

**Regional Autism Assistance Program (RAP)
Expert Advisory Committee Meeting Minutes**
April 10, 2019, 10:00 – 2:00
Link Associates, West Des Moines, IA

Regional Autism Assistance Program Expert Advisory Committee Members		
Name (& Designated Representative)	Organization/Role Representing	Attend In Person/GTM
Alyson Beytien	Hills & Dales/Family Member	
Josh Cobbs	Family Advisor	
Kimberly Cooke	Family Advisor	
Peter Daniolos	UI Stead Family Children's Hospital Child & Adolescent Psychiatry	
Connie Fanselow	Iowa Department of Human Services, Iowa Mental Health and Disability Services Commission	X
Heather Hanzlick-Jaacks	Family Advisor	X
Megan Hartwig	Iowa Department of Public Health	X
Erika Hertel	Iowa Regional Autism Assistance Program/Family Member	X
Michelle Holst	Iowa Department of Public Health- 1st Five	X
Leann Hotchkiss	Family Advisor	
Andrea Keith	Iowa Vocational Rehabilitation Services	X
Aaron Kauer	UICH Child & Adolescent Psychiatry	
Vanessa Kimm	Family Advisor	
Shawn Kolb	ChildServe	
Toni Fuller Merfeld	Metro West Learning Center	X
Steve Muller	Balance Autism	
Nathan Noble	Blank Children's Hospital	
Michelle Nuehring	Grant Wood AEA	
Analisa Pearson	Iowa Department of Public Health	X
Kelly Pelzel	UI Stead Family Children's Hospital Autism Center	X
Sacha Pence	Drake University	X
Mary Roberts	Family Advisor	
Kelli Robertson	Grant Wood AEA	X
Leslie Rogers	ChildServe	X
Natalie Sandbulte	Seasons Center for Behavioral Health	X
Thomas Scholz	Division of Child & Community Health	X
Kristine Steinmetz	Autism Society of Iowa/Family Member	X
Jill Stevenson	Family Advisor	X
Melissa Stimmler	Family Advisor	
Blake Stephenson	Tanager Place	

Rachell Swanson-Holm	Learn the Signs. Act Early., Regional Autism Assistance Program	X
Wendy Trotter	Iowa Department of Education	
Kathy Francois	RAP support, Iowa City	X

Welcome and Introductions

Facilitator: Erika Hertel

- Roll call was taken and introductions were made.

Get a Good Start:

- **Rachell Swanson-Holm** received notification from the Association of University Centers on Disabilities (AUCD) and the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC that she has been selected to serve as an Act Early Ambassador for the 2019-2021 cohort, continuing her role with the Learn the Signs. Act Early. Program for a second term.
- Rachell also continues her work with the AUCD grant piloting the use of these materials in Early Head Start settings.
- **Erika Hertel** shared that Child Health Specialty Clinics applied for the HRSA grant *Innovations in Care Coordination for Children with ASD and other Developmental Disabilities*. Five grants will be awarded for \$372,000/year for four years. The grant period is 9/1/2019-8/31/2023. Applications were due March 8. The purpose: to improve access to coordinated and integrated care for children with, or at risk for, ASD/DD and their families in medically underserved areas and populations by implementing the following two strategies:
 - 1) Family Navigation - Increasing family navigation services to improve communication between families and primary and specialty providers; link children with/at risk for ASD/DD to diagnostic evaluations, ASD/DD services, and community resources; and provide education to families of children with/at risk for ASD/DD to improve self-efficacy in navigating the system of care for children with/at risk for ASD/DD; and
 - 2) Provider Training - Providing education, training, and technical assistance to providers, and community based-organizations providing services to ASD/DD on improving care for children with/at risk for ASD/DD through a learning community.

Have Well Informed, Empowered, and Supported Families and Caregivers:

- RAP has added additional Family Navigators to meet the needs of families.
 - Megan Sprecher started in December and will be in our Fort Dodge Regional Center serving Ames, Marshalltown, and nearby communities.
 - Renee Speh started in December to serve Cedar Rapids and nearby communities and working from our Iowa City office.
 - Ann Mohr previously worked at CHSC with the Health and Disease Management Program and started with RAP in February, to serve Black Hawk county, which includes Waterloo.
- Starting this week, RAP has 4 hours of dedicated RN support for our four RAP Family Navigators who are not connected to a Regional Center. This includes the three FNs just mentioned and Clementine Karl of Des Moines. They will create a team and have Tamra Ruff, RAP RN from Council Bluffs, for additional clinical support.
- Tom Scholz provided additional information about Child Health Specialty Clinics Regional Centers and where they are located.

