

Iowa Developmental Disabilities Council Meeting Minutes May 12, 2022

Council Member Attendees: Hugh Kelly, Kristen Aller, Mike Vratsinas, Alecia Balduf, Al Fagerlund, Jean Willard, Julie Bergeson, Judy Warth, Brady Werger, Kitty Hedderich, Robert Fisher, Mark Schneider, Brittney Funston, Paula Motsinger, Steve Steveson, Carol Cross, Tiffany Poage, Scott Lyon, Rob Roozeboom, Mark Smith, Eric Evans

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

Council Members Absent: Roxanne Cogil, Jason Goulden, Amber Gale

Members of the Public: Amy Campbell, Nicole Nosbisch, Connie Fanselow, Marsha Fisher, Josh Ellis (Brady's support person), Jenn Wolff, Lisa Yunek, Alex Carper (public information Officer for DHS), Kelly Garcia

Call to Order:

Council Chair Fagerlund called the Iowa Developmental Disabilities Council (DD Council) meeting to order on May 12, 2022, at 10:32 AM. A quorum was established.

Welcome and Introductions:

All meeting attendees introduced themselves.

Agenda Item/Approval of Minutes and Agenda:

Kelly motioned to approve the minutes from the March 10, 2022 meeting and today's agenda, Werger seconded. Motion passed.

Executive Committee (EC) report:

Actions and Recommendations since March Meeting: Werger led the EC meeting today.

Budget Review: Lovelace reviewed the Council budget detail. Lovelace reviewed the Council Spending chart. All of our funds for 2021 and 2022 are obligated so there was no need to look at the Obligation chart. We have \$347,540.58 left of the 2021 award to spend. The Council will apply for a no cost extension so we can spend the 2021 funds after 9/30/2022 for one year. Roozeboom asked why we are over obligated. Lovelace stated we have over obligated because projects do not always spend all that we contracted for and if they do, we can use our second year of funding to pay for costs. Lovelace stated Council's are able to ask for a no extension because we are still in a public health emergency.

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Public Health Funding:

Lovelace stated that the Administration on Community Living (ACL) gave funds to help the public health workforce as well as to assist people with disabilities cope with disasters and health emergencies. The DD Council did apply and receive \$95,000. These funds are to be used for two years. The DD Council wants to contract with the University Center for Excellence on Developmental Disabilities (UCEDD) because it is not enough for the DD Council to hire an employee. UCEDD would hire a public health worker to go out in the community and do outreach to assist people deal with stressors in relation to disasters and develop coping skills. UCEDD is going to hire or contract for Mental Health Ambassadors who have lived experience to help with this outreach. Aller asked what communities would be assisted with this project. Lovelace stated the communities would be Sioux City, Council Bluffs, Mason City, Fort Dodge, Carroll, Atlantic, Marshalltown, Waterloo, Decorah, Cedar Rapids, Burlington, Clinton, Dubuque, and the Quad Cities. The project will connect people with resources in their communities to assist them. Poage stated that the communities that would receive this assistance seemed to be larger communities and asked if rural communities would be able to access these benefits as well. Lovelace stated there would be some rural areas that would be assisted as well. Lovelace stated that we would recommend that UCEDD partner with local county health departments and local Mental Health Disability Services (MHDS) regions. Warth stated Mike, the contact person at UCEDD about this project, said the plan is to have small group interventions in a lot of rural communities.

The EC did the first motion. Steveson seconded the motion to spend the \$95,000. Warth abstained from voting as she is employed by UCEDD. Motion passed.

Bylaws and Bylaws committee:

The Bylaws need to be reviewed for changes to meeting in-person requirements. The EC will act as the bylaw committee and if there are changes needed and the full council will vote on these changes.

State Plan Work Plan Review:

Fagerlund stated the workplan was reviewed by the EC. Lovelace stated that this is for the Council to see the changes and progress we are making. Our new objectives, 1.3 and 1.4, are on the workplan. We still do not have federal approval of the state plan. Aller asked when it will be approved. Lovelace stated it is out for public comment right now. It will be closed for public comment on 5/15/2022. The electronic system that we need to submit it to is not ready for the state to submit. Once it is, we will submit it. The deadline the ACL set for when state plans need to be submitted by is August 15, 2022. Roozeboom asked if there were a lot of public comments. Lovelace said there was not.

Council Member Recruitment:

Lovelace stated we are losing two family members and two self-advocates that are male on the Council. We did have people apply for these positions and the applications are at the governor's office for

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approval. We may get people appointed before July. Balduf, Hedderich, Werger, Roozeboom, and Kelly will need to be reappointed.

