

Iowa Autism Council Meeting

Final Meeting Minutes – November 8, 2023

Meeting minutes taken by Beth Buehler-Sapp and Wendy Trotter

Present: Erika Hertel, Beth Buehler-Sapp, Carlyn Crowe, Connie Fanselow, Pam Gronau, Caleb Primrose, Wendy Trotter, Colin Wixted

Zoom: Wendy Andersen, Carrie Elser, Michelle Grant, Andrea Keith, Rhonda Kortenkamp, Cheryl Mulligan

Absent: Angela Burke Boston, Bill Carlson, Evelyn Horton

Caleb Primrose, Co-Chair, called the meeting to order at 10:06 am. Council members introduced themselves. Council members reviewed the minutes from the September 13, 2023 meeting. Edits were suggested and made. Colin Wixted made a motion to approve the minutes as edited, and Pam Gronau seconded the motion. A vote was taken with no abstentions to approve the minutes as edited. Minutes approved.

The Council discussed the recently released [Final Report from the Boards & Commissions Review Committee](#) with their findings and recommendations.

Wendy Trotter shared the following:

According to the report, they recommend **reorganization** of the Autism Council with the following statement:

Iowa Autism Council. Awareness of autism issues are critical in the education space; however, the Council could be reorganized to include representation for students with other disorders that may affect learning.

Wendy Trotter stated that she shared the following concerns with her Bureau Chief:

Although there is very limited information included in this recommendation, I have some concerns:

- First, the Autism Council does not only focus on education and school-aged individuals, it covers the life span of autistic individuals and their families, so it's not just about how "learning" is affected. In fact, our focus in the last few years has been on adult services and supports.
- Second, knowing that the goal of this review committee is to streamline the State's boards and commissions and to eliminate duplication, adding "representation for students with other disorders that may affect learning" to the Autism Council would be duplicative of the Special Education Advisory Panel, as well as the Developmental Disabilities Council.
- Additionally, the responses I provided to the surveys asking if the board should be eliminated or merged indicated that:
- "If the Autism Council is eliminated, it will be vital to ensure we have intentional representation (family/individuals with autism and/or autism service providers) on other boards/councils to ensure continued efforts to support Iowans with autism, such as: Iowa's Developmental Disabilities Council (DD Council), Special Education Advisory Panel (SEAP), Iowa Council for Early ACCESS (ICEA), Iowa's Early Hearing Detection and Intervention (EHDI) – Advisory Committee,

Iowa State Rehabilitation Council (SRC) through IVRS; as well as continued support of the Regional Autism Assistance Program (RAP) Expert Panel."

- I believe it is still vital that there is intentional representation for the autistic community on some board, in some capacity, but creating a third council that focuses on a broader range of disabilities seems counterproductive to the goal of this initiative.

Connie Fanselow shared that this report is just the recommendations from the Board and Commissions Review Committee and there will need to be some sort of bill from legislators and/or the Governor in the next legislative session before anything changes.

Legislative Report:

Wendy Andersen shared the draft of the legislative report. She stated that the only section she still needs help with is the wording for the issue of the Hawk-I insurance coverage of ABA therapy.

Council read through and discussed the report draft.

Connie suggested adding something about the waiver redesign to encourage consideration of the lifespan needs of individuals with autism in the redesign of the HCBS waivers. Council discussed that this should be one of our priorities for this year. Connie suggested referencing this redesign in the recommendation for exploring the gaps in adult services as well. Wendy T stated that we should also reference the gaps in adult services in the waiver redesign priority, so that we are tying them together in both sections of the report.

Carlyn Crowe suggested the Council include their concerns about the recommendations from the Board and Commissions Review Committee somewhere in the legislative report.

Wendy T mentioned that once the report is finalized, she will make the "one-pager" for folks to share at the Day on the Hill event in February of 2024.

Ideally Wendy A would like to get the draft out to the Council next week and then Wendy T will send out a Google Form once Council members have had a time to review to take a vote on approving the report. The goal is to get the final report approved before Thanksgiving if possible.