- RAP is offering a four-week Autism Basics webinar series running April 16- May 7, from 12-1, aimed at parents and caregivers of children with a new autism diagnosis. Dr. Kelly Pelzel will present:
 - 1) What is Autism?
 - 2) Autism Interventions
 - 3) Challenging Behavior
 - 4) Educational Programming
- RAP is partnering with University of Iowa Hawkeye baseball for an Autism Awareness & Acceptance Game to be held Sunday, May 5. Discounted tickets, a section of reserved seating, and sensory packs will be available. Tickets available at www.hawkeyesports.com/tickets, use promo code IOWAAUTISM19.
- The RAP Caregiver Retreat and Transition Conference will be held June 7 and 8 at the Gateway Hotel in Ames. This conference will be offered at no cost to families. A flyer will be shared as soon as it becomes available.

Have access to and Obtain Needed Services

- **Connie Fanselow**, Department of Human Services, gave an update on the Autism Support Program (ASP). DHS has a new logo and forms have been updated to include this. Paper copies of the ASP Annual Report were shared, and this is available on the Legislative Reports website at:

<https://www.legis.iowa.gov/publications/otherResources/reportsFiled>

Funding:

For **SFY 2016-2017** - \$2 million appropriated to fund:

- \$250,000 for Board Certified Behavior Analyst (BCBA) and Board Certified Assistant Behavior Analyst (BCaBA) Grants Program Fund
- \$25,000 for grant to a child welfare services provider (Four Oaks summer program)
- \$25,000 for grant to a hospital-based provider for pilot project (Mercy Dubuque)
- Available for ASP services \$1.7 million - **\$474,194 expended**

For **SFY 2017-2018** - \$950,000 appropriated to fund:

- \$25,000 for Four Oaks summer program
- \$25,000 for Mercy Dubuque pilot (not used)
- Available for ASP services \$900,000 - **\$359,557 expended**

For **SFY 2018-2019** - \$573,000 appropriated to fund:

- \$25,000 for Tanager Place after school program
- ASP funds for services **\$548,000 available to expend**
- SFY 19 expenditures are anticipated to be less than SFY18

SFY18 Utilization:

- Received **23 applications** for the ASP during SFY18
- **Approved 17** (74%) of the 23 applications
 - 2 denied - over income
 - 3 denied - private insurance benefit
 - 1 denied - Medicaid eligible

- **24 children actively enrolled during SFY18**
- 11 to 15 children actively receiving services each month

SFY19 Year-to-Date

- 8 applications received; 5 approved and enrolled
- 9 to 10 actively receiving services each month

Overall Program Utilization:

- **Total of 55** children have been served thru SFY18
- 14% of applicants were female and 86% were male
- Average age of applicants is 4.75 years
- Average income of applicant families is 362% FPL
- **Average monthly cost paid per participant is \$2,360**
- **Average amount of ASP funds expended per month is \$27,441**
- **Average monthly service cost share** paid by families is **\$110** (4.3% of the cost)
- **Average length** of time a child receives services is **10 months** (of 24 months max)
- **Average total** amount of ASP funds **spent** for each child served is **\$26,174** (of \$72,000 max)
- Only 10 children have used full 24 month/\$\$ eligibility
- **No waiting list** has been used

Recipients use less than full benefit because:

- Make significant gains and ABA services **no longer needed**
- Become eligible for ABA funding through **Medicaid**
- Become eligible for ABA funding through a **private insurer**
- **Move** out of state or other family circumstances change
- Services discontinued when deemed **ineffective**

ASP fills short term gaps when children are:

- On the **waiting list** for an HCBS Waiver slot
- **Medicaid coverage is lost** due to increase in family income
- **Private insurance coverage is lost** because of a job layoff or have a waiting period for coverage when starting a new job, as well as when their policies do not offer an ABA benefit

