

Regional Autism Assistance Program
Expert Panel Advisory Committee Meeting
April 14, 2021, 10:00-12:00

Name	Organization/Role Representing	In Person/Phone/Decline
Alyson Beytien	Life Connections/Family Member	
Josh Cobbs	Family Advisor	Present
Kimberly Cooke	Family Advisor	
James Curry	Family Advisor	
Connie Fanselow	Iowa Department of Human Services, Iowa Mental Health and Disability Services Commission	Present
Brianna Harvey	Tanager Place	Present
Erika Hertel	Iowa Regional Autism Assistance Program/Family Member	Present
Michelle Holst	Iowa Department of Public Health- 1st Five	Present
Leann Hotchkiss	Family Advisor	
Marcus Johnson-Miller (Analisa Pearson Bridget Konz)	Iowa Department of Public Health	James Olson arrived at 11:10
Aaron Kauer	UI Stead Family Children's Hospital Child & Adolescent Psychiatry	
Andrea Keith	Iowa Vocational Rehabilitation Services	Declined
Vanessa Kimm	Family Advisor	Present
Shawn Kolb	ChildServe	Declined
Toni Fuller Merfeld (Candice Fedeler)	Metro West Learning Center	Toni and Candice were present
Caroline Moniza	Mercy Family Counseling & EAP	
Steve Muller (Evelyn Horton)	Balance Autism	Steve and Evelyn were present
Nathan Noble	Blank Children's Hospital	
Michelle Nuehring	Grant Wood AEA	Present
Kelly Pelzel	UI Stead Family Children's Hospital Autism Center	Present
Mary Roberts	Family Advisor	
Leslie Rogers	ChildServe	Present
Thomas Scholz	Division of Child & Community Health	Present
Kristine Steinmetz	Autism Society of Iowa/Family Member	Present
Jill Stevenson	Family Advisor	Present
Rachell Swanson-Holm	Learn the Signs. Act Early., Regional Autism Assistance Program	Present
Wendy Trotter (Lisa Kemmerer)	Iowa Department of Education	Wendy declined, Lisa present
Maria Valdovinos	Drake University	Present
Guests		
Brad Zelinger	Stride Autism Centers	Present
Cheryll Jones	ARNP with CHSC	Present
Rep. Art Staed	Iowa State Representative for District 66	Present for a portion
Sen. Sarah Trone Garriott	Iowa State Senator for District 22	Present for most of the meeting

Welcome and Introductions

Facilitator: Erika Hertel, Regional Autism Assistance Program/Family Member

- Roll call was taken and introductions were made.

Guest Speakers

Senator Sarah Trone Garriott, District 22, joined our meeting today. She shared with us that her brother is on the autism spectrum. She knows that services were lacking way back when and that her parents didn't really talk about it. She just knew her brother was 'different'. She shared her mom's feelings of isolation. Discussion followed.

Erika Hertel shared an overview of the Regional Autism Assistance Program (RAP).

Steve Mueller spoke about the huge wage gap between state employees at a resource center and staff at a community based provider. This is directly tied to Medicaid reimbursements (poor reimbursements) and their hands are tied regarding raising the wage. He and a group of colleagues have proposed a '10/75'. This is asking for a 10% increase in funding with 75% of that funding going towards direct services professionals. Senator Garriott suggested we contact Mark Costello (mark.costello@legis.iowa.gov) or Jeff Edler (jeff.edler@legis.iowa.gov).

Cheryll Jones talked about the Regional Autism Assistance Program (RAP) that is funded by the state. One important piece of the RAP program is the family navigator program. The waiver waiting list is another important conversation. The dollars spent on RAP and the Autism Support Program is very well spent. Autism is a cradle to grave condition and the system needs to work seamlessly to provide life-long services to these individuals. Cheryll has never seen the level of stress as this past year; the mental health needs of not just the kids, but the families, too.

Senator Trone Garriott shared there is an upcoming Facebook live event about the waiver waiting list

Vanessa Kimm is an ARNP with the University of Iowa Stead Family Children's Hospital Autism Center and a parent. When her child was 5 year old, they moved to California for better services. They could get ABA therapy up to 40 hours (they used 25 hours per week) for two full years paid by the state of California. Her child is now doing very well with no IEP in school.

Connie Fanselow talked about the Autism Support Program (ASP). This small program is entirely state-funded and was created six years ago to help families pay for Applied Behavior Analysis (ABA) services. The current level of funding is \$573,000. ASP serves 6-12 children per year. The income cap is 500% of the Federal Poverty Level (FPL) and children cannot have insurance coverage for ABA to qualify. An insurance mandate means that many companies are now required to provide ABA therapy coverage, but the out-of-pocket costs may still be too high for families. The cost for ABA is approximately \$3000/month. It would be most beneficial to 'tweak' the ASP to assist families who have high co-pays and/or deductibles.

