

Iowa Developmental Disabilities Council Meeting Minutes November 9, 2023

Council Member Attendees:

In Person: Hugh Kelly, Steve Steveson, Kevin Harris, Brady Werger, Paula Motsinger, Roxanne Cogil, Kitty Hedderich, Diane Brenneman, Melissa Lawson, Kitty Hedderich, Emma Bouza, Caitlin Owens, Alecia Balduf, Kristen Aller, George Thompson, Josh Lawrence, Mike Vratsinas
Virtual Attendance: Matthew Conaway, Rob Roozeboom, Amber Gale, Mike Hoenig

Council Staff: Brooke Lovelace, Carlyn Crowe, Lindsay Hommer

Council Members Absent: Brittney Drinovsky, Eric Evans, Julie Bergeson

Members of the Public: John McCalley-Amerigroup Iowa, Morgan Casey, Megan Marsh – Iowa Finance Authority, Tonya Heiman- Iowa Total Care Sandra Hamilton, Destiny McCormick, Jim Kain – Disability Rights Iowa (DRI),

Call to Order:

Council Chair Werger called the Iowa Developmental Disabilities Council (DD Council) meeting to order on November 9, 2023, at 10:30 AM. A quorum was established.

Welcome and Introductions:

All meeting attendees introduced themselves.

Agenda Item/Approval of Minutes and Agenda:

Minutes from the September 14th meeting were approved, Balduf made a motion, Hedderich seconded. Agenda for the November 9th meeting was approved, Brenneman made a motion, Steveson seconded.

Executive Committee (EC) Report:

Actions and Recommendations since September Meeting:

EC reviewed the bylaws meeting minutes from October.

Current Budget Review and 2023 final review:

Lovelace stated there may be a change to the final 2023 budget due to receiving changes from the Health and Human Services (HHS) on the last HHS cost report. We will spend all the 2021 award. 2022 award is also spent. 2023 administrative costs were lower due not having staff for a few months. There is about \$56,000 left of administrative funds.

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

October phone costs are higher than usual due to the Department of Administrative Services (DAS) paying three phone bills at once. This budget sheet shows the 2022 funds are spent and 2021 funds will be spent.

Lovelace reviewed the 2023 obligation chart. It appears that there is \$38,000 unobligated because we didn't spend all our administration costs. Also, there are still some outstanding invoices that will come out of this. Community Ambassadors is now funded at \$5,000. There will be a little left to do some educational opportunities. Funds must be obligated by September 2024.

Bylaws:

Werger stated that there were changes to the bylaws. Lovelace stated that the changes were made to add the Public Policy Committee as a formal committee. This would include a chair and at least four members. The EC would appoint these members. The duties of the committee include proposing a public policy agenda annually, working with the Public Policy Manager to review and track current and proposed legislation impacting persons with developmental disabilities, providing education to the legislature, and other duties as assigned. The Council chair will serve as ex-officio of all committees. Public Policy committee would serve 1-year terms. They may be elected to additional terms. Terms start on July 1 except for this initial appointment. Hoenig wanted to clarify that this committee was previously called the Legislative committee. The conflict-of-Interest policy would also be reviewed and updated annually. EC made the first motion to approve, Aller seconded. Motion is approved.

Public Policy members:

Harris would like to remain the chairperson. Volunteers to join the committee are: Bouza, Thompson, Roozeboom, Owens, Aller

Workplan Review:

This workplan is through September. It does not include what was done in October. Lovelace stated that we have done a better job this year with townhall meetings. There was a townhall hosted by Bouza in August, University Center for Excellence on Developmental Disabilities (UCEDD) hosted one in Iowa City, Realizing Educational and Career Hopes (REACH) hosted one in Iowa City, and family advocate will host one in Council Bluffs in November.

Some posts were made on the DD Council's social media about the election that occurred on Tuesday.

Five advocates attended the Seeking Opportunities for an Advocacy Revolution (SOAR) conference.

We are continuing to work on increasing the members in our network. Crowe suggested a business card- a QR code could be added to our business cards to ask people to join the network. Thompson asked what are social media sources he should be following as a Council member. Lovelace stated there is Facebook, Instagram, Infonet has their own Facebook, and Infonet has a Twitter account. Thompson asked about LinkedIn. Lovelace stated the DD Council is not on LinkedIn, but we can look into this.

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

Lovelace stated the DD Council is funding a small portion of the Community Ambassadors so they can speak at conferences.

In December, there will be a Youth Leadership Academy (YLA) alumni event and they are starting to plan YLA for next summer.

