

## Iowa Developmental Disabilities Council Meeting Minutes January 13, 2022

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

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

**Council Members Absent:** Colin Priest, Amber Gale

**Members of the Public:** Josh (with Brady), Connie Fanselow – Mental Health and disabilities services division of DHS, Maggie Ferguson Brain Injury and Disability Program Manager at the Iowa Department of Public Health, Matt Highland, Kelly Garcia, John McCalley, Marissa Eyanson

### Call to Order:

Council Chair Fagerlund called the Iowa Developmental Disabilities Council (DD Council) meeting to order on January 13, 2022, at 10:33 AM. A quorum was established.

### Welcome and Introductions:

All meeting attendees introduced themselves.

### Agenda Item/Approval of Minutes and Agenda:

Aller motioned to approve the minutes from November 4, 2021 meeting, Kelly seconded. Motion passed.

Agenda changed for today due to Director Garcia joining us at 11 AM instead of 1 PM. Council member presentations will be this afternoon.

Fisher motioned to approve the revised agenda, Kelly seconded. Motion passed.

### Executive Committee (EC) report:

#### **Actions and Recommendations since November Meeting:**

There was an EC meeting on January 7, 2022 to talk about the legislative priorities that needed to be approved to get out to the legislators. EC meeting prior to this meeting reviewed the budget, the state plan progress, and the legislative agenda again.

#### **Budget Review:**

Reviewed spending chart. 2020 funds we have until the end of September to spend those. We have an invoice that still needs to go through the DHS system. 2021 funds looks like we have a lot of spending

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left, but it is all obligated so this will all be spent. Cross asked if money is spent on lobbyists to try to work on our legislative priorities or is that a conflict of interest. Lovelace stated that we are not allowed to lobby, only to educate. Approximately eighty percent of Kallestad's responsibilities is doing this when we are in session. Cross asked why this is. Lovelace stated because people are not allowed to use federal money to request money. These are the same rules that apply to UCEDD and Disability Rights of Iowa (DRI). Lyon stated DRI has unrestricted funds that they occasionally use for lobbying but they cannot lobby with grant money. Kallestad reiterated that the money is used to educate and inform and our legislative priorities does this along with InfoNET and the capitol chats.

## **State Plan Review:**

Lovelace stated that the Council members names have been added to the workplan that responded with what they would like to assist with. Lovelace asked if anyone has questions after reviewing the plan. Aller asked that the green highlighting on the state plan be changed as she cannot read it. Lovelace stated a cheat sheet for legislators about why input is helpful is something we would like Council members input on. Fisher would like to help with Capitol chats and host a meeting. Lovelace stated that not all Council members picked an activity yet but can do so still. Werger was reminded that he offered at the November 4 meeting to host a meeting. Aller would like to help with MYM Conference this year. Lovelace reiterated that we would like every Council member to be involved and pick an activity. Willard wanted to make sure that we are capturing all participants activities such as Director Garcia speaking with us today would be a part of talking with a policy maker. Funston stated she would like to help Roozeboom with his hosting a community conversation. Kallestad stated he knows the State Plan is a lot to look at and if anyone would like to speak to him or Lovelace, to give them a call.

## **Annual Survey results:**

Fagerlund stated we will not be going into detail about this but if anyone wants to, we can add this to the next meeting agenda to talk about.

## **Department of Human Services Discussion with Director Garcia:** With Marissa Eyanson State Disability Director from DHS.

Director Garcia stated she will give an overview about the DOJ report. We will walk through where we stand today. There are 2 parts of this investigation. In November of 2019 DHS got a letter from the Department of Justice (DOJ) that they were opening an investigation at Glenwood and Woodward and they are looking at two different things. At Glenwood they were looking at substandard medical care, substandard behavioral health supports, and human subject experimentation. The second part of the investigation is that they opened an investigation under the Americans with Disabilities Act as well as the Civil Rights Act that protects institutionalized persons with intellectual and developmental disabilities. It is referred to as CRIPA. They are looking to see if the state of Iowa violates the civil rights of individuals at Glenwood and Woodward by not allowing them to access community supports and over-utilizing beds in an institutional setting. A link to the timeline is: <https://dhs.iowa.gov/doj> DOJ launched their investigation at Glenwood as well as DHS launched their own investigation at Glenwood.

