

Regional Autism Assistance Program
Expert Panel Meeting
October 22, 2024, 9 AM – 11 AM
Via Zoom

Name	Organization/Role Representing	Attended
Megan Abramski	Division of Aging and Disability Services, Iowa Department of Health and Human Services	
Alyson Beytien	Life Connections, Family Member	X
Josh Cobbs	Autism Speaks, Family Member	X
Amy Chebuhar	Iowa Department of Health and Human Services	X
Vanessa Curtis	Child Health Specialty Clinics, Division of Child and Community Health, University of Iowa Stead Family Pediatrics	
Allison Drew	Regional Autism Assistance Program, Family Member	
Kristin Hanson	Axis Therapy and Support Services	X
Erika Hertel	Regional Autism Assistance Program, Family Member	X
Michelle Holst	Iowa Department of Human Services, 1st Five	
Andrea Keith	Iowa Vocational Rehabilitation Services	X
Vanessa Kimm	Center for Disabilities and Development, University of Iowa Stead Family Children's Hospital	
Monica Kurtz	Grant Wood Area Education Agency	
Toni Fuller Merfeld - represented by Megan Christiansen	Metro West Learning Center	X
Caroline Moniza	Mercy Family Counseling	
Steve Muller – represented by Evelyn Horton	Balance Autism	X
Kelly Pelzel	ChildServe	X
Jillian Reiher	Center for Disabilities and Development, University of Iowa Stead Family Children's Hospital	X
Leslie Rogers (& Samantha Cermak)	ChildServe	X
Kristine Steinmetz	Autism Society of Iowa, Family Member	X
Wendy Trotter	Iowa Department of Education	
Maria Valdovinos	Drake University	
Brad Zelinger (& Abbi Fletcher)	Stride Autism Centers	X

Welcome (Facilitator: Erika Hertel)

Member Updates (Alyson Beytien, Beyond Behavior)

- Opening Carrol clinic in 3 weeks- staff are ready to go, so Beyond Behavior can take patients right away- there is no waiting list
- Lease has been signed for a new Waverly clinic- tentatively opening January 1, 2025
- Expanded spaces in Bettendorf and soon, Harlan clinics
- Able to do diagnosis with one individual and a supporting psychologist (can serve individuals older than what UI can currently take and can give an updated diagnosis)
- Still seeing insurances challenging diagnostic assessments that are over 5 years old for the request of ABA- have been using the Mental Health Parity Law to push back
- Anyone can do the referral on the website and designate what that referral is for

Member Updates (Kris Steinmetz, Autism Society of Iowa)

- Friday, November 1st is the fall conference
 - Liz Delsandro is the keynote speaker on emotional regulation with breakout for 2 different plans and 6 other breakouts
- Resource fair going on at the same time- 30 tables have been filled, including 5 for businesses of adults with Autism
- The Benefit Auction is that night
- Sunday, October 20th, ASI had a drive-through pumpkin patch for those with higher needs
- ASI is getting calls about autistic individuals getting called for Federal jury duty now that they are voting.
 - At the Federal level, a disability does not exclude you
 - Sometimes they have to stay for up to 7 hours, with no phones
 - No one seems to have any information on the accommodations/how to work through that stringent process
 - If the individual is in college, they can get deferred until summer but then that is on their mind that they will have to go later
 - If they get an attorney to get out of it, then the judge questions if they even have the capability to vote
 - At the county level, you can use a medical excuse but for Federal level there are only exclusions for age and competency (which again brings up the ability to vote conversation) and if you're going through some type of treatment (such as cancer).
 - Contact Disability Rights Iowa- to help guide the individuals receiving jury duty notifications

Member Updates (Brad Zelinger, Abbi Fletcher, Stride Autism Centers)

Brief reminder of their services

- Serve 2–6-year-olds in a clinical setting
- Locations across the state include
 - Des Moines Area (Des Moines, Johnston, & Urbandale)
 - 2 locations in Davenport
 - 1 each in Hiawatha, Coralville, and Sioux City
 - Opening a clinic in Cedar Rapids in 2/1/25 and actively working toward a location in Council Bluffs