Boards and commissions are downsizing, and we need to see what will happen. We will do a public policy brief once this is decided.

We are assisting the Allies in Advocacy group and they are planning an open house to be held January 24th at the Historical Society.

We still need help with connecting the rural school districts to hold voter and advocacy trainings. In December, there will be a training in Adair, Casey, Guthrie Center (ACGC).

The DD Council has been working with the Disability Innovation Fund grant (DIF), Blueprint for Change. Grant about increasing employment opportunities. Judy Warth is leading the work with the Disability Innovation Fund (DIF) grant that is a \$13 million grant. Lovelace stated that she will invite Judy Warth to a future meeting to discuss the DIF grant.

Lovelace, Derrick Willis, and Catherine from Disability Rights Iowa (DRI) met with new director of the Harkin Institute.

Infonet fall issue came out and included a story about Sarah Young-Bear Brown.

Six people participated in Take Your Legislator to Work day this year. Lovelace encouraged Vratsinas to participate in this next year. He agreed this is a good idea.

Motsinger asked for the acronyms to be attached to the workplan. They are currently in the binders.

EC Meeting times:

Werger stated that it was decided in the EC meeting that Council meetings will be extended by 30 minutes and will now end at 3:00 PM starting in January.

Proclamation:

The Historical Society did a "Civics in Action" exhibit that features Mia Peterson and Sarah Young-Bear Brown and others. The Historical Society wants to honor Mia Peterson and do a proclamation on November 21st and proclaim November 24th, which would have been her 50th birthday, Mia Peterson. Self- Advocacy Day. Lovelace invited council members to attend this. If the Governor cannot attend and read the proclamation, they will invite Terry Branstad to read the proclamation along with Werger. Attendees will be wearing their advocacy shirts if they have one. Hoenig asked that when things like this occur, could an email please be sent to the Council members. Lovelace stated we could do this.

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

Public Policy Committee Update:

Crowe went over the Public Policy agenda. The new publication is at the printer right now. Working together is the theme that includes education, employment, community living, voting, and direct support professionals (DSPs). We will be working on policy briefs for each section. The QR code on the bottom of the publication will take people to the website that will have the policy briefs that are more detailed about each section. The education section talks about the goal, which is that all students receive a quality education, no matter if they're going to public school or non-public school. This issue came about because of the changes that took place last year regarding funding to non-public schools that may affect special education. This section also includes information about supporting comprehensive transition and postsecondary programs. The final point of this section includes supporting training programs for seizure safe schools Wendy Anderson's story about her family from Council Bluffs, connects these points in the publication. She has been working with her legislators sharing their story about their son Dexter. Her son cannot get the services and care he needs in public school and must be homeschooled. This has changed their lives dramatically.

The employment section promotes competitive integrated employment. The Blueprint for Change grant promotes employment first values. Any public funds going to people with disabilities have to be for competitive integrated employment and cannot be sub-minimum wage jobs. The DD Council will be talking with the legislators about what support systems need to be in place and what support VR has lost. Also, the workforce programs the governor is working on will be discussed. JD's story tells how he was supported through VR in Spencer, IA. Once he graduated from high school, VR helped him with a grant and business plan. He now has his own shop and studio where he creates his own art and does welding.

The third section, about independence and community living, focuses on Medicaid funding and eliminating the waiting lists. It also addresses the DSP crisis and wage crisis. Crowe was at a legislative event yesterday and it was shared that 30% of DSPs are on Medicaid. The last bullet addresses the length of time it takes individuals to get an Intellectual Disability diagnosis. It is asking to expand the number of doctors that can give these diagnosis's. The story features Missy's son, Raddix who has Spina Bifida. The initial issue, a couple of years ago, was that Missy couldn't get physical therapy for their son. Now, their issues have multiplied. Raddix was born during the pandemic and was on Medicaid automatically because of that. In April, they were dropped from Medicaid because Missy was unaware of how to reapply for Medicaid. Raddix's doctor prescribed him a wheelchair in April but because he was dropped from Medicaid, the wheelchair was not ordered. Raddix was then placed on Hawk-i, but the wheelchair was denied. There has been no consistent case management if at all. This story highlights tremendous gaps in services.

Crowe shared that the last section is about voting and there will be upcoming changes due to the new Attorney General so we will need to keep a close eye on these changes.

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

Hoenig stated that several years they worked on creating a disability history bill. This bill stated that part of the curriculum in schools would do with teaching disability history. He believes it is important for young people to learn about the struggle that people with disabilities have gone through. He would like to work with policy makers in the future to create another bill like this. Bouza proposed a similar bill last session and hopefully can work to get this passed in the future.

