

# Iowa Autism Council Meeting

## Final Meeting Minutes – June 12, 2019

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Meeting minutes taken by Beth Buehler-Sapp

**Present:** Caleb Primrose, Andrea Keith, Evelyn Horton, Connie Fanselow, Erika Hertel, Andrew Beer, Blake Stephenson, Michael Zehr, Jenny Phan, Rik Shannon, Wendy Trotter and Beth Buehler-Sapp

**Absent:** Nicholos Nopoulos, Christine Bowker, Jeanne Kerkoff and Chris Kliever

**Call-In:** Matthew O'Brien, Angela Logsdon, and Angela Burke-Boston

Caleb Primrose, Co-Chair, brought the meeting to order at 10:05 am. There were three new Council members in attendance, so Council members introduced themselves. Council members reviewed the minutes for the March 13, 2019 meeting. Edits were suggested and made. Erika Hertel made a motion to approve the minutes as edited, and Blake Stephenson seconded the motion. A vote was taken by voting council members to approve the minutes as edited. Minutes approved.

### **Strategic Plan:**

Wendy Trotter shared *Iowa's Strategic Plan 2016-2021: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families* to inform the new members. In the plan, the following areas of focus were identified:

- Get a good start
- Have access to obtain needed services
- Have well informed, empowered, and supported families and caregivers
- Successfully transition to adult life
- Be assured of ongoing coordination of systems of care and support

Updates on progress on the Strategic Plan were provided:

#### **Focus Area A (Get a Good Start)**

- Wendy Trotter reported that the DE is continuing the Autism Navigator project for Iowa's Early ACCESS providers (early intervention providers) – entering year five of the project.
- Erika Hertel reported that the Regional Autism Assistance Program (RAP) enrolled 19 Family Navigators in the new online Autism Navigator course: *Jumpstart to Coaching in Everyday Activities*. Family Navigators started the course in June and have one year to complete it. In addition, RAP enrolled 5 clinical staff (2 ARNPs, 3 RNs) in the Autism Navigator for Primary Care Course.

#### **Focus Area B (Have Access to and Obtain Needed Services)**

- Wendy reported that the work of the ASD Design Team has identified social emotional engagement as the focus for work moving forward – specifically, exploring how to provide

professional learning to teachers to support social emotional engagement within specially designed instruction and other academic lessons at the universal tier. The DE will draft an RFP to solicit proposals for moving this work forward and scaling it statewide. She will provide updates as this work develops.

- Autism Support Program (ASP) Update: Connie Fanselow reported –
  - They are still seeing fewer applications than they have in the last few years
  - 6 applications in last few months – one denied because they have insurance but it's cost prohibitive
  - \$573,000 for ASP for FY20 - \$25,000 allocated to Tanager Place, the remainder for ASP services
  - 1 new provider has requested to enroll as a network provider – a sole proprietor from Sioux Center – Sarah Hawley
  - IDPH re-issued the RFP for the BCBA education grant the end of April, but Connie has not heard anything more about the applicants. Currently applications have closed. Hopefully new awards will be available for the qualified applicants for this next school year.
  - Jenny Phan stated that physicians in the area have reported significant wait lists for providers which may be impacting the number of ASP applications being submitted.
- Telehealth – as of right now, ASP is the only provider using telehealth.
  - Connie reported that she hopes there will be movement with Medicaid soon to approve telehealth.
  - Evelyn Horton reported that Iowa is the only state that has interpreted the new CPT codes this way. Matt O'Brien concurred that other states are still able to provide telehealth.
  - Jenny reported she is hearing that a lot of families are leaving Iowa due to lack of available services – especially in more remote areas of Iowa.
  - Matt stated that there is a lot of research out there related to the efficacy of telehealth to reach underserved and remote areas. He suggested that perhaps we need a sub-committee to further investigate/study the issues in Iowa with telehealth and generate some type of report for informing/sharing. If any Council members are interested in participating on a telehealth sub-committee, email Matt.
- Tanager Place – Blake Stephenson reported that they are offering social skills groups: a Pre-K/early learning group, an elementary group, and a middle school group.
- Balance Autism – Evelyn reported they are opening a clinic in Iowa City in the next 6 months. Still looking for a location. They have also revamped admissions and are cleaning out waitlists (families who haven't replied after 3 attempts).

