

Iowa Developmental Disabilities Council Meeting Minutes September 14, 2023

Council Member Attendees:

In Person: Hugh Kelly, Steve Steveson, Rob Roozeboom, Julie Bergeson, Kevin Harris, Eric Evans, Brady Werger, Paula Motsinger, Amber Gale, Roxanne Cogil, Kitty Hedderich, Diane Brenneman, Melissa Lawson, Mike Hoenig, Kitty Hedderich

Virtual Attendance: Matthew Conaway, Alecia Balduf, George Thompson, Kristen Aller, Mike Vratsinas, Josh Lawrence

Council Staff: Brooke Lovelace, Carlyn Crowe, Lindsay Hommer

Council Members Absent: Brittney Drinovsky, Emma Bouza, Caitlin Owens

Members of the Public: Georgette Wallace georgette.wallace@fema.dhs.gov
Connie Fanselow, Jim Kain

Call to Order:

Council Chair Werger called the Iowa Developmental Disabilities Council (DD Council) meeting to order on September 14, 2023, at 10:30 AM. A quorum was established.

Welcome and Introductions:

All meeting attendees introduced themselves.

Agenda Item/Approval of Minutes and Agenda:

Steveson motioned to approve the minutes from the May 11, 2023 meeting, and Kelly seconded. Motion approved. Hoenig motioned to approve the agenda for September 14, 2023, and Aller seconded. Motion approved.

Executive Committee (EC) Report:

Actions and Recommendations since May Meeting:

Werger stated that there was a new council orientation held in August.

Current Budget Review:

Lovelace reviewed the budget. There is one month left to spend in the FFY23. We are underspent by approximately \$101,000 currently. There will be approximately \$25,000 more spent in September. Jim Kain asked if there are delays in receiving funding every year. Lovelace stated there are. Lovelace

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reviewed the spending chart. Lovelace stated that our 2022 award must have the work completed by the end of September. We only have about \$43,000 left to spend and she thinks we'll spend it. We did ask for a no-cost extension in case we don't. We spent about \$17,000 on projects including interpreters.

2024 Budget Approval:

Lovelace stated we increased the Council support budget by \$3,000. National dues and out of state travel were also increased in FFY24 by \$1,100. Personnel costs were lowered by about \$7,000. We do not have landline phonelines anymore and reduced our budget by about \$2,000. Budget overall is \$4,500 less than last year.

EC motioned to approve. Aller seconded. Motion is approved.

Bylaws:

EC decided to amend the Bylaws to make the Policy Committee a formal committee with elected members. EC will be the Bylaws committee and a meeting was set up. Council members need to have 30 days to review the Bylaws. The Bylaws will be voted on as amended in the November meeting.

Workplan Review:

Lovelace asked if anyone has any questions about the workplan. Lovelace stated that we would like the Council's help with school projects in rural areas. Lovelace stated our goal is to do two trainings regarding self-advocacy and voting to rural schools per year. Cogil, Thompson, and Brenneman stated they will check with their school districts about this. Jim Kain stated that Disability Rights Iowa (DRI) would love to partner to do rural voter outreach. Motsinger stated that her department could put something out on social media about increasing our network membership.

2024 Legislative Agenda:

Crowe stated that they would like to call the legislative committee the "Public Policy Committee" going forward. The 2024 priorities are framed around the mission statement which is "working together to create an Iowa where people with disabilities learn, work, and thrive." Crowe stated that the 2024 priorities were put together by gathering input from many different sources and experiences.

Harris reviewed the public priorities for 2024 draft document.

Priority #1: Iowans with disabilities learn. Students with disabilities at all ages receive a quality education with the supports they need to learn and thrive. This would include public and non-public school special education programs, people with disabilities being able to attend college, and support in-school programs and trainings for teachers, staff, and students on health conditions and disabilities. Lawson stated she really liked the idea of changing Iowa Code so that students can receive the assistance they need in public and non-public schools.

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Priority #2: Iowans with disabilities work. Iowans with disabilities are employed and working toward financial independence. This would include making competitive integrated employment the only option for publicly funded employment services for Iowans with disabilities, investing in vocational rehabilitation services at a level that includes that maximizes federal match, and increase Iowa's workforce programs for targeted populations. Hoenig asked if the state is getting the maximum federal match now at Iowa Vocational Rehabilitation Services (IVRS). Evans stated they are not. Evans stated that the self-employment program through IVRS supports the Department of Blind also. Hoenig stated that perhaps we should include for the Department of the Blind to get increased funding also. Roozeboom asked why IVRS is not currently pulling down the maximum federal match. Evans stated that what the state puts in, IVRS draws down 78%. The state would have to allocate more funds to IVRS in order for IVRS to draw down more federal match. Cogil stated perhaps the wording needs to be changed to not include "self-employment."

