disability Services and can make sure they get the information and will share it with the Autism Society of Iowa board of directors.

Make Your Mark! Conference Update:

Registration for the Make Your Mark! Conference opened last Thursday. Registration is free for self-advocates and is at the Prairie Meadows Conference Center on September 14 and 15. We are looking for Council members to volunteer. Motsinger, Kelly, and Aller would like to volunteer. Aller asked how much it would be for a friend of hers to come. Lovelace stated self-advocates are free. Lovelace stated that Eric Garcia is our first key-note speaker, has autism, and is a correspondent for the Washington Post. The second key-note speaker is Kayla McKeon. She is the first person with Down's Syndrome to be a lobbyist. Kelly stated that he registered and shared it on his Facebook page. Lovelace stated IAble, Work let's your superpower shine, Ambassadors and their superheroes, Customized Employment Project by Vocational Rehabilitation, how to develop your superpowers as a leader, and Special Olympics, past superheroes for Disability Rights, Connections to Advocacy, and a voter educational panel will all be sessions at the conference. Secretary of State has been invited to speak with Kallestad about voting. Aller asked if anyone is coming by or near Cedar Rapids she would like to carpool. Cogil stated she could volunteer on the second day of the conference. Lovelace stated we want to have two people assigned to each room to be a host/hostess and a helper to those in the rooms. Balduf is interested in volunteering. Kallestad stated that last year certain things in the rooms were forgotten or chairs were rearranged. He stated there is a need for volunteers to solve any issues that may arise. Werger asked what his roles will be at the conference. Lovelace stated Werger will be helping present

Creating change with and for persons with developmental disabilities so they can live, work, learn and play in the community of their choosing.

the Mia Peterson Award and introduce one of the key-note speakers. Aller asked how much rooms are. Lovelace stated they are \$139 per night. Kelly asked if Council members can be reimbursed. Lovelace stated that they can. Lovelace stated it is yet to be determined if people would like to do a group activity at night.

Below is the link to register. For volunteers to register for free, please use code: **Volunteer2022**

<https://cvent.me/3rDOzK>

Mathematica Home and Community Based Waiver Services Evaluation Project:

Jessica McNab (Deputy Project Director), Jody Schimmel Hyde (Evaluation Lead), Kimberly Aguillard (Advisory Committee Facilitator),

Program Evaluation and Analysis of Community-based Services for Behavioral Health, Disability, and Aging Needs in Iowa. What does a well-functioning community-based services (CBS) system look like? In what ways does Iowa's system for CBS work well?

In the fall of 2021, Iowa Department of Human Services (DHS) issued a call for a contractor to help the state conduct a systemwide evaluation of community-based services (CBS). The focus is lowans with disability, aging, and behavioral health needs. The funding was for at least two years with the possibility of two additional years.

They are in year one of their contract and are evaluating and assessing. In year two, they will look at technical assistance and how it will be implemented across the state.

Guideposts for redesigning CBS across the state will include coordinating care across programs, ensuring equitable access to services, and delivering high-quality care.

The purpose of the evaluation is to understand how Iowa DHS can improve equitable access to high-quality services through Medicaid and other programs, identify gaps and inequities in services and opportunities to reduce inefficiencies, and provide recommendations to improve service delivery. There are three phases in the evaluation stage. Phase one is documenting the current landscape. Phase two is identifying successes to spread and opportunities to improve. Phase three is mapping promising pathways.

They have three teams to support the evaluation. There is the policy and program review team, quantitative data analysis team, and the engaging invested lowans team.

The current priority areas of analysis are the barriers to CBS and home and community-based services (HCBS) Medicaid waiver design.

The team has learned that there is misalignment in services and spending across waivers, the waitlist data suggests Iowa's waiver waitlist population has more than doubled since January 2019, while the number of people served on a waiver has stayed consistent, and consumers experience a reactive system, particularly as they transition in out of facilities. Lovelace asked what a reactive system is. Jessica McNab stated there needs to be clear hand offs and open communication between community and facilities. She said that right now hand offs seem reactive and need to be proactive. Although

Creating change with and for persons with developmental disabilities so they can live, work, learn and play in the community of their choosing.

financial incentives exist for hand offs from facilities to communities, there are logistical challenges that hinder this process. Jody Schimmel Hyde stated sometimes situations become crisis' that didn't need to be if the system was easier to navigate. Werger said that his sister had to wait years to get on a waiver. Werger then stated his sister could not be served in state anymore and is living in another state. She now is being told she will need to reapply to be on a waiver in Iowa and will have to wait years again to get on a waiver. Werger stated he would like to follow up after the meeting with Mathematica staff about his concerns. Jessica McNab stated there is an online feedback form and she would like him to fill this out so they can get his feedback.

