

Iowa Developmental Disabilities Council Meeting Minutes January 11, 2024

Council Member Attendees:

In Person: Hugh Kelly, Steve Steveson, Kevin Harris, Brady Werger, Kitty Hedderich, Alecia Balduf, George Thompson, Eric Evans, Julie Bergeson

Virtual Attendance: Matthew Conaway, Rob Roozeboom, Amber Gale, Mike Hoenig, Kristen Aller, Roxanne Cogil, Paula Motsinger, Diane Brenneman, Caitlin Owens, Joshua Lawrence, Emma Bouza, Mike Vratsinas, Melissa Lawson

Council Staff: Brooke Lovelace, Carlyn Crowe, Lindsay Hommer

Council Members Absent: Brittney Drinovsky

Members of the Public: Dr. James Williams, Jim Kain – Disability Rights Iowa (DRI), Connie Fanselow – Aging and Disability Services, William Lloyd – Director of UI Reach, Christy Kaiser – Molina Healthcare, Maggie Fergeson – Iowa Health and Human Services, Anne Crotty – ADA Coordinator, Jeffrey Lund, Kevin McRae – Goodwill services, Tim

Call to Order:

Council Chair Werger called the Iowa Developmental Disabilities Council (DD Council) meeting to order on January 11, 2024, at 10:34 AM. A quorum was established.

Welcome and Introductions:

All meeting attendees introduced themselves.

Agenda Item/Approval of Minutes and Agenda:

Minutes from November 9th meeting were approved, Balduf made a motion, Hedderich seconded. Agenda for the January 11th meeting was approved, Steveson made a motion, Aller seconded.

Executive Committee (EC) Report:

Current Budget Review:

Lovelace reviewed the December 2023 budget sheet. There has been \$5,700 spent on Council travel and support in three months. Lovelace stated we will most likely go over this line item this year. There is more Council involvement this year with events. Lovelace is encouraging everyone to attend the legislative reception on January 24th. We will reimburse for travel, and this will add to the spending on this line item.

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National dues and out of state travel has also increased. Yearly national dues are approximately \$6,500. There are three more conferences coming up this year. Two are in Washington DC and Washington DC is very expensive. Harris asked if the Council is able to request more funds for next year award. Lovelace stated that the DD Council appropriation has remained the same for five years. There is not an approved federal budget for FFY24 yet so, we have not received our total amount for the year yet. We could see a cut to our budget. We are still within our administrative cap though. Lovelace stated we could start looking at grants to fund projects. Judy Warth suggested when she was on the Council that the Council asks for more funds from the State. Lovelace stated we can only use the current years funding for administration.

Lovelace shared the spending chart. Hommer will change "sponsorship" on spending chart.

Lovelace shared the obligation chart. Hommer will change "sponsorship" on obligation chart.

Legislative Reception:

January 24, 2-4 PM at the state capitol. Werger asked for all Council members to be there at 1:30 PM. Please ask your legislators to attend. Crowe sent out invite for legislative reception for Council members to share. Twelve people are planning to attend currently. Cinnamon rolls will be served at the reception.

Allies in Advocacy will be having an open house from 4:30-6 PM on January 24th at the Iowa Historical Society. The Civics in Action exhibit will be available to see. There will be a taco bar. Hoenig asked if the Allies in Advocacy agenda follows the DD Council agenda. Lovelace stated they are going to talk about direct workforce issues, finding help at home, and how advocacy works. Lovelace stated it's more of a networking event and there will be a short presentation. There is an Allies in Advocacy Facebook page called Iowa Allies in Advocacy. Cogil asked if the Allies in Advocacy group addresses just disability issues. Lovelace stated at this time, yes.

Succession Plan:

Three Council members, Kelly, Roozeboom, and Werger are ending their terms on the Council in June 2025. Cogil ends her term on the Council in June 2024. The EC may have members step down so there can be new members on the EC. According to the Bylaws, the DD Council chair must serve on the EC for at least one year before being able to be the chair of the Council. If anyone is interested in serving on the EC, reach out to Lovelace or Werger.

Make Your Mark Volunteers:

Volunteers for the planning committee are Bergeson, Kelly, and Werger. Hoenig offered to help with the accessibility aspect of the conference.

Workplan Review:

Hoenig asked where we were at regarding educating poll workers, Section 1.1, activity 4. Lovelace stated that the Secretary of State (SOS) asked for more funds from the legislature to train poll workers. We will assist the SOS if they would like. Hoenig stated DRI used to have funds for training poll workers and

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asked if there are still funds for this. Jim Kain said there are still funds and would like to work with the DD Council to utilize these funds.