Priority #3: Iowans with disabilities thrive. Iowans with disabilities live independently in their community by getting the support they need. This would include establishing a livable wage for direct support professionals (DSPs) to decrease their dependence on public assistance, prioritize home and community-based services by eliminating gaps in waiver services and waiting lists, and revise evaluation requirements for an intellectual disability (ID) diagnosis. Aller asked what does "decrease their dependence on public assistance" mean. Harris stated that DSP's wages are so low sometimes that DSP's are on food assistance, or Medicaid, or other public assistance programs. Motsinger stated that there are many DSP's that are on Medicaid because their wages are so low. If wages would increase, people could get off Medicaid and receive other benefits. The funds that were being spent on Medicaid could be reinvested into HCBS. Motsinger stated we may want to change the wording from livable wage to "targeted investments for HCBS". Motsinger also suggested some targeted funding that would go into the rate structure.

Priority #4: Iowans with disabilities vote. Affirm the right to vote for people with disabilities by ensuring their access to participation by lengthening early voting options, having additional and accessible voting places, expanding days to receive and return absentee ballots, increasing absentee ballot drop box options, and approving assistance to deliver an absentee ballot.

The bottom highlighted section of the document states that the document lists the 2024 priorities, but the public policy committee will still have the option to wordsmith the document as needed. Also, for each bullet point there will be a detailed fact sheet produced to distribute to council, lawmakers, advocates, and others. Stories will also be collected and written for each priority area.

Aller stated that a lot of people can't drive which impedes people from voting, working, etc. Harris stated the priorities would help with the length of time you have to vote but would not address the transportation issue. Conway stated we may want to advocate for ballots in plain language.

EC motioned to approve the priorities. Steveson seconded.

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Health and Human Services Update:

Director Kelly Garcia and Director of the Division of Aging and Disability Services Zach Rhein

Director Garcia stated there will be meetings about the Medicaid waiver redesign project called HOME (Hope and Opportunities in Many Environments). She would like to hear from the DD Council members, guardians, and caregivers. Part of the Department of Justice settlement agreement requires Department of Health and Human Services (HHS) to have a monitor. The monitor is employed by a third party and they check and make sure the improvements are being made. The monitor did an on-site visit in August. The monitors report showed no significant findings which is good. Director Garcia stated there are less than 20 people living in Glenwood that are without placement in the community, all other residents have placement in the community.

Director Garcia introduced the new director of the division of Aging and Disability Services, Director Zach Rhein. Director Rhein stated that one of the first projects is to build an Aging and Disability Resource Center (ADRC). The ADRC will help navigate the home and community-based services (HCBS) system. In the new division, they are making sure they have staff in the right places to make sure they illustrate they do both aging and disability work. Currently they are building out a structure to support ADRC. Bergeson will be leading the division work for the ADRC. Werger asked what if the goal of the department will be to bring people back to Iowa who were sent out of state to receive services. Director Rhein said he will work to improve the system so that supports are available and people do not need placed out of state. Hoenig stated HHS is hiring an American with Disabilities Act (ADA) coordinator and he is excited about this. Hoenig would like to invite the person who gets hired to come speak to the Council. Lovelace asked what this person would do in this role. Director Garcia stated that this person would make meetings and media content accessible to everyone. Thompson asked for an update at the next meeting about the waiver redesign.

Make Your Mark Review:

Emily Koss and Teri Freeman

<https://cbs2iowa.com/news/local/make-your-mark-conference-celebrates-10th-year-empowering-iowans-with-disabilities-to-advocate-for-their-rights#>

Teri Freeman stated that "Lift off to Advocacy" was the theme this year. We had several more sponsors and exhibitors this year than we did last year. Total attendance this year was 159 people, 51 were people with disabilities, 44 were family members/DSP, 27 were professionals, 10 were volunteers, 19 were sponsors, and 18 were exhibitors. Revenue of the conference was \$2,700 in registrations, \$7,750 in sponsors, and \$3,400 in exhibitors which was a total revenue of \$14,330. The total cost to the DD Council was \$39,670. The proposed budget for the conference was \$40,000. 75% of people said they were very satisfied with the conference as a whole, 21% were satisfied, and 3% were neutral. Some of the conference feedback was that people hope for more interactive sessions in the future, smaller group sessions with legislators, and some would like to not have speakers during meal times and more breaks.