Kris Steinmetz asked the Senator to talk about SF587. This will shift mental health funding from County control to State appropriation. There is a lot of concern that the state will not keep their promises, but there could be some "pros" to the state appropriation. Cheryll Jones serves on the Children's Advisory Committee to the South Central Mental Health Region (Davis, Appanoose, Wapello, Mahaska). Property tax is not the answer in these counties due to the low population. However it is funded, how is it best going to meet the needs for both children and adults? Will the system be disrupted?

Senator Garriott asked about successes.

Rachell Swanson-Holm has worked for CHSC for 14 years. She has seen an expansion of programs for children with autism in the state of Iowa. Improvement has been made with diagnosing autism and using evidence-based therapy (ABA). Rachell wanted to point out that even if a family has accessed some funding to pay for services, the families can't always get to where the services are provided.

Kelly Pelzel talked about how telehealth has been a phenomenal tool to use during the pandemic. However, parity will end soon. There are papers done to show how well telehealth works. Evelyn Horton with Balance Autism added that Medicaid would not allow ABA therapy via telehealth. Group therapy has been extremely successful. Iowa will not allow parent group therapy nor double staffing for those with intense needs. The Iowa Department of Human Services (DHS) is the one determining whether or not to allow the AMA codes for telehealth.

Tom Scholz added that CHSC does a lot of telepsychiatry. However, the pandemic allowed us to deliver services into the families' homes and that has been a game changer. It avoids transportation barriers and allows the provider to see into the homes, which can help with medication management and/or counseling therapy.

Senator Garriott disclosed that Jeff Edler did not call for a sub-committee meeting regarding telehealth mental health services. Brad with Stride Autism Centers pointed out that most of the pioneering research in support of services being delivered by telehealth was done at the University of Iowa. All of the other states have used this research, but Iowa has barred this modality. With Iowa having such a rural population, the families would really benefit from ABA via telehealth.

The Senator asked if the rural constituents are talking to their senators and representatives. She hears older senators say they will do what their constituents want. She feels this is vital to change. Tom Scholz stated that all of our centers are strategically placed in rural areas and the staff are doing an excellent job letting the legislators in their area know what they are offering. There is nothing like a family story to have a positive impact on people's perspective of the importance of various legislative issues.

Cheryll Jones added that they do a community legislative forum and have very good participation. Senator Rozenboom has been very supportive of this work. One legislator said no to telehealth, rural communities need bodies. Cheryll said that if she can consult with a specialist via telehealth it has tremendous benefit. It is not an either/or issue, to have the resource of a telehealth consult is a boon for the rural communities.

Leslie Rogers with ChildServe described telehealth to IME as a modality to prevent service disruptions due to weather. Instead of all or nothing, to have telehealth as an option to use on and off. The Senator commented, "It's just another tool in the toolbox." Leslie added that the outcomes were positive. The service disruptions were less.

Erika Hertel welcomed **Representative Art Staed, District 66**, who joined mid-way through the meeting. Art Staed stated that he is going to be in and out of the meeting, but he is here to listen.

The Senate sub-committees are all on Zoom making those meeting much more accessible. The Senator pays more attention to family stories. However, the House sub-committee meetings are closed. Senator Garriott asked to take a photo of those in attendance to share on social media. She went on to add that she is on the Human Resources committee, the Education committee, and is the ranking Democrat on the Natural Resources committee.

Member Updates:

Wendy Trotter, Iowa Department of Education, was unable to attend, but sent an update via email:

- Cohort 6 of the Autism Navigator project for Early ACCESS Providers continues. Participants will attend

- a virtual spring workshop in May to wrap up their learning from this year's project.
- Beginning to explore development of trainings and supports for Specially Designed Instruction for literacy comprehension for neurodivergent learners.
 - The social engagement work that was to start last spring is still on hold. Hoping to move the work forward come fall 2021.

Alyson Beytien, Life Connections/Family Member was unable to attend and sent a concern via email: The Dubuque Community School District has announced that it will no longer allow students to be absent from the school day to attend outside therapy due to the Iowa Department of Education. The change will begin April 26, 2021.

No further information available. Allison wondered if this is just Dubuque.

The Panel discussed the issue: Connie Fanselow added there have been some legal precedents already set across the nation. Would Allison be willing to share this letter? Connie has some friends at the national level that would be very interested in this letter. Is this for ANY therapy? If the student is having cancer therapy, will that apply? (For students participating in regular, ongoing therapy; for example: ABA therapy) Iowa City and Muscatine have also given a couple of families some grief. Families shouldn't have to choose between therapy and education. The irony is that the therapies will help the student be more successful in school. Kelly Pelzel asked if mental health therapy is also included.