Hoenig asked about Section 1.2 and the intern activity. Lovelace stated we do not have the funding for this right now and cannot find someone with a disability who wants to do policy work as an intern. Lovelace stated we are trying to figure out how to make this work. Amy Campbell through InfoNet did pay Libby Schwerts to do some work. The Council also paid Schwerts to do some work with the Allies in Advocacy marketing.

Hoenig asked about 2.1, distributing documents in plain language to legislators. Lovelace stated we continue to work with legislators and encourage them to get input from people with disabilities.

New Vocational Rehabilitation Director Dr. James Williams:

James Williams – Director of Vocational Rehabilitation

Dr. Williams has a background as a special education teacher in Texas. He has a passion working with people with disabilities. He became a certified rehabilitation counselor and got his master's degree in rehab counseling. He then worked for a provider in the Houston area where he placed people with disabilities into employment. He then managed a provider that served six states. This is his first time being a VR director. He is a person with a disability and was served as a VR customer. His doctoral degree is in educational leadership and his focus was on individuals with autism 26 years or older and what their parents did or didn't do that led to a successful employment outcome. He found that parents having higher expectations led to better outcomes.

VR undertook a big change with the realignment under Iowa Workforce Development (IWD). The reporting structure changed and now VR gets a lot of attention which is good. There have been challenges moving from the Department of Education as far as changing processes. One of the best benefits being under IWD now is the focus on work. Clients are getting all the benefits that IWD offers. VR is looking for more training opportunities in the future and working with the DD Council.

Another focus of VR is how VR can be more intentional about how they work with businesses. IWD has a division called business engagement that works with businesses across the state to help Iowans get jobs. VR is looking at how they can collaborate with this division.

Hoenig stated that when VR was under Dept of Education there was a focus on transitioning students. Hoenig asked if this is still a focus. Dr. Williams stated this is still a focus but, this is harder now because they are not a part of the Dept of Education. VR wants to do more work-based learning in supporting people with disabilities. They would like to have even more collaboration with Dept of Education.

Werger stated there are people with disabilities that have graduated high school but do not have the funds to go to college. Is there anything that can be done in Iowa to provide vocational training for them. Job Corps has an age limit and Werger asked if Iowa could make more opportunities available. Dr. Williams stated that before programming is looked at, the relationship with the schools needs to be

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solid. VR would like to improve relationships and strengthen relationships with schools. VR would like to do a pilot program in a region and see if that works first. Per pupil spending in Iowa is high and results are not. Dr. Williams would like to know what more can VR be doing for students and transitioning. Evans stated that if people are on benefits and have decided on a program in school, VR will totally or partially fund the student's education. Evans stated they need to take another look at the Realizing Educational and Career Hopes (REACH) program. Werger suggested re-looking at the age limits for programs. William Lloyd stated there also needs to be some supports in place for people with disabilities in the workplace. Support amounts would need to be highly individualized. William Lloyd stated the REACH program is willing to participate in discussions on how to get supports in place. Brenneman stated they are hearing from family members that there are not enough funds for VR counselors to serve the students. Is there any talk about growing these funds? Dr. Williams would like to draw more funds from the federal funds and pull the full match for VR. Also, he would like to see full time employee (FTE) caps increased. If they cannot get these funds increased, it will need to be figured out how to make processes more efficient. Also, they are looking at how they allocate their resources. Finally, VR is asking the legislature for funds to revamp their case management system that is 25 years old.

Last year, Cogil's son was a senior in high school and was needing assistance from the VR for both part-time employment and assistance in figuring out his career path and future. Her son was not allowed through VR to receive services for part-time employment and long-term goals at the same time. She suggested when VR looks at reallocating resources, please keep this in mind. Dr. Williams would like to assist anyone if they have questions and invited them to contact him at James.williams@iwd.iowa.gov

Public Comment:

William Lloyd praised the DD Council for their work and their support.

Public Policy Committee Update:

Crowe shared the Public Policy agenda. The virtual open house was held last week. Harris stated there was good attendance and legislators from both parties joined. Crowe stated there were more legislators that attended than in the past.

Crowe stated that funding for VR is a priority and is in the DD Council policy agenda. Prior to this meeting, Crowe spoke with the VR Finance director to get better understanding about the federal match.

All the grants for capitol advocacy days have been spoken for. Six groups are confirmed to come. Several other groups are coming that will not receive grant funds.

The Public Policy committee is meeting every other week now during session. Everyone is invited to those meetings.

