

Iowa Autism Council Meeting

FINAL Meeting Minutes – June 26, 2024

Meeting minutes taken by Beth Buehler-Sapp and Wendy Trotter

Present: Beth Buehler-Sapp, Angela Burke Boston, Carlyn Crowe, Connie Fanselow, Michelle Grant, Erika Hertel, Evelyn Horton, Andrea Keith, Rhonda Kortenkamp, Cheryl Mulligan, Wendy Trotter

Zoom: Wendy Andersen

Absent: Bill Carlson, Carrie Elser, Colin Wixted

Caleb Primrose, Co-Chair, called the meeting to order at 10:05 am. Council members greeted one another and shared one thing they are looking forward to this summer.

Council members reviewed the minutes from the March 13, 2024 meeting. Michelle Grant made a motion to approve the minutes, and Cheryl Mulligan seconded the motion. A vote was taken with no abstentions to approve the minutes. Minutes approved.

Legislative Update:

Wendy Trotter shared that SF2385 was signed into law on May 17, 2024. This act eliminates the Autism Council and creates an Iowa Special Education Council. Language in the act is as follows:

DIVISION XXI

AUTISM COUNCIL ELIMINATION AND CREATION OF IOWA SPECIAL EDUCATION COUNCIL

Sec. 482, NEW SECTION. 256.35B Iowa special education council.

1. An Iowa special education council is created to act in an advisory capacity to the department in promoting, directing, and supervising education for children requiring special education in the schools under the supervision and control of the department.
2. The council shall consist of seven voting members appointed by the governor and confirmed by the senate. Each of the following shall be represented among the voting members:
 - a. One member who is a parent or guardian of a student who has a disability in obtaining an education because of autism.
 - b. One member who is a parent or guardian of a student who has a disability in obtaining an education because of a behavioral disorder.
 - c. One member who is a parent or guardian of a student who has a disability in obtaining an education because of physical disability.
 - d. One member who is a parent or guardian of a student who has a disability in obtaining an education because of mental learning disability or head injury.
 - e. One member who is a parent or guardian of a student who has a disability in obtaining an education because of a communication learning disability.

- f. One member who is a parent or guardian of a student who has a disability in obtaining an education because of dyslexia.
- g. One member who is a special education teacher.

EFFECTIVE DATE. **This division of this Act takes effect July 1, 2025.**

Carlyn Crowe shared that Capitol Chat is being held this Friday (6/28) at 11:00am. They will be focusing on federal regulations and other issues going on, perhaps council members could join and propose something for the future that is needed to be able to represent the autistic community since the Autism Council will be sunseting next year.

Wendy Andersen asked if the Council still needed to complete a legislative report for this year? Wendy T responded that yes, we do.

Agency Updates:

Iowa Department of Education (DE):

Wendy Trotter reported the following updates:

- Autism Navigator – Participants are in the process of being enrolled. This is the last year the DE is offering to purchase seats in the AN family of courses. AEAs can continue to purchase seats for interested participants moving forward.
- New position – Wendy shared that she has accepted a new position at the Department. She is now an Administrative Consultant in the Special Education Bureau. Her former Education Program Consultant – Autism position will be posted sometime in the near future.
- The Department has an OSEP (Office of Special Education Programs) visit scheduled for the second week of September.

Regional Autism Assistance Program (RAP):

Erika Hertel shared the following updates from RAP:

- RAP held the webinar Autism Spectrum Disorder: A Primer for Case Managers on June 14, 2024 with Todd Kopelman, PhD, BCBA & Kelly Pelzel, PhD. This was sponsored by RAP, Child Health Specialty Clinics, the Autism Society of Iowa, ChildServe, and University of Iowa Communication Sciences and Disorders. There were 180 in attendance and the recording will be available for anyone interested.

