

Iowa Developmental Disabilities Council Meeting Minutes September 11, 2025

Council Member Attendees:

Eric Evans, Wendy Andersen, Rachel Bussan, Kevin Harris, MeLissa Lawson, Julie Bergeson, George Thompson, Nicole Nosbisch, Daryn Richardson, Aaron Swartz, Casey Wilkinson, Kevin Harris, Andrea Maher, Caitlin Owens, Jayde Henry, Mike Dierdorff, Lori Trujillo Roush, Amber Gale

Virtual Attendees: Kimberly VanBeek, Diane Brenneman, Dakota Caldwell, Mike Hoenig

Council Staff: Brooke Lovelace, Carlyn Crowe, Lindsay Hommer

Council Members Absent: Charlene Wyatt Sauer, Joshua Lawrence

Members of the Public: Patty Orger – Persons with Disability Ministry Coordinator for the Diocese of Des Moines, Megan Marsh – Housing Programs Coordinator at the Iowa Finance Authority, Nicole's driver and mother

Call to Order:

Council Chair Thompson called the Iowa Developmental Disabilities Council (DD Council) meeting to order on September 11, 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 July 10th meeting were approved. Nosbisch made a motion, Henry seconded.
- Agenda for the September 11th meeting was approved with the following change: Vote on the 2026 Public Policy.
 - Gale made a motion and it was seconded by Lawson.

Executive Committee (EC) Report:

Actions and News Since July and Summary of What was Discussed at EC Meeting

2026 Budget Approval

- The budget review revealed concerns about administrative costs approaching their cap.

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- The Council currently spends approximately \$48,000 on Health and Human Services (HHS)-related costs, but these may decrease in the future.
- The possibility of moving the Council office to the Lucas building, was presented as an option by Director Garcia to cut administration cuts. This could impact the Council's autonomy as a separate entity from HHS.
- The executive committee motioned for the budget to be approved. Richardson seconded. The Council approved the 2026 budget.

Budget Summary

- HHS costs and DAS Human Resources (HR) costs were higher this year.
- Project relief grants and educational opportunities section on the budget paid for interpreters for Allies in Advocacy, \$5,000 in sponsorship to the Seeking Opportunities for an Advocacy Revolution (SOAR) conference, a sponsorship for the Association of People Supporting Employment (APSE) conference, and a sponsorship for the Boy Scouts Youth Safety Summit.

MYM! Update

- MYM! is expected to have a high attendance. Everyone is encouraged to come to the talent show and evening dinner

State Plan Update

- Wilkinson suggested the idea that Council members participate in a "member spotlight" each meeting to learn more about each other. The person presenting would share about their values, what they're working on, and/or information to get to know them more. Other networking opportunities outside of meeting times are also an option.
- Thompson discussed a campaign called "Workday with Your Legislators". People are encouraged to invite their legislators to their workplace. This event aims to showcase the talents and contributions of people with disabilities to their legislators.
- There is a new coalition of over twenty organizations that was formed to address federal threats to disability rights and funding.
- Hoenig inquired about incorporating health-related issues into the state plan, and Lovelace explained that health advocacy aligns with the council's current focus with Medicaid Policy education. We also do health advocacy projects.

Future Meeting Agenda Topics/Idea

- The group discussed streamlining the remote attendance approval process and the lunch order for meetings by potentially using a Google form or something similar instead of the current email-based system.

Public Policy Committee:

- The Public Policy Committee's priorities for 2026 were discussed, with a focus on employment for individuals with disabilities and the development of one-pager resources for legislators.