Other topics for discussion:

The DD Council received a request from DHS asking for the DD Council to weigh in on the Glenwood closure. They asked that the DD Council write a letter to Director Garcia on behalf of the Council. The letter would include the expectations that the DD Council would have for DHS to consider during the next two years while they are closing Glenwood. Lovelace stated that the EC suggested that one of the areas that could be addressed is making sure that the clients that are with the Glenwood community services continue to be supported and staffed at an appropriate level to support these clients. Fisher asked if there was any way that he could help the Glenwood clients. Lovelace stated that Fisher may want to suggest a peer support mentoring program for the clients transitioning out of Glenwood. Lovelace stated that Director Garcia is coming to speak to the DD Council later in this meeting and a question that may come up is how DHS is deciding which clients get transferred to Woodward and which ones get transferred to the community. Funston stated she cannot attend this afternoon session and would like the recording sent to her. Lovelace stated we could do this. Motsinger stated we should stress the importance of member choice in our letter to Director Garcia.

Election Committee Report:

Fisher shared the slate of candidates for the Executive Committee. Roozeboom and Funston would be new members at large. Werger has been nominated as Chair and Kelly as Vice-Chair. Warth would remain a member at large. These positions would be effective as of July 1, 2022. Election Committee made the first motion for the slate of candidates for the EC, Schneider seconded the motion. Motion passed.

Policy Updates:

Amy Campbell and Bill Kallestad

Kallestad stated that there is a primary election coming up and if you want to vote during this, you have to register as a Republican or a Democrat. May 18th is the first date you can vote in person at your county auditor's office. You can already request your absentee ballot but you cannot do this past May 23rd. June 4 is the date that the county auditor's office or satellite offices will be open for voting. Election day for the primary is June 7. Ballot's have to be received by the end of the day on election day to count, not post marked as in previous years.

Kallestad stated that many self-advocates spoke on bills that were signed this legislative session. Some of the bills were signed such as updating the autism definition, special education task force, and updating the newborn screening. There are four bills that are on the governor's desk waiting to be signed. The four bills are: Language development for children who are deaf or hard of hearing (HF 604), Allowing individuals who have a permanent disability to access

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state childcare (HF 2252), updates health care loan repayment programs to increase rural access (SF 2383), allows PTs/OTs to sign off on accessible parking permits (HF 2259).

The legislative session has not ended yet. It was supposed to end in the middle of April. The following are the budgets that still have not been voted on:

\$14.6 million increase for Home and Community Based Services (HCBS) rates – going directly to direct support staff wages

\$7.4 million increase to take an estimated 250 people off Intellectual Disability (ID) waiver waiting list

\$3.1 million increase for Intermediate Care Facilities/ Intellectual Disability (ICF/ID) rates – going directly to direct support staff wages

\$4 million to increase rural access to home health care

\$3 million increase for Psychiatric Medical Institutions for Children/Behavioral Health Intervention Services (PMIC/BHIS) rates

\$385,000 to increase applied behavioral analysis (ABA) rates

\$2 million increase for psychiatric tiered rates

\$1.1 million for substance use disorder residential treatment

\$120,000 increase for vocational rehabilitation

\$1.5 million for new mental health loan repayment program.

Other policy bills that we are still waiting for legislatures to vote on are a post-secondary transition program scholarships bill (HF 2575 that is for \$200,000), a children's audiological services bill (HF 2568 and HF 2578), a bill pertaining to guardianship changes (SF 348), and a mental health loan repayment program bill (HF 2549 and HF 2575).

Amy Campbell stated that the challenges in the 2023 legislative year will remain similar. A challenge will be funding the needed infrastructure to support community-based services and aligning these changes with the tax bill passed in 2022. The health and human services budget is a large portion of the overall budget, and the legislators proposed a six year reduction in spending. Additional things to pay attention will be the transition of Glenwood State hospital, a new Medicaid Managed Care Organization (MCO), and the election changes due to 40 out of 150 legislators retiring or moving to other positions that will appoint new chairs to key committees.

Amy Campbell stated that infoNET has for the first time had their first Editorial board. They have been very helpful to help point out what needs to be thought about and what issues need focused on.

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Fisher asked about the accessible communities. How do people in wheelchairs know where they can and can't go? How do we report that? Amy Campbell said that people should work with their city councils, county supervisors, or legislators. Amy Campbell said she will speak with Kallestad about this issue. Kallestad stated the Secretary of State's office reached out to the DD Council and they are proposing some grants to the county auditors to make voting more accessible through the eyes of people with disabilities. They would have forums with people with disabilities to get their opinions on how to make voting more accessible. One of our legislative priorities is making Iowa more accessible. Kallestad said that if there are local town halls that we need to travel to, he would be willing to go and let them know the DD Council's priorities. Amy Campbell said for example, curb cuts, are a city's responsibility. Fisher stated that the Adel post office does not have a handicapped button for the door. Fisher stated that the post office said they do not have to put a handicapped button because they are federal building. Kallestad said that this should be brought up with legislatures. Fisher said he met with Jake Heard and he told him to wait. Fisher said that the senator Chuck Grassley represents the Adel area did not know about this issue. Fisher got a complaint form and he is going to mail the form to Senator Grassley. Fisher said that maybe this form will help get an automatic button at the Adel post office.

Roozeboom said that the ADA Act of 1990 needs to be re-looked at and revamped. There are still many accessibility issues. Kallestad stated he wondered if we should connect with the Harkin Institute about this. Kallestad said that we will be pulling our public policy committee together this next month.

Kallestad stated that Youth Leadership Academy (YLA) for the summer of 2022 is now taking applications. We have a graduate of YLA that has applied for the DD Council. June 17 is the application deadline. July 25-29 are the dates of YLA.

May 25, 2022 at 12 PM is the next capitol chat.

Willard stated that the policy updates that are now part of the DD Council meetings are very helpful.

[Legislative Update.pdf](#)

State Plan Update and Workplan Review:

Lovelace stated that the yellow highlights are items we have been working on since the last meeting. All of our voting material should be ready in the next couple of weeks. Objective 1.2

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points out that we are working with people with developmental disabilities. Ambassadors hosted a legislative day as part of Disability Awareness month in March. Six legislators attended. Lovelace said one of the stories that was shared at this event was of Michael Gillette, who is a parent who has a disability and there is not a lot of support for parents with disabilities and he brought this to the attention of the legislators.

Lovelace stated that we would like to hire an intern to help with policy work. It needs to be a student or someone with Vocational Rehabilitation (VR). We are working on this.

Under Objective 1.3, it states the DD Council supports organizations that are led by individuals with developmental disabilities. We will host a leadership summit in the afternoon after the Make Your Mark! Conference (MYM!) that is led by people with developmental disabilities.

Under Objective 1.4, Targeted Disparity, we are targeting youth ages 18-26 to increase their self-advocacy and civic engagement. Our first activity will be in the Spencer area in September with Funston and Roozeboom's assistance. We are looking for suggestions of where to do another activity. Kelly suggested doing one in the Sigourney area and Kelly would host it. We are working on a white paper (a very short document that explains an issue and why we think it needs to change or make people aware of it) about voting restrictions and how they negatively impact people with disabilities. The plan is to have this completed by the primary.

Kallestad is looking for new members on the policy committee and this committee will reconvene in May. Lovelace stated that we are going to ask the Council to vote on our legislative agenda in September instead of January.

Lovelace stated we are trying to share as many grassroots stories as we can. Kallestad stated that one of the advocates that came to the capitol from the Spina Bifida group brought her daughter, Bliss. Bliss does not have use of her legs and cannot bare weight. Bliss was in a homemade wheelchair made by her grandfather. While at the capitol, Bliss met many legislators. One of our priorities is to eliminate the waiting lists. She has been on the HCBS waiting list since she was born. Lovelace stated that the legislators did put funding in a bill for the Spina Bifida association because of meeting Bliss. The bill unfortunately did not pass. Lovelace stated the grassroots advocacy stories make such a difference. Aller stated that when she attends advocacy days at the capitol, legislatures remember her and it makes a difference for them when they hear stories from people with disabilities. Kallestad stated smaller groups of people meeting legislators is sometimes beneficial so they can talk to them one on one. Objective 3.1, had to have extra verbiage added per ACL.

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MYM! Conference Update:

Lovelace stated that on 5/16/2022 there is a meeting at 2 PM of the MYM! committee. We will talk about some of our break-out sessions. MYM! Conference will be held Sept 14-15 at Prairie Meadows in Altoona. One key-note speaker, Eric Garcia, who identifies as having autism is confirmed. We have not confirmed another speaker. Dave Price, a political journalist, is confirmed to attend. Kallestad said that last year we had some legislators come and we had a panel that Roozeboom was on and that was really well received. Kallestad thinks having a bi-partisan legislative panel is important. Lovelace we are still trying to figure out what the last day at MYM! will look like. Lovelace stated we still need exhibitors and sponsors. Werger stated that Special Olympics Iowa wants to do an exhibit. Kallestad stated we want to do something pertaining to voting. Werger asked if someone could reach out to the Secretary of State and have someone from their office come. Kallestad stated he would think about this. Kelly stated he reached out to his district manager at Goodwill and they will be at MYM! as an exhibitor. Lovelace stated we may have to charge attendees this year due to budget.

Recognition of Leaving Council Members:

Schneider, Fagerlund, Fisher, and Goulden are leaving the council as of June 30, 2022. A slide show with messages from the council members for each was shown and certificates were handed out to the four members leaving.

