

**Regional Autism Assistance Program (RAP)
Expert Panel Advisory Committee Meeting
April 8, 2020
12:00 - 1:00 pm
Via Go To Meeting**

Name	Organization/Role Representing	Attended in person or via Go To Meeting
Alyson Beytien	Hills & Dales/Family Member	x
Josh Cobbs	Family Advisor	
Kimberly Cooke	Family Advisor	
James Curry	Family Advisor	x
Peter Daniolos	UICH Child & Adolescent Psychiatry	
Connie Fanselow	Iowa Department of Human Services, Iowa Mental Health and Disability Services Commission	
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
Toni Fuller Merfeld	Metro West Learning Center	x
Steve Muller	Balance Autism	x
Nathan Noble	Blank Children's Hospital	
Michelle Nuehring	Grant Wood AEA	X
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
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
Rachell Swanson-Holm	Learn the Signs. Act Early., RAP	
Wendy Trotter	Iowa Department of Education	
Kathy Francois	Administrative Support	x
Guests		

Welcome and Introductions

Facilitator: Erika Hertel

- Roll call was taken and introductions were made.
- It is noted we are currently in a pandemic and COVID-19 is impacting day to day life and the services we are able to provide to families at this time. This meeting was originally scheduled as a day-long, in-person meeting to be held at Balance Autism in Altoona. Due to the current situation, it was moved to a virtual meeting
- Membership update: Natalie Sandbulte is no longer with Seasons Center and resigned from the Panel. She has opened her own practice.

Crisis Planning: Continue work from last meeting

MCO information: James Curry reached out to Iowa Total Care on behalf of the panel to ask about crisis plans and Autism training of case managers. He found out they have no crisis plan nor any training specific to Autism. He was unable to find out if there was anyone on staff with that specific expertise. When asked about crisis placement coverage, they shared there is not a general policy and this is determined case by case. So the question was posed to ITC was what happens after a standard 72 hour hold and the patient still needs services? ITC thought there might be a cap of one week and documentation will be needed to support the extra stay. James thinks this is an opportunity to draft a crisis protocol and present it to the MCOs.

Kris Steinmetz spoke with Emma Ferguson, Community Relations Representative, Amerigroup. They have the same story, no crisis plan nor any Autism training. People are encouraged to reach out to their case managers if they have problems or call member services if their case manager is not reachable. Amerigroup asked about available trainings or webinars for the case management team.

RAP will collaborate with Kris Steinmetz, Todd Kopelman, and Kelly Pelzel to offer a training. The one hour training will be recorded and archived, and will have a record of who participated. Kelly and Todd are working on content for this webinar.

Another question posed was if discharge plan doesn't work, what happens next? The patients go back to whoever they were working with before, outpatient care or PIH (Pediatric Integrated Health), to create a follow-up plan.

Alyson Beytien presented on what families should to do prepare for a crisis situation with their child, where they may need inpatient care and/or residential placement. She created a list of helpful information to have gathered in the event of a crisis, and panel members are asked to provide any edits or additions:

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Crisis Planning for Families

Keep a CURRENT copy of the following documents:

1. Current medications including dosage and time
2. List of prior medications including dosage and results
3. List of prior medical treatments or surgeries if applicable
4. Individual Education Plan and/or Individual Program Plan
5. Current physicians or healthcare professionals supporting child (name, address, phone number)

6. Medicaid and/or Insurance cards for your child (front and back)
7. Birth Certificate and/or Social Security Card.
8. Guardianship papers if applicable.
9. Diagnostic report completed within last 5 years (especially if Autism)
10. Prior placements

Know the name of your case manager with your Insurance or Medicaid provider AND their phone number. Write a BRIEF timeline of major changes in Behavior, life events or other significant changes including prior hospitalizations if applicable. Have 2-3 copies of this available.

Determine what agencies or Community Providers are available in your area. BEFORE a crisis happens, contact the providers and ask about the admission process.

Visit providers in your area EVEN IF YOU DO NOT NEED SERVICES NOW. This will establish a relationship with a provider, and allow you to determine whether a particular environment is appropriate for your child or not when you are NOT in crisis.

All providers in Iowa have a referral list or “wait list” for services especially residential support. Opportunities for residential placement are highly limited. If an agency has an opening but your child does not need support, you can decline the opening but request that you remain on the list for future consideration.

Most residential environments require Iowa Waiver funding to access. If your child does not have waiver funding, explore this option to determine eligibility and begin process if applicable.

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Obtaining Admissions information for Families: RAP Family Navigators can contact admissions coordinators at their local agencies and providers to ask about the placement process to help families have that information in advance.

Safety Trainings for First Responders

James Curry mentioned it would also be helpful to know the First Responder services in your area before needing them and to inform providers about autism and the needs involved.

Mary Roberts and Renee Speh have been putting on trainings to first responders, along with Dina Bishara. To date, they have worked with over 1000 personnel. Leslie Rogers and Shawn Kolb have also been doing trainings in central Iowa. Balance Autism has done trainings in the past as well. All agreed these trainings need to be expanded.

Future Crisis Planning Training Opportunities: RAP collaborates with CHSC’s Iowa Family Leadership Institute to offer family trainings. A number of topics have been presented in the past. This content would incorporate well into what is currently being done to help families create Care Notebooks. Binders and components to create an organized space are provided for families and they review how to organize the child’s health care information. There is usually another learning component included in the session.