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- The committee has approved to adopt the 2025 priorities for 2026.
- The committee plans to align its two-year cycle with the legislative session.
- The committee is awaiting a study on Medicaid for employed persons with disabilities to inform future policy changes.
- Andersen discussed the challenges faced by students with disabilities in accessing appropriate educational environments, highlighting issues with school choice, waiver systems, and capacity constraints in specialized programs.
 - Andersen shared her personal experience of navigating these challenges, emphasizing the need for better resources and support for families.
- The group explored potential policy solutions, including allowing school choice for students with Individualized Education Programs (IEPs) and increasing funding for public school programs, though concerns were raised about capacity limitations and administrative discretion in approvals.
- Andersen discussed challenges with Direct Support Professionals (DSP) funding and the need for increased reimbursement and tax incentives.
- The group reviewed goals for community living and healthcare, including fully funding home services and eliminating barriers.
- The group also considered adding two issues for 2026 for study, education, and possible policy recommendations. The two issues are:
 - Requirement for a Medicaid member or insured private insurance enrollee with pervasive developmental disorders and/or autism to receive a rediagnosis to maintain waiver eligibility or coverage for specific treatments.
 - Abuse and neglect of persons with disabilities in public and private long-term care facilities.
- Concerns were raised about the possibility of Medicaid waivers being cut, and the need for advocacy was mentioned.
- Nosbisch seconded the motion to approve the Public Policy Priorities. Council approved the motion.
- There is upcoming deadline of September 30th for Congress to pass the Federal budget which is really twelve budgets to avoid a government shutdown. There are concerns about funding for disability programs and cuts in certain areas.
- Crowe discussed the effects of the "One Big Beautiful Bill" on Iowa, including changes to Medicaid eligibility and work requirements for non-disabled low-income adults, which will be implemented over a year.
- The group also addressed potential cuts to Medicaid spending and the impact on coverage, with projections of up to 100,000 Iowans losing Medicaid over the next decade.
- Crowe reviewed error requirements for processing Supplemental Nutrition Assistance

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Program (SNAP) and Medicaid. States must be below a 6% error rate, or they will be fined. Iowa currently has a 5.9% processing error rate.

- Crowe discussed several federal policy changes and proposals by the Trump administration that affect people with disabilities, including potential cuts to Supplemental Security Income (SSI) benefits, changes to voting methods, and modifications to minimum wage requirements for caregivers.
- Crowe highlighted ongoing budget appropriation processes and emphasized the importance of monitoring executive orders and rule changes affecting disability rights and services.
- Crowe also mentioned upcoming deadlines for public comments on Iowa's Home and Community Based Services (HCBS) waiver amendments and consumer choices option (CCO) changes, urging attendees to review the information and provide feedback to Iowa HHS by their deadline of Sept. 19 @ 4:30 PM. We are getting a lot of questions and concerns expressed from families regarding this change.
- Maher provided information from Iowa HHS on the proposed policy changes to supported community living (SCL) under the CCO.
 - It is important to share stories during the comment period.

- Full statement by Iowa HHS was read by Maher:

Iowa Medicaid is proposing administrative changes to the service limitations for Supported Community Living (SCL) services. The goal of these changes is to give families access to daily SCL services in the family home by removing the prohibition on the daily unit of service being provided in the family home and align the limitation on the number of 15-minute units of SCL available each day with the definition of a daily unit of SCL service. A daily unit of service is defined as 8 or more hours per day of direct staff supervision and support as averaged over the course of a calendar month. Members requiring 8 or more hours of SCL per day will have services reimbursed through the daily unit of service whereas those needing fewer hours of supervision and support services will be reimbursed through the intermittent SCL 15 min unit of service.

Consumer Choices Option (CCO) individual budgets are developed based on needed hours of support reimbursed at the upper rate limit for the traditional service with a utilization factor applied. The service limitations applicable to traditional services are applicable to those services chosen for self-direction. Participants choosing to self-direct their services may choose from a variety of available traditional services to self-direct to meet their assessed needs for support, services, or goods that directly support the participant. Participants may receive a combination of traditional agency-directed services and self-directed services. Participants can choose self-direction and then choose to go back to traditional services at any time.

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Public Comment Period:

30-day public period started on August 20, 2025 and will close on September 19, 2025 at 4:30 PM.