Iowa Developmental Disabilities Council (DD Council):

Carlyn Crowe shared the following updates from the DD Council:

- Events coming up:
 - Offering a virtual youth leadership academy in July for one week in the mornings. Struggling to get participants – only have 12 registered this summer. Hoping to move to hybrid in the future. Looking to build a youth advocacy movement.
 - The Make Your Mark Conference is in September – hoping to get parents to present on how to advocate for their children in addition to a focus on self-advocacy.
- Pulling together a public platform that will focus on the following topics: education, employment, community living, and healthcare.
- Looking at AEA legislation and the impact on climate or what may need to be addressed
- Town hall meeting in August will focus on wrapping up results of the legislative session. We also

intend to focus on helping folks know where to put their advocacy efforts. We will be having a panel discussion with representatives from the Department of Education, ASK Resource Center, Disability Rights Iowa, and others. Wendy Andersen is helping with this too.

- Capitol Chat is a monthly discussion about what is going on related to policy – this month will be about federal policies. Garret Fry from Cedar Rapids, will be speaking about his situation on Friday.
 - A little background about him: he was not getting the round the clock care he needed to live independently; was denied by Medicaid for exceptions filed; he filed a complaint to federal civil rights office indicating that the low Medicaid reimbursement rates were preventing him from getting the care he needs. They sided with him so now he is getting the care he needs, but this decision only applied to him – not wide-spread change.

Iowa Vocational Rehabilitation Services (IVRS):

Andrea Keith reported the following updates from IVRS:

- Starting July 1st, all those determined most significantly disabled will come off the waiting list; on Aug 1st, those determined significantly disabled will come off the waiting list; and then on Sept 1st, all others will come off the waiting list. This will put extreme pressure on our staff as they are understaffed. Andrea also shared that they will also be offering a “Mobile Unit” which will allow staff to be virtual and reach more areas.

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

Connie Fanselow reported the following updates:

- Connie is retiring this Friday, June 28th. Lin Nibbelink will be replacing Connie on this council.
- Connie has been training Megan Abramski to take over ASP upon her departure. They have decided to set up an email box specific to ASP as well as a support phone number; that way whomever is assigned to supporting the program will be able to address the incoming requests. Connie will send out an email with the new contact information to all the practices/providers.
- Struggled to get payments out this year, hoping to get completely caught up by July 1. Hoping to identify some kind of software to assist with payments because current process is a huge time commitment.
- Enrollment in ASP is way up – now getting approximately 3 applications a month.
- Appropriations bill ensured funding for ASP this year, but removed all the earmarked contracts/funding – so will not be contracting with Tanager Place for their social skills program this year (was \$25,000 earmarked funds). They may do an RFP for this type of funding for programs this year.
 - Evelyn asked how organizations can learn of the RFP opportunity – Connie said she will put a bug in Megan’s ear to send an email out to organizations when/if an RFP is posted.
- Wendy A asked about Hawki and ASP – Connie said they can get ASP if on Hawki, but Hawki does not cover ABA. There was legislation about a study to look into adding ABA to Hawki as a covered benefit – could happen as soon as next legislative session. If this happens, this could make ASP less necessary.

Other Agency/Organization Updates:

Evelyn Horton reported the following updates from Balance Autism:

- Tech homes are going really well! Seems to be fostering independence!

- Medicaid has been given another installment of American Rescue Plan Act (ARPA) allocations which will go to HCBS services (which include ABA services) and directed to focus on attraction and retention for providers.
 - This year we lost 13 of 35 BCBAAs – so we are in a crisis right now.
 - We have a really hard time competing with the for-profit organizations/providers.
- Residential Based Supported Community Living (RBSCCL) has not been very attractive to get more residential services for kids because the kid takes their “slot” with them. The fee schedule is atrocious – we are having to enact a huge rate increase to address the fact that we may be short a bed for a period of time if a child moves out and takes slot with them. Hoping to entice more providers to provide intensive supports to keep more challenging children in state instead of so many having to go out of state.
- Expect within next 5 years the approval for ICFs will get reduced.
- We have been offering a teen training group that addresses sex education. It includes online safety and a parent training as well. We have completed our first group; will be enrolling another group soon.
- Our integrated PK program will run in the Quad Cities (in addition to Clive) - 2 classrooms offering morning and afternoon sessions.

Cheryl Mulligan with Green Hills AEA reported that the Green Hills AEA autism team is going through some significant changes.