Additional Topic/Discussion:

Wendy T reported that Lisa Cook, Senior Advisor, Office of the Medicaid Director, asked her to share information with the Council about upcoming "Hometown Conversations" that they are hosting. Here is what Lisa asked to share:

- *Would you mind sharing with folks that attend that we are doing events across the state, including 2 virtual events? <https://hhs.iowa.gov/ime/HOME/hometown-conversations> it's not too late to get involved and we are super thankful for the participation of each and every person we serve, their families and their communities.*

Lisa is also willing to come to our next meeting and share more information about the HOME project – Council agreed would be beneficial, so Wendy T will attempt to schedule her for our March meeting.

Wendy A shared that there is a "Hometown Conversation" happening in Council Bluffs next Thursday the 16th, and an in-person one during the day.

Wendy A also shared that her nonprofit got a grant to hold a town hall meeting, that Director Matney will be attending also, to discuss the lack of providers and services in SW Iowa. We are working on getting another representative to attend as well.

Carlyn, encouraged folks to go to their local “Hometown Conversations” that are left because you have a unique opportunity to give input and have your voice heard. Most people who have been coming have been staff/professionals, so they need more families and individuals on the waiver to give input. They are currently looking at two waivers: one for adults and one for children. Great way to hear why they came up with those options and give your input. We at the DD Council included in our legislative agenda support for the redesign which is based on looking at individual’s needs rather than their diagnosis.

Connie sent information to Wendy T via email that she can share with Council about the HOME project (the waiver redesign) and the Hometown Conversations. Wendy T will forward that information to Council members.

Cheryl Mulligan encouraged folks that are talking with their legislators to put in a good word about the importance of AEAs as there is some speculation that there may be some legislation about AEAs coming down the pipe.

Caleb called for a motion to adjust the agenda to move updates to before lunch. Colin motioned, Pam seconded.

Agency Updates:

Iowa Department of Education (DE):

Wendy Trotter reported the following updates:

- Autism Navigator – still awaiting contract approval for this year.
- SEE-KS:
 - Another district will be starting the SEE-KS work beginning in December – Glenwood School District – starting with 2 buildings: an elementary and the high school.
 - So we are now up to 4 districts/buildings participating. The others were: Washington Elementary in Mt. Vernon; RCCBA (Roosevelt) in Cedar Rapids school district; and East Mills Elementary in Hastings, IA.

Regional Autism Assistance Program (RAP):

Erika Hertel shared the following updates from RAP:

- RAP has the Spanish Autism Basics webinar series starting at the end of this month. This will be three sessions with Dayrin Lovan presenting. Kelly Pelzel, PhD worked with Dayrin on the content. Sessions will be recorded and links to the recordings sent to all registered participants. Live sessions are eligible for foster parent training credit.
- Kelly Pelzel, PhD will be leaving University of Iowa Hospitals and Clinics at the end of the year and will no longer be the Psychology Technical Consultant for RAP. Jillian Reiher, PhD will step into this role on January 1, 2024. Jillian is a clinical psychologist with the Center for Disabilities and Development at UIHC. Kelly will continue as a member of the RAP Expert Panel.
- Danielle Fitzgerald has been hired to take over the Family Navigator position left open when Allison Drew took over the RAP Program Coordinator role. Danielle will work out of the Fort Dodge Regional

Center working with RAP and Early ACCESS. Her coverage area for RAP is a number of counties in central Iowa, southeast of Fort Dodge.

- Erika is also on the ASI Board of Directors and they also have an adult subcommittee and they inquired about our adult services subcommittee and possible collaboration and/or sharing. They are focusing on: residential care, and end of life planning for when caregivers pass or are hospitalized and the individual with autism no longer has a caregiver.

