

**Regional Autism Assistance Program
Expert Panel Meeting
January 23, 2024, 9 AM – 11 AM
Via Zoom**

Name	Organization/Role Representing	Attended
Alyson Beytien	Beyond Behavior ABA, Family Member	
Samantha Cermak	ChildServe	
Amy Chebuhar	Iowa Department of Public Health	X
Josh Cobbs	Family Advisor, Autism Speaks	
Megan Christensen	Metro West Learning Center	X
Vanessa Curtis	Division of Child & Community Health	X
Allison Drew	Regional Autism Assistance Program, Family Member	X
Connie Fanselow	Iowa Department of Health and Human Services, Iowa Mental Health and Disability Services Commission	X
Kirstin Hanson	AXIS Therapy Centers	X
Erika Hertel	Regional Autism Assistance Program, Family Member	X
Michelle Holst	Iowa Department of Public Health- 1st Five	X
Evelyn Horton	Balance Autism	X
Aaron Kauer	UI Stead Family Children's Hospital Child & Adolescent Psychiatry	
Andrea Keith	Iowa Vocational Rehabilitation Services	
Lisa Kemmerer	Star Autism Support	X
Vanessa Kimm	Family Advisor, UI Stead Family Children's Hospital	X
Monica Kurtz	Grant Wood Area Education Agency	X
Stacie Lane	Tanager Place	
Toni Fuller Merfeld	Metro West Learning Center	X
Caroline Moniza	Mercy Family Counseling & EAP	X
Steve Muller	Balance Autism	
Jillian Reiher	CDD Clinical Psychologist, RAP Psychology Consultant	X
Mary Roberts	Family Advisor, UI Stead Family Children's Hospital Autism Center	
Leslie Rogers	ChildServe	X
Kristine Steinmetz	Autism Society of Iowa, Family Member	X
Wendy Trotter	Iowa Department of Education	
Maria Valdovinos	Drake University	X
Brad Zelinger	Stride Autism Centers	X

Welcome and Introductions (Facilitator: Erika Hertel)

Guest speaker Note - Cancelled due to illness.

Josephine Gittler, JD, University of Iowa College of Law - Autism Advocacy Efforts, Guardianship

Member Update (Monica Kurtz, Grant Wood Area Education Agency)

Changes Governor Reynolds has proposed for Iowa Area Education Agencies (AEAs) with the introduction of legislation [HSB 542](#)

- proposed to take effect the 24/25 school year
- significant changes proposed for the entire state that would eliminate quite a few services for all students including those to public, private, and Christian schools
- because of significant outpouring of concern, the Governor has created a subcommittee to explore upcoming changes (which indicates that the current bill will not go through as is)
- bill states that the services AEA provides are only for special ed students, but this is not accurate, services are provided to all students
- given 3 choices: schools could choose their special ed services through an AEA, they can provide the special ed services themselves, or they can provide a private special education provider at their own cost
- there are concerns about who exactly those private providers would be and their level of understanding of the needs of the children they're serving as well as the areas that they are willing to service (urban vs rural)
- the best way to influence this situation is to contact your legislators
- Maria Valdovinos mentioned Des Moines Metro does not use AEA services and instead does everything in-house and wondered if that is the model that the Governor is proposing. Monica stated that the Grant Wood AEA had the same questions of "what is this supposed to look like" and no one really knows.
- Evelyn asked for a list of the services that would be missing so that those points can be raised with legislators. The list includes social-emotional behavior health coaches- the people who provide the critical incident stress management services such as responses to school shootings, (CVH & PVIS teams would be gone eliminating approx. 400 jobs across the state). Math and literacy teams, science consultants, and those teams that provide training would all be eliminated. Monica has provided a highlighted list of the services that would be cut under the current proposal.

Member Update (Evelyn Horton, Balance Autism)

Iowa Autism Council 2024 Priorities & Recommendations

- The council is a group of parents, individuals with autism, service providers, and state agency representatives appointed by the Governor to make priority recommendations.
- Top 3 priorities for this next year include:
 1. Continued funding of the Autism Support Program (ASP) with modifications to provide for flexibility in program benefit limits.
 2. Ensure that the service needs of children and adults with the full range of Autism Spectrum Disorders (ASD) are considered in Iowa's redesign of the home and community-based services (HCBS) waiver program.