Eligibility remains unchanged:

- Child is under age 14 at the time of application
- Has an ASD diagnosis made within 24 months of the date of application
- Does not qualify for Medicaid and does not have private insurance coverage for ABA
- Family has a household income at or below 500% of the FPL

Coverage issue:

- Most families who do not qualify for Medicaid coverage have access to affordable private insurance through their employers or are able to access low cost coverage for their children through hawk-I

- From 2010 through 2017, only state employee health insurance plans in Iowa were required to provide an ABA benefit for children with autism
- Private insurance coverage for ABA was expanded effective January 1, 2018 to all group health insurance plans subject to state insurance commission rules that have 50 or more employees (does not include plans governed by federal ERISA regulations)
- The challenge is that some private insurers provide a plan benefit for ABA treatment, but apply high out-of-pocket cost shares that prevent families from being able to access the benefit because of:
 - High deductibles
 - High co-pays for each ABA session
 - Limited number of “in network” providers and higher cost share to access “out of network” providers

Example:

- A family of 4 with an income of \$100,000, and no private insurance ABA benefit
 - Can receive assistance through ASP, paying 10% of the cost
 - Out-of-pocket cost is likely to range from \$150 to \$350/month or \$1800 to \$4200/year
 - The same family with a private insurance benefit does not qualify for ASP
 - Yet may be required to pay a deductible of \$10,000 and then a 50% co-pay of the next \$10,000
 - Out-of-pocket cost could be \$15,000 or more/year
- **Kelly Pelzel**, University of Iowa Hospitals and Clinics, provided an update:

**University of Iowa Stead Family Children’s Hospital Autism Center
activities Fall 2018-Spring 2019**

○ **Faculty and Staff Changes**

Pixie Plummer

She is a physician- board certified in Internal Medicine, Pediatrics, and Neurodevelopmental Disabilities who was brought here by the IDMI team to support the medical evaluation and care needs of patients with autism and intellectual disability served by their program. Dr. Plummer previously worked in Massachusetts with a broad range of patients including adults with autism.

She is also seeing patients of all ages at the CDD one day a week. Across departments, Dr. Plummer primarily help with coordinating between specialists, supporting issues that are common severe problems for bowel, bladder, sleep, and looking for undiagnosed health issues that may be contributing to problem behaviors. Her clinical practice has tended to be with patients who do not use spoken words for communicating primarily because they seem to be at higher risk for medical complications or difficulties accessing care.

Goodbye to Dr. Koen Van Braekel – Rady Children’s Hospital, San Diego

Dr. Meaghan Peters assumed role of CDD Psychology supervisor

- **Wait times for autism team evaluations** (2 or 3 providers on the same day for young children who have screened positive on standardized autism screeners)
 - CDD = June 18th
 - Psychiatry = October 10th
- **Extra IMPACT** being offered this spring and summer to reduce wait time
- **Lectures, Workshops, Conferences, etc.**
 - -free caregiver self-care workshop in November
 - -Mike South – Jan Ped Grand Rounds on his research on anxiety and autism
 - -a listening session on the proposed Chapter 103 rules on seclusion and restraint in February
 - -ASD workshop for daycare providers that ASI co-hosted with the Iowa City Autism Community and CCR&R in February.
 - -Autism Center safety conference – March
 - -"Police and First Responder" trainings on autism for Johnson, Henry, and Linn counties since October (ongoing).
 - -Fun Walk will be April 20th Terry Trueblood
 - -CDD LEND program offering ADOS training (June); external clinicians with a background in testing and measurement may attend
- **Research registry** (mechanics look good, but approval has not been given by UIHC legal department)
- **Megan Hartwig**, IDPH, shared the BCBA grant program RFP will be posted within the next month and posts one time per fiscal year. They are looking into options to have this post more frequently to meet the needs of the applicants. UPDATE: posted at <https://www.iowagrants.gov/insideLinkOpps.jsp?documentPk=1542296597047> Pre-Application Deadline: 05/22/2019, Application Deadline: 07/31/2019.
- **Leslie Rogers**, **ChildServe**, was asked if they are providing ABA therapy. Leslie replied they have a small ABA program at their Johnston location, which is currently for internal referrals only. They hope to expand this in the future.