[PUBLIC NOTICE: 1915\(c\) Home and Community Based Services \(HCBS\) AIDS/HIV, Brain Injury \(BI\), Children's Mental Health \(CMH\), Elderly, Health and Disability \(HD\), Intellectual Disabilities \(ID\), and Physical Disability \(PD\) Waivers | Health & Human Services](#)

All public comments will be considered before final decisions are made.

- Crowe also mentioned that Iowa Medicaid is forecasting a deficit of \$76 million for the current fiscal year and \$181 million for 2027, urging vigilance with the legislature and planning for potential federal funding cuts.
- There will be an event on November 14th at the Harkin Institute to discuss federal policy impacts on Iowa, with Senator Harkin confirmed to do the introduction. The time has not been set yet.
- Crowe encouraged members to have town hall meetings and community roundtables to discuss disability issues.
 - Caldwell will be having an event called "Keys to Success for People with Disabilities" in Sheldon on October 8 to explain how people struggle on Medicaid and Medicare.
 - Event is tentatively planned for 11 AM – 12 PM with an optional tour of Village Northwest at 1 PM.
 - Caldwell is asking for people to help clean up after the event.
- Crowe stated there will be a legislative panel on Thursday, September 18th at 11 AM at the Make Your Mark conference. There will also be a lunch event, and Crowe is asking for volunteers to help run a policy game and take notes. Crowe will send an email asking for volunteers.

- **Public Comment:**

None

State Partner/Council Member Updates:

Maier - Medicaid

- Maier discussed the proposed waiver amendment changes, noting that public comments will be considered before final decisions and HHS will request Centers for Medicare and Medicaid Services (CMS) approval for implementation by January 1, 2026.
- She outlined ongoing work including IT implications meetings, budget reviews, and waiver applications. Hopefully public comment will be December 1 – January 8.

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- They are planning for a uniform assessment with core supplemental questions.
- Maher also mentioned attending the HCBS Conference in Baltimore, where she and colleagues presented on their quality approach using scenarios. One scenario included a person named Alex who would like to transition from an Intermediate Care Facility (ICF) to community living. They identified necessary conditions for a successful outcome.
- Maher discussed ongoing work in Iowa, including proactive system monitoring and sharing updates about Medicaid.

Lawson – Dept of Education

- Lawson provided updates on staffing, policy webinars, and the procurement of assistive technologies for reading and writing.
- Lawson stated they have started their policy and practice webinars. These webinars are geared towards administrators and special education staff, but anyone is welcome to join. They are held on Wednesdays at 8:30 AM. They are also recorded: [Special Education Policy & Practice Webinars](#)
- Lawson also mentioned the upcoming release of special education district designations and explained the differences between these and building-level designations under Every Student Succeeds Act (ESSA).
- Lawson discussed recent changes at the federal level in education funding and compliance, noting that Iowa's obligations remain unchanged despite these shifts.
- She also shared that Iowa received a report from Office of Special Education Programs (OSEP) regarding special education program compliance, with seven findings identified. [Iowa Part B Differentiated Monitoring and Support](#)
- Lawson mentioned that new staff hires in July have helped improve work capacity and timelines.
- The discussion included details about two fiscal findings related to financial processes and contract language requirements, as well as improvements in handling state complaints within the 60-day timeline.
- Lawson discussed strategies for special education, emphasizing universal design for learning and behavior plans to help children.
- The topic of children transitioning from special education to general education classrooms was briefly discussed.
- Lawson explained that the Department of Education is taking action to support a federal grant that was threatened with discontinuation due to budget cuts, particularly focusing on resources for students who are blind or visually impaired. She mentioned that the Department is working to send a letter of support by the next day's close of business.
- Lawson addressed an issue regarding mediation services, noting that AEA (Area Education Agency) mediation has been discontinued and removed from their website, as it was not recognized by the federal government and could potentially

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confuse families about their rights and timelines for filing complaints or pursuing other legal actions.