Crowe stated that people who participated in Take Your Legislator to Work day got to talk one on one with their legislators about what people with disabilities need. This is a great way to do advocacy.

Crowe stated that two townhalls were done in Iowa City last week and all townhall's are different. Bouza's townhall was more of an open house and a sensory fair. At another townhall, there were very formal presentations. At yet another, the REACH students talked about what they have been able to accomplish since graduation. There is a townhall coming up in Council Bluffs that Liz Matney will be attending. Events coming up are: January 4th 12 PM virtual open house with legislators, January 24th 2-4 PM is the DD Council's legislative reception at the capitol, January 24th 4:30-6:30 is the Allies in Advocacy open house at the Historical Society. Council members are encouraged to attend the open house and the legislative reception.

Provider Prevention and Support Services:

Bob Lincoln – Project Director at Elevate CCBHC (Certified Community Behavioral Health Clinic)

Bob Lincoln stated that the Provider Prevention and Support Services program was awarded through the Department of Health and Human Services (HHS) on January 1, 2023. This program was the culmination of many years, starting in 2005, in the anticipation that they would be reducing their reliance on the state resource centers. The objective is to build the capacity of the providers to support people that have complex needs associated with intellectual disability and co-occurring mental illness. Previously the only way to support these people was through institutional care. The model they use to deliver this program is the START model. The START model was initiated at the University of New Hampshire in 1988. This model was brought to one region in 2015. The START model is an interdisciplinary approach to providing mental health intervention for individuals with intellectual disabilities and co-occurring mental illness. Relatively speaking, mental illness in people with intellectual disabilities is considered a fairly new thing. Mental health symptoms used to be addressed as behaviors. This program takes a comprehensive assessment of the person to determine the real issues. The assessment is a biopsychosocial assessment. This assessment determines if there is a co-occurring genetic disorder and/or a medical condition. This assessment also determines if there is any trauma, depression, psychosis, treatment needs, does the person have friends, and is the person part of the community. The product that is developed for the person, after the assessment is complete, is called a cross systems crisis plan. They try to identify areas of crisis or stress in the person's life and come up with strategies of ways to support the person. The way this is done is by a team, led by a psychiatrist. The team does a deep dive to determine if there are any other variables affecting the person. There has been a long-term collaboration with the University of Iowa for this project. The University's Psychology department is part of the team. There is also a Clinical Director on the team who is a licensed mental health counselor. She

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

is the primary quality assurance person on the team. The Director, Tiffany, oversees the team. Members of the team are located throughout the state of Iowa. Each professional on the team has a collaborating team across the nation. All the work that is done in Iowa is collected and entered into a national database. The START model is used in California, New York, Colorado, Tennessee, North Carolina and is 30 years old. This is the go-to model to use for people that fall out of the traditional setting.

Lawrence asked if I-START and START are the same thing. Bob Lincoln said yes, they are the same thing.

Motsinger asked if Bob Lincoln could expand a little more. If someone is on a waiver and living in a waiver home, if they are taken to the hospital because of their behaviors, what can this program do? Bob Lincoln stated this program could start a deep dive and do a biopsychosocial assessment. Once that person was in the program, if the person was brought back to the hospital, there would be a plan in place on how to support this person.

Bob Lincoln stated that this is a public health model, and they are trying to educate hospitals and law enforcement about it.

Aller asked what CCBHC means. Bob Lincoln stated it means certified community behavioral health clinic. This model is very different because it integrates substance abuse treatment with mental health treatment and a focus on chronic medical conditions.

Cogil asked if someone is over the age of 18 and has an intellectual disability (ID) and mental health issues and are on the brain injury (BI) waiver, why are they not eligible? Bob Lincoln stated it comes down to funding. Funding is through grant, and it is only for four years. Cogil asked if people on the ID waiver waitlist can be served. Bob Lincoln stated that they could not. Bob Lincoln stated the team could provide consultation though.

Bob Lincoln stated that one Managed Care Organization (MCO) is in talks to expand this program because sooner the intervention, better the outcome.

Lovelace asked Bob Lincoln to clarify that this program is for anybody in the state. Bob Lincoln stated they can serve anybody with an intellectual disability and a co-occurring mental illness.

Werger stated he has struggled throughout his life with mental health and is really glad to hear this program works with local law enforcement.

Brenneman wanted to clarify that youth 6-17 need to be residing in a residential setting. Bob Lincoln stated that this is correct.

Bob Lincoln stated that people with lived experience are a powerful component to effective service delivery.