Caleb Primrose shared that he was able to attend a sensory friendly baseball game. Iowa Cubs partnered with ChildServe to offer a special room with sensory supports and a special sensory friendly area for observing the game. The event was well received and they are considering offering it again next year.

Subcommittee Updates:

Adult Services Subcommittee:

Wendy Andersen shared that she spoke with ASI and shared that we had identified priorities related to adult services; asked if they could house and share some of our resources and findings related to adult services. Michelle added that she has been working on identifying residential supports – wonders if perhaps we should write up a summary of what we have found and share it with the ASI adult services committee. Evelyn stated that she would like for us do something meaningful and helpful before we are disbanded, so working with ASI may be helpful.

Carlyn asked for a clarification of what the focus was in this committee. Is it to identify gaps or to identify barriers? If the adult perspective that is a part of this council goes away, and we instead rely on a nonprofit for that voice, who will be able to advise state government?

Future Planning Discussion:

September meeting date:

Wendy T had proposed Sept. 18 as an alternative date for our meeting, but this conflicts with the DD Council’s Conference. Council members discussed moving the meeting to September 4th instead. Cheryl Mulligan motioned to move the September meeting to the 4th; Michelle Grant seconded the motion. Motion approved.

Planning for future:

Council members discussed concerns and ideas for the future when this council is no more.

- Concerns that there is not a broad representation of agencies on the new special education council like there are on this council – no VR representation, no provider representation, no AEA representation, etc. – just parents
- Caleb proposed establishing a task force with DD Council and ASI adult services subcommittee to work together for improving adult services.
- Partnering with these two organizations would also help to identify supports for younger people with autism.
- Evelyn stated – what have we accomplished and how do we capitalize on our successes and ensure those initiatives continue once this council is ended?
- Concerns about getting input from a diverse representation like we have on this council
- RAP will continue to update the strategic plan; RAP Expert Panel will continue to convene
- Wendy T suggested that RAP Expert Panel could potentially provide yearly updates on progress on the strategic plan since they are the only entity that solely focuses on autism.
- DD Council’s public policy committee can be another space for autistic representation. Wendy A is on this committee.
- Wendy A wondered if another organization could create an adult autism task force – not sure where it would sit, but with an organization that could work on advocacy – DD Council, ASI, ARC, others?
- Wendy A, Carlyn, and Caleb can start the conversation and begin discussing how to best support autistic individuals when this council ends. Can identify who should be invited and what organizations to include.
- Wendy A asked if anyone knows of any other models out there to guide us?
- Erika said that really what we need to do is piece out the various pieces of this council to other organizations to continue the work.
- What government agencies do we want to bring our concerns to before this council dissolves – ie. Workforce development, public safety, health human services, Medicaid, etc?
- Wendy A wondered if we could go to other organizations and ask if we can add someone to represent the autistic community on their council/committee/board etc.
- Council could develop a resource to identify where to go to learn about different avenues that individuals can get their voice heard.
- Challenge – we have gathered and shared information related to autism supports, now how will this information be gathered and shared?
- What if in this next year we more actively advise (not just write a report) on what is needed – we become really vocal in sharing our advice. Who to invite: Director Mattney, legislators, AEA directors, VR directors, public health departments in the individual counties, share with broader range of parents, could possibly have a Town Hall
- Really defining the audiences, leaders but also boards who will be continuing (heads of departments and boards) – focus on advising
- Create a list and assign council members to invite targeted audience
- Carlyn shared town halls are often not well attended.
- Community events, locally focused town halls, may be a more successful avenue.

- Erika – Iowa Autism Speaks advocacy group – we could get an audience with them to share what our goals are
- First we need to clarify our “advise”, second who is most important to share this with, third develop a plan to move forward.
 - Need to get very specific
- Proposed a task force/committee: Priorities Advisory Committee – Wendy A (lead) Carlyn, Caleb, Michelle, Evelyn
 - Cheryl motioned to create a task force/committee and Wendy A seconded the motion; committee is approved.

Final Comments:

Caleb reminded members that our next meeting is September 4, 2024

Michelle motioned to adjourn the meeting. Cheryl seconded the motion.

Meeting was adjourned at 2:00 pm.

Next meetings:

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