Member Updates:

Blake Stephenson, Tanager Place, was unable to make this meeting as initially planned, but sent the following update that Erika shared with the panel:

- Tanager Place is still open. Our behavior health clinic (licensed therapist, etc.) have moved to tele-health and are offering services to families who are interested and to ongoing clients.

- Check social media for short term offerings. We are working on creating zoom support groups, and other innovative ideas to create a sense of community during a time of social distancing.
- Tanager Place autism services are still open. We have a **very small** group of clients who have elected to come into the clinic. We have separate treatment rooms for 1:1 services to limit contact, and are actively practicing social distancing. Staff and clients wear masks (when able to) and staff meet families in the parking lot to “pick up the client” to limit the amount of people in and out of the building.
 - For client’s not coming into services but want tele-health support, we are providing weekly parent training from a BCBA and RBT staff to assist the parent in supporting their child.
 - Furthermore, for some clients, we are running short direct service ABA sessions via tele-health. We have a discussion with the parent, staff, and client (when appropriate) about the clinical feasibility of doing such a session. So far, we have 4 families who have been successful in tele-ABA
 - Some criteria we look for to determine clinical feasibility:
 - Instructional control
 - Target behaviors
 - Parent involvement
 - Treatment priorities and feasibility to address goals through tele-health
 - Ongoing compliance with treatment when receiving clinic services
- Tanager Place social skill groups have been canceled for the time being due to large number of client in groups and current pandemic
 - We do have limited options for groups but are taking it slowly to ensure the health and wellbeing of staff and clients/families. These offerings are only made to current clients, we are not enrolling new clients at this time but are still taking referrals for groups.
- Med Mgmt. services are still happening at Tanager Place through tele-health avenues
- All inpatient services and programs are still functioning (not taking new admits for the time being)
 - This is being evaluated daily.

Child Health Specialty Clinics (CHSC): Erika shared CHSC has been moving clinical visits to telehealth and most of the employees are working from home. Family Navigator are still able to call and email families. They are using personal cell phones, so the number will show up as blocked in caller ID. This can be a barrier in getting people to answer, however, a number of FNs have reported families *are* answering the calls. Processes continue to be developed and we recently learned how to make calls using Skype, which lists the University of Iowa Hospitals and Clinics in caller ID. Anyone trying to call that number will not reach the person who called them as the hospital operator will not know who placed the call. Another alternative is scheduling calls via email so the family knows to answer at a specific time. There have been a growing number of requests for food resources from families.

ChildServe: Leslie and Shawn shared ChildServe is open for business, however most of the visits have transitioned to telehealth. In person visits are limiting numbers to one parent/caregiver per patient. Telehealth is working very well for both patients and providers. The day health is still open, but limited to room sizes of 10 or less, with about half attending Screenings are done every day when the participants arrive. About half of the ABA visits are via telehealth. The psychologists are still seeing some evaluations in person. The wheelchair adjustment and other services are still open. Project IMPACT is being done by telehealth as well.

Iowa Vocational Rehabilitation Services (IVRS): Andrea states that most employees are working from home, but still doing intakes and work search. They are moving forward to visit with participants virtually throughout the summer.

Hills and Dales: Alyson shares they are doing much the same as CHSC and ChildServe. They are screening clients as they come in, some visits are in person and some telehealth. They are working to maintain rapport and support.

Balance Autism: Steve states they are doing much the same as the others. They have some in-clinic and some telehealth. They have decreased exposure to outside influenced for adult and residential clients. If residents visit home, they stay there for the duration. He shared it is remarkable to see the direct service providers go after roles, they are crucial to helping keep families together. In residential people are where they need to be and the people they support have had few critical incidents so this is a positive through all of the changes.

University of Iowa Stead Family Children's Hospital Autism Center: Kelly states they are doing much the same as well and increasingly moving appointments to telehealth. Child Psychiatry met recently to discuss plans for autism evaluations and plans to do diagnostic interviewing via telehealth with observation still needing to be done in person. They participated in a webinar on conducting diagnostic evaluations via telehealth and continue to consider how this might work and who may fit best for this type of evaluation. Interventions and FCT by telehealth, 10 years of the telehealth study has them well prepared to do this. Project IMPACT also moving to telehealth.

Metro West: Toni states Metro West has moved everything to telehealth...speech, OT, ABA, feeding and social groups. Families are very excited to do this.

Autism Society of Iowa: Kris shared ASI is receiving a lot of calls from families needing assistance. They are also working on how to do Autism Awareness Month activities without having the option for in-person events.

Drake: Sacha shared Drake has moved to remote classes. They are still seeing a couple of clients for ABA, some have paused therapy. Remote work will continue through the summer.

Questions and Other Discussion

- **Can families still apply for services during this time?** The general consensus is yes, agencies are still taking referrals. Whether or not new clients can begin services right now varies so families should contact them to discuss options.
- **Appendix K has been approved by the federal agency over Medicare and Medicaid, CMS.** Appendix K is may be utilized by states during emergency situations and allows for flexibility in the way home and community based waiver services are provided. This provider manual provides some preliminary info about what that means for families:
https://dhs.iowa.gov/sites/default/files/DHS_COVID19_MedicaidProviderToolkit.pdf?032320202045. Information for families should come out soon.

Action Step

- Members should review crisis planning document for any edits, additions.

Next Meeting: dates to be determined for the next fiscal year.

