

# Iowa Autism Council Meeting

Final Meeting Minutes – June 13<sup>th</sup>, 2018

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Meeting minutes taken by **Beth Buehler-Sapp**

**Present:** Caleb Primrose, James Curry, Angela Burke Boston, Andrea Keith, Evelyn Horton, Jane Brown, Connie Fanselow, Christine Bowker, Erika Hertel, Rik Shannon, Wendy Trotter and Beth Buehler-Sapp.

**Absent:** Matthew O'Brien, Angela Logsdon, Chris Kliewer, Jeanne Kerkoff. Sean Peterson, Nicholas Nopoulos, and Jenny Phan

Began with introductions. The council reviewed the minutes from the March 14, 2018 meeting. Edits were suggested and made. Christine Bowker made a motion to approve the minutes as corrected and James Curry seconded the motion. Minutes approved.

Evelyn Horton reported that The Homestead recently changed their name to Balance Autism and shared her updated email address.

## **Iowa's Strategic Plan 2016-2021**

Wendy Trotter reviewed the Iowa Strategic Plan:

### Our Vision

The vision of the Strategic Plan is to ensure that all Iowans with Autism Spectrum Disorder (ASD) have the opportunity to develop the skills and knowledge necessary to live independent and interdependent lives within their community and to reach their full potential.

### Our Mission

The mission is to build the state infrastructure for comprehensive lifespan supports to individuals with ASD and their families through access to information and resources, coordination of services, and implementation of evidence-based practices.

### Summary of Recommendations:

The following areas of focus were identified so that all Iowans with ASD will:

- A. Get a Good Start
- B. Have Access to and Obtain Needed Services
- C. Have Well Informed, Empowered, and Supported Families and Caregivers
- D. Successfully Transition to Adult Life
- E. Be Assured of Ongoing Coordination of Systems of Care and Support

*To see full report please refer to the Iowa Department of Education's website under Iowa Autism Council.*

Jane Brown asked if we had data or if a survey had been completed to determine high need service areas?

Wendy Trotter replied that the Autism Council is an advisory council so they do not have the authority or ability to access data systems, etc. However, representatives from other agencies that have access to data etc. serve on the council and provide the council with information when needed.

Wendy Trotter reminded the group, with three new members attending, that the Iowa Autism Council is an advisory council and not an advocacy group (according to the by-laws). Therefore, as a group we cannot advocate, but as individual constituents you may reach out to your own legislators to discuss topics of concern to you. The council's charge is to collect information and make sure it's disseminated statewide so everyone is aware and to make recommendations to better services and supports for individuals with ASD and their families.

#### Strategy 4 (of Strategic Plan) Discussion:

Evelyn Horton of Balance Autism announced that in July of 2017 they opened their 6<sup>th</sup> clinic – this one is in Burlington, IA. They have hit a roadblock with providing services via telehealth – particularly with United HealthCare.

Jane asked for clarification regarding United HealthCare not covering telehealth services.

Evelyn replied that United HealthCare has informed them that telehealth is not a covered service.

Jane indicated that she will investigate this further to determine what the barrier may be because telehealth in general is a covered Medicaid benefit.

James Curry asked if there is any anecdotal information related to the efficacy of telehealth?

Jane stated that there is data regarding the use of telehealth in emergency services.

#### Strategy 5 (of Strategic Plan) Discussion:

Erika Hertel shared that the Resource Directory that was developed through the HRSA Grant has transitioned to the Child Health Specialty Clinic (CHSC) website through University of Iowa Health Care. It can be found under the resources tab.

CHSC is also sponsoring a family leadership training coming up soon in the Des Moines area. Erika will e-mail the council members a flyer so they can help get the word out.

James asked how are these resources being shared with the public?

Christine Bowker reported that she has a Facebook Page for parents of children with ASD. It's called "Salute to Parents of Autism".

Erika Hertel said that typically families access information via word of mouth, organization websites such as Autism Society of Iowa or the Child Health Specialty Clinic website, or social media.

Jane Brown asked if there is a DHS website page that serves as an access point to direct traffic?

Connie Fanselow said that the DHS website is just a basic website.

