

# Iowa Autism Council Meeting

## Final Meeting Minutes – June 21, 2023

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Meeting minutes taken by Beth Buehler-Sapp and Wendy Trotter

**Present:** Caleb Primrose, Wendy Andersen, Evelyn Horton, Michelle Grant, Andrea Keith, Erika Hertel, Bill Carlson, Rhonda Kortenkamp, Wendy Trotter, Beth Buehler-Sapp, Stephanie Boyle, Colin Wixted, Carlyn Crowe, Carrie Elser, Angela Burke Boston, Cheryl Mulligan.

**Zoom:** Pam Gronau

**Absent:** Connie Fanselow

Caleb Primrose, Co-Chair, called the meeting to order at 10:06 am. Council members introduced themselves, including new Council members, Rhonda Kortenkamp and Bill Carlson. Council members reviewed the minutes from the March 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.

### Subcommittee Updates:

#### Bylaw Subcommittee:

Council members reviewed proposed edits from the subcommittee. Additional edits were suggested by various Council members. Wendy Trotter, bylaw subcommittee chair, stated she will make the new edits and send those electronically to Council members to review prior to the September meeting. Then at the September meeting we can review again and potentially vote to approve.

- Carlyn introduced a discussion around advocate vs advise; she asked if it is accurate to remove the word *advocate* from our mission statement that currently states: “Identify the needs, make recommendations and advocate for improving and enhancing the lives of individuals and families living with autism spectrum disorders”. She stated we as a Council should be able to advocate for best practice for the population we serve. We may not be able to “lobby” but we should be able to advocate. We need additional clarification on what is meant by advocate vs advise.
- Council members also asked “who are we making our recommendations to?” If it’s to the Governor and Legislators, how do we get them to hear our recommendations?
- Evelyn – we need to get more public involved in our legislative recommendations – we need to get public input on what is actually NEEDED for lowans with autism.
- Council also discussed possibly changing the months we hold meetings to better align with getting information to legislators prior to legislative session.

#### Adult Services Subcommittee:

Wendy Andersen, Adult Services Subcommittee chair, reported that they met on May 31, 2023 via zoom and divided up the areas of adult services for subcommittee members to explore: what is available, what are the gaps, can we define it by type, location, etc.

- All are noticing a lack of services, in general, for adults – can get a list of providers that may be able to offer types of service, but no guarantee that they will take Medicaid or have autism experience.
- Wendy A asked: how do we really define what the gaps are? Because what is on paper may not be actuality (like not accepting new patients on Medicaid). Is the real issue the lack of providers or is it reimbursement? We are hoping to pull together what is available first and then identify the gaps.
- Cheryl Mulligan shared it is probably both because there are a lot of unfilled positions for many therapist positions in both schools and clinics.

Michelle Grant shared that she is focusing on residential services for adults.

- She participated in a residential services lunch and learn and asked if there was a comprehensive list of residential services. The response was “not really”.
- She worked through making her own list based on a Google search and is now trying to call all these locations to see if they actually exist. A lot of residential facilities have spots available on a “best fit” basis – so even if they have an opening, it may not actually be available for an individual in need of a placement.
- She also heard from a parent that they are closing a home in Storm Lake, but she doesn’t know why.

Colin asked, “Do we know how many residential facilities Iowa currently has”?

Carrie Elser pulled up the list and shared that her best guess was a little over one hundred, but she doesn’t know if all of these on the list still exist.

Wendy A shared that subcommittee members are looking at a number of types of services including: transportation, job support, life skills, driver’s license training, waiver services, transition services, etc. The biggest challenge may be affordability.

- Waiver services – are there services available if they are on waivers?
- Post high-school education – struggling to find information.

Rhonda stated that she reached out to all the AEAs asking what kinds of information/resources they have on vocational transition; she has only heard back from 3 of the 9 AEAs.

Evelyn stated there is a goal in the strategic plan for RAP (Regional Autism Assistance Program) and ASI (Autism Society of Iowa) to be the holders of information for families, so can we get information to the Family Navigators at RAP, and to ASI for posting/sharing on their website?

Wendy A asked, once we get more information on adult services, what should we include in our report as a recommendation? And how can it be an actionable recommendation?

## Agency Updates:

### Iowa Department of Education (DE):

Wendy Trotter shared there is nothing new to report.

### Regional Autism Assistance Program (RAP):

Erika Hertel shared the following updates from RAP:

- Hired Alison Drew as the RAP Program Coordinator (Rachelle Swanson-Holm’s vacated position) – was previously a Family Navigator and she has 2 children with autism.

- Michelle Holst at HHS will now be the Learn the Signs. Act Early. (LTASE) ambassador for Iowa.
- CHSC applied for an additional year of funding from the HRSA grant they have, haven't heard yet – funding would help to continue funding/establishing Family Navigator services.
- RAP is experiencing translation needs that are becoming cost prohibitive; they are looking for solutions.

### Iowa Developmental Disabilities Council (DD Council):

Carlyn Crowe shared the following updates from the DD Council:

- Shared with the Council that the DD Council has a magazine which describes what they do and their priorities, events, etc.
- The Make your Mark conference is in August in Coralville, 8/30-8/31.
- Council members can sign up for emails from DD Council and then they will get updates on legislation and events.
- DD Council continues to offer Capitol Chat zoom meetings; next meeting looking to get input from audience on needs.

### Iowa Vocational Rehabilitation Services (IVRS):

Andrea Keith reported the following updates from IVRS:

- Their administrator resigned – workforce dept has appointed a temporary administrator.
- They have developed a new consent sheet for parents to sign with their move out of DE until something else gets addressed in the system.
- They will be offering a session and have a table at DD Council's Make Your Mark conference.

### Other Agency/Organization Updates:

Evelyn Horton reported the following updates from Balance Autism:

- Iowa Medicaid released an informational letter listing codes that can be billed under telehealth, and ABA is now included – so that is a win!
- Got wording change that they can hire non four-year degree people to train to be RBTs – Wellmark initially stated they were sticking with the 4-year degree requirement. However, after many conversations, they have developed new guidance that Wellmark will now be accepting non 4-yr degree RBT services.
- Safety Care training for families was piloted a few weeks ago – will be coming out with a calendar of sessions they will be offering. Will be able to train up to 50 families.
- Ran pilot for Clive integrated preschool last summer; now offering full scale integrated (50% children with autism/50% neurotypical children) preschool option for this school year. One classroom will begin in September and a second classroom in January. They are looking for more “neurotypical” peers to enroll.

Colin Wixted reported the following updates from the Insurance Industry:

- Reached out to federation of Iowa insurers to find out the state of autism services, awaiting response.

Caleb shared that he has been asked to serve on the statewide independent living council – which is another governor appointed Council. His term begins 7/1/23 and it is a 3 year term.

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

Full Council meeting was adjourned at 2:00pm to allow for subcommittee work to continue.

The Adult Services Subcommittee met from 2:00pm to 3:00pm.

Next meeting is scheduled for Wednesday, September 13, 2023 from 10:00am – 3:00pm in Room B-100 in the Grimes State Office Building. Wendy T will send out a meeting reminder.