

Iowa Autism Council Meeting

Final Meeting Minutes – March 13, 2024

Meeting minutes taken by Beth Buehler-Sapp and Wendy Trotter

Present: Beth Buehler-Sapp, Angela Burke Boston, Bill Carlson, Carlyn Crowe, Carrie Elser, Connie Fanselow, Michelle Grant, Pam Gronau, Erika Hertel, Evelyn Horton, Andrea Keith, Rhonda Kortenkamp, Cheryl Mulligan, Wendy Trotter, Colin Wixted

Zoom: Wendy Andersen, Caleb Primrose

Guest: Gary Van Den Boom, Thomas Mayes

Caleb Primrose, Co-Chair, called the meeting to order at 10:06 am. Council members introduced themselves. Gary Van Den Boom, public guest, introduced himself. He has been researching autism since 2016 and hoping to answer any questions members may have. Shared that his research has focused on causes of autism.

Council members reviewed the minutes from the November 8, 2023 meeting. Edits were suggested and made. Colin Wixted made a motion to approve the minutes as edited, and Michelle Grant seconded the motion. A vote was taken with no abstentions to approve the minutes as edited. Minutes approved.

Wendy Trotter shared that the Council has 5 terms ending on April 30, and 4 of the members whose terms are ending have agreed to renew their term: Wendy Andersen, Evelyn Horton, Cheryl Mulligan, and Caleb Primrose. Pam Gronau will not be renewing her term so this will be her last meeting. In addition to these 5 terms ending, we also continue to have 4 vacancies that have not yet been filled. With Pam's upcoming vacancy, our vacant positions are:

- Family member/person with autism (2)
- Research
- Mental health provider
- Service provider

Wendy encouraged Council members to refer anyone interested in serving on the Council to apply via the link on the DE website.

Legislative Update:

Thomas Mayes, General Counsel - Iowa Department of Education, provided an update on proposed bills resulting from the recommendations from the Board and Commissions Review Committee. House File 2574 makes no change to the Autism Council, and focuses mostly on striking unnecessary boards/councils. Senate File 2385 proposes eliminating the Autism Council and creating a new special education council (this would be in addition to the existing Special Education Advisory Panel). Some of the concerns regarding SF2385 include:

- The Special Education Advisory Panel (SEAP) is a federally required council and has required representation, and the proposed "special education council" membership does not meet those requirements, so it could not replace SEAP.

- The Autism Council does not only address school-aged individuals with autism, but covers the lifespan of autistic individuals and their families; the proposed “special education council” will focus on school-aged individuals.

The Council is free to take a position regarding this proposed legislation. Additionally, council members can also express their individual concerns with their legislators.

Thomas shared information about several other proposed bills that may be of interest to the Council: 3 bills related to the BoEE, one bill related to therapeutic classrooms, and the AEA reform bill.

Agency Updates:

Iowa Department of Education (DE):

Wendy Trotter reported the following updates:

- Autism Navigator – contract has been enacted. Will be offering 5 seats/courses per AEA/DMPS and will begin enrolling participants in June.
- SEE-KS:
 - We continue to have participation in 4 districts across Iowa: Washington Elementary in Mt. Vernon; RCCBA (Roosevelt) in Cedar Rapids school district; East Mills Elementary in Hastings, IA; and West Elementary and Glenwood High School in Glenwood, IA.

Regional Autism Assistance Program (RAP):

Erika Hertel shared the following updates from RAP:

- RAP had six staff members attend the Autism Society of Iowa Autism Advocacy & Acceptance “Day on the Hill” event at the Iowa State Capitol on Thursday, February 22, 2024. Allison Drew spoke to the group about RAP and Erika Hertel answered questions and spoke to legislators and others one on one. Staff members all made attempts to connect with legislators and left materials. Jackie Schott, RAP family navigator, was able to talk with her legislator regarding a visit to the Child Health Specialty Clinic in Mason City.
- The RAP Autism Basics webinar series Spring of 2024 session begins March 27, featuring Jillian Reiher, PhD. Jillian is the new RAP Psychology Technical Consultant, replacing Kelly Pelzel, and is a staff psychologist at the Center for Disabilities and Development. This free, four-part series is aimed at parents or primary caregivers of children with a new autism diagnosis. Anyone is welcome. Sessions will be recorded, and links sent out to registered participants. Live sessions are approved for foster parent training credit.
- Jillian Reiher is also working with Dayrin Lovan to provide a free three-part webinar series for Spanish-speaking parents or primary caregivers of children with a new autism diagnosis that begins May 15. This is based off of the Child Health Specialty Clinics, Regional Autism Assistance Program Autism Basics Webinar Series that is offered twice per year. Webinars will be given in Spanish. These will also be recorded, and live sessions are approved for foster parent training credit.
- The next meeting for the RAP Expert Panel is scheduled for Tuesday, April 23.
- Referrals continue to grow.
- Wendy T will send flyer out to council members.

