

**Regional Autism Assistance Program (RAP)
Expert Advisory Committee Meeting Minutes**

October 10, 2018, 10:00 am – 2:00 p.m.

100 Hawkins Drive, 102 Center for Disabilities and Development (CDD), Iowa City, IA

Regional Autism Assistance Program Expert Advisory Committee Members		
Name (& Designated Representative)	Organization/Role Representing	Attend In Person/GTM
Alyson Beytien	Hills & Dales/Family Member	
Josh Cobbs	Family Advisor	
Kimberly Cooke	Family Advisor	
Peter Daniolos	UI Stead Family Children’s Hospital Child & Adolescent Psychiatry	
Connie Fanselow	Iowa Department of Human Services, Iowa Mental Health and Disability Services Commission	
Heather Hanzlick-Jaacks	Family Advisor	X
Megan Hartwig	Iowa Department of Public Health	X
Erika Hertel	Iowa Regional Autism Assistance Program/Family Member	X
Michelle Holst	Iowa Department of Public Health- 1st Five	X
Leann Hotchkiss	Family Advisor	
Andrea Keith	Iowa Vocational Rehabilitation Services	X
Vanessa Kimm	Family Advisor	X
Shawn Kolb	ChildServe	
Toni Fuller Merfeld	Metro West Learning Center	X
Steve Muller	Balance Autism	X
Nathan Noble	Blank Children’s Hospital	
Michelle Nuehring	Grant Wood AEA	
Analisa Pearson	Iowa Department of Public Health	
Kelly Pelzel	UI Stead Family Children’s Hospital Autism Center	X
Sacha Pence	Drake University	X
Mary Roberts	Family Advisor	X
Leslie Rogers	ChildServe	X
Natalie Sandbulte	Seasons Center for Behavioral Health	X
Thomas Scholz	Division of Child & Community Health	X
Renee Speh	Family Advisor	X
Kristine Steinmetz	Autism Society of Iowa/Family Member	
Melissa Stimmler	Family Advisor	X
Blake Stephenson	Tanager Place	X
Rachell Swanson-Holm	Learn the Signs. Act Early., Regional Autism Assistance Program	X
Wendy Trotter	Iowa Department of Education	
Lea VanHorn	Family Advisor	X
Kathy Francois	RAP support, Iowa City	X

Welcome and Introductions

Facilitator: Erika Hertel

- Roll call was taken and introductions were made.
- Welcome from Tom Scholz, MD: Thank you all for traveling to Iowa City and joining the call. Tom is grateful to IDPH for recognizing the gaps in service during the funding reduction. Erika Hertel did well to keep things moving as much as possible. Erika has done an exceptional job moving forward once the funding was restored. Please feel free to contact her as a resource or to help promote your activities around the state. One of our main focuses is working to quantitate successes for legislators. Any chance we can get to educate the funders who control the money is well worth the effort. Your advice is appreciated to help us help families. We are also looking for suggestions to make these meetings and/or the programs better. Thank you again for your support of Iowa RAP.

2018 Legislative Session Update

Josh Cobbs—There is not an update available currently as Josh was not present.

Connie Fanselow— Please see the attached ASP update.

Autism Support Program (ASP) Update

Connie Fanselow

Please see the attached written update. Shared by Erika during the meeting.

Regional Autism Assistance Program (RAP) Update

CHSC

- Erika talked about the limitations on staff hours for the RAP during the past year since the funding cut. RAP received a reinstatement of state funding through the Iowa Department of Public Health for the 2019 fiscal year which began July 1. These funds have allowed RAP to reinstate dedicated Family Navigation hours in all 14 CHSC Regional Centers, rehire Clementine Karl for the Des Moines Family Navigator position, and hire Amy Kula for Iowa City combined RAP- Autism Center Family Navigator, a position that had been vacant
 - Hiring position to be housed in Fort Dodge to provide coverage to Story, Marshall, and Tama counties
 - Hiring position to be housed in Iowa City to provide coverage to Cedar Rapids and surrounding counties. CR, IC large area and we saw need for additional support for combined Autism Center RAP FN in Iowa City
- A new RAP logo was created in response to the negative feedback from the Autism community regarding the use of puzzle pieces as a symbol for Autism. RAP Family Advisors were consulted on the proposed change, provided input, and voted on three logo options to help make the final decision. (see upper right corner of this paragraph).
- Education and training opportunities a priority



- Spencer Family Leadership Training
- Other locations planned
- Rachell Swanson-Holm and Erika Hertel will attend the National Autism Leadership Summit and OCALICON in Columbus, OH in November.
- Erika shared the Caregiver Guide and Strategic Plan and let everyone know RAP has copies of both of these available for distribution.

Learn the Signs. Act Early.

Rachell Swanson-Holm

Rachell was appointed by the CDC to serve as the Act Early Ambassador in Iowa. She was approached about Iowa participating in a four-state collaborative study with Early Head Start to see if LTSAE integrated into Early Head Start curriculum would help identify developmental delays sooner. Right now, the average age of diagnoses of a developmental delay is 4.5 years. We all understand the importance of recognizing these delays as early as possible.

The four states involved are Iowa, Alabama, Wisconsin, Indiana. There are 1200+ families participating, and the study will continue into June 2019. Rachell will have a lot of data to share at the next meeting. If the pilot is successful, Rachell will reach out to all Early Head Start programs in Iowa.

Rachell offered to help obtain free materials for anyone who is interested. She also talked about the new app called Milestones Tracking App. It's great and it's FREE.