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DHS has a 600 plus item improvement plan for Glenwood. About a year ago DOJ issued their own findings on Glenwood and confirmed that we have areas that we need to improve medical care and behavioral health supports. We have remediated most of those issues. We have improved more than 2/3 of the 600-item list so far. DOJ sent the framework of a legal document which is the rest of what they expect us to do to improve Glenwood. We overutilize beds at Glenwood and Woodward and other settings and are out of compliance with CRIPA also. We are also out of compliance by over utilizing beds in nursing facilities and private Intermediate Care Facilities (ICFs). We are working with DOJ to get into compliance. Eyanson and her team are building out community capacity which is challenging during a global pandemic. We are revising the way we work with Managed Care Organizations (MCOs). DOJ wants stronger oversight in that capacity. DHS agrees with this. DHS thinks a significant investment needs to be done on the community side. One of the ways would be a re-evaluation of our seven waiver structure's. We don't have an easy way to track who needs community support in Iowa. The Medicaid team, Eyanson's team, and Director Garcia's office are working on this. There is a year-long evaluation of the waiver's occurring. People are waiting on multiple waivers and this needs to be fixed. We are close to cementing the consent decree related to Glenwood and the items that need fixed. Glenwood is too big and needs to right size. We are constantly at a staffing shortage. There are people living there that want to move to the community. Guardians are trying to do the best for their loved ones. The goals will be hard to accomplish due to the pandemic and staffing. Director Garcia is talking to legislators about Glenwood and how to get back in compliance and talking about what Woodward needs. How the two ICF that are state run can help stabilize the community. ICF can assist in the community in two ways: First, clinical expertise: How do we harness the expertise of medical providers and let the community access this in an easy way. DHS is willing to pay a rate to garner real expertise. Psychiatric residency rounds in Woodward is happening now. Second, we have found that there are a number of kids that find themselves without placement. We don't have the appropriate services in this state to support children with ID or DD designations. Woodward and Glenwood could be temporary places for these children to go to. Woodward has had children placed there recently and it has worked well. DHS has to have a system commitment to do this work. This work is going to take time and significant financial contribution from the state. We need our federal partners to help fund this work. Eyanson stated we are keeping an eye on all facets of the system. Director Garcia then opened it for questions and comments. Schneider stated when MCO's are involved, how do they build in accountability to do what's best for the individual and not for the bottom line. What does the state do to ensure that MCO's are doing what they are supposed to do. Director Garcia stated that DOJ addressed this and wants the state to have stronger oversight of MCO's and she agrees. Director Garcia wants to add people to the Medicaid structure. Director Garcia wants to see more strategic use of data points are reported to hold MCO's accountable. We recognize there are improvements to be made here. Liz Matney should come and speak about what her Medicaid strategic plan looks like. Cogil asked while reviewing the seven waivers to review that people are getting the appropriate supports at critical points and/or transitional points. Director Garcia stated they are honing in on transition points. Cogil asked if there are any potential solutions to the waiver wait list times that constituents could advocate for. Director Garcia stated she is needing more information before she can thoroughly answer this question. Director Garcia does not know what it will cost for sure and there is an assessment happening now to establish this. Fisher asked Director Garcia if she got his message. Garcia stated she go this message and delivered it. Fisher also