3. Encourage the Hawki insurance plans to cover ABA therapy and all necessary services for autistic individuals; or modify/expand the ASP program to allow these individuals to utilize this funding source for a longer period of time to assist with therapy needs.
- Additional recommendations:
 1. Continued funding for the Regional Autism Assistance Program (RAP) to support families and strengthen early identification of ASD.
 2. Support of the Legislative Priorities established by the Iowa Developmental Disabilities Council for 2024.
 3. Continued support for implementation of *Iowa's Autism Strategic Plan – 2022 - 2027: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families*.
 4. Continued exploration of the gaps in adult services for individuals with autism and consider innovative ways to expand services for adults.
 - If you speak with legislators, it might be helpful to say “the Governor’s appointed counsel recommends [these]” to put the Governor’s name in there.

Member Updates (Kris Steinmetz, Autism Society of Iowa, Family Member)

2024 Autism Advocacy and Acceptance Day on the Hill

- Thursday, February 22nd
- Registration starts at 8am and the rally starts at 9am and you can meet with legislators at 10:30am
- <https://autismia.com/event/2024-autism-advocacy-and-acceptance-day-on-the-hill/>
- Register a couple of weeks early to get your shirt.
- As a note, some legislators are looking at the AEA proposal as a method to save money. As you advocate, add in some language to remind them that these are services that still have to be provided, it’s not just extra money being spent. Remember that their knowledge of the topics might not be what you think it is.

Member Update (Leslie Rogers, ChildServe)

- Kelly Pelzel will be mostly seeing clients/patients for diagnostics, she has a huge role in Project IMPACT but may not see those clients right away.
- Intake process is to call the main number and ask for the intake team to get scheduled on the waitlist.

Member Update (Jillian Reiher, CDD)

- CDD has been working with Representative Josh Turek out of Council Bluffs to eliminate the need for reevaluating cognitive every 3-5-7 years for folks with ID- which also affects ASD with ID.
- CDD proposed that if a patient evaluation diagnosis is ID, we do not reevaluate again because most likely will not see a positive change. If a child is diagnosed with mild ID, reevaluate in 3 years and if it’s the same, that’s the last evaluation they need.
- A member added that there was recently a patient that was diagnosed with an ID and got on the waitlist for the waiver, but this list is about 4 years and the cognitive test results are only good for 2-3 years. So, by the time they come up on the waitlist, their testing is already expired.

Input Requested

- Are insurance companies requiring a reevaluation of autism if the original evaluation was 3+ years ago for ABA or other therapies?
 - If so, is a confirmation of the diagnosis at a visit acceptable or is a full evaluation and a score from a diagnostic tool required?
 - Is this limited to certain companies? If so, which ones?
 - Balance Autism has noticed there are some that are requiring specific tests to be used- have been working with the Department of Labor on this.

- Provider recommending ABA which shouldn't require a referral, but there are some companies asking for a referral.
 - A member mentioned have seen a couple of instances with older students coming in for ABA. They were diagnosed at 3-4 and are now 12-13 and the insurance company is asking for another diagnosis or other testing (not just a recommendation but actual scores). There was another patient where they were asked for cognitive testing to access ABA.
 - AXIS says that it's typically payor specific and there are some that you have to use a specific test
 - Metro West Learning Center is having some difficulties with reevaluation for children 10+ through United Healthcare Management Optum- have actually asked for new testing within the last 3 years. Tri-Care is wanting a full, comprehensive evaluation.
 - The Autism Support Program requires a diagnosis within 24 months, but Connie's work around is to request a visit summary or contact with a professional in the last 24 months showing the ASD diagnosis
- Are there resources available to help undocumented individuals who need an autism evaluation and therapies?
- As far as we are aware, they are as welcome to the services as anyone
 - A Family Navigator for the RAP program suggests asking where the child was born to make sure that, even though the parents are undocumented, if the child was born in the US. If the child is a citizen, they can apply for waivers. These processes can take a bit longer for this demographic and parents may also be nervous because they don't have paperwork.
 - Families have to have a green card and live in the US for 5 years otherwise unless they are in a refugee status. Schools are a great resource.
 - Des Moines Family Navigators mentioned the Federally Qualified Health Centers- if a family goes there needing specialty care, the provider will help pay for it and the family would be charged on the clinic's sliding fee scale.
 - Grant Wood AEA could use expert consultants for English Language Learners (ELL) and autism services especially around joint attention and language.

Meeting adjourned early.