Kimberly Aguillard asked what does a well-functioning CBS system look like in Iowa. Lyon would like to see it be less adversary in regards to Medicaid appeals. Cross has recently started working as her daughter's direct care worker and who is on the health and disability waiver. Cross said we need adequate workforce so people with disabilities can stay in their home. Parents helping with their children's needs would help the workforce shortage as they are often the most skilled to care for their children. Warth stated she recently worked with a family who were providing primary supports for their child and were receiving some funds through Community Choice Options (CCO), they could not access respite care and the system suggested that the parents institutionalize their child. This is an issue that needs addressed. Willard stated that acknowledgement of differences needs to be noted between children on waivers and adults on waivers. Systems do not seem to work well together. For example, schools don't always work well with health care systems. There needs to be a higher authority that brings these systems together. Werger asked Balduf her thoughts. Balduf stated she has issues with transportation at night to her job and her hours are restricted because she doesn't have transportation at night. Aller stated she does not work because transportation is bad in her area also. Thompson stated he is a parent advocate for his daughter and the waitlist for waivers is long and it is very complex. The waivers are hard to utilize and too complex. Steveson stated that since the pandemic the transportation in Indianola is virtually non-existent. Cogil stated her daughter just turned 18 and transitions of children to different waivers needs to be looked at. Worked with numerous people whose case manager suggested they move from one waiver to another due to needs. There needs to be a menu of services so people don't have to switch waivers to get their needs met. Cogil stated that there is no transportation outside of business hours which prevents her daughter from doing social outings at night. Also, the developmental disability diagnosis is often a gap in the system and they need support even if they don't fit the criteria of qualifying for a waiver. Motsinger stated we need to think about crisis support and stop overwhelming hospitals.

Kimberly Aguillard asked what is working well in Iowa. Cogil stated that people on HIPP (Health Insurance Premium Payment Program) who have a case manager seem more pleased. Cross stated the HIPP program is really working for her daughter. Hedderich stated she can use Medicaid for doctor appointments, eye doctor, and dentists. She stated the waiting list is really long though. Vratsinas said when he was in the REACH program he was looking into services but ended up not needing them after getting a job in West Des Moines. Balduf said she likes that she has transportation but doesn't like how long of waits there are for transportation. Kallestad said that some of the programs to address the staffing shortages, such as the Host home program, is flexible and works for some. Motsinger's team at

Creating change with and for persons with developmental disabilities so they can live, work, learn and play in the community of their choosing.

Iowa Medicaid has been really open to feedback this last year which is helpful. Having flexibility and responsiveness is helpful. Gale stated that being able to give her respite worker additional funds has been very helpful and flexibility is key.

Lyon asked if Mathematica staff is meeting with stakeholders or just receiving feedback through the web form on their website. Jessica McNab said they are meeting with stakeholders.

Jody Schimmel Hyde addressed Thompson's question of how they are seeing things in Iowa versus other states. Jody Schimmel Hyde stated the issues that were brought up today are some of the same issues that are prevalent across the country. They are looking at how other states do waivers more effectively to do a waiver redesign in Iowa.

Council Updates:

Kelly stated he is co-hosting sometime during the week of October 10 a voter education town hall meeting in Sigourney.

Cogil stated her daughter participated in the Youth Leadership Academy last year and was nominated and awarded a special education award and a scholarship for \$500. She is going to use the funds to purchase a laptop. Cogil stated one of her daughter's neurology nurses asked her to speak at the University of Iowa Neuroscience Conference and she will give a patient testimonial.

Motsinger stated that people need to advocate at a legislative level to get the waiver waitlist brought down.

Werger stated he will be moving to a group home with two other individuals in Waverly in about a week. He will be eight minutes from his parents and is very excited. Werger stated his parents want to attend a couple meetings in the future.

Baldur asked what she could share at her ARC (north central Iowa) meeting. Lovelace stated she could share about Make Your Mark! Conference and the Mathematica slides. Lovelace stated they could apply for our townhall grant or a voter grant.

Public Comments:

None

Adjourn: Aller made a motion to adjourn, and Kelly seconded the motion. The meeting adjourned at 2:24 PM.

Creating change with and for persons with developmental disabilities so they can live, work, learn and play in the community of their choosing.