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Amy Campbell has hired an intern who is working on policy analysis. She is a Drake journalism student. Bill of the Week will be introduced which focuses on one bill that is being worked on. The weekly video will focus on Bill of the Week. This week the focus is on comprehensive transition programs. The bill addressing this has moved out of the house and is now in the Senate. On Tuesday the video will come out about this. Crowe stated there are some bills that have been introduced and many more in the works. Representative Josh Turek is working on sixteen bills that are all disability related. He knows half of them won't be introduced but, just putting them together gives other states and legislators opportunities to see policies that could be worked on. Bills introduced by the minority party don't get very much attention so, Representative Turek is trying to get bipartisan support. He is working on language for the ID (intellectual disability) diagnosis that is in the public policy agenda.

Crowe stated we are focusing on education right now. A bill came out yesterday about education that is 120+ pages long. There is a lot of administrative stuff in this bill. Our support will really focus on the individuals that will be impacted. Crowe would like to have input from the Council about AEAs. The DD Council is thinking of sending a letter to the governor and/or doing a townhall meeting as soon as next week about the education reformation.

Lawson stated that up to this point there are nine AEA's in Iowa. There were fifteen and now there are nine. The AEA's provide general education services, special education services, and technology and media services. District special education dollars were sent directly to AEA's to do all evaluations and determine if students are qualified for special education services. In the condition of the state address, the governor stated the core mission of the AEA's when they were introduced was special education. Lawson says is that some believe they have grown outside of the capacity of their original intent. [House Study Bill 542](#), on pages 30-31 is where a lot of the information about special education is. The governor is proposing in that bill that AEAs have one more year as a transition period. They are restructuring so special education is its own department. There will be a deputy director, two division administrators, and four special education bureau chiefs. Several positions were just posted. One position that will be very helpful will have a greater focus on secondary transition. One of Lawson's roles is to investigate complaints parents send in regarding the Disabilities Education Act. They have had concerns about secondary transitions and there will now be an administrative consultant specifically for secondary transition. The special education team will increase from 20 people to 139. The districts will get the funds for special education, and they will then decide whether they want to opt in to the AEA system or whether they want to opt out. There will also be a hybrid option. 0-3 years olds services will continue to be provided by AEAs. Hoenig asked what is going to happen to the AEAs. Lawson stated that in the past, the special education dollars went directly to AEAs. Now, the dollars will go to the school districts, then they will decide how to spend them. There is a one-page overview that has been written for families. [One-Page Overview for Families](#) Brenneman said that the Governor said school districts can contract with private providers. The problem is that so many of the rural areas don't have these providers. Lawson stated that school districts have a deadline, that by the end of April, they have to state their intent as to whether they want to opt in or out of AEA services. Harris stated that providers in the community are not going to be versed on IEP (individualized education program) requirements. Harris also stated that it was interesting at our open house last week, Senator Taylor stated there was no talk

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about a change to the AEA's. Then the news broke this week that there are major changes happening. Harris also said that 0-3 years olds have no services in the summer due to funding and this disrupts progress. Also, K-12 needs support in the summer.

. Owens stated systems need reformed but there are unintended consequences to huge systems changes. The speed of this change may cause problems. Crowe stated a couple problems with the bill are the services will be working against each other and the teacher salary increases are in this bill. Lawson stated that the schools will now be in charge of general supervision. Thompson asked if the premise is the efficacy of dollars based on test scores. Crowe stated we have asked for more information from the governor's office. Thompson stated test scores did not mean anything for his daughter. Harris also wondered how AEA's will fit into non-public schools going forward. The virtual townhall about this will be next Thursday 6 PM, tentatively.

Health and Human Services ADA Coordinator:

Anne Crotty-ADA (Americans with Disabilities Act) Coordinator

Anne Crotty is from Marshalltown, IA and attended the University of Northern Iowa. She has a master's in public health and has experience working with children, older adults, people with Alzheimer's and dementia, and people with IDD (intellectual and developmental disabilities).

Anne Crotty shared a graphic that showed the differences between exclusion, segregation, integration, inclusion, and belonging. The purpose of the ADA is to make society fully accessible to people with disabilities and ensure that people with disabilities have the same rights and opportunities as everybody else. There are five sections to the ADA. Section II, Public Services, will be the focus of this presentation. State and local requirements prohibit discrimination based on disability, require government entities to provide reasonable accommodations to make programs, services, and activities accessible, cannot deny or force participation in separate programs, and all states must follow these guidelines regardless of size. Government entities are encouraged to consult with the person assure needs are met.