Member Updates (Amy Chebuhar, Iowa Health and Human Services)

- Iowa Health and Human Services (Iowa HHS) has 15 different collaborative service areas (CSA) that are screening centers
- A lot of Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services
- Previously, developmental screenings were not able to be done telehealth but that is possibly going to change in the future, over the phone (audio-only telehealth)

Member Updates (Leslie Rogers, ChildServe)

- Recently purchased the old Mercy One on 48th and Franklin in Des Moines
 - This move expands the capacity from 60-600 served
 - Neuro-behavioral focus
 - Medical childcare and other outpatient services will expand (OT/PT, behavioral health, and ABA)
- Kelly Pelzel- on November 7th and 8th, Project Impact Training near the Coralville location
 - Has 13 signed up- some of which are ChildServe providers (building capacity in-house)
 - Opened the training up outside of ChildServe for caregivers and people interested in getting trained on naturalistic behavioral interventions
 - Working to move this to an annual training
 - Last week, she finished the train the trainer process and is now a trainer for the Parent-Child Interaction Therapy (PCIT)

Member Updates (Andrea Keith, Iowa Vocational Rehabilitation Services)

- IVRS is working to shift the qualifications for the Rehabilitation Counselors from master's to bachelor's degree
 - Public hearing was held on October 10th- available to watch on their website
 - No answers given yet

Member Updates (Evelyn Horton, Balance Autism)

- Recently moved to a regional model (some of the people who you formerly knew as Clinic Directors are now Regional Directors)
 - Greatly impacts Cedar Rapids
 - Recently went through a crisis period
 - Now have 5 new Board-Certified Behavior Analysts (BCBA)s from out of state
 - Resources from Iowa City and Waterloo have made this a really strong region
 - Looking into a Specialized Social Skills Program
 - Responding to Iowa HHS request for more Residential Based Supported Community Living Services (RBSCL) offerings in the state
 - Not there quite yet, but looking into it
 - Iowa HHS also asked for an increase Supported Community Living (SCL) hourly services
- For adult services- BA has opened Technology Homes in their residential services
 - 2 homes are completely technology-based (somebody in an office 24 hours that is available to be visible through screens and contactable in multiple ways)
 - So, staff don't have to be in the homes all the time
 - Even though staff didn't live there, the clients felt like it was a 'staff home' and institutional- now the client and their families feel like they are actually in their own home and families have increased visitation/gatherings
 - Takes less staff

Member Updates (Jillian Reiher, CDD & University of Iowa Health Care Stead Family Children's Hospital)

- Have a new Autism Center Coordinator- Ali McCue
 - Ali is currently following up with patients on the evaluation waiting list (wait list is currently over 1 year) to get as much background on the families as possible before they come in
 - She is also collecting data on the efficacy of the CDD's current clinic structure (meaning different ASD teams and diagnostical interviews for younger children with clear MCHAT scores)
 - Anticipating clinical structure changes due to those results in the future

Member Updates (Josh Cobbs, Autism Speaks)

- National Disability Employment Awareness Month (NDEAM) is wrapping up
- Just released a couple of stories
 - Wilson's Sporting Goods employment training for their teams
 - State-wide initiative in Georgia regarding inclusive environments for the schools' food and nutrition programs
- First parent support courses are out for individuals with moderate to higher support needs (lets parents know what they can do to start preparing for employment)
 - Registration is required but there is no cost- open to anyone

Member Updates (Kristin Hanson, Axis Therapy Centers)

- Locations in Ames, Ankeny, Fort Dodge, and West Des Moines providing ABA, Speech, OT, Feeding, Social Skills groups, preschool prep groups, and group caregiver training
 - Getting ready to start next round of group caregiving training for current families, families on the wait list, or anyone looking for support and resources
 - via zoom, 1 night each week over an 8-week period (depending on the focus)
 - Looking to move Ft. Dodge, Ankeny, and West Des Moines clinics into bigger offices
- Looking at Creston area and possibly Grinnell- possibly next year
- Starting a project with a local nonprofit- working with schools to bring ABA therapy directly into schools