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stated that there is a shortage of direct-care workers. Director Garcia stated that they had a federal request that was granted to give direct support professionals a bonus and DHS is thinking about more sustainable ways to keep and acquire direct support professionals. Fisher stated that he is more comfortable working with a man instead of a woman. Garcia stated these are issues they are addressing. Werger stated Director Garcia walked into the DOJ thing and wanted to give her kudos for coming to Woodward and Glenwood and meeting with staff and clients. Werger would like to sit in on the meeting if she comes to Glenwood again. Werger would like to advocate for the people there and bring the information to the Council so we can all advocate. There are staffing shortages there and this is a concern that needs to be addressed. Werger would like to work with Director Garcia to address these concerns. Director Garcia wants community ambassadors to come and talk. There are monthly meetings on Saturdays that Director Garcia does that she would like Werger to attend. Fisher would like to attend also. Eyanson stated that having the community ambassadors come talk is something she has been working on. Funston stated that her daughter is 10 and is currently on the brain injury waiver and has been for several years. Her services have been passing the buck. She would like to know what is an MCO's responsibility. Director Garcia stated that this is being looked at now to define roles of providers. Eyanson stated she is working on this and trying to define gaps and fix this. Case management is often based on payor source and this is not always the best way to do things. Roozeboom stated he does not know what a lot of the abbreviations mean and asked what the timeline is to see action? Director Garcia stated this is really complicated and very interconnected with bigger systems. Director Garcia thinks the big system issues need to be solved. Director Garcia is guarding on the time. There is a year-long evaluation then 3-5 years to rebuild the system. There will be clear timelines after the 1 year evaluation. Eyanson stated they are working on their long-term future vision. Cross has 22-year-old daughter on Health and Disability waiver. Parents of kids of all ages have been able to be paid for being direct support care workers. Permanently allowing parents and family members to be direct care workers for their children and letting them get paid as an easy fix. Roozeboom asked if advocates can give input to Director Garcia for insight. Director Garcia said we do want constructive input from us. The team at DHS is trying to fix the system and make foundational changes. Speaking with legislators is really important. Director Garcia cannot land on these changes without the backing of policy makers. Funston shared that resources for her daughter are a few hours away. It is almost impossible to work and care for her daughter. She has contemplated placing her daughter in a residential facility so she can get care due to living in rural Iowa makes it difficult to find care. Director Garcia stated that the rural component is in the forefront of their minds. Eyanson stated that we haven't done a good job yet of really thinking if we can do something short term to stabilize a current situation.

The summary of the DOJ findings on the second part of the investigation can be found here:

<https://dhs.iowa.gov/sites/default/files/DOJ%20SRC%20Findings%2012292021.pdf?011220222054>

## **Council Member Presentations:**

### **Judy Warth, Center for Disabilities and Development:**

In 2000 the DD Act was enacted. This law created UCEDD (University Centers for Excellence in Developmental Disabilities), Disability Rights Iowa (DRI), and the DD Council. It was designed to let people have access so they could have the kind of lives they want. There are 67 UCEDDs

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nationwide. There are 52 Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, and there are 16 Intellectual and Developmental Disabilities Research Centers (IDDRCs.) LEND Programs provide graduate level interdisciplinary training. The purpose is to improve the health of people with disabilities across the lifespan. Vratsinas stated that LEND is a wonderful project. Aller asked how much it costs to participate in LEND or how much time does it take. Warth stated that it takes over 300 hours to participate and participants are paid. HAWK IDDRC is the research wing and is brand new and is in the children's wing of the hospital. UCEDD is to help implement and build capacity for the system to move forward. UCEDD partners with as many people as they can to help make things happen. Core functions are interdisciplinary and pre-service training, job coaching, continuing education, technical assistance, model and demonstration services, information dissemination, research, and work to leverage funds. Areas of emphasis are employment, health and wellness, education, and community living. Projects include the DD Council and the Community Ambassador Program II, Department of Human Rights and the Youth Leadership Academy, Iowa Medicaid Enterprise regarding Money Follows the Person (MFP), Department of Human Services regarding Covid Recovery Iowa, Administration on Community Living regarding the ON TRAC program (health care project), Iowa Department of Aging, Iowa Department of Transportation, and Iowa Compass regarding the SOAR Conference.

Fisher wanted to know if he could do the LEND program. Warth stated the person needs to be in Iowa City or close.

Funston asked if the LEND program would go state-wide. Warth didn't think so but she would ask the person that runs the program.