Christine Bowker commented that it seems that most families rely on social media for accessing information. She has noticed that keeping it simpler and visual seems to be more effective.

Caleb Primrose responded that he agrees that information presented in a visual and simple/direct way works better. Caleb also mentioned that he has worked with Community Supports Advocates (CSA) who can help with transition and adult services.

Andrea Keith stated that a lot of Vocational Rehabilitation (VR) folks work with CSA.

#### Strategy 6 (of Strategic Plan) Discussion:

Jane shared that crisis intervention and stabilization is now a Medicaid covered service. Providers are being trained now but it is still inconsistent across the state. We need it to become more standardized across the state. New legislation related to mental health that just passed will help with statewide consistency in time. Crisis intervention is a covered benefit and not just a single line item, but multiple levels. They are working with DHS to remove barriers to crisis intervention.

Rik Shannon added the Complex Needs Services bill is addressing this. You can find a lot of good information about it on the [infontiowa.org](http://infontiowa.org) website.

Connie added that the first step in the bill was to add an array of service options/choices. Second step – the Complex Needs group met and put into legislation – creating varying steps/levels of care. There are Access Centers now in place. Goal is to create a system anyone can access and then provide guidance to appropriate services from there.

#### Strategy 7 (of Strategic Plan) Discussion:

Andrea Keith briefly discussed Voc Rehab's role with WIOA (Workforce Innovation Opportunity Act) which focuses on entities/agencies working together to ensure an appropriate transition plan/services for individuals moving into the workforce. The goal is to eliminate duplication of services.

Caleb Primrose stated that he had heard that services stop after age 25 – is that true?

Andrea stated that some funding sources are limited to up to age 25.

Jane added that Iowa does not have an autism waiver, so that complicates things.

Caleb asked if the council could advise legislators to look into creating more supports for individuals older than 25.

Jane Brown added that Medicaid, by law, cannot cover housing, so individuals often rely on waivers or other sources of funding for housing support – but these sources can vary significantly from one region to another.

James asked who oversees the regions to allow these differences?

Connie replied that DHS ensures all regions meet minimum requirements, but regional areas can offer more if they have additional funding available.

Jane Brown stated that regions are funded through property taxes. There is a list of 25 services that must be provided (the minimum requirements Connie referred to). Some regions are more creative than others and have been able to get grants, etc. to provide additional funding for their regions.

Evelyn Horton stated that another problem exists when individuals age out and have to switch from their childhood primary care provider to an adult primary care provider.

Erika added that CHSCs are working on transition services related to healthcare.

#### Strategy 10 (of Strategic Plan) Discussion:

James Curry stated Hills & Dales had rolled out housing models for individuals with significant behavior challenges – Do we know of any updates?

Erika reported Hills & Dales was in the news recently due to issues they have been experiencing with reimbursement rate cuts with the new MCO Medicaid system, putting their program at risk.

Jane talked about RB-SCLs (Residential Based Supported Community Living) which is a group housing model for individuals over the age of nine. She said in Iowa there are 35 beds. She also talked about the Family First Act (the Family First Prevention Services Act) which provides federal funding to help families get the support they need to keep their children in their homes.

Evelyn asked what do we do with the individuals who do not qualify for ICF (Intermediate Care Facility) because they do not have ID (Intellectual Disability) waivers or ID diagnosis but their behaviors are a significant issue?

#### Co-Chair Nomination/Vote:

Wendy Trotter explained that voting council members needed to nominate and vote on co-chairs for this next fiscal year. Caleb Primrose and James Curry agreed to be nominees for co-chairs. Council voted and unanimously approved their appointments.

#### Autism Support Program (ASP) Update:

Connie Fanselow reported that the ASP funding was renewed.