Member Updates (Megan Christiansen, Metro West Learning Center)

- Added new speech therapists to their team
- Had a Trunk or Treat event and had about 40 families turn out

General Updates

- The Iowa Autism Council will end in July 2025
 - RAP will continue to update Iowa's Autism Strategic Plan
 - The RAP Expert Panel will need to prioritize monitoring progress on the Plan

Strategic Plan Updates

Strategic plan overview and review of progress and needs

Area A – Get a Good Start

- Progress may have slid backward since wait times have gotten longer since COVID
- RAP is emphasizing that anyone waiting for an evaluation is connected to Early ACCESS or other therapies while they are waiting to use that wait time to their advantage
- CDD is hoping to grow this area through Ali McCue (the new Autism Center Coordinator)

Area B – Have Access to and Obtain Needed Services

- Seems to be moving along fine- growth is definitely happening and resource lists are growing
- Use of technology also helps with that access

Area C – Have Well-Informed, Empowered, and Supported Individuals, Families, & Caregivers

- An area where we may still be failing our families- especially when the client reaches pre-teen to teenagers (there are so few options for families who are in complete crisis)
- When we see an increase in challenges among the more severely affected individuals, grandparents don't know the system or options for crisis services (this may need to be escalated to an Iowa HHS focus)
- Even looking at the network of support- a lot of places won't take families with profound autism even if they were set up to do so
- We may need to look at reimbursement rates so that the providers who want to take them, can and still sustain the care as a business model

- We have figured out how to do it from an ABA standpoint, and we need to look at the medical, dental, and supplemental transition resources
- Alyson- also looking at it from a business model- constant Emergency Department/police cycle needs to be interrupted
How do we support these families and kids
- Kelly- there is a wild card with the new system for state waivers- what role will that play?
On education front, with ASK Resource taking over, over time, what role can that have?
- Evelyn- the RAP Expert Panel that has been the pushers that get things done. The Strategic Plan has been the guidance for our focus. There has never really been an 'absolute' entity who has been responsible for the action of following up on the plan, but it forces the Expert panel to stay focused on what is in the plan and what are we doing about it.
- Evelyn- the Iowa Autism Council will be greatly missed because it has served as the only real combination of family member advocates who are as informed as the Expert Panel participants. Maybe the panel could consider picking up some families to make up for that?
- Brad- it seems like with sunset of council, that potentially engaging with lobbyist to help us align with our needs- will cost money but might help push forward initiatives.
- Evelyn- feels if providers had a joint voice- that would help increase the power of the voice. We've never had a true network of providers saying, "this is what we want."
- Brad will be happy to help organize groups. He will follow up with email after the meeting to ascertain interest.
- Samantha- could we possibly form a Council of Autism Services Providers (CASP) group
- Evelyn- there are some remaining dollars left for families that are interested in the Safety Care Training for families
- Erika- RAP staff have asked about for more information on adult service training for families who do not have a waiver. Does anyone have speaker suggestions?
 - Centers for Independent Living
 - Housing Equal Opportunity Department
 - Disability Rights Iowa might have general information
- Samantha notices that there are a lot of children who should be on a waiver list but are not, how do we get them on and how do we support them.
 - It's often an informal connection (found out from ASI)
 - Family Navigators ask if the family has applied for waivers
 - Would be good if we did that from a school perspective
 - CDD refers families but maybe we need to reach out to some providers that are not based in Iowa
 - Some families don't fully understand what it is, ASK has a really good handout- get the family to understand how important and what it is
 - Important to remember that even though the child is doing well now, things can change in a few years

Area D – Successfully Transition to Adult Life

- Technology houses
- ASI Support groups seeing young adults is empowering
- IVRS no longer has a waitlist

Area E – Be Assured of Ongoing Coordination of Systems of Care and Support

No comments

Kris- 2025 Autism Advocacy and Acceptance Day on the Hill is early this year- 1/16/25

Meeting adjourned at 10:08am