### **Jean Willard, Child Health Specialty Clinic:**

CHSC stands for Child Health Specialty Clinics which is in the University of Iowa College of Medicine. In 2021 CHSC provided direct service care to approximately 7000 families. They provide telehealth, pediatric specialists, health and behavior assessments, medication management, care coordination, and family support. CHSC tries to fill in the gaps where other resources are hard to find. CYSHCN (Children and Youth with Special Health Care Needs) are children that have health concerns and need to use more services than other children. There are about 143,000 in Iowa. They receive most of their funding from Title V which is a Maternal and Child Health Block Grant. There is a lot of flexibility on how to use the funds but states are held accountable. Title V is a section of the Social Security Act. It is the oldest partnership between the federal government and state governments in the United States dating back to 1935. Title V tries to help women, mothers, babies, children, adolescents, teenagers, and children with special health care needs. Iowa Department of Public Health (IDPH) and CHSC work together. Every 5 years a comprehensive needs assessment is done to determine what to spend the Title V funds on. The 3 top priorities are support for families, access to health care and services, and help with transitioning to adulthood. CHSC works with the DD Council to

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achieve common goals which include advocacy, networking, and joint sponsorship of activities. The Iowa Family Leadership Training Institute is a project CYSHCN does which trains parents and primary caregivers of children between 3 and 19 with special health care needs. They are invited to participate in a special leadership training. The goals of the training are to understand how to work with partners, become aware of one's own path to leadership, discover strategies for advocacy, and prepare a community service project. Funston stated that she is a graduate of the Iowa Family Leadership Training Institute so if anyone knows anyone that has questions about it, she is more than happy to speak with anybody and it is a great resource.

### **Scott Lyon, Disability Rights Iowa (DRI):**

DRI is the Legal Protection and Advocacy System in Iowa. There is one Protection and Advocacy (P & A) system in every state and territory in the United States and they provide legal representation to persons with disabilities. DRI is an independent non-profit agency and is not a government agency. DRI has eight attorneys on staff and 20 total employees. They provide services state-wide and are located in Des Moines. DRI serves residents of Iowa who must have a disability and have a disability related issue that falls into DRI's areas of focus. There is no age, income, or immigration status requirements. The Board of Directors decide the areas of focus for DRI. Areas of focus currently are Abuse and Neglect, Accessibility, Assistive Technology, SSA beneficiaries, Community Living, Education, Employment, Guardianship Alternatives, Healthcare, Housing, Juvenile Justice, Prisons and Jails, Representative Payee Review, and Voting. Federal statutes grant DRI the right to investigate and monitor facilities, except for federal facilities. DRI provides professional inquiry and direct legal advocacy. Monitoring can involve an announced or unannounced visit. DRI also provides short term assistance, self-advocacy assistance, professional inquiry, and provides information and referrals. DRI's systemic work currently is Medicaid and Managed Care for individuals with disabilities, abuse and neglect of residents at facilities, reforming the juvenile justice system, and arrests, suspensions and exclusion of students with disabilities. DRI Factors in deciding whether to take a case include the type of disability (intellectual, developmental, physical, brain injury, other), legal issue is within board-approved areas of focus, severity of harm, imminence of risk, and potential to create systemic change.

Fisher asked if Lyon could assist him with the accessibility issue of the Adel Post office. Lyon stated he could email him and he would take a look.

### **Julie Bergeson, Iowa Department on Aging (IDA):**

Administration for Community Living (ACL) is the IDA's federal partner. The guiding legislation that guides all that they do is The Older Americans Act which was the first federal initiative aimed at providing comprehensive services to older adults (age 60 plus) which was passed in 1965. IDA does not provide direct services. IDA is the designated state agency designed to assist older persons in leading independent, meaningful and dignified lives in their own homes and