- \$573,000 allocated – no new money for BCBA education grant because still have money left
- \$25,000 for program at Tanager Place – have not yet developed a plan for how the money will be used
- That leaves just under \$550,000 for ASP services
- As of end of March, DHS had paid \$290,000 for Fiscal Year 18 – she estimates they will pay approximately \$370,000 by end of Fiscal Year 18, so \$573,000 for next year should be sufficient
- As of March, 2018:
  - 16 individuals accessing services
  - 24 found eligible (8 are either newly enrolled and not started yet or on waiting list)
- Current Providers for ASP include:
  - Balance Autism (formerly The Homestead)
  - Pier Center
  - Seasons Center for Behavioral Health
  - Behavioral Care Specialists
  - Hills & Dales
- Still seeing a decrease in applications:
  - April – none
  - May – one

- June – two
- Approximately 2/3 of applications are found eligible for ASP; some of those that are not eligible typically have private insurance, but no in-network providers for ABA services, or no provider close enough to where they live, or the co-pay/deductible is way too high for the family to pay. Unfortunately legislation still states that they cannot have ANY insurance coverage not just usable coverage so these families cannot access services.

Evelyn asked if many families have hit the cap (the \$36,000 cap)?

Connie replied, very few.

James asked if anyone has heard any feedback from Autism Speaks in regard to the legislation they helped with last year.

Evelyn responded that Judith has been really accessible if anyone needs help or resources. She said Autism Speaks has never been a big supporter of ASP.

James Curry asked if the council should propose changes in the language of the rules to be able to assist these families with non-usable coverage.

Connie said we could propose that ASP can be used to help cover costs up to when their insurance kicks in. Connie also said she will send a copy of the updated provider list to Wendy to send out to council members.

No report available on the BCBA education grant. But we do know that 16 applications were evaluated, but not sure how many were awarded. Most of the applicants were Drake University BCBA students.

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

Erika reported that RAP funds were reinstated by the Governor. They are working on building up the program again.

RAP continues work in the focus area Get a Good Start of the Strategic Plan with their LTSAE (Learn the Signs Act Early) Ambassador. Child Health Specialty Clinics (CHSC) received a grant to implement the LTSAE materials in several Early Head Start programs across the state.

Kelly Pelzel, a psychologist who serves as a consultant for RAP is helping RAP to start a pilot project for primary care providers utilizing Autism Navigator® for Primary Care course seats – she is currently recruiting primary care providers to participate.

They are also utilizing a HRSA grant for telehealth initiative – working with Pier Center to provide ABA services via telehealth, they are helping to provide equipment. Miranda Smally is the replacement for Sean Peterson at Pier Center.

### **Iowa Department of Education Update:**

Wendy Trotter shared updates on the Department of Education's Autism Navigator® project and ASD Supports project for school-aged learners. In May 2018, the Department hosted a 2 day face-to-face workshop led by the creators of Autism Navigator®, Dr. Amy Wetherby and Dr. Juliann Woods for all participants in the Autism Navigator project.

Wendy also shared that the 2018 Special Education Summer Symposium was June 11th & 12th, 2018 at the Iowa Events Center. Maureen Ziegler from Michigan presented at the symposium on Michigan's Peer to Peer Program. This program is designed to increase opportunities for students with ASD to access general education settings and curriculum. Peers model typical academic and social behavior in educational environments throughout the school day and provide support for students with ASD to promote independence and socialization. Peer to peer support programs and inclusion of students with ASD not only affects outcomes for the students with ASD, but can also impact a number of outcomes for typical peers and at risk students. The sessions were well attended and received.

### **Legislative Update:**

Connie shared more information regarding the Complex Needs Bill.

- This bill is designed to make sure a continuum of care is available (mental health, substance abuse, and other diagnoses)
- Access Centers will be established that have a no eject/no reject policy in plac.
- These will be the first point of contact
- They will also be an expansion of ACT teams
- Also includes Intensive Residential Services – not tied to a facility, but rather wrap-around services
- Rules are being developed and will be presented to the commission and voted on in July 2018 then will be published
- Should go into effect January 2019
- Rules must be fully implemented by July 2021

BCBA licensure bill passed.

- Behavior Analysts must be licensed by January 2019
- Includes BCaBA (Board Certified assistant Behavior Analyst)
- Big concern is the proposed license cost of \$600.00.

Developmental Disabilities Council has a new executive director – Brooke Lovelace Hundling. She starts in July 2018.

The council reviewed the 2017 legislative report and the identified priorities for 2018.

Wendy Trotter will email the list of resources gathered today from council members out to the group.

Christine Bowker made a motion to adjourn. Caleb Primrose seconded the motion.

Meeting adjourned at 2:00 pm.