Iowa Developmental Disabilities Council (DD Council):

Carlyn Crowe shared the following updates from the DD Council:

- DD Council is monitoring a lot of the proposals and education bills – Thomas only touched on a few of the DE initiated bills – but there are a lot of other bills out there regarding education:
 - SF251 – A revived bill that would restrict administrative spending at districts to 5% - that includes everything but teachers’ salaries
 - Board/commissions bill concerns: Gives people with disabilities less opportunities to serve on some of these boards – less opportunity for public input
 - DD Council has registered in opposition to both AEA bills – held 2 town hall meetings to get input from public – overwhelming opposition from parents of children with special needs
- Carlyn reiterated Thomas’s point: your advocacy is important as an individual. You can contact a chair of a committee even if you are not their constituent.
- Autism Awareness Day on the Hill – Carlyn was able to talk to and train a lot of people on how to talk to your legislator.
- HF2589 - work without worry – this bill would eliminate income and assets limits so that they can keep working and maintain their Medicaid benefits. (MEPD)
- Carlyn shared that folks can access additional information on any of the above-mentioned bills on DD Council’s website, Capitol Chat, and Infonet.
- Events coming up:
 - Youth leadership academy in July – still virtual for this year, for one week in the mornings.
 - Conference in September – hoping to get parents to present on how to advocate for their children in addition to self-advocacy

Iowa Vocational Rehabilitation Services (IVRS):

Andrea Keith reported the following updates from IVRS:

- Target/projected date to start releasing individuals from waiting list is June 3, 2024. Order of selection, need to first serve those found most significantly disabled first.
- Still down staffing across the state.

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

Connie Fanselow reported the following updates:

- She is planning on retiring the end of April – no one has been identified yet to take over ASP, but HHS is aware that they need to make sure the work is covered when Connie retires.
- ASP –
 - we are seeing an uptick in enrollees, a lot from Balance Autism;
 - since reorganization at HHS, and all the changes in processes and people, the ASP process seems to be taking longer;
 - looks like if legislation goes through, the ASP report may be one of those annual reports that will go away.

Other Agency/Organization Updates:

Evelyn Horton reported the following updates from Balance Autism:

- Still have grant money for family safety care trainings that are open to anyone. Trainings are being provided on the following dates/locations:
 - April 19 – Cedar Rapids
 - April 26 – Altoona
 - May 24 – Quad Cities
 - June 20 – Iowa City
 - All are 9:00-3:00, she believes they are all on a Saturday
 - Evelyn will send flyer
- In Council Bluffs we are using a church space to do center-based services – hope this summer to offer an adolescent/teen social skills group with a focus on social skills and introductory sex ed / relationships.
- Adult services – We have opened our first 4 high technology use homes. This has allowed for a reduction in the number of staff needed on-site. Residents have been assessed and demonstrated that they could be alone for periods of time and the technology is very specific to their needs. Staff continue to monitor remotely 24 hours a day, and staff are onsite part of the time. It has been super successful, about to roll the fifth one.
 - Families are more comfortable going into the homes now since there are not staff there all the time
 - 2 in Ankeny
 - 2 in Altoona
- Hawki to cover ABA services – ASI and Iowa ABA lobbyists have taken this up – suggest that this may be addressed in appropriations bill.

Cheryl Mulligan with Green Hills AEA reported that Project Lifesaver is now at Glenwood PD; Hoping to have the whole of Mills county covered by the end of the year.

- Project lifesaver is a radio frequency device/technology, the individual wears a transmitter that has a unique number, so if they wander/elope the caregivers can call 911 and officers who are trained as search specialists go out with a specific device that tracks just them
- typically the individual is reunited with their caregiver within 30 minutes of when they are notified that they are gone
- it is waterproof
- can be used for any age depending on who is sponsoring it

Vote/Confirm Chair and Co-chair for 2024-25

Wendy Andersen and Caleb Primrose were nominated for chair and co-chair for the next year. Caleb Primrose motioned to approve, Colin Wixted seconded. Approved.

Final Comments:

Wendy T shared she will continue to update the Council on the status of the Boards and Commissions bills so that we know the future of the Council.

Colin motioned to adjourn the meeting. Pam seconded the motion.
Meeting was adjourned at 1:15 pm.

Next meetings:

- June 12, 2024 – *Grimes Bldg. Room B100*
- September 11, 2024 – *Grimes Bldg. Room B100*
- November 13, 2024 – *Grimes Bldg. Room B100*
- March 12, 2025 – *Grimes Bldg. Room B100*