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Bergeson stated the keynote speaker with Bitsy was great. Stella was so joyful ringing the bell. She liked the legislative panel and they seemed very engaged. Kelly liked the self-advocacy panel. Werger did an interview with KGAN which is on their website. Werger also stated he was in the hotel pool the night before the conference and was speaking with a man. The man stated he is the owner of 515 Signs in Des Moines and would like to be a sponsor next year for the conference. Hoenig stated that the legislative panel did very well working with each other. Hoenig stated that there were 51 people with disabilities that attended and wonders if there should be more. He suggested providers bring people with them that have disabilities. Cogil asked if we could look into using the exhibitor costs to fund providers to bring people with disabilities. Lovelace asked Emily and Teri to send a survey to exhibitors. Harris asked if we could get a date set for next year. Emily stated that proposals will be sent out around the first of the year. Werger stated he heard from people that the hotel was great. Lovelace stated that advocacy shirts will be available for purchase. <https://www.rayguncustom.com/collections/iowa-developmental-disabilities-council/products/this-is-my-advocacy-shirt>

It was noted that sessions ran over so there was not as much time for exhibitors this year because breaks were short. Breaks may need to be longer next year. Hoenig loved that the Mia Peterson award was given out again. Aller suggested timers for speakers and getting the layout of the hotel the night before. Lovelace stated that volunteers need to be given more instruction on what they are doing and what rooms they are to be in.

Powerpoint presentation:



DD Council MYM!
Presentation 2023 (1)

Public Health Workforce Grant Update:

Mike Lightbody – Center for Disabilities and Development (CDD)

Mike Lightbody stated in March of 2020 Lovelace and him had a conversation about how they were going to support the state and connect to them to resources. Mike Lightbody stated they discussed that it would take a team of 2-3 people to do this work. Covid Recovery Iowa was started through HHS. CDD got involved to be a band-Aid for community mental health centers. Clients would be seen virtually to assist with mental health issues and provide access to resources. In 2022 the name changed to Project Recovery Iowa. There were a lot of people helped with this project via phone and virtually but there were still some people that could not be reached via phone or virtually. They saw the Public Health Workforce funding as a way to reach people in-person. Kelly asked if this program is to get people with developmental disabilities in the workforce. Lightbody stated this program would provide people in the community access to mental health counseling and provide them with access to resources. The CDD would gradually move away from virtually services and move to more in-person services. The CDD has been having focus groups in Iowa City to research emotional wellness related to people with developmental and intellectual disabilities. The next step in this project is to introduce concepts of peer support into the mental health ambassador project. They are currently recruiting and training mental

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health ambassadors. Currently there are approximately twelve people in the state interested in being a mental health ambassador. The end result they are trying to reach is to go throughout the state with the mental health ambassadors and have several small group public health interventions called “house parties.” These house parties would be led by a mental health ambassador with a CDD representative there also. It is the hope that when next disaster occurs, the mental health ambassadors could activate and assist. ISU Extension office is working on a project called “what about me.” This project includes concepts that address mental health, financial assistance, and nutrition. CDD is hoping to build upon the “what about me” curriculum. Hoenig stated mental health ambassadors are being recruited and is concerned training hasn’t been developed. Mike Lightbody stated that training has been developed. It will be one on one training and the training will go on throughout the winter. Werger asked if this project is similar to the Community Living Ambassador program. Mike Lightbody stated this is very similar. The defining difference is mental health ambassadors are less about themselves and more about helping others. Brenneman stated that mental health ambassadors would function in group settings. Cogil asked if mental health ambassadors would go through the mental health first aid courses for part of the training. Mike Lightbody stated it is more psychological first aid training.

State and DD Network Updates:

Evans stated VR currently has an interim administrator. A new administrator, James William, was hired and will start on October 2nd. He is from Texas and identifies as an individual with a disability.