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

Bob Lincoln stated that an IRSH is an intensive residential support home. They will be opening a fifth IRSH to support individuals. IRSH will be an alternative to using law enforcement and/or psychiatric housing. Hoenig asked how many IRSH's there will be and where they will be located. Bob Lincoln stated that there is a need for 120 beds. The fourth IRSH just opened. They are in Spirit Lake, Sioux City, Council Bluffs, and Burlington. A person can be in an IRSH for up to a year opposed to a crisis center which is a 2-5 day stay. Harris asked how IRSH's are created and maintained. Bob Lincoln stated these are created in DHS regions. There is supposed to be one within 120 miles of anyone in the state.

2023 Annual Survey Review:

Emily Koss and Teri Freeman

Emily Koss stated that there were 139 total responses of people that has used resources or had engagement in some way with the DD Council. A majority of people responding were family members. 89% respondents are white, 65% were female, 30 % were male, 55% lived in an urban area, and 70% attended a DD Council event or InfoNET event in 2023.

98% of respondents were satisfied or very satisfied with the information that was provided. Lovelace stated that some of the questions asked are a federal requirement. Last year there were a lot of responses from people who didn't use the resources. This year, those responses were not used in the results.

31% of respondents are likely to vote in an upcoming election and 65% already vote in major elections.

76% of respondents had a conversation with their legislators and 16% thought they saw a change as a result of this conversation. 51% used infoNET's Take Action Center and 80% used infoNET's Guide to the Iowa Legislature.

63% of respondents identified as a person with a disability, 71 were family members, and 72 people responded that they were another type of advocate.

70% of respondents did attend a DD Council event or infoNET event. For people who didn't attend, they were asked why they did not. Some of the responses were timing issues, not knowing about the events, and transportation challenges.

98% of respondents used some type of resource. There were two responses as to why people did not use resources. The responses were, they were still learning what resources are available and they are still researching IABLE for their family member.

86% stated that their advocacy efforts have increased because of the Council's resources. There were many responses as to how their advocacy efforts have increased. Harris stated that there were a lot of comments written in and asked if this is typical. Lovelace stated there were more responses received this year compared to last.

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

95% stated they were able to say what they want and what's important to them.

Aller stated that some of the questions sounded the same as previous questions.

Overall, 98% of respondents were very satisfied or satisfied with the resources the DD Council provides. The legislative guide was stated as being the most helpful from respondents. Emily Koss stated some respondents stated we could improve resources by adding pictures and descriptions. There were a handful of people that stated they do not generally use a computer or email.

Teri Freeman stated that a majority of the respondents contacted an elected official, convinced others to take action, encouraged another person to register and vote, and got involved with local causes. A majority of respondents did not serve on an advisory board, disability coalition, policy board or council, or volunteer on a campaign. 50% served in a leadership role in their community.

Lovelace stated someone provided a response and stated they would like more information about iAble. Lovelace asked Teri and Emily to find out who this is and send them information.

A majority of respondents are more likely to vote in upcoming elections due to their involvement with the DD Council and most spoke to their elected official. Most people who did not speak with their elected official stated they did not have time.

About 50% of respondents used the Take Action Center.

80% of respondents used the Iowa Legislative guide and felt it was helpful. The most common answer from those who did not use the Legislative guide was that they were not aware of it. A majority of respondents stated they will talk to their elected officials in 2024 about direct care workforce, education, employment, home and community-based services (HCBS) waiver waiting lists, housing, Medicaid funding, Medicaid managed care, public transportation, and mental health and disability services.

The sexual identity of respondents was 78% were straight, 14% chose not to answer, 4% lesbian or gay, 4% were bisexual, 1% was none, and 1% was gender fluid. 55% urban.

40% of respondents live in a rural area and 5% are not sure.

43% would like to share their stories with the DD Council.

Lovelace stated someone said the survey is too long and it is hard for people with intellectual disabilities to do. Owens stated an option could be a plain language survey. Hoenig said sometimes the questions are tricky. Aller stated the length and language of some of the questions were hard to understand. Lovelace stated people could call and we would walk them through the survey.

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

Lawrence asked how many total responses there were. Emily Koss stated that is hard to answer because of the spam responses. 139 of responses were people who used resources. There were some respondents who completed the survey but did not use any of the resources or attend an event. Teri Freeman stated there are 2,300 people on the email list and the mailing list is more than that. Harris asked if there is a way to see the comments from family members vs a person with disability. Emily Koss stated they are working on that now. Lovelace stated the raw data on the Excel spreadsheet will be sent out.

SOAR Conference Review:

Kelly stated that the keynote speaker did a very good job. He started his own business. He really liked the two breakout sessions also. Kelly enjoyed the breakout sessions the most.

