

**Regional Autism Assistance Program (RAP)
Expert Panel Advisory Committee Meeting
October 9, 2019 – in person
10:00 am- 2:00 pm
Coralville Public Library, Schwab Auditorium
1401 5th Street, Coralville, IA 52241**

Name	Organization/Role Representing	Attended in person or via Go To Meeting
Alyson Beytien	Hills & Dales/Family Member	
Josh Cobbs	Family Advisor	
Kimberly Cooke	Family Advisor	
James Curry	Family Advisor	
Peter Daniolos	UICH Child & Adolescent Psychiatry	
Connie Fanselow	Iowa Department of Human Services, Iowa Mental Health and Disability Services Commission	X
Megan Hartwig	Iowa Department of Public Health	
Erika Hertel	RAP/Family Member	X
Michelle Holst	Iowa Department of Public Health- 1st Five	X
Leann Hotchkiss	Family Advisor	
Aaron Kauer	UICH Child & Adolescent Psychiatry	
Andrea Keith	Iowa Vocational Rehabilitation Services	X
Vanessa Kimm	Family Advisor	
Shawn Kolb	ChildServe	X Represented by Emily Monahan
Toni Fuller Merfeld	Metro West Learning Center	X Represented by Candice Fedeler
Steve Muller	Balance Autism	
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 GTM
Mary Roberts	Family Advisor	X
Leslie Rogers	ChildServe	X
Natalie Sandbulte	Seasons Center for Behavioral Health	
Thomas Scholz	Division of Child & Community Health	X
Kristine Steinmetz	Autism Society of Iowa/Family Member	X
Blake Stephenson	Tanager Place	
Jill Stevenson	Family Advisor	X GTM
Rachell Swanson-Holm	Learn the Signs. Act Early., RAP	X
Wendy Trotter	Iowa Department of Education	
Kathy Francois	Administrative Support	X

Welcome and Introductions

Facilitator: Erika Hertel

- Roll call was taken and introductions were made.
- Membership update: Megan Hartwig will no longer be a panel member. She left her position at IDPH and is now the Brain Injury Program Director with the Iowa Association of Community Providers. Heather Hanzlick-Jaacks is moving out of state and will no longer be a RAP Family Advisor

Get a Good Start

- **Tom Scholz**, Director of the Division of Child and Community Health and the Title V Director for Iowa:

The Division of Child and Community Health division has been awarded a 4-year, \$1.4 million grant from the Health Resources and Services Administration (HRSA) to implement a new project "Innovations in Care Coordination for Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities." The grant period began September 1, 2019 and the main objectives are:

1. Integrating Family Navigators into five primary care practices, including River Hills Community Health Center in Ottumwa, Unity Point Clinic Family Health Center in Storm Lake, People's Community Health Clinic in Waterloo, Blank Children's Pediatric Clinic in Des Moines, and Medical Associates Pediatrics in Dubuque.
--A question was asked whether children need to have ASD to obtain Family Navigator services. The answer is no.
2. To develop a Learning Community to increase the capacity of primary care providers in medically underserved areas to identify and treat children and youth with ASD.
3. To increase the capacity of families of children with ASD to develop family-professional partnerships.

- **Erika Hertel**, Regional Autism Assistance Program, Child Health Specialty Clinics:

One ARNP and two RNs are taking the *Autism Navigator for Primary Care* online course. Five ARNPs and RNs who had started the course earlier in the year continue with that training. Sixteen RAP Family Navigators and three program staff continue with the *Autism Navigator Jumpstart to Coaching in Everyday Activities* course that opened in May. These enrollees are allowed one year to complete the course.

Erika also announced that the building that housed Mason City CHSC regional center sustained substantial damage during a storm in the spring. They have now relocated their office and are back up and running. Jackie Schott has been hired as the Family Navigator there, to replace Loni Jorgensen who left for another position.

- **Rachell Swanson-Holm**, Regional Autism Assistance Program, LTSAE Ambassador, Child Health Specialty Clinics:

Learn the Signs. Act Early. (LTSAE) and WIC are collaborating at Broadlawns, Carroll, and Sioux City to have parents fill out developmental monitoring checklists while completing WIC paperwork. They are modeling the program after one in Missouri that has been very successful. This pilot will run through April, then they are hoping to implement statewide. However, this program will be voluntary.

Another pilot training is planned involving Childcare Resource & Referral in Region 2 (Waterloo). They are developing the training to roll out in November.

The books for 1, 2, and 3-year-olds are now available with all the developmental milestones included. Rachell announced that they are always trying to partner with other agencies to print copies of the books for distribution.

--Michelle Holst said that 1st Five would like to do a printing for Autism Awareness month. She will meet with Rachell in private to discuss.

Have access to and Obtain Needed Services

- **Kelly Pelzel**, University of Iowa Stead Family Children's Hospital:
On October 1, the 4-week webinar series entitled, "Autism Basics" began for the second time. Sessions are at noon on Tuesdays in October. The target audience is parents or primary caregivers of children with a new autism diagnosis. The course has been approved for continuing education credits for foster parents. Registration is at capacity with 100 participants signed up. Sessions are recorded and additional participants will be able to access the recordings. Sessions include:
 1. What is Autism?
 2. Autism Interventions
 3. Challenging Behavior
 4. Educational Programming

Erika added that RAP is collaborating to offer several Autism Safety Trainings for first responders, police, fire departments and others with a recent training in Marquette and additional planned soon. Renee Speh is our Family Navigator for the Cedar Rapids area and she is one of the speakers, along with Mary Roberts and Dina Bishara. The group has done this work for several years, with Renee previously involved as a parent volunteer. Over 1000 first responders have already been trained.