Motsinger stated that the current assessment that they use to determine the level of care and eligibility for the ID waiver is called the SIS (Supports Intensity Scale.) There is a SIS A for adults, and a SIS C for children. A is being updated and current one will not be able to be used after June 2024. Director Matney is having a roundtable discussion with many people and programs across the state because there has been a significant increase in people with ID and cooccurring behavioral health not being able to find providers and/or the daily supportive community living program homes are discharging them in rapid numbers to hospitals. The hospitals then say they won’t treat them because it is a behavioral issue and not a psychiatric issue. Werger stated that the crisis centers are not trained to deal with people with behavioral issues and he brought this up with Governor Reynolds a couple years ago when he met with her. The goal of this group is to make changes in this area. Please attend the HOME meetings if they are in your area. Point in time screening is one of the priorities for the HOME project. The initial draft has been submitted for the point in time screening. The goal is to screen everyone on waitlists to ensure they are on the waitlist for the appropriate waiver and determine if there is a priority needs assessment or emergency needs assessment can be submitted. This would be for individuals who are at risk for fairly rapid institutionalization to get them on waiver services more quickly. Harris asked if people on waivers currently would take the point in time screening to determine if they are on the correct waiver. Motsinger stated that this would only be done for people on the waitlists. They are addressing the waitlist policy and recently had a meeting with Mathematica. Targeted case management and case management through our managed care plans are receiving concerns due to inadequacies. There will be an updated case management specific training and will be required for all case managers to have. American Rescue Plan Act was used to purchase vans, homes, and land and some of these home builds will be completed in the winter so some clients in Glenwood will have homes to go to. Motsinger is

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going around the state doing provider visits to speak with providers that are doing well. The end goal is to have the providers that are doing really well speak with other providers and improve their company culture. Thompson asked, “Is part of the conversation on waitlists evaluating if someone is only waiting for 1 or 2 benefits as opposed to more needs and able to serve just that need versus waiting for full waiver benefits?” Motsinger stated that one of the projects they are working on is called “In lieu of service.” They’re looking at having people on the waitlist be able to access some of these services and managed care plans would pay for these. Motsinger’s team is currently looking at what services would be a part of the “in lieu of service” services. Cogil asked if there will be a form to fill out to provide feedback if people can’t attend the HOME meetings. Lovelace stated there will be 2 virtual sessions. Motsinger provided the following information:

- 1) We have an [expression of interest form](#)! If someone wants to get involved, please have them fill it out. It is super helpful for our outreach and engagement efforts.
- 2) We will share recordings and a summary of engagement events.
- 3) Use this email for questions and comments: iowahcbs@mathematica-mpr.com

Bergeson stated she is learning about HHS.

Lawson stated that children from birth to age 21 have individualized education programs (IEP). In the last couple of years, a new program called “Achieve” has been developed. This program is interactive for IEP teams when they’re developing the plans for the children. All children are in this program now. Families are stating the conversations that they’re having with schools and providers are more meaningful. Lawson stated they are also planning for visits from their federal partners. Brenneman asked if Achieve is now the way the IEP’s are developed and stored and where all interested parties of the children can access. Lawson said that this was correct. Cogil asked if the individualized healthcare plan and student help needs will be a part of Achieve. Also, will school nurses have access? Lawson stated yes to all. Hoenig stated he received an inquiry about a blind student who was recommended to be educated out of state. Hoenig asked why they would recommend the student be educated out of state when services are available in state. Lawson stated that all placement decisions are made at the IEP level. Lawson stated her guess was that there are needs that surpass the level that can be provided in state.

Brenneman stated they are running a family training this fall called “Storytelling for Family Leaders.” Brenneman stated they are closing their pediatric integrated health home (PIHP) and the community circle of care, which serves children with serious emotional disorders. Lack of enrollment is the reason for the closing. The new director of the agency will be Dr. Vanessa Kirks and she will start January 1, 2024.

Council Updates:

Balduf shares DD Council information with the Arc during their meetings. Lovelace asked Balduf to share with the Arc that townhall grants are available. Balduf will check and see if she would like her legislator to come to her work with her.

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Vratsinas will send photos to Lovelace of the MYM! conference.

Thompson stated, "I am reaching out to some local architecture organizations to gauge if there'd be interest in having DD council members come and speak to accessibility."

Cogil stated Guthrie county had their fair. They have a program called Bacon Buddies that involves people with disabilities interacting with animals. She has also reached out to both her local legislators to come to her daughter's work and has not heard back from either. The Iowa Department of Transportation (DOT) is up for a transportation award for adult changing tables being at rest areas in Iowa. The Seizure Smart conference will be on October 14 in Des Moines.

Kelly, Werger, and Aller are going to the Seeking Opportunities for an Advocacy Revolution (SOAR) conference in October.

Lovelace encouraged everyone to complete the DD Council Annual survey and share with others. Link: [Please take our annual survey!](#)

Public Comment:

None

Adjourn: Cogil made a motion to adjourn, and Roozeboom seconded the motion. The meeting adjourned at 2:25 PM.

Action Items: