

Iowa Developmental Disabilities Council Meeting Minutes March 10, 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, Roxanne Cogil, Mark Schneider, Jason Goulden, Brittney Funston, Paula Motsinger, Steve Steveson, Carol Cross, Tiffany Poage, Scott Lyon, Amber Gale, Rob Roozeboom, Mark Smith

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

Council Members Absent:

Members of the Public: Tammie Amsbaugh, Monte Hall, Michael Martin, John McCalley, Eric Evans, Connie Fanselow, Nicole Nosbisch, Monnie Hall, Michael Martin, Wendy Peterson-Buley, Michelle Arenholtz, Sam Blatt

Call to Order:

Council Chair Fagerlund called the Iowa Developmental Disabilities Council (DD Council) meeting to order on March 10, 2022, at 10:30AM. 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 January 13, 2022 meeting and today's agenda, Aller seconded. Motion passed.

Executive Committee (EC) report:

Actions and Recommendations since January Meeting:

None

Budget Review:

The 2020 funds we have about \$6000 left to spend which needs to be spent by September. This will be spent by the end of this month. The 2021 funds are all obligated but not spent yet. The 2022 funds only have administrative costs coming out right now.

On the obligation charts, for 2020 and 2021 all the funds are obligated.

The budget detail was provided to all.

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Executive Committee Nomination Committee:

Fagerlund stated we have two openings on the EC committee starting in July. We need three volunteers for the election committee. This committee will assist Lovelace and go through nominations for the EC committee. Funston, Roozeboom, and Fisher volunteered for this committee. The election will be held during the May meeting to appoint two council members to the EC.

Administration on Community Living (ACL) Public Health Funding:

ACL released funding that we could apply for. We did apply and received \$95,319 in funds. These funds are to do public health related outreach. Our plan is partner with University Centers for Excellence in Developmental Disabilities (UCEDD) as the funding was not enough for the DD Council to hire someone. This person will go into the community to visit with people with disabilities pertaining to health needs and/or Covid. UCEDD is putting together a proposal for this. We will vote on this during the May meeting. Cogil supports what this grant is being used for. Fagerlund asked if ACL asked for a plan of how we will spend this. Lovelace stated they have not asked for one but may in the future.

State Plan Work Plan Review:

Lovelace shared the state plan work plan. Fisher asked if Kallestad could change the capitol chat day to a Tuesday or Thursday. Kallestad stated Fridays work the best because it's the end of the week at the capitol and we can summarize in real time what has happened during the week. Also, Amy Campbell can only attend Fridays during the legislative session. They are on Fridays at 11:30 AM. They are also recorded and can be viewed on InfoNET.

Social Media and Email Promotion:

Lovelace asked for all persons to like our social media posts and share them. Also, please share emails that are sent to others. If council members are not getting the InfoNET emails, Lovelace would like the council members to email her and let her know. Fisher asked if Lovelace wants him to forward all emails that are sent to him. Lovelace stated that is correct. Kallestad stated Fisher does a great job of this.

Policy Updates:

Kallestad it is busy at the capitol during this time. We have been doing a lot of capitol days with groups such as Spina Bifida, First Resources, and Life Connections. Coming up we will be meeting with the Family Leadership Institute. Spina Bifida got to meet with the Governor's office about a financial ask. First Resources got to meet with their representative. Life Connections CEO Todd Novak is a strong self-advocate related to mental health. During capitol days, the group comes to the DD Council and receives advocacy training and then they go up to the capitol. Todd Novak was able to get a meeting with both chairs of the Health and Human Services committee. The capitol days have been very effective. We have taken 40 advocates up in the last two weeks and have one more group to take. We have registered for 16 bills this year and commented on six bills. We are watching carefully about voting laws. There may be

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IOWA DD Council

Preparation, Participation, Power

a big change coming. Medicaid funding, mental health funding, and child-care settings are some of the topics of the other bills we are watching. We don't lobby but we instead try to educate from a perspective of what it's like to live with a disability and how laws may affect them. Each Monday we send out a weekly email called this week at the capitol. We have tried to make sure these emails are really user friendly and easy to read. These emails are complimented with our weekly video. Amy Campbell and Kallestad do a weekly summary of what the newsletter says. We have had eight weekly emails go out, six capitol snapshots, and two capitol chats. We've had legislators on each of the capitol chats. We are currently averaging more than 50 people in attendance for the capitol chats.

The policy committee is making sure we are getting our legislative agenda out sooner.

We also have an editorial board that Amy Campbell is chairing. We look at the material we are providing and make sure it makes sense to everybody.

Kallestad shared that Werger attended National Alliance on Mental Illness(NAMI) advocacy day on the hill. Werger reached out to the Governor's office and got meetings with the Governor and the Lt.

Governor. He shared our legislative priorities with them. Werger stated he did not know he would be getting to meet with the Governor and Lt. Governor and he was thrilled. He felt the governor was moved by his story. He strongly feels the issues he addressed with her will be addressed. He encourages everybody to reach out to the Governor for her assistance. Werger will bring to the next council meeting the letter he received from the governor that thanked him for visiting with her. He was thankful for her acknowledgement of their meeting.

Kallestad stated that Bill Stumpf, a former council member, spoke about a guardianship bill and both of his representatives attended the meeting with him at the capitol.

Kallestad stated that Cross spoke about a bill she is passionate about. Cross shared that three years ago she tried to get the disorder that her son and daughter were born with to be placed on the newborn screening panel in Iowa. Three years ago it did not make it to sub-committee. Last year she got in touch with Every Life Foundation who advocates for the rare disease community. Cross wrote to every parent advocate that she knew to try to get more parents involved. There were about parents that partnered with some staff members from Every Life Foundation who hired a lobbyist. They got legislation this year and got the bill sponsored by the chair of the Human Resources Committee in the House and Senate. On Tuesday the Senate passed the bill 47-0. We are waiting on the House to vote on the senate bill.

Hopefully we will see it become law. It was a great experience. She is very grateful to be on the DD Council and have encouragement from others. Kallestad stated it was great to be involved and to see the legislative process for this.

Representative Chad Ingels will be introducing a bill on the house side that has to do with the REACH program. Vratisnas stated the Realizing Educational and Career Hopes (REACH) program is at the University of Iowa and is a four-year program for people ages 18-25 to learn independent living skills and job skills while getting the college experience. Kallestad and Lovelace registered in support of the bill so they can track it. There was a committee meeting today about this at 11:00 AM.

Kallestad stated that Senators and Representatives really want to hear from people with lived experience. Kallestad said that his job is really to educate about advocacy.

Yesterday, there was young girl that attended the capitol days with Kallestad and her name is Bliss. She is three years old and has been on the HCBS waiting list for three years, her whole life. Her mom was introducing her to her representative at the end of the day and the representative asked how long she

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had been on the waiting list. The mom stated that Bliss has been on the waiting list her entire life. Bliss cannot bare weight on her legs and there is no doubt she needs support services and her mom told the representative how many times she has been denied assistance. There's nothing more powerful than for the representative to hear that message and meet Bliss and make a difference. It was very powerful.

Community Ambassador Presentations:

Tammie Amsbaugh, Center for Disabilities and Development with Ambassadors Monnie Hall and Michael Martin:

Werger stated the Community Ambassador project started in 2018. This program is facilitated by UCEDD and it is for 10-12 persons that have lived in an Intermediate Care Facility (ICF) facility and have moved out into the community. Currently there are also two parent guardians of loved ones that have lived in an ICF facility and have moved to a community. Werger stated that he is a Community Ambassador. Werger introduced Michael Martin and said that he started as a Community Ambassador in 2020 and lives in West Des Moines in an interim waiver home. The second guest Werger introduced is Monnie Hall. Monnie Hall started as an ambassador in 2020 and lives in Des Moines in a home supported by Mosaic. Werger said that Tammie Amsbaugh has been the person that started this project and got it going. Werger said that Joe Schumacher is a staff member that helps runs the community ambassador program. Wendy Peterson has just recently joined the community ambassador program. Michelle Arenholz is a parent guardian of her son, Jonah who has a disability and is a community ambassador. The community ambassador project is currently funded by the Iowa DD Council. Michael Martin stated Michelle Arenholtz helps with the whole program. Werger asked Michael Martin to tell us about himself and his transition to the community. Michael Martin stated in 2019 his mother and him decided to apply for Money Follows the Person (MFP). By September he was moved to the community. His move was done during Covid and all done via internet. He lived in a nursing home before moving to Mosaic because he had undiagnosed medical conditions. Mosaic helped him get medical care then he got to the point he didn't require their assistance. Without MFP's help he wouldn't have been able to move. He got moved to the top of the waiver list. MFP is there to support the individual and they did a remodel of the bathroom and got him set up with medical services. It has been a year and a half since his transition and he now has a power wheelchair. He would not have got the power wheelchair if he was not in the community. He can more easily attend social events now. He stated people in the community have plenty of access to services. It gave him back medical control and gave his family peace of mind. He would have none of this without MFP.

Werger asked Monnie Hall to share his story about his transition into the community. He lived at home until he was 21 with his family. When his mother passed away his sister and him decided it was time for him to start a new journey. He has lived in many facilities before moving to the community.

Werger asked Michael Martin what he likes about the ambassador project. He stated he likes educating guardians and consumers about their rights and choices.

Werger asked Monnie Hall what he likes about the Ambassador Project. Monnie said that it shows the humanity we all share. It allows us to have a voice and share our stories, concerns, hopes and dreams. It

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has connected us with people who have dedicated their lives to helping others. Every person deserves a voice on this platform.

Werger asked Michael Martin how he thinks telling his story about community living is making a difference. Michael Martin stated he has complex medical issues and he is getting medical support living in the community so others can to.

Werger asked Monnie Hall how his story is making a difference. Monnie Hall said that by people telling their stories, it gives perspective, wisdom, and opportunity for those who may share their experiences and needs and parents looking for help and siblings for connection. He feels sharing his story unites people.

Fisher asked if Michael Martin was born in a wheelchair. Michael Martin stated he was diagnosed with cerebral palsy when he was six months old. Fisher stated he was born in a wheelchair. Fisher asked Michael Martin what caused the cerebral palsy. Michael Martin stated when he was in utero he laid on the umbilical cord and cut off oxygen to his brain. Fisher stated his brain cells aren't connected and don't talk to his other brain cells. Michael Martin stated what doesn't kill you makes you stronger. Fisher stated he would like to meet Michael Martin in the future. Tammie Amsbaugh thanked Werger and the DD Council for supporting this project. The ambassadors have done 16-17 presentations this last year and have done six conference presentations. They have also done other presentations across the state.

Council Member Presentations:

Tiffany Poage, Department of Education:

Poage is an Education Program Consultant and she provides technical assistance, guidance, and educational professional guidance related to educating students with the most significant and complex needs. She is on the special education team with 30 other educators throughout the state. The Special Education Team works to ensure a continuum of high-quality services birth to age 21 to accomplish desired results. The current initiative the team is working on involves families supporting their children to develop and learn, make sure learners are educated in safe, healthy, and caring environments, make sure learners are proficient readers by the end of third grade, make sure learners progress at a rate which ensures success, and making sure all learners graduate as college and/or career ready. Some of the Special Education Teams tasks are to address the targets set by the state performance plan (SPP). States set targets for 16 indicators every six years. There are five compliance indicators, eleven results indicators, and the SPP includes improvement strategies based on stakeholder input. The Special Education Team prioritized targets. One of the targets is to replenish instruction. They want to provide individualized education for every student. They are also looking to simplify their system and are moving to a new reporting system. They want to collaborate with general education teachers. iowaideainformation.org website is a great website for information about policies and procedures. Specially Designed Instruction Framework (SDI Framework) is intended to engage educators and families in diagnosing, designing, and delivering special education services to best meet the needs of learners 3-21 with disabilities and a range of educational needs. To do

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this they guide decision-making to support learners with disabilities, self-assess their own skills in providing SDI, guide coaching conversations around critical features of SDI, and inform ongoing professional learning focused on SDI. Coming up with the SDI framework started in 2015. The new Achieve System will replace the current webIEP system. The Achieve System was designed with intent to assist Individualized Education Program (IEP) teams in designing services and supports for the individual, maximize system functions to support practices, increase opportunities for team collaboration and communication, increase use of the system to collect procedural compliance through system functionality and less need for people to worry about documentation, and to have one system birth to 21. Families will be able to go onto this portal anytime and see how their student is progressing on their IEP goals. Teachers will be able to share information and documents with families in a timely manner.

Cross asked what was going on with the House Study Bill (HSB) that reduced Area Education Agencies (AEA) down to four. Poage did not have knowledge of this. Kallestad stated he has heard about this but the bill and attended the committee meeting the other day. Amy Campbell said it was one that we were following and was trying to figure out what the intent of the bill was. The bill left out a lot of detail. The people who spoke at the committee raised a lot of concerns about this bill. Cogil provided the following: HSB 727: Reduces the number of AEAs to four and includes requirements for reorganization. Requires AEAs to allow teachers who teach over the internet to live outside the AEA area, but only if the content can be adequately provided over the internet. Salary: Increases the state teacher salary supplement. (HF 2182 failed to advance in House Education, but this bill is now funnel-proof as an Appropriations bill). <https://www.legis.iowa.gov/legislation/BillBook?ba=HSB727&ga=89>

Aller stated she had an IEP for many years. Aller asked how this new system works if you are still in college. Poage stated they will still have an IEP system but they will just be transferred to a new system to provide more collaboration with the IEP team members. IEP's are not going away, the system is just switching of where it will be housed.

Fisher asked if he wants to take an online class has Poage heard about colleges teaching classes online. Poage stated he would need to check with the colleges about which classes are taught online. Poage stated she would send Fisher an email and they could communicate that way. Cogil stated that she met with the state school nurse consultant with the Department of Education, Melissa Walker yesterday. She mentioned a new state wide program for an Individualized Healthcare Plan (IHP). Cogil is wondering if Poage has insight about IHP's. Poage stated they are trying to move all plans into one system, the Achieve system, so people will not have to go to multiple places for information.

Werger stated he was in special education for most of his schooling and has never pursued college. As an individual on Iowa Medicaid and SSI, what programs are out there assist him because he is low income? Aller stated there are grants for people with disabilities. Eric Evans from Vocational Rehabilitation stated that they can pay about forty percent of tuition based on what program they are interested in. Werger stated he would contact Eric Evans via email.

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Paula Motsinger, Medicaid:

She is the Bureau Chief of Medical and Long-Term Services and Supports (LTSS). Today's discussion will address how the Medicaid team supports the work of the DD Council, individual bureaus and the role of each bureau, and the primary focus on medical and LTSS policy. Medicaid is made up of state employees and contracted specialty vendors. Medicaid staff are assigned to one of four bureaus based on specific skills and interests. They have a Managed Care Bureau that is responsible for Managed Care Organizations (MCO) oversight, contracting, quality and reporting. The operations bureau is responsible for vendor contracts, pharmacy, and program integrity. The eligibility policy bureau is responsible for member eligibility and Health Insurance Premium Payment (HIPP) policy. The Medical and LTSS bureau has connections to the work of the DD Council. Just under 500 people work in Medicaid. More than 400 of these people are vendor staff and are responsible for member services, provider services, provider cost audit and rate setting, program integrity, quality improvement organization, revenue and collections, pharmacy, and the CORE unit handles the systems Medicaid uses. Motsinger's team is responsible for establishing and maintaining Medicaid policies related to medical and long-term services and supports. Her team is responsible for policy development for Medicaid, Children's Health Insurance Program (CHIP), Healthy and Well Kids in Iowa (Hawki), and Iowa Health and Wellness Program (IHWP). Motsinger shared her slide that includes all members of her team and their roles. Current priorities are Strategic planning by having a strong focus on building our provider network and adding additional reserved capacity waiver slots. Another priority is pandemic response. This will be addressed by making sure everyone has access to vaccine and the Public Health Emergency (PHE) Unwind. A third priority are listening sessions to identify issues and resolutions. They will have member and provider townhalls, address durable medical equipment (DME) and prior authorization, maternal health, school-based services, transition aged services, and have consumer choice option (CCO) workgroups. Another priority is that the American Rescue Plan Act (ARPA) spending plan will increase training and support. Another priority is expanded access. This will be addressed by behavioral health, aging and disability services statewide system evaluation and pilot projects such as therapeutic foster homes and community based neurobehavioral rehabilitation services for children. The final priority is workforce support. This will be addressed by expanding the direct care registry and issuing recruitment and retention provider payments.

Wenger asked in the chat: "I have a ? Awhile back I was hired on for 2 separate jobs in the Glenwood Iowa Community I had to turn both jobs down because I was told I would lose my Medicaid and SSI services what services are out there to accept the jobs with the hours provided to not lose our benefits." Motsinger responded "Brady - I will connect you with LeAnn Moskowitz who can assist with answering some of your questions about employment." "Brady -

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it looks like Eric can also help with the employment question. If you have questions after meeting with Eric, please reach out to me.” Cogil asked in the chat: “Any update on Director Garcia's 1 year HCBS waiver review?” Motsinger responded “Roxanne - Mathematica is still in the process of the statewide system evaluation. I will share updates with the council as I receive information.” Motsinger stated in the chat “Carol, I would appreciate any conversation around the workforce shortage. I am hopeful you have some recommendations for improvement. Do you participate in the workforce shortage workgroup? Please email me with some times that will work for you. pmotsin@dhs.state.ia.us”

State Plan Corrections Requested by ACL:

We received a response from ACL in late February and they did ask for some changes to our state plan. Lovelace stated when we developed this, we were trying to keep the goals as simple as possible. The ACL wants some of these explained more in depth. We have added another objective and changed some of the goals.

Goal one was changed to include the year 2026 and the wordage “developmental disabilities” and we needed to add an expected goal outcome. Objective three is new and states “with the support of our disability network of advocates, annually invest and support leadership training by state self-advocacy groups led by individuals with developmental disabilities. Our goal is not create a new self-advocacy group but to create a more unified self-advocacy movement.” Warth suggested during the EC meeting that we do a leadership summit with all of the different advocacy groups in Iowa. We thought of maybe doing this during the last day of the Make Your Mark conference. It was suggested to move the prior objective three into an activity and delete this objective. This objective addressed people advocating for their own healthcare needs.

Goal two has added language but did not change what we are doing. What we are going to do with objective three is to host some community conversations and figure out in the rural areas, what the actual needs are. ACL thought we should have already done that. We did do some of this when we did our needs assessment. We found out from our surveys that there needed to be more civic engagement, advocacy and voter training done in some of these rural communities with younger adults. Lovelace stated that one of the areas we are going to focus on is the rural area where Roozeboom and Funston are.

Goal three was narrowed down to state that we will partner with the DD network, state agencies, and/or other community programs to respond to emergent needs that impact individuals with developmental disabilities and their families.

Aller asked what on page ten of the workplan what NDEAM means. Lovelace answered it is National disability employment awareness month.

Fagerlund made motion to accept the changes. Funston seconded. Motion passed.

Lovelace has a meeting with the director of ACL on Monday so there could be additional changes. After her meeting on Monday, she will send everybody the full plan. Lovelace thinks there are significant enough changes that we will have to put the plan back out for public comment.

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Make Your Mark Discussion:

Aller, Schneider, Kelly, Fisher, Werger and Roozeboom want to be on the planning committee. There is a planning committee meeting set up for March 24 at 3:30 PM. Lovelace will send out the invitation. This year's conference will be September 14 and 15 at Prairie Meadows in Altoona. We are needing big sponsors to help put this on and have quality key-note speakers. Lovelace stated in previous years we have had extra funding but we do not have extra funding this year. Aller asked for an example of a sponsor. Lovelace stated an example would be Amerigroup. Aller asked what the theme of the conference is this year. Lovelace stated it is "Knowledge is your super power." Lisa Yunek stated that there is a Alliant grant, Mercy One has a mission division, and rotary and Kiwanis have grant application processes.

Kallestad we are not limiting sponsors to corporations that have connections to persons with disabilities. We are looking at any corporation or non-profit. Werger suggested we ask Goodwill.

Roozeboom asked if there a budget as far as what sponsors will receive for certain sponsorship amounts. Lovelace stated we do have that and Capture is putting it in a format right now. We will share these with the DD Council members when they are complete. Lovelace stated she believes the top sponsorship amount is \$5500 and that is for the key-note speakers sponsor. We are also asking for a lunch sponsor and a breakfast sponsor and there are dollar amounts related to each of these.

Roozeboom said that we should not be afraid of asking non-profit groups especially if they want to get their name out there. They may have marketing dollars.

Werger asked if we could do fundraising. Lovelace stated we cannot do that.

Lovelace stated we will be charging a registration fee.

Council Updates:

Lovelace stated we are looking for new council members once we lose four council members in June. The replacements will need to be male and they need to be two family members and two self-advocates. Warth suggested we look for diverse council members.

Fisher introduced Sam Blatt from Progress Iowa who is working with him on the Adel post office. Sam Blatt stated the post office is compliant with ADA but the door is still not accessible for wheelchair users. They are trying to figure out how to change this at the Adel post office and hopefully this will create further change. Kallestad asked Fisher to share in the chat the petition he has. Sam Blatt stated she will share the petition. Werger asked what organization Sam Blatt works for. She stated she works for Progress Iowa as an organizer with many advocacy groups. Werger asked that Sam Blatt put her contact information in the chat. It is sam@progressiowa.org 641-204-9305. Petition link is <https://progressiowa.actionkit.com/sign/accessibility/>

Public Comments:

Lisa Yunek asked if Nicole Nosbisch would be appointed to the council. Lovelace stated that the Governor's office is following the gender balance guidelines and maile appointees may be all the Governor will appoint.

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Adjourn: Kelly made a motion to adjourn, and Aller seconded the motion. The meeting adjourned at 2:10 PM.

Addendum: Poage provided the answers to questions that were asked during her presentation.

- Will 504 plans be a part of the ACHIEVE system?
 - No. 504 plans are managed by the school the student attends.
- Will Individual Health Care Plans be uploaded/attached to student IEPs?
 - Yes. If a student has an Individual Health Care Plan, it can be uploaded to the IEP.
- What is the thinking behind reducing the number of AEAs to 4? How will this impact the availability of services and supports to families and students?
 - Please contact our Legislative Liaison, Eric St Clair with any legislative questions. eric.stclair@iowa.gov or 515-326-0274. He should be able to provide you with additional information.