

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

Name	Organization/Role Representing	Attended
Alyson Beytien	Beyond Behavior ABA, Family Member	X
Samantha Cermak	ChildServe	X
Amy Chebuhar	Iowa Department of Public Health	X
Josh Cobbs	Family Advisor, Autism Speaks	X
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	
Aaron Kauer	UI Stead Family Children's Hospital Child & Adolescent Psychiatry	
Andrea Keith	Iowa Vocational Rehabilitation Services	X
Lisa Kemmerer	Star Autism Support	
Vanessa Kimm	Family Advisor, UI Stead Family Children's Hospital	
Monica Kurtz	Grant Wood Area Education Agency	X
Stacie Lane	Tanager Place	
Toni Fuller Merfeld	Metro West Learning Center	
Caroline Moniza	Mercy Family Counseling & EAP	
Steve Muller	Balance Autism	X
Jillian Reiher	CDD Clinical Psychologist, RAP Psychology Consultant	X
Mary Roberts	Family Advisor, UI Stead Family Children's Hospital Autism Center	
Leslie Rogers	ChildServe	
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** Josephine Gittler, JD, University of Iowa College of Law  
Guardianship Legislation, Advocacy Efforts, Resources

### **Q&A:**

- Do End of Life healthcare (life sustaining treatment) decisions have to be made while the situation is occurring or can that court decision happen as part of the full plan?
  - Both. It can be put in the initial care plan if the guardian suspects that this type of decision might need to be made within the year, during the writing of the annual report or at any time through a request to the court. (Since these are submitted electronically now, there is an “emergency” box to be checked so that the request will go to the judge’s queue. These are usually approved if the request is accompanied with some medical documentation of the person’s terminality, that they do not have a living will, or a life sustaining treatment declaration that withholding would be against their wishes.)
- If guardians leave an afflicted person with caretakers, what should they set up so that caregiver can get the person emergency medical treatment?
  - This is actually a gap in the law. The Iowa code does not have any kind of provision where a caregiver can transfer decision making rights temporarily to another person. You can use a document that has been notarized, stating that you, as the guardian, give permission to the temporary caregiver to make medically necessary decisions. Then you hope that nothing happens and if it does and that the hospital cooperates.
- Does the College of Law have financial resources for families who can’t afford an attorney?
  - No. There’s no requirement for a family to have an attorney to establish a guardianship or conservatorship for an individual. But if the person who is subject to the petition objects or if there is some question about meeting criteria or standards for guardianship, then you probably will need an attorney. Typically, though, you would probably want to retain an attorney. Once a petition is granted, the guardian/conservator has reporting requirements but again, you don’t need an attorney for that. The guardianship paperwork asks questions that you a lawyer wouldn’t have the answers to anyway. On the conservatorship side, if the person is limited income and doesn’t have many assets, you wouldn’t need an attorney. But if there is significant income and/or assets, depending on the conservator’s knowledge and experience managing financial affairs, you may or may not need an attorney.

### **Member Update** (Allison Drew, RAP)

- Just finished the Autism Basics series and are now moving into the Spanish Autism Basics series starting in May with Dr. Jillian Reiher and Dayrin Lovan. This reaches out to families with children who have a new Autism diagnosis and will be given twice a year in Spanish. It's a 3-week series that starts on May 15 and is approved for foster parent training credits.

### **Member Update** (Erika Hertel, RAP)

- Another training coming up is the Case Manager Training on Autism in June. This was a partnership between ASI and RAP in 2020 with Kelly Pelzel and Todd Kopelman. It was very successful and they have agreed to do it again this year. Erika will send out a flyer when that is available.

### **Member Updates** (Connie Fanselow, IHHS)

- Although her retirement date keeps moving, she is pretty sure that June 28<sup>th</sup> will stick. As of a couple weeks ago, she is working with another staff member, Megan, in the Aging and Disability Services Division who is learning what is needed to keep the Autism Support Program functioning until Connie's replacement can be put in place. She will share contacts soon.

### **Input Requested**

- Input requested as we continue to monitor insurance requirements for ABA and other therapies:
  - Are you seeing any new requirements for insurance authorization of ABA or other therapies?
  - The Autism Support Program requires that the autism diagnosis be made by a child psychiatrist, developmental pediatrician, or a clinical psychologist.
    - What do insurance companies require?
    - Are you receiving any denials based on diagnostic provider?

### **Discussion – accomplishments, barriers, legislative priorities**

- Brad mentioned that Speech and Language Pathologists are not allowed to give a diagnosis. As Stride expands into other states, they are realizing that this appears to be state-specific. With a wide range of approaches, it can be very onerous and strict.
- Samantha mentioned that they are seeing that it has to be an Autism-specific assessment tool- which appears to be what the Insurance companies are looking at. She has seen language like “as long as the diagnosis is within their scope of practice”
- Erika suggests that it would be good for RAP staff to ask, “Are you sure this is the Iowa Policy?”
- Kris stated that families finally coming off wait lists of years and then they are told that they need to get their IQ done within two weeks. So, she's looking for ways to help families navigate this. Jill suggested that families reach out to Meaghan Peters ([meaghan-peters@uiowa.edu](mailto:meaghan-peters@uiowa.edu)) at the Center for Disabilities and Development.
- She also mentioned that service members with TRICARE who are trying to get an adult Autism diagnosis are being told that the University of Iowa no longer does adult diagnoses. Then TRICARE gives them three people they can go to, none of which have Autism experience. So, the Autism Society of Iowa is getting calls from these people and therapists who are trying to help. She's looking for anyone who might know anything about this and how to help. Josh mentioned emailing Krista Stevens with Autism Speaks.
- Josh reminded everyone about the CARES Act in the process of getting reauthorized before it expires in September. So, sign up for the action alerts from Autism Society or Autism Speaks.
- Monica reminded about the Area Education Agency changes in Iowa and Autism Teams.

Meeting adjourned.