Aller learned that Nebraska has a bill about how to do advocacy in practice. It requires the state to have a disability statement about how it will impact the state and each person. She stated they also talked about the conference that some disabilities aren't visible. They also talked about how to teach self-advocates to teach others. Aller would like to attend the next conference in Omaha, Ne.

Vratsinas really enjoyed the keynote speaker and the first breakout session. The session was about how the Kansas University UCEDD is involved in research. He feels that he did a lot of great networking at this conference.

Hoenig went to a breakout session about relationships where safety and finances were addressed. This was the highlight of the conference for him. He also went to a breakout session about the settings rule, and he has a lot more to learn about this. He also thought the keynote speaker was very good. Partners in Policy making was mentioned and we did this in Iowa 30 years ago. He would like at some point for the Council to get that going again in Iowa. Hoenig and Crowe had a discussion about how the states around us have self-advocacy groups and now Iowa does too with the Allies in Advocacy. Hoenig stated he learned we are a DD Network family.

Werger stated he had a great time at the conference. A woman was speaking with him about advocacy at the conference who he did not know. She gave him a good perspective about how to speak to legislators and that you need to have a plan about what to talk about.

Crowe stated that self-advocacy coalition of Kansas (SACK) was very impressive and helped organize the conference. They did the closing session and focused on the theme of starting a revolution which was impressive.

State and DD Network Updates:

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

Motsinger stated that they are working on a waiver redesign right now. The plan is to go from seven waivers down to two waivers. Services and supports will be more available to more people. Waiver slots are being released but there are not enough service providers right now. Infrastructure for providers needs to be invested in before reducing waiver lists. Bob Lincoln's program is funded through a five-year grant and when this ends, they are not sure how these supports are going to be maintained. In the last meeting she shared that they have submitted waiver amendments to make sure they can move forward with the flexibilities they want to keep. They are still waiting to hear from Centers for Medicare and Medicaid Services (CMS) about these. Parents and family members as caregivers will help close the provider gap that we have now. The HOMETown conversation that are happening now need members to attend because this is a critical time. They want to submit waiver packages in Spring of 2024. They have had great turnout so far and there are three meetings left. The meetings coming up are in Ft Dodge on the 13th, Sioux City on the 15th, and Council Bluffs on the 16th. There is also virtual option. More can be found out here; <https://hhs.iowa.gov/ime/HOME/hometown-conversations> Transportation is a continuing issue that is also brought up in these meetings. People with lived experiences need to share their stories about this at the meetings. Cogil asked if people bring up Consumer Choice Option (CCO) at these meetings. Motsinger said they do. Thompson asked if there is a way to identify if people are on a waiver and cannot find services but are then being kicked off for not using services. Motsinger stated that there is an exception to policy that they can do but there are federal requirements they need to follow. Lawrence asked if there have been any changes to hold the providers responsible when they are declining to take on clients. Lawrence stated that it appears providers are cherry picking their clients. Motsinger stated they cannot force a provider to provide services and providers are saying that they don't have the wraparound supports to care for some people.

Brenneman stated there will be a family training happening in Cedar Falls this year. The goal is to have a family member at every table where decisions involving children and youth with special health needs are made. Brenneman asked for recommendations from DD Council members of families they know that could benefit from this training.

Council Updates:

Balduf shared that she learned at the Autism conference that people with autism have different behaviors. She also shared handouts that she received that have pictures on them that help some people with autism communicate.

Cogil stated that the Iowa Miss Amazing Pageant is for people with disabilities ages 5 -36. Their pageant will be held on January 13th at Urbandale high school. They are looking for one on one mentors to assist with this.

Public Comment:

Sandra Hanson stated that this meeting is very interesting. She understands the shortage of DSPs and it is very critical to get more DSPs.

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

Bob Lincoln stated their annual conference is September 12th at Prairie Meadows and would like to partner with the DD Council. Costs can be waived for anybody who isn't able to pay and would like to attend. There will be scholarships available also.

John McCally is with Amerigroup. They have pivoted to start focusing on whole health. Amerigroup has partnered with UCEDD to focus on webinars that are about health equity. There will be thirteen webinars and their rollout will be in February of 2024. He is requesting 10-15 minutes during one of the 2024 meetings to promote the webinars.

Adjourn:

Aller made a motion to adjourn, and Steveson seconded the motion. The meeting adjourned at 2:33 PM.

Action Items:

Lovelace will investigate getting the DD Council on LinkedIn.

Hommer will send raw survey data that is on Excel spreadsheet out.