Update on Glenwood Closure and other News from Department of Human Services (DHS):

Director Kelly Garcia

In 2019, the Department of Justice sent DHS a letter stating they opened an investigation in Iowa for two issues. The first is under the Americans with Disabilities Act and the Civil Rights Act that protects institutionalized persons. One of the things they were looking at is do we serve too many people with intellectual and developmental disabilities in facilities. Our funding trends show that we put a lot of money into institutional settings. The second part of the investigation was specific to Glenwood and contained three main areas which were sub-standard medical care, sub-standard behavioral healthcare, and human subject experimentation. DHS asked doctors to come to Glenwood immediately to assess the clients that were involved in the experimentation aspect. The medical treatment and intervention called the perfect care index or the optimal hydration study was in violation of the standard of care. It involved giving individuals that had a higher propensity for having pneumonia additional

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fluids and had poor clinical outcomes. It was not based on any literature that could be supported. Clinical supports and behavioral supports were provided immediately.

DHS hasn't been able to hire the level of expertise that is needed at Glenwood. It was decided by leadership to close Glenwood. We are going to concentrate on building up expertise at Woodward. It will be good for community integration efforts. Institutional spaces can provide structure and supports for children on a temporary basis. We need to build more supports in home and community-based services. Schneider asked how it is going to be decided who will be moved to Woodward and who will move to the community from Glenwood. Director Garcia stated that it is person centered. There are about 40 people they are looking to send to Woodward. We have fifteen providers that have stepped up and said they want to expand services. This is a multi-disciplinary effort by all teams. The American Rescue Plan provided \$10 million federal dollars that we can use towards wage stabilization, direct care, crisis stabilization services, buy down the intellectual disability waiver, and give seed money to providers for home modifications. If individuals are struggling in the community, Woodward or an mental health institute (MHI) will be used as short-term respite, but not as a permanent placement. It is the goal to get the individual back into the community. Werger stated he used to live at Glenwood and he would like to advocate for the clients and staff at Glenwood who are going to be moved. Werger stated people need to hear more of the success stories from Glenwood clients like himself. Werger stated he hopes the client teams are really finding them the appropriate services so they don't fail in the community. Director Garcia said there was a client that transitioned out of Glenwood was struggling in the community. As a last resort after not doing well in the community, they were placed in an MHI where their meds were stabilized and this client is now living in the community and doing well. Director Garcia would like see the new system work so clients can live in the community successfully. Director Garcia stated that we need to make a smooth of a transition as possible for the staff as well. Director Garcia said that staff are going to be offered transfers within DHS as possible and offer re-training programs. The school district has already indicated they may want Glenwood for a school. Fisher asked how DHS is going to ensure that clients who move to the community are put with good people. Director Garcia stated that we are going to make an investment in our oversight. We will expect in-person visits and we will also be hiring persons in Central Office for quality assurance. There will also be social workers and one entry point for clients to go to in DHS so clients do not get lost or not know where to turn for help. Warth stated there are people that need a depth of services, such as special psychiatric care and special medical care. Warth asked if there is a plan to deal with this. Director Garcia stated that we are short on providers and we need a pipeline of providers that deal with all services. Director Garcia stated there will also be doors for telehealth opened. Warth asked what safeguards are going to be put in place when clients go to communities of their choice to receive proper services. Director Garcia stated that they first need to find the right provider, then it involves conversations between the MCO, that provider,

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and DHS. Lisa Yunek asked if a client is struggling in their placement, what is going to be done. Director Garcia stated that more training is needed for staff, a 24/hr. hotline for staff to call if there is a situation that they don't know how to handle, local crisis response specific to the ID population, and short-term respite.

Schneider asked what grade Director Garcia would give the MCO system. Director Garcia said she thought it was unfair to assess a grad right now because we started from a faulty platform. We rolled out managed care with a rate structure that couldn't support it. Our MCO's didn't have a chance to become engaged and the state did not build out a strong oversight team to do that work. The state received proposals from MCO's recently that want to work with DHS and the new MCO's will be chosen after the summer. LTSS (long term services and supports) will be one of the areas that the chosen MCO's will need to be able to support and commit to. Lisa Yunek asked if the current MCO is coming back. Director Garcia said we do not know yet since we are in an active procurement. Director Garcia stated she was unsure if there will be a third MCO added.

Council Updates:

None

Public Comments:

Marsha Fisher said that the Council does great work and has really assisted Robert Fisher. Marsha Fisher stated that the public in general needs more training and education about people with disabilities such as EMS, police, and other community businesses.

Lisa Yunek stated she hears from parents that have adult children who fail in their placements. We need to keep a continuum of care. Also, we have had reduced transportation due to not being able to find drivers and we need to find a solution for this. Finally, keep the meeting information accessible to all people.

Adjourn: Warth made a motion to adjourn, and Kelly seconded the motion. The meeting adjourned at 2:39 PM.