Iowa Developmental Disabilities Council (DD Council):

Carlyn Crowe shared the following updates from the DD Council:

- Our [Legislative agenda](#) is posted now – open house on January 4, 2024.
- Public Policy committee – members of public are able to attend – this may be a way to have the autistic community voice represented on DD Council. So, if interested in attending, let Carlyn know and she can send invites.
- Capitol Chats – Dec. 1, 2023 – legislative team from HHS giving report on their legislative priorities – another way to hear more about the waiver redesign process.
- Day on the Hill – people talk to whole group, another way to share IAC priorities and concerns about status of Council.
- Allies for Advocacy – helping individuals to be more independent in self-advocacy, still floundering a bit right now, but hoping it will grow into a strong movement.
- More one on one contact with self-advocates and legislators; one idea was inviting legislator to your workplace – was a great way to highlight how policy can change to be more helpful – especially in light of redesign and reorganization – VR especially – now have a waitlist for services.

Caleb shared he is committed to going to Day on the Hill this this year (being held on Feb 22, 2024).

Iowa Vocational Rehabilitation Services (IVRS):

Andrea Keith reported the following updates from IVRS:

- Had to implement a waiting list – struggling with staffing – for example, DSM office down 8 counselors – losing staff with redesign.

Iowa Health and Human Services (HHS) / Autism Support Program (ASP):

Connie Fanselow reported the following updates:

- She is planning on retiring in April – will hand ASP off to someone else in HHS.
- ASP –
 - we had a situation where a Medicaid Managed Care Organization (MCO) was authorizing ABA for kids enrolled in Hawk-I in error – Hawk-I does not cover ABA;
 - this MCO cut families off retroactively in some cases and left families with unpaid bills;
 - Connie told providers to have families contact her and she would see what she could do – only one family contacted Connie, but learned that their bill was covered (MCO paid it); other families have not reached out to Connie yet;
 - encouraged folks if you know of anyone who was affected by this to contact Connie because their bill should be paid by Hawk-I since they authorized the service.
- She is part of the team that is working on the HOME program (waiver redesign) – the team is seeking the Council’s input on what you think is most needed for persons with autism that they don’t have:

- Effective case management
- Therapy/services coverage (SLP, ABA, OT, behavior/Mental health)
- Adult living supports/employment support – especially if do not have ID as well
- Job coaching
- Social Skills
- Independent living skills
- Housing support
- Mental health crisis supports – with comorbid ASD diagnosis
- Crisis care/coverage
- Respite
- Parents as paid caregivers
- Transportation (both children and adults)

Wendy T asked what supports are available for homeless adults with disabilities – Connie responded, not a lot of direct services right now – most are focused on getting them signed up for Medicaid/waiver services so they have a source of income.

Connie also said to start by calling county DHS office to connect with social worker to coordinate services – could also contact Medicaid MCO, county disability services coordinator, centers for independent living in Iowa (can help but there are huge gaps), but there is one in Iowa City, possibly some of the private women’s shelters.

Wendy A stated that Easter Seals league of human dignity could be of assistance if the individual resides in SW Iowa. She encouraged them to seek out local organizations for assistance. She shared that if a family goes to a homeless shelter with an autistic child, they won’t allow them to stay, so this is an issue in Iowa.

Colin shared that he finally heard from Federation of Iowa Insurers - working to get a full update on private insurance as it relates to autism and mental health.

Final Comments:

Wendy T shared an agency report template that can be found in our Google folder – is this something that we would like to use, especially if agency representatives cannot be present for the meeting? Or to help agency representatives prepare for meetings and assist with minutes? Council discussed and agreed to have it as an option – asked Wendy T to remind them to complete it when send out meeting RSVP.

Wendy T also shared that Stephanie Boyle has submitted her resignation from the Council. We now have 4 vacancies.

Caleb mentioned that it was brought to our attention that the March meeting is over spring break. Is the date okay with everyone? Council decided to keep March meeting as scheduled, March 13, 2024.

Colin motioned to adjourn the meeting. Pam seconded the motion.

Meeting was adjourned at 11:45 am.

Next meetings:

- March 13, 2024 – *Grimes Building, Room B100*
- June 12, 2024 – *Grimes Building, Room B100*

Wendy Trotter will send out a meeting reminder.