Modifications can be turned down if the result would be a fundamental alteration of basic nature of the program service, the modifications threaten others safety, or the modification results in undue financial or administrative burden. If the entity is turning down the modification, they must find an alternative. The goal is to have communication be as effective for people with disabilities as it is for people without disabilities. An entity with 50+ employees must have a grievance procedure and an employee to coordinate the agency's efforts to comply with ADA. The ADA is regulated and enforced by the US Department of Justice.

The role of the ADA coordinator is promoting ADA compliance, receive and process accommodation requests, develop trainings on disability inclusion, collaborate with partners to eliminate disparities that impact people with disabilities, and to participate in data management, quality improvement, and strategic planning initiatives. Some current projects that are being worked on are accessibility of web and print communication, health equity assessment, develop and deliver staff trainings, building capacity among HHS staff on disability inclusion, and outreach to diverse populations with disabilities through commissions. Lovelace stated that she would like to work with Anne Crotty on reaching underserved populations. Some disability inclusion projects that are being worked on are juvenile

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justice, diabetes, hearing screenings, and children's mental health. Some of the training topics Anne Crotty would like to do are ADA and disability inclusion, panel of people with disabilities and family members, hosting accessible hybrid meetings, and 508 compliance. Complicit bias as it relates to disability is another project Anne Crotty would like to work on. 508 is the standard that makes sure websites are accessible to people with disabilities. Jim Kain stated DRI just made their website accessible and offered them as a resource if needed.

Harris stated she spoke about charging different rates earlier and he sees this a lot with accessible hotel rooms. There is always an upcharge. How is that allowed? Crotty was not aware of this. Harris asked who people can report this to. Crotty stated it would be to the DOJ [The Americans with Disabilities Act | ADA.gov](https://www.ada.gov/). There is a form on the website to fill out. Anne Crotty stated the Supreme Court just threw out a case where a hotel got sued for not providing information about accessibility on their website. The supreme court protected people with disabilities in this case. Anne Crotty will look into hotels up charging accessible rooms.

Bouza stated that she went to an event and people who needed accessible parking were made to pay but there was free parking available across the street but no accessible parking spots. This is why Anne Crotty believes we need implicit bias training. Some of these trainings will be available to everyone and some will be for HHS staff.

Overview of Child Health Specialty Clinics:

Diane Brenneman

The Child Health Specialty Clinics is a series of twelve clinics spread throughout the state in underserved areas. They are funded by Title V of the Social Security Act and have been in service for 87 years. Most of their time is spent on infrastructure building, less is spent on population-based services, even less on enabling services, and the least on direct services. 143,000 families in the US have a child with special healthcare needs. Dr. Vanessa Curtis is their new director.

The two areas that Brenneman is involved in are Iowa Family Leadership Training Institute (IFLTI) and Storytelling for Families. They believe that there needs to be a family member at every table where decisions about children are made. They train families on how to tell their story and advocacy. They also give trainings on conflict communication. They are currently wrapping up their application period for IFLTI. Brenneman created a set of narrated slides that tells Iowa's history and what is being done today at the Iowa Health Specialty Clinics.

Hoenig stated that so much of training that is offered by Brenneman would be very beneficial to people with lived experience.

Conaway asked if the storytelling session employ narrative medicine principles. Brenneman stated that they do not. Their trainings are largely based on something called Parents as Presenters that came out of the Department of Education. Their digital storytelling is based on some training from Story Center.

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Links:

Digital stories: <https://youtu.be/stVNMXFFXL4>
[history of Iowa advocacy video including CHSC](#)

IFLTI YouTube Channel: <https://www.youtube.com/@iowafamilyleadership>

LEND application: <https://ucedd.uihc.org/iowa-lend>

Overview of Center for Disabilities and Development:

Caitlin Owens – University Center for Disabilities and Development (UCEDD)

The Center for Disabilities and Development is in Iowa City. There are four main things they do. Clinical services, UCEDD, Leadership Education in Neurodevelopmental and related disabilities (LEND), and Iowa's Hawkeye Intellectual and Developmental Disabilities Research Center (Hawkeye-IDDRC). Big initiatives that the UCEDD focuses on are patient care, education, community and systems, and research. Their clinical services do diagnosis and treatment of children and youth neurodevelopmental disorders. They also do some services for adult patients. Over 50% of patients that they see had Medicaid as one of their payors. Last year, staff performed nearly 14,600 evaluations of children with autism and developmental disorders.