**Focus Area C** (Have Well-Informed, Empowered, and Supported Individuals, Families and Caregivers)

- RAP held the *Autism Basics* 4-week webinar series with Dr. Kelly Pelzel in April and May. Sessions included:
  1. What is Autism?
  2. Evidence-based interventions

3. Challenging Behavior
  4. Educational programming
- The RAP brochure and new ASD Fact Sheet are now available in Spanish, French, Arabic, and Karen. The RAP's *Navigating Iowa's System of Care: A Caregiver's Guide to Autism Spectrum Disorder First Steps After Diagnosis*, is also available in Spanish.
  - Evelyn reported the Autism Society of Iowa, Balance Autism, and the University of Iowa Stead Family Children's Hospital Autism Center are sponsoring a conference featuring Peter F. Gerhardt, Ed.D. for August 15<sup>th</sup> at Prairie Meadows in Altoona. Dr. Gerhardt has more than 30 years experience utilizing the principles of ABA in support of adolescents and adults with ASD. This conference will address employment, life skills, sexuality, and social skills for teens and adults with ASD. More information, including how to register, is available on the Autism Society of Iowa's website.

#### **Focus Area D (Successfully Transition to Adult Life)**

- RAP held the 2019 RAP Caregiver Retreat and Transition Conference Friday, June 7 – Saturday, June 8 at the Gateway Hotel and Conference Center in Ames. Approximately 50 people participated. Child Health Specialty Clinics, Center for Disabilities and Development at University of Iowa Stead Family Children's Hospital, Iowa Department of Education, Iowa Vocational Rehabilitation Services, and Money Follows the Person were represented by speakers. Sessions included:
  - A Young Adult and Parent Panel
  - Life After High School And Leaving Home: Living, Learning, And Working – SueAnn Morrow, Lynette Plande, Kirsten Varnum Lane
  - Legal And Financial Rules Of The Road – Frank Varvaris
  - Keynote speaker—Mike Dierdorff
  - Parent Café sessions:
    - Encouraging Independence – Erika Hertel
    - Finding Your Tribe: Social Supports and Family Navigators – Martha Hanley
    - Grief and Loss – Diane Zaerr Brenneman
    - Navigating the Waiver System – Lynn Park
    - Planning Your Caregiving Future – Rachell Swanson-Holm
    - Self-Care for the Caregiver – Rachel Charlot
    - Getting Ready to Work – Judy Warth
    - Social Skills and Behavior – Mary Roberts
  - Laughing yoga and chair yoga sessions were included.
- High Quality Living Options – Evelyn reported that Balance Autism has been buying homes that will house 4 adults with 2 staff per house to foster more independent living. They bought 6 houses last year and 6 more this year. This has allowed some adults to move out of ICF facilities into actual homes with roommates – they have been very happy. They have also noted reduced turnover rates for staff with this model – staff are staying longer.

#### **Focus Area E (Be Assured of Ongoing Coordination of Systems of Care and Support)**

- RAP Expert Panel met 4/10/19 at Link Associates in Des Moines. Members shared updates and assisted with planning for RAP's next fiscal year.

Council members discussed ways of gathering data to measure progress in the focus areas of the Strategic Plan. Wendy suggested that various agencies represented on the Council gather data related to their individual initiatives that the Council can then pull together to gain a statewide perspective of progress.

Jenny Phan suggested the Council develop and disseminate a survey to gather community input. Wendy suggested a small task team work on developing a survey – those Council members interested should let Wendy know.

### **Legislative Updates:**

Rik Shannon reported that the special education study group bill (SF316) did not move forward, but it may be brought up again in the second session.

Connie reported that this summer the rules for the new Children’s Behavioral Health System are being developed.

### **Regional Autism Assistance Program (RAP) Updates:**

Erika Hertel reported the following additional updates for CHSC/RAP:

- The Child Health Specialty Clinics Mason City Regional Center is being relocated. Over the weekend of May 18 – May 19, 2019 the building they had been in, the Mohawk Square building, located at 22 N Georgia Avenue, suffered extensive water damage from the storms that came through North Iowa.
- RAP presented to the University of Iowa dental residents recently – they will be collaborating more with them moving forward.

### **Voc Rehab Updates:**

Andrea Keith reported that they are sponsoring a transition conference coming up in August that includes a break-out session related to ASD.

### **Nominate/Vote on Co-Chairs for 2019-20:**

The following two Council members expressed interest in serving as co-chairs for the 2019-20 session: Erika Hertel and Caleb Primrose. Council members voted and unanimously confirmed the appointment of Erika and Caleb as co-chairs.

### **Review Goals for 2019/Outline Action Steps:**

The Council reviewed the goals outlined in the 2018 legislative report, which is posted online, <https://www.legis.iowa.gov/docs/publications/DF/971812.pdf>, and identified the following action steps:

- Each agency should collect data related to efficacy of their initiatives and bring to September meeting so the Council can start pulling data together related to the Strategic Plan.
- Two sub-committees/task groups were suggested:
  - Survey Task Team (let Wendy know if interested in participating on this task team)
  - Telehealth Task Team (let Matt know if interested in participating on this task team)

Next meeting is scheduled for Wednesday, September 11, 2019.

Jenny Phan made a motion to adjourn the meeting.  
Erika Hertel seconded the motion.  
Meeting adjourned.