STRATEGIC PLAN DISCUSSION

GET A GOOD START:

The Corridor Autism Resources Expo is an excellent event with services from Iowa City all the way up to Cedar Falls. There is also a newly formed Cedar Valley Autism Spectrum Community. In addition, the Iowa City Autism Community is a resource for families and information.

L TSAE

RAP has been expanding diagnostic services to southeastern Iowa, with Dr. Kelly Pelzel providing mentorship to providers in two clinics who recently completed ADOS training and providing them with ADOS test kits. These providers will work in collaboration with Ottumwa Regional Center ARNPs to screen and evaluate children for ASD.

RAP and the Iowa Department of Education have launched a pilot project for primary care providers utilizing Autism Navigator® for Primary Care course seats.

HAVE ACCESS TO AND OBTAIN NEEDED SERVICES

The Olmsted Task Force.

CHSC and the Pier Center are collaborating to bring telehealth to the area. CHSC provided equipment. It was noted United Healthcare is not covering ABA therapy via

telehealth at this time.

Renee Speh is serving on a newly formed Children's Board through November to develop a strategic plan and present it to the governor. Focus groups are being formed now. You can find the locations on ChildServe, Facebook, or the NAMI website.

Sacha Pence with Drake University reported that they had an 8-week ABA summer clinic. Mostly teachers that are completing the program and doing their practicum at their school.

Natalie Sandbulte with Seasons Center reported that they just hired a BCBA provider and have started an Autism Clinic with Todd Kopelman serving as a mentor. Today is the third clinic overall. They are very excited about this clinic.

Tanager Place is actively looking for another BCBA and wants to expand to in-home therapy. With the \$25,000 coming from Four Oaks, we are serving more students on the spectrum. Cedar Rapids remains the primary focus.

Toni Merfeld with Metro West reported they are continuing to increase capacity over the past year. They now have a full diagnostic team in-house and the referrals are growing.

Evelyn Horton with Balance Autism reported they have doubled their space and are intaking kids as fast as possible. They also just opened an office in Burlington and working on building capacity and ABA capacity as well. They have a 5-student cohort.

Renee said there is a new initiative called Johnson County Children's Mental Health Coalition. They are hoping to be a model for the state.

WELL INFORMED AND EMPOWERED FAMILY MEMBERS

Rachell thought that as we complete training in the IFLTI, to have graduates go to the capitol and advocate.

The Corridor Expo

Iowa City Autism Community

Iowa City Community School District Mental Health and Special Education

A social worker at ChildServe is running some transition trainings and would like to create an ASD newsletter under the ChildServe umbrella.

The Iowa Disability in Action has a self-advocacy program called Make your Mark.

Crisis intervention is a big item. 6 access centers for persons in a mental health crisis can go to the access center to stabilize rather than go to ER.

There should be suicide prevention training in all schools

Continue law enforcement training

The Autism Society of Iowa will have Dennis DeVoe conduct a training for law enforcement and first responders. They also hold employment conferences and hold

mock interviews for transition age CYSHCN.

Transition planning. RAP teams have begun utilizing healthcare transition checklists and resources to families of children ages 12 year and above.

Andrea Keith said Voc. Rehab is providing pre-employment transition services opportunities with schools for 14 year old individuals with special needs (WIOA).

ChildServe is working with Drake OT dept to teach cooking and driving. They have a full-size apartment and a car set up for training.

Shared Plans of Care (SPoC) new initiative begun in CHSC clinics across Iowa. They are using ActMD as the platform.

Some names of legislators that have an empathetic ear for our programs: Dave Heaton (retired) Chris Hagenow, Kevin Kester, Liz Mathis.

Another empowerment would be to ask the candidates where they stand on Autism and/or Children's Mental Health.

Autism Day on the Hill, NAMI Day on the Hill dates to watch for.

BARRIERS

Barriers with United Health Care and telehealth. They will allow remote supervision, but not a diagnostic visit. Jane Brown with UHC has been very supportive and helpful in negotiating UHC coverage of autism.

Providers have closed shop due to low reimbursement and hassles with MCOs. Conversely, we can't get providers here because of the MCOs.

The DHS tiered rates.

Where there is greatest need, the community is lacking jobs for spouse, no entertainment, etc. The smaller towns need economic development. Also, there are no opportunities for internships for psychologists in Iowa.

Bullying—there has been an effort to standardize bullying curriculum; however, schools are not required to adopt the new curriculum.

UCLA has a program called PEERS. ChildServe has 2 persons ready to train others. Leslie Rogers reports that the cost of have a PEERS person come and train a group is \$10,000. MN has a program called PACER, but Iowa is not a partner of this program.

We need to find sustainable funding.

We need to develop ways to find adults/kids who get lost. There was a law passed, but the funding to enforce it is lacking.

University of Iowa will not be providing BCBA courses at this time.

There should be some legislation regarding emergency preparedness.

There is a lack of practitioners who treat challenging behaviors and there is a cliff that

children fall off at either 18 or 22. There needs to be more transition supports in place. Also, well-being programs with social and leisure opportunities.

All the AEA Autism Consultants met in western Iowa last year. Will this be an annual thing? Can we get involved?

Seclusion/restraint policies in school. Parents can ask school board members.

There is a new initiative in the Cedar Valley: Cedar Valley Diversity Inclusion. They are looking into asking the state to create a modified driver's license or ID that would indicate to authorities that the owner has a disability of some sort. Erika said that Florida has Wallet Cards that can be kept in the glove compartment with vital information in case of an accident. The Medic Alert law was passed, but how to implement it has not be finalized.