- Lawson discussed Iowa's approach to monitoring district data, explaining that unlike most states with a 5-year cycle, Iowa uses a different method focused on improving outcomes rather than compliance. She expressed concern about how OSEP might interpret this, potentially leading to issues with data documentation and check-box compliance.
- **Owens – University Centers for Excellence in Developmental Disabilities**
- Owens highlighted a recent youth suicide prevention summit organized by the Center of Excellence for Behavioral Health, which attracted nearly 100 attendees, and mentioned cautiously optimistic news about funding being recommended at current levels by House and Senate subcommittees.
- Owens discussed the Iowa Department of Health and Human Services' redesign of Iowa Compass, which they have been partnering on. Iowa Compass expanded its call center and database to serve as a statewide information and referral source for aging and disability services. She highlighted the ongoing effort to merge systems and launched a survey that is open until October 3rd to gather feedback on Iowa Compass, which will inform decisions on website improvements and backend systems.

Evans – Vocational Rehabilitation (VR)

- Evans shared updates on serving high schools across Iowa, noting challenges with providing services to students in charter schools, and mentioned a new case management system being implemented to streamline data collection and improve efficiency.
- Evans discussed the availability of Individualized Education Plan (IEP) information and the new system that allows parents to access it, emphasizing the need for parental approval.
- Evans mentioned a webinar on accessing resources and assistance with college funding.

Brenneman – Child Health Specialty Clinics

- Brenneman shared details about the Iowa Family Leadership Training Institute's (IFLTI) 10-year anniversary celebration, highlighting its impact on families and advocacy efforts. The celebration is September 12th from 1:30 – 3:30 PM at the UCEDD. <https://uiowa.zoom.us/j/4533877103?omn=94224206200>
- Brenneman also mentioned upcoming storytelling trainings and a crowdfunding campaign to secure funding for future programs.
- Brenneman provided updates on the organization's efforts to understand and partner with new state systems, including Certified Community Behavioral Health Clinics (CCBHCs) and Your Life Iowa.

Hoenig

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- Hoenig discussed the recent graduation of twelve students from the Youth Leadership Academy (YLA), highlighting successful partnerships and a ceremony held at the State Historical Society. Lovelace confirmed that new pictures from the graduation were posted on the Council's website, and the group discussed potential support for a talented graduate with autism.

Bussan

- Rachel provided an update on the Autism Society of Iowa Fall Conference, where she will speak on an adult employment panel.

Johnson – Disability Rights Iowa (DRI)

- Johnson discussed several key initiatives, including a federal grant application through Administration for Community Living (ACL) for intensive work on elder maltreatment in Iowa's nursing homes. DRI will identify and monitor the worst nursing homes if funded. She highlighted concerns about Iowa's nursing home conditions, noting that the state ranks among the worst in the US, and mentioned a new Frequently Asked Questions (FAQ) resource on their website covering twenty different legal areas.
- DRI is also running a social media campaign about voting and has developed frequently asked questions to assist self-advocacy, with plans to make these resources American Sign Language (ASL) accessible in the future.

Richardson

- Richardson shared his work with a refugee task force in Omaha, highlighting significant refugee populations in Nebraska and Iowa with disabilities who face challenges accessing services and are sometimes forced to start their own provider agencies due to language barriers and cultural differences. He is collecting information to better understand the situation and identify potential solutions. Owens will connect with Richardson about a person she knows in Iowa City that may be able to assist.
 - Hoenig mentioned a program called Tapestry Farms that works with refugee families. He noted a specific case of a family with a child with cerebral palsy struggling to navigate the system. Hoenig will talk with Richardson about this program.
- Wilkinson mentioned the "Welcome Weekend" festival in Iowa City this weekend aimed at assisting immigrants.

Public Comment:

None

Adjourn:

Johnson made a motion to adjourn, and Nosbisch seconded the motion. The meeting adjourned at 2:30 PM.

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Action Items:

- Hoenig and Owens will talk with Richardson about some resources for assisting refugee families.