

**Regional Autism Assistance Program
Expert Panel Meeting
August 27, 2024, 9 AM – 11 AM
Via Zoom**

Name	Organization/Role Representing	Attended
Alyson Beytien	Life Connections, Family Member	
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	X
Allison Drew	Regional Autism Assistance Program, Family Member	X
Connie Fanselow- replacement to be determined	Division of Aging and Disability Services, Iowa Department of Health and Human Services	
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	Metro West Learning Center	X
Caroline Moniza	Mercy Family Counseling	
Evelyn Horton (representing Steve Muller)	Balance Autism	X
Kelly Pelzel	ChildServe	X
Jillian Reiher	Center for Disabilities and Development, University of Iowa Stead Family Children's Hospital	
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 and Introductions (Facilitator: Erika Hertel)

Guest speakers

9:15 Taking Charge of My Healthcare - training to support adults with intellectual disabilities to navigate the healthcare system
Laury Scheidler, LMSW
Iowa's University Center for Excellence in Developmental Disabilities (UCEDD)
University of Iowa Health Care

Curriculum includes 4 sessions:

- Basics Part 1- Discuss the patient's rights according to the law and go over the Americans with Disabilities Act (ADA) and what self-advocacy is. In this session, they will also learn about creating an "about me" profile: a card with information about themselves that they can take to their health care provider and give any information to help the appointment go smoothly that might not be in their chart.
 - Basics Part 2- Discuss how to find and work with a doctor, healthy eating habits, staying active, dental care and how to make appointments, annual checkups, and dental care.
 - Basics Part 3- Discuss seeking help and understanding when to visit a health care team. Understanding levels of urgency and knowing when it is appropriate to call the doctor, go into emergency room, etc., mental health and when it is important to talk to someone, and seeking preventative care.
 - Basics Part 4- Go over getting treatment, more details about how to read a prescription label and not sharing medications with other people, side effects and signs of issues with a medication, rights to ask questions if a doctor says they need to have surgery, discharge plan and how to take care of yourself when you get home
- Urge self-advocates to present and train other trainers.
— Training is funded through a grant so there is no charge.
— In October will be training at System's in Cedar Rapids and working to set the training up as a webinar sometime this year for online delivery.
— Sessions are about an hour, and they are working on creating shorter versions.
— Currently training, and presenting at the *Make Your Mark Conference* in September. They are ready to go outside of the Iowa City area if there is an interest

Tammie-amsbaugh@uiowa.edu

Edward-esbeck@uiowa.edu

Dayrin-lovan@uiowa.edu (English and Spanish)

Laury-scheidler@uiowa.edu

9:30 Family & Educator Partnership (FEP) Services at ASK Resource Center
Karen Thompson
Executive Director
ASK Resource Center



ASK Overview
8.12.24.pdf

Karen Thompson has worked in disability advocacy, rehabilitative training/counseling, and public program administration serving people with disabilities for thirty years. She has served as the Executive Director at ASK since 2010. At ASK, Karen works across all projects at the organization, facilitates board and stakeholder

collaborations, and serves on a number of federal and statewide boards and committees representing persons with disabilities and their families in the areas of education, healthcare, and advocacy. She holds a bachelor's in psychology from Nebraska Wesleyan University. Her lived experience with disabilities spans three generations. She is the daughter of a massive stroke survivor, the mother of two neurodivergent children, and is a person with dyslexia. Karen sees disability as an attribute and challenges others to do the same.

- ASK- supports families of children (from birth to end lifespan) with disability across Iowa.
 - Funded for up to age 26 but will still help for older individuals
 - For families and caregivers and sometimes work with individual themselves to make sure they get the support and advocacy they need
 - In worlds of education and healthcare
 - Run and led by families- almost everyone is a caregiver or family member with lived experience
 - Provide individualized support, collaborative advocacy, training, resources, and leadership development
 - Founded by two parents with children with special needs who met in the grocery store. One was a political activist and organizer, and the other was a social worker. Decided that there was a gap to fill for parents with special needs kids navigating systems
 - Started a support group and met in their basements with families, then moved to Mercy and in 1997 became a nonprofit. They were supposed to serve the Des Moines area, but were getting requests for support from across the state. Since 1998, ASK has held the grant to be the PTI for the state of Iowa (Parent Training and Information Center)
 - Years later expanded with a partnership with Iowa Department of Education after they decided to no longer fund the Family & Educator Partnerships (FEP) through the AEA system and chose to draw up a contract with ASK
 - 2023: supported 38,000 families with in person training, support, or individual services, but doesn't include online services
 - Currently housed in the AEA regions with the family support staff
 - Team-based approach to support across the state- everyone is onboarded the same way with a 90-day training period
 - Professional family support staff with very specific training – need you to refer the family, they really need to talk to the family because the support is completely individualized
- Services at ASK include:
 - Individual Assistance: professional family support staff with a 10-week onboarding training that includes shadowing and practicing before they go out on their own
 - Mentoring: network of leaders and mentors who reiterate importance of active listening, when to use your story, confidentiality, how to help people come to their own stories- informational, navigational (guidance to other resources), and emotionally supportive
 - Training: provide on-line (webinars), virtual (YouTube with trainings, small and mid-sized support groups, conferences, state-wide conference (always the first Saturday in May)
 - Information dissemination: send out informational sheet. If you have information or events that you want to get to the families, send them to ASK and they will be put in their eNewsletter. Write and search for informational sheets that are already in parent-speak- professional level language/out of state information that needs information added about how things are done in Iowa. If not, they will rewrite it in parent-speak
- Specific services that families love:
 - Postsecondary Transition Information: <https://www.transitioniowa.org/>
 - *Together We Can* Conference is always 1st Saturday in May: offer daycare, resource fair, keynote speakers, 15-18 breakout sessions, CEUs available, by families for families, professionals are there but mostly presented by parents in parent-speak
 - ASK Each Other online Support Group: <https://www.askresource.org/events> - 1st Monday of every month (typically), run by mentors and leaders, starting new in-person groups soon

- Families who want to be a mentor/have a mentor- you can contact ASK on their contact us page
- Iowa requires transition plans at age 14 but ASK suggests starting at 5
- ASK doesn't speak in terms of programs or projects, instead, just contact ASK "just ASK". If you need support contact them, Family Support Specialists are cross-trained- just have the family contact ASK and they will follow up with the family. Call volume is high enough that a single person cannot handle the volume. Use the Contact Us tab <https://www.askresource.org/contact>. This is a detailed contact form, with skip logic questions make sure that your form is submitted efficiently.
- They will then be placed on an Intake List
 - Take calls first come, first served. Everyone at organization can take calls, it may take up to 7 days for someone to get back to you but that is rare. Response time is currently at 4 days.
 - When turned in contact request, web page shows "thank you" and you get an email with resources so that you are prepared when they call back.
 - You can sign up for eNewsletter in the footer of the ASK website
- ASK serves the whole child: any staff member knows the whole system. Only if they need someone in their area would there be a handoff to those people who can develop direct relationships with schools and hospitals in the area and can help with higher-level interactions like facilitated IEP meetings or remediation.
- Respect Training- on hold as the Department of Education moves through their changes with the AEAs and the Governor's Bill. They are restructuring what conflict resolution processes look like- will come back probably next year (trainers still on staff so reach out if you're interested)
- ASK each other virtual support group is found on the events tab (ASK is working on a series of webinars "ASK an Expert Webinars"- working on calendar year 2025 and should be up in next few weeks)
 - Use prior year's data to determine what families need- these are recorded, and captions and translations are available
 - YouTube@ASKResource
 - Go to 'videos' to find anything you might want
 - 'Shorts' are tiny blurbs with specific how-to information
 - 'Playlist' series webinars

Additional Resources

- Transition Iowa <https://www.transitioniowa.org>
- i3 <https://iowaideainformation.org> (a lot of links are broken and info incorrect, so give them 6 months to catch up to changes)
- CPIR (Center for Parent Information and Resources) <https://www.parentcenterhub.org> (national technical information- what you're finding is from a lot of different states so verify with ASK that the information pertains to IOWA's rules)
- Iowa Department of Education <https://educate.iowa.gov>
- Family Voices <https://familyvoices.org>

Contact information for Karen

- 6165 NW 86th Street, Suite 234 Johnston, IA 50131- not best route of contact
- 515-243-1713 is best way to contact
- Email: info@askresource.org

Q&A:

- Has Call volume been increasing and if so, why?
 - Yes, call volume has increased across the state since before COVID. Theoretically, this is because the PTIs and F2Fs have existed for some time, so the lower-level questions are more easily answered online. So now 1:1 support calls are pretty complex. Things are getting more confusing, programs are more elaborate, funding is more difficult for people, there are more families, more kids, larger wait lists,

and outcomes of COVID. Things happening in the school systems such as loss of funding, programming, shortened day, and an increase in challenging behavior.

- Are there any resources or handouts that are family friendly that explain changes to laws or policies and impact an education such as the recent AEA change?
 - Resources tab – hundreds of them so if you can't find what you want, click on the contact us tab to have someone help.
 - Many families don't know the jargon so there is a double search bar, starts with general topic headings, including Spanish translation. Click on that area then click on the subcategory that you're looking for. Ex: Health, Mental wellness and brain health. This will give you links that will redirect you to other pages or provide the resource if it's an ASK resource
 - AEA information is limited because they still don't know what is going on.

Member Update (Kristin Hanson, Axis Therapy & Support Services)

- Axis is going to open another location in Creston in Spring 2025

Member Update (Josh Cobbs, Autism Speaks)

- Recently released first parent course for individuals with significant to moderate support needs – registration is required but it's free, codeveloped with research partners at VCU
https://autismspeaks.streamlxp.com/register?utm_source=autismspeaks.org&utm_medium=community&utm_campaign=win&utm_content=lp_register
- Coming soon- courses for moderate to high support needs for job coaches and other people working directly with individuals
- All courses are public

Member Updates (Andrea Keith, Iowa Vocational Rehabilitation Services)

- Entire waiting list is cleared so if you know anyone who hasn't heard from their counselor, please have them follow up
- Staffing is still an issue, so contacts are a little behind

Member Updates (Kris Steinmetz, Autism Society of Iowa)

- On November 1st, in West Des Moines- Annual Fall Conference- keynote will be on Emotional Regulation and Anxiety in Autism
<https://autismia.com/event/2024-autism-society-of-iowa-fall-education-conference/>
 - Panel of women with autism
 - Parent panel on “what I wish I knew, when my child was first diagnosed”
 - Vocation/rehabilitation: Dr. Williams will speak
 - Teaching prevocational skills with ChildServe
 - Kristin Hanson from Axis will be speaking on picky eating
 - Social networking for autistic adults at the end of the day
- Registration is up and there are parent scholarships available
- Everyone with Autism attends for free
- Reminded us that Autism Society of Iowa has an eNewsletter [E-Newsletter – Autism Society of Iowa](#)

Member Updates (Allison Drew, CHSC/RAP)

- Registration is now open for the fall Autism Basics Webinar series
 - Wednesdays from 12-1 starting on Sept 18
 - 4-week series of parents or primary caregivers for newly diagnosed ASD (geared toward parents)

Member Updates (Brad Zelinger, Stride Autism Centers)

- In the CR/IC metro areas, both the Coralville and Hiawatha clinics have been experiencing heightened staff turnover, so they are trying to work through those issues
 - wait times are a little longer and there are some cancelled services and service interruptions

Member Updates (Kelly Pelzel, ChildServe)

- In Iowa City location, have been doing ASD evaluation work and other referral questions
- Model is different from the University of Iowa
 - see families 3 times: intake, testing day, feedback day
 - if things are going well on ASD testing day, able to do cognitive testing on same day
- She and Todd Kopelman are teaching a graduate seminar on autism spectrum disorders
 - 16 graduate students: mix of school psychology and speech pathology students

Member Updates (Monica Kurtz, Grand Wood Area Education Agency)

- Locally, they serve 33 school districts within Grant Wood Area 10
- Were 7 employees in the spring but now there are only 4: assignments have changed
- Support kids with anxiety and ADHD and can brainstorm strategies the same way they would for ASD but primarily focus is still on ASD
- These services are a special education service- free to school districts
- Ed Serve and Media Serve are now charging for services

Member Updates (Erika Hertel, Iowa Regional Autism Assistance Program)

- We have not heard of a replacement being hired yet for Connie Fanselow, with the Autism Support Program, so Megan Abramski is still the contact for this

Member Input Request (Josh Cobb, Autism Speaks)

- Asked about dentists who accept Medicaid, work with individuals with autism, and will provide local or complete anesthesia needed, especially in western Iowa. Their area has had some dental providers that have exited, and many families cannot drive to providers.
 - Kris Steinmetz shared that she and Todd Kopelman are working on a project to compile this information since it is a need. They did a survey and have a list of a few people.

Meeting adjourned at 10:31