Kelly also talked about Project ImPACT, which the U.I. Autism Center offers and which she is participating in further training to enable her to train others to implement the program. Improving Parents as Communication Teachers (Project ImPACT) is a 12- to 24-week intervention program designed to improve the social skills of young children who have an ASD. It has been around for 10 years. UI has five to six families/semester who participate in group sessions, which also provide informal support as families are in the groups together. Ages are around seven or under, it depends on their language level and works best with kids not yet talking in sentences. It is a 12-week, brief intervention program. They have run about 14 groups by now and they have been well received by parents. It can sometimes be used individually for 12-24 weeks, with 15-18 being the ideal. Graduate students assist. Late afternoons work best for families since childcare can be a problem. Five copies of the parent manual were purchased and are available at the Disability Resource Library. Todd Kopelman, Kelly Pelzel, Jenny DiVita from Wendell Johnson, Jon Goodwin, and Leah Volt, a clinical psychology grad student doing a rotation with Kelly. Kelly will be able to provide ImPACT training to people outside of UI. The goal is to eventually offer it to other areas where there are gaps in services, such as no ABA or long waiting lists. She is hoping to be able to start doing this next academic year.

--A question was asked if insurance is covering. Kelly replied, yes, speech/mental health codes are used.

--Can this be done at the same time as ABA? Yes, ABA works cooperatively. ABA involves more prompting than ImPACT.

-- ChildServe also offers ImPACT at their Johnston location.

- **Connie Fanselow**, Iowa Department of Human Services:

The end of the fiscal year report for the Autism Support Program is not quite ready. Connie will present it at the next meeting. The number of applicants continues to decline to maybe one/month. There are currently 8-9 children actively receiving services. There are plenty of dollars to help families, so continue to spread the word about the program. A discussion ensued about how to open up the requirements. Connie felt that as long as we are not requesting more money and just proposing new guidelines, we may have a chance to change it. Also, Connie has just updated the provider list and it has expanded to two pages, with the addition of additional locations for Tanager Place and Hills & Dales. An update on the BCBA grant program was not available at the time of the meeting. Michelle Holst shared Cristie Duric will be the new contact for this program, replacing Megan Hartwig.

- **Mary Roberts**, University of Iowa Autism Center Coordinator and parent:
Mary provided information on Iowa's Medical Cannabidiol Program. Medical Cannabidiol has been approved for a number of conditions, including epilepsy and severe autism with self-harm or aggression. To apply online, go to the Office of Medical Cannabidiol within the Iowa Department of Public Health website. Mary shared she has been through the application process with both of her adult children who have seen benefits from its use. She said the website is WONDERFUL, contains a wealth of information and is easy to navigate. It also contains an online application to make the process easier. If you have a minor child, you only need to complete the caregiver application. If your child is an adult, you will need to fill out both the patient application and the caregiver application. For those who have a child that cannot go the DMV for a photo ID card, there is a Photo ID Waiver form to fill out so that the card will have your photo.

There is not a lot of information provided regarding dosing. Med Pharm has a titration chart. There are 4 formulations and it takes some time to determine the right dose for your child. The cost can be prohibitive, and payment is cash only. Insurance does not cover it. There are five dispensaries in the state, located in Windsor Heights, Sioux City, Council Bluffs, Davenport, and Waterloo. The product is still considered a Federal Schedule 1 substance, so it is important to go through legal channels to obtain it. Carl Olson at Drake University is working on a proposal to submit to create an exemption to the Federal law for the state of Iowa. There is a Healthcare Practitioner Certification Form - a form the patient's physician will need to sign to certify the patient's condition. They are not prescribing Medical Cannabidiol, only certifying the patient has one of the qualifying conditions.

- **Sacha Pence**, Drake BCBA Program:
Drake had six master's students graduate in May. They currently have nine students who are in their second year of the program who will graduate in May of 2020 and eleven new students. Of the six graduates, two work in schools, two in clinics, one moved out of state to work in a clinical position, and one is waiting for personal reasons.
- **Leslie Rogers**, ChildServe:
ChildServe would like to reach more rural families next year, offering their life skills and transition trainings with the option of remote access via Zoom. Their trainings are typically offered at 4:00-5:00 pm and are advertised through social media. They were approached by Drake to teach a graduate level course on social-emotional learning for teachers with more than 17 students including a principal. This will be offered two to three times per year. ChildServe is also providing an Autism Safety Training for First Responders in Nevada, IA.
- **Kris Steinmetz**, Autism Society of Iowa:
The 2019 Autism Society of Iowa Fall Educational Conference will be held November 1. Keynote

speaker Dr. Scott Bellini will present *Building Social Relationships through Evidence Based Social Skills Programming for Youth and Adolescents with Autism Spectrum*. They will have tables available at lunch where newly families with a new autism diagnosis can sit together and they already have two tables of ten parents filled, many of these being rural families.

Input Requested from Expert Panel Advisory Members

- **Iowa's Strategic Plan**- updated list of Successes, Challenges, and Needs



Expert Panel
Brainstorming Note:

- **Crisis response for families**- The panel decided a developing a one-page crisis response form would be helpful. Started draft of ideas and resources.



Crisis Planning-
draft.docx

Upcoming Meetings

- Wednesday, January 8, 2020, 12:00-1:00, via GoToMeeting
- Wednesday, April 8, 10 am - 2:00 pm, in person
Balance Autism,
1625 Adventureland Drive, Suite B
Altoona, IA 50009
Lunch Provided

Resources Shared

Iowa's Medical Cannabidiol Program

- IDPH Website on the program: <https://idph.iowa.gov/omc>
- Healthcare Practitioner Certification Form:
https://idph.iowa.gov/Portals/1/userfiles/234/Files/Health%20Care%20Practitioner%20Form%20v_5_2019_1.pdf