Rachell Swanson-Holm, *Learn the Signs. Act Early.* (LTSAE)

Rachell provided an update on *Learn the Signs. Act Early.* (LTSAE) and the small grant awarded to DCCH by the Association of University Centers on Disabilities (AUCD). Through this project, WIC is embedding the Milestones checklist into their certification visits. During the pandemic, home visits were suspended, and checklists were printed for WIC, Child Care Resource & Referral, and 1st Five to mail out to families. If any red flags appear, the agencies are referring to Early ACCESS or their primary provider. Rachell has arranged for five trainings on LTSAE in the five regional centers of Child Care Resource & Referral. 1st FIVE received 520 3-ply non-medical children's masks as part of mitigation training plus milestones checklist booklets. Continuing to promote LTSAE across the state.

Connie Fanselow, Iowa Department of Human Services- Autism Support Program (ASP)

Newly updated ASP application and provider lists have been distributed. The provider list is 1-2 pages in length and she has been working with several new providers. There are 10 active service authorizations and 3 more eligible. From July 1 to Dec 31 there were six enrollees and since January, six more enrollees. Things are getting more back to 'normal' with the numbers served. Funding will remain level with \$25,000 going to Tanager Place for social skills groups. Rebuild Iowa Infrastructure (RIF) repurposed some of the carryover ASP to ChildServe for additional brick and mortar infrastructure. Connie will share a document regarding ASP that was developed for legislators. RAP is going to help with having the parent documents translated into Spanish.

Kelly Pelzel, University of Iowa Stead Family Children's Hospital Autism Center

The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program sponsored PEERS® for Adolescents Certified Training Seminar in November. Last week the trainers came back to present the adult version. UISFCH will be pulling together a PEERS adolescent group soon. They also had training in Tele-ASD-Peds that is a diagnostic measure from Vanderbilt University. It is similar to an ADOS, but with the parent acting as the psychometrician with objects they already have in their home. The research is still coming in, but it was pushed out early. Todd Kopelman has been researching this measure to determine when this may become a standard at the University. The workshop series went virtual. Lea Boldt has accepted a faculty position in Child Psychiatry. She has a lot of interest and experience working with individuals with Autism. Center for Disabilities and Development (CDD) has hired an additional psychologist

scheduled to begin in June. Kelly shared a trailer for Functional Communication Training (FCT) video developed by Autism Center staff with some previous limited funding. There will be additional videos going to production in a partnership with RAP.

Kris Steinmetz, Autism Society of Iowa, Legislative Updates

The Iowa Department of Transportation agreed voluntarily to put adult changing tables in rest stops and legislation was not needed. The ABLE account bill is moving forward. SF532, which also creates an easier path for behavior analysts to be hired by the IDOE. SF129: Rural Primary Care Loan Program. Psychiatrists are included in this program. Tom Scholz added that the AAP has put out a request to contact your representative and they indicated they will support with \$50M.

Federal level, the America Rescue Plan. 10B for HCBS programs. Dr. Matt O'Brien has contacted the Department of Education for information for the ASI and will share what he learns. The American Jobs plan includes \$400B for HCBS services. The HCBS Act which would make HCBS services mandatory in the state and would not allow states to have wait lists.

ASI has been doing Lunch and Learn sessions in April. This week is about poor sleep in Autism, next week is about depression with the following week about higher IQ influence. On Friday, they had an Autism Gender and Sexual Diversity conference with international participants and excellent speakers. There were three pages of resources from the conference Kris will gladly send out. The recordings for the Lunch and Learn sessions can be accessed through the You Tube link on the ASI website.

Brad Zelinger, Stride Autism Centers began with one center in Clive. They are now also open in Davenport, Cedar Rapids, and additional center in Johnston. A large portion of their clients is on Medicaid and the staff have found working with those individuals very rewarding.

Steve Mueller with Balance Autism: The Iowa City location has recently opened. Cedar Rapids has moved to a new space. Their employment program is doing very well.

A change in requirements for Registered Behavior Technicians (RBT) is moving forward in the state. There is a push for these direct services providers to have the option of either a bachelor's degree in an approved field or the RBT certification. Behavior Technicians who are direct care staff work under Board Certified Behavior Analysts to provide Applied Behavior Analysis (ABA) treatment. In Iowa, Behavior Technicians are required to have a 4-year degree and training in ABA. There is a shortage of Behavior Technicians who meet these criteria in some parts of the state. The Behavior Analyst Certification Board regulates a credential that is called a Registered Behavior Technician (RBT) that has not been sufficient as a prerequisite in Iowa if the person does not also have a 4-year degree. The RBT credential is acquired by taking an approved 40-hour course in ABA and passing a national exam. RBTs maintain their credential by receiving a high level of direct supervision by a BCBA. A State plan amendment to extend to RBT's could take months.