LEND is grant funded program that is federally funded. There are sixty LEND programs across the country. The program has expanded from traditional grad students as their focus, to now include anyone who might want to work with people with disabilities as their career. Also included are people with disabilities, family members, and community members. LEND students learn about patient and family centered care, disability policy and advocacy, and leadership skills. They are currently recruiting for the 2024-2025 school year. <https://ucedd.uihc.org/iowa-lend-apply-contact-us>

UCEDD is also federally funded. They work with people with disabilities, their families, state and local government agencies, and community providers on projects that provide training, technical assistance, direct service, research, and information sharing, with a focus on building the capacity of communities to support all their residents.

Money Follows the Person program is a focus. They also do a lot of work regarding employment, direct services, self-advocacy, health and wellness, behavioral health, and information and referral services. Some examples of work that the Iowa UCEDD does is Iowa Compass, Iowa Blueprint for Change, Money Follows the Person, Center for Excellence for Behavioral Health, and Technical Assistance to Iowa Department of Health and Human Services.

IDDRC's are federally funded centers who do research on how to prevent and treat disabilities through biomedical and behavioral research.

Harris asked if you have to be in a graduate program in order to get the LEND training. Owens stated you do not have to be in a graduate program. Harris asked if the LEND program could be part of the curriculum for students to take who are going into fields that include working with people with

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disabilities. Hoenig stated that for many years there was a devoted funding stream for the LEND program. Trainings with providers are upon request. Current trainings are virtual and happen about every six weeks.

Council Updates:

Motsinger's updates via email:

1) Gearing up for legislative session

- a. *There will be a large focus on our HOME project and the waiver redesign so we are preparing for and anticipating conversations related to the benefits of supporting the redesign*

2) Needs on Waitlist (NOW) Surveys -gearing up and letters are going out to individuals

- a. *These are surveys for individuals who are currently on waitlists for one of our HCBS waivers. We hope to learn more about specific supports that are needed for lowans in need of waiver services.*
- b. *The responses will help HHS improve our system to meet the needs of lowans*
- c. *Participation is voluntary and if people chose not to participate, it will not impact their waitlist status.*
- d. *Will help connect people to resources while waiting on waiver waitlist*

3) Website updates

- a. *We know some links are broken*
- b. *We are prioritizing HCBS links that need fixed*
- c. *Apologize for the inconvenience*
- d. *If there are links that are broken and you need information, please reach out*

4) Electronic Visit Verification

- a. *Went live January 1 for home health services. So far, the go live is going well.*

Bergeson from Aging and Disability Services stated they just finalized their organization chart. Their director is Zach Rhein and he has spent the last six months trying to get out and meet with groups and individuals. There is progress happening with the Hope and Opportunity in Many Environments (HOME) project. Screening of individuals on the waitlist will be starting at the end of February. Thompson asked if the point in time screening intent is to find people who might be served without the whole waiver? Bergeson stated that Motsinger would be more able to answer that question but, it is a way to get a snapshot of those people's needs. The Aging and Disability Services division, along with the DD Council and others, submitted an application for a technical assistance project opportunity called Bridging the Gap Between Aging and Disability. They will hear at the end of January if it is awarded.

Evans stated due to budgets VR had to put people on waitlists. They are serving thousands of more people than they did five or six years ago with the same amount of staff. They hope this is temporary and they get offices back where they need to be, then they will look at the waitlist. Right now, staff is over capacity.

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Jim Kain with DRI stated they set their public policy agenda for 2024. This is on their website under policy advocacy. The four areas that they are focusing on are special education, employment, voting, and home and community-based services. Website is: <http://www.disabilityrightsiowa.org/>

Steveson's daughter is a new client of VR.

Werger shared that his sister was sent out of state for placement. After four years, she just got approved for the brain injury waiver and will be able to move back to Iowa for services. Motsinger was instrumental for this success. Werger is moving to his own apartment in three weeks. This will allow him more independence because he will be able to walk places.

Cogil stated it was great seeing people at the Iowa Energy basketball game. The Iowa Miss Amazing pageant has been postponed.

Lovelace stated that Harris asked about subsidizing funding for students to get their certifications through community colleges to work with people with disabilities. Lovelace is looking into this. The annual magazine is done and at the printers. Lovelace also shared the business cards with QR codes for people to easily join our network

Balduf shared that the ARC of northcentral Iowa had a conference.

Bouza took the iAble training in July. She works at a high school and conducted an iAble training in her school.

Public Comment:

Dr. Williams will be at the legislative reception at the capitol on January 24th.

Adjourn:

Hedderich made a motion to adjourn, and Aller seconded the motion. The meeting adjourned at 2:32PM.

Action Items:

Hommer will send Brenneman's DCCH Year in Review out with meeting minutes.
Hommer will send the NACDD Grant application out with meeting minutes.

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