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communities for as long possible. Some of IDA's themes are Health and Nutrition, Employment, Caregiver Supports, Supportive Services, and Elder Justice. A new program is the Iowa Café. This is a restaurant meal voucher program where older adults can go to their local cafes for meals. They have several employment programs for seniors. Caregivers are the backbone of the healthcare system and often aren't paid for their time. ACL recognized and provides services for family caregivers who are caring for older adults or persons with dementia and Alzheimer's'. Some supportive services that IDA provides are information assistance, information referral system, IDAs system can chat with Iowa Compass, options counseling, case management services, and funding for transportation and chore service. There is also legal assistance for older adults and hotlines. IDA houses the office of Public Guardian and Office of Last Resort. IDA focuses on elder abuse and prevention and awareness. The state Long-Term Care Ombudsman also falls under IDAs umbrella. The Ombudsman office advocates for people and there is also the Managed Care Ombudsman Office. In the future the number of older adults will increase.

## Legislative Agenda:

Our three areas we are focused on are: workforce crisis, inclusion and accessibility, eliminate the waiting lists. We changed the format of the handout this year to focus more on stories instead of having bullet points. The DD Council's open house is tomorrow and there are 94 people registered including 15 legislatures. The blue box on the handout is our "ask," the middle section is our "call to action," and then there is the story that goes along with everything to help the legislators really think about the issue. The first ask is to fully fund healthcare services and community-based supports to address the workforce crisis in both rural and urban areas. Kallestad reviewed the call to action and Tucker's story. The second ask to legislators is to support an inclusive community for all Iowans. Kallestad shared the call to action. Roozeboom shared that high schools and restaurants are not accessible for persons in wheelchairs. Handicapped accessible port-a-potties do not fit oversized wheelchairs. People with physical disabilities want to travel but it is hard to find bathroom facilities to use. Aller asked if adult changing tables would be a factor for him. Roozeboom stated that he does not need one but there are many people that do. Rest areas when traveling are problematic. Werger stated he is advocating for a person in Glenwood that is in a power wheelchair and his wife can no longer lift him. His son gave him a 2015 minivan. Werger asked Roozeboom if he knows of any programs that can turn the van handicapped accessible. Lovelace stated that there is a waiver if he is on the Home and Community based waiver service. Lovelace encouraged the gentleman to reach out to his legislators for assistance. Roozeboom stated to check with Vocational Rehabilitation. Werger said he has checked with Vocational Rehabilitation but he did not believe they were able to assist him. Kallestad stated the final area of focus is to reduce or eliminate Home and Community-based Supports (HCBS) waiting lists.

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The call to action is that there are over 17,000 Iowans on waiting lists. Lovelace stated that next year the legislative agenda will be done sooner and voted on by the whole council.

## **Council Updates:**

Capitol chat will be on January 28<sup>th</sup> at 11 AM. After the capitol chat there will be an Advocacy training. Every Friday a summary of what happened at the capitol that week will be sent via email. Every Monday Kallestad and Amy Campbell will do a video blog called the Capitol Snapshot which will be 3-5 minutes. Fisher stated that he went to the Iowa Machine Shed and they do not have a family restroom and he can see Roozeboom's point about the restroom accessibility issue. Funston doesn't believe she has the link for the open house and asked for the link to be sent again to her. Kallestad said he would send it to her. Motsinger stated that in her role on policy for Medicaid, she has asked her policy team to look at the issue of family members not being paid for caretaking for family members. Kallestad stated that people across the state are feeling positive in the direction the DHS is going. Cogil said that her daughter does a lot of dance. For the first time this year she had the opportunity to dance at Iowa State Dance Competition at Wells Fargo in the new Beyond Limits category. This category is for dancers who have special abilities. Her daughter did a solo and was the first one ever to dance in this category. PBS did a story on her daughter, Rachel, that will air on January 29 at 7:00 pm. Werger said that when Director Garcia was on earlier pertaining to staff shortage, the issue is state-wide. He has been off work due to staff shortages and it is hard. Werger wrote a letter to the Director of Glenwood related to this issue.

## **Public Comments:**

Fanselow stated that the meeting was very good.

**Adjourn:** Aller made a motion to adjourn, and Kelly seconded the motion. The meeting adjourned at 2:27 PM.

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