Successfully Transition to Adult Life

Andrea Keith with Iowa Vocational Rehabilitation gave an update. Vocation Rehabilitation works with students who have IEPs or 504s and provides Pre-Employment Transition Services, including career counseling on job opportunities, job exploration, job shadows, interview support, work-based learning, and self-advocacy--how to talk about disability. They are working with NW Iowa Community College on the development of an ASD program with the focus on hands-on work and is a two- year CNC program. DMACC is looking at the potential for a similar program. IVRS works with employers Nationwide. Microsoft is one such employer. IVRS looks at employer development to create job opportunities for individuals with disabilities.

Be Assured of Ongoing Coordination of Systems of Care and Support

- The RAP Expert Panel Advisory Committee met 2/14 with Rik Shannon presenting on Advocating for Change with the Iowa Legislature in preparation for the Autism

Society of Iowa Day on the Hill. Unfortunately, due to bad weather conditions, only one RAP staff member was able to attend the Day on the Hill event.

- **Kris Steinmetz**, Autism Society of Iowa gave a legislative update for proposed budgets. *Note this information was current at the time of the meeting and has since changed:*

HF 690—Children’s Mental Health Services

Established a children’s behavioral health system state board and established core behavioral health services for children.

Allows mental health and disability services (MH/DS) regions to keep more money in their reserve accounts to help pay for new complex needs services or the build-out of children’s mental health services. HF690 allows regions to retain up to 40% in reserve until 2023; current law would have required them to spend that down to 20-25% this year. This does not help the regions with a permanent funding fix, and no bills have been introduced to do that.

\$384,000 to RAP, ASP Fund is fully funded.

- Spends total of \$1.94 billion, which is \$30.2 million less than the current year.
- Includes \$150.3 million in supplemental spending for the current year (mostly Medicaid)
- Adds \$1.2 million to eliminate the children’s mental health waiver waiting list.
- Increase of \$306,000 to IDPH to expand YourLifelowa to add 24x7 children’s MH hotline/info.
- Adds \$1.1 million to increase rates for Assertive Community Treatment (ACT) teams (a complex needs service).
- Required DHS to notify the HHS Budge sub and staff within 40 days of an MCO contract change.
- \$400,000 for four new rural psychiatric residencies and \$150,000 for psychiatric training for Pas and ARNPs
- Autism CARES Act Health Resources Services Administration Budget is completely eliminated (100%). This funds training for health professionals and funds research on services and supports.
- Supported Employment state grants are completely eliminated (100%)
- Lifespan Respite Care Act is cut by \$1 million (25%)
- Developmental Disabilities Councils get a \$20 million (26%) cut
- IDEA Technical Assistance is cut by \$18 million (28%)
- University Centers for Excellence in Developmental Disabilities: \$33 million, a cut of \$8M.
- Autism and other Developmental Disorders (which includes LENDs) is zeroed out, a cut of \$52M.

Autism CARES Act Reauthorization

The Autism CARES Act continues to gain bipartisan co-sponsors. The House bill ([HR 1058](#))

Now has a total of 24 supports; the Senate bill (S. 427) now has 6 co-sponsors.

Money Follows the Person

Legislation introduced late last month known as the EMPOWER Care Act would reauthorize the Money Follows the Person (MFP) for five years.

The Medicaid Services Investment and Accountability Act of 2019 HR 1839 <https://www.congress.gov/bill/116th-congress/house-bill/1839/text?q=%7B%22search%22%3A%5B%22HR+1839%22%5D%7D&r=1&s=1>

Passed the House on Monday the 25th of March. The bill extends spousal impoverishment protections through September 2019, includes a new version of ACE Kids, includes an additional \$20 million for Money Follows the Person and has a very small extension until June 2019 for Excellence in Mental Health states. It is unclear if and when the Senate will take up these issues.

- **Kelli Robertson** with Grant Wood Area Education Agency:
 - Interest in twice exceptional students.
 - GWAEA is hosting a mental health conference June 10-11, 2019 addressing trauma, mental health, and diverse backgrounds.
 - They will be running a pilot for mental health supports in the classroom, providing two mental health support staff as resources and utilizing a train the trainer model.
 - They work to promote evidence-based practices in classrooms. A shortage of substitute teachers to allow teachers time to attend professional development is a barrier.
 - They utilize a Google + Community which reaches approximately 500 educators and family members.
 - There is a strong push for inclusion.
- **Analisa Pearson**, IDPH, stated IDPH and CHSC are working on the Title V Needs Assessment for 2020-2025. They are seeking input from families in Iowa on the status of health, mental health, and behavioral health needs.

Discussion

Input was requested from members on:

- Iowa's Strategic Plan- Successes, Challenges, and Needs
- RAP priorities for FY 2020

Updates Shared Via Email

- **Heather Hanzlick-Jaacks**
 - Safety:
 - Project Lifesaver and Vitals Aware Services- Both organizations are working closely on the model and eventual launch of an integrated program that will provide full-circle elopement protection, as well as enhance the current procedures and abilities for locating lost Project Lifesaver clients and returning them home safely

See link: <https://projectlifesaver.org/project-lifesaver-international-vitals-aware-services-are-proud-to-announce-a-strategic-partnership/>

https://thevitalsapp.com/vitals/project-lifesaver-international-vitals-aware-services-are-proud-to-announce-a-strategic-partnership?fbclid=IwAR0Jq7ujsx6pr_PgbwsVpZHfT6zYEghvItXS_hF4ldBmfgQw1p3SIxyJcDE

➤ Local Safety event and articles:



CVLI Flyer LOST
Fundraiser FINAL DR

Project Lifesaver updates:

https://wccourier.com/news/local/a-year-after-jake-wilson-s-disappearance-deputies-begin-project/article_95c806fd-adbf-5801-b418-4fc3e80801e8.html?fbclid=IwAR2KQwY2VQPcU1CG8HYNBQFJuhMVDk99JTpsPeJ3hZKdVAiqx-hW7RP4clk#tracking-source=home-top-story

<https://kwwl.com/news/2019/04/04/police-test-project-lifesaver/?fbclid=IwAR1uHadcFosgXpBkQs1aOaknTYBHSNvKvsGqjKaRQ1DbiSAyToG3nSkDWKw>

○ Local group updates:
Self advocates group



self advocates flyer
April 2019.pdf

Parent/Family Support Group - including self advocates



Cedar Valley Autism
Warriors flyer March :

○ The Autism Spectrum Self Advocates wanted me to extend a special thank you to RAP for all your assistance with Iowa Autism Voter's Guide and have been sharing the following materials at during Autism Acceptance month (See attachments Preparing for the 2020 elections/Current Leg priorities, Self advocate communities and Self Advocate events). Mike Dierdorff, Joel Shrader (with collaboration with Leah Parker) will be presenting at the Make Your Mark conference this year in September.



Autism Advocate
communities CARE EX



Legis pri 2019



Self advocate events
Autism Spectrum Self 2019 CARE EXPO.pdf

● Tech Camps at Hawkeye Community College, including an August Autism Spectrum session.



2019 Technology Camps Scholarship



2019 Summer Tech Camp Flyer

- **Megan Hartwig**

Additional information for transportation concerns that were discussed:

- Passenger Transportation Summit



DRAFT 2019 Passenger Transport:

- DOT links related to transportation planning as well as a map of the local transportation advisory groups. Attached – map and contacts for the local TAGs



Find your local TAG .pdf

- TAG Guidance (into language you were looking for) https://iowadot.gov/systems_planning/pr_guide/Passenger%20Transportation%20Plan/TAGguidance.pdf
- Office of Systems Planning – Passenger Transportation Plan https://iowadot.gov/systems_planning/Planning-Resource-Guide#26634645-passenger-transportation-plan-ntp
- Public Transit in Iowa (physical listing and map) <https://iowadot.gov/transit/iowa-Transit-services/Transit-agency-maps-and-listings>
- Mobility Management info <https://iowadot.gov/iowamobilitymanagement/Mobility-resources>
- MM, .pdf Map https://iowadot.gov/iowamobilitymanagement/pdf/mobilitymanagers_map.pdf