

Iowa Autism Council Meeting

Meeting Minutes – September 11, 2019

Meeting minutes taken by Beth Buehler-Sapp

Present: Christine Bowker, Erika Hertel, Evelyn Horton, Caleb Primrose, Blake Stephenson, Michael Zehr, Beth Buehler-Sapp, Angela Burke-Boston, Andrea Keith, Rik Shannon, and Wendy Trotter

Absent: Andrew Beer, Jeanne Kerkhoff, Angela Logsdon, Nicholas Nopoulos, Connie Fanselow, and Chris Kliewer

Call-In: Matthew O'Brien and Jenny Phan

Caleb Primrose, Co-Chair, brought the meeting to order at 10:05 am. Brad Zelinger, public guest, was in attendance, so Council members took time to introduce themselves. Council members reviewed the minutes for the June 12, 2019 meeting. Edits were suggested and made. Erika Hertel made a motion to approve the minutes as edited, and Evelyn Horton 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) - getting ready to begin year five of the project.
- Erika Hertel reported that the Regional Autism Assistance Program (RAP) has a couple initiatives related to "Get a Good Start":
 - Autism Navigator: Registered one additional ARNP, two RNs for the Autism Navigator Primary Care course
 - Iowa Act Early: Rachell Swanson-Holm, continues to serve as the Act Early Ambassador for Iowa. Act Early Ambassadors serve as state liaisons to the Centers for

Disease Control and Prevention Learn the Signs. Act Early. campaign and work as community champions with programs that serve young children and their parents including Head Start, Early Head Start, and WIC.

In 2018 CHSC received funding to assess the feasibility and impact of the Learn the Signs. Act Early. program in Early Head Start Settings. Along with three other states (Indiana, Alabama, and Wisconsin), Iowa worked with Early Head Start agencies to conduct focus groups and interviews about the use of these materials. This project was completed June 30, 2019.

- Blake Stephenson shared the Children's Mental Health Services Board released a list of the screenings that they intend to use, and the M-CHAT was on the list.

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 posted an RFP to solicit proposals for moving this work forward and scaling it statewide. She will provide updates as this work develops. Wendy also reported that Grant Wood AEA is hosting a training in December for Peer-to-Peer programs. Peer-to-Peer programs are volunteer programs linking general education students, with students who have autism or other disabilities, in order to support them throughout the school day. The pairing of students leads to greater socialization and independence.
- At the last meeting, Erika shared that the Child Health Specialty Clinics Mason City Regional Center had been damaged following a storm. The Center has relocated and is once again up and running. Jackie Schott has been hired as the new Family Navigator there, replacing Loni Jorgenson who left for another position.
- Balance Autism - Evelyn reported they are still looking for a location for a clinic in Iowa City.
- Tanager Place - Blake Stephenson reported that their summer social skills group ended. They are now starting new school year groups for Pre-K, elementary, middle, and high school aged individuals. They have hired a BCBA and are piloting in home ABA service delivery model in Johnson, Linn, and Muscatine counties. They continue to provide school-based programs delivering services to 44 different schools across six districts and seven counties.
- Evelyn and Matt O'Brien both reported that there are still issues with telehealth being covered by Medicaid/insurance. Evelyn stated she was told the new CPT codes do not allow for telehealth. She intends to reach out to other states to see what they have done to allow for success in utilizing telehealth. Matt and Evelyn will form a sub-committee to further investigate this issue.

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

- Erika reported that RAP is offering, for the second time, the Autism Basics free four-week webinar series with presenter Kelly Pelzel, PhD. The series is for parents or primary caregivers of children with a new autism diagnosis and has been approved for continuing education for foster parents.

The webinars are on Tuesdays: October 1, 8, 22, 29, 2019 12:00 pm- 1:00 pm. Registration is now open and is limited to 100 participants. Sessions included:

1. What is Autism?
 2. Evidence-based interventions
 3. Challenging Behavior
 4. Educational programming
- Evelyn reported the Autism Society of Iowa, Balance Autism, and the University of Iowa Stead Family Children's Hospital Autism Center sponsored a conference featuring Peter F. Gerhardt, Ed.D. on August 15th at Prairie Meadows in Altoona. They had 100 people in attendance. Dr. Gerhardt addressed employment, life skills, sexuality, and social skills for teens and adults with ASD. He really challenged those in attendance to think about their focus for adult skills.
 - Evelyn also reported that the Iowa ABA's (Iowa Association for Behavior Analysis) seventh annual conference is being held in West Des Moines on October 3-4, 2019. The preconference session on that Thursday also focuses on sexual behavior.
 - Erika reported that Autism Society of Iowa (ASI) and RAP are sponsoring a lunch and learn in October for first responders titled: Autism Risk and Safety Training for First Responders. Renee Speh, a RAP family navigator, along with Mary Roberts, the Autism Center Coordinator at UIHC/CDD, and Ashten Hayes, a police officer with the Iowa City Police Department, are leading the discussion.
 - Rik Shannon reported that the 2019 Autism Society of Iowa Fall Educational Conference is Friday, September 13, 2019 and will feature keynote speaker Dr. Scott Bellini presenting *Building Social Relationships through Evidence Based Social Skills Programming for Youth and Adolescents with Autism Spectrum*. The Developmental Disabilities Council is a co-sponsor of this conference.

Focus Area D (Successfully Transition to Adult Life)

- High Quality Living Options - Evelyn reported that Balance Autism now has twelve HCBS (Home and Community Based Services) houses in Iowa. Each home has four residents with two staff per house to foster more independent living. 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.
- Vocational Rehab (VR) Update - Andrea Keith reported that now that they are in the schools and getting involved earlier, they have seen an increase in the number of students with ASD. She stated that because they are getting involved earlier, it should lead to better transitions for students.

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

- Erika reported that on July 18th, the Division of Child and Community Health was awarded a four-year, \$1.4 million grant from HRSA to implement a new project, "Innovations in Care Coordination for Children and Youth with Autism Spectrum Disorder." The main objectives of this project are:
 - To integrate Family Navigators into five primary care sites in medically underserved areas of Iowa. These sites are River Hills Community Health Center in Ottumwa, Unity

Point Clinic Family Health Center in Storm Lake, People's Community Health Clinic in Waterloo, Blank Children's Pediatric Clinic in Des Moines, and Medical Associates Pediatrics in Dubuque.

- To develop a Learning Community to increase the capacity of primary care providers in medically underserved areas to identify and treat children and youth with ASD.
- To increase the capacity of families of children with ASD to develop family-professional partnerships.

Project activities began September 1, 2019.

- RAP Expert Panel has a meeting October 9, 2019 at the Coralville Public Library.

Data Review:

At the last meeting, 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.

Andrea reported that Iowa Vocational Rehabilitation Services continues to work with local high schools to implement pre-employment transition services to youth with IEPs and 504 plans to assist with a seamless transition after high school. Those services include; job exploration, work-based learning, counseling on opportunities, work readiness, and self-advocacy skills.

Andrea reported the following data from VR:

WIOA Program for Youth (Workforce Innovation and Opportunities Act) – ages 14-24

Number of individuals identified as having ASD:

- 2016 - 869
- 2017 - 1083
- 2018 - 1237
- 2019 - 1322

WIOA Program for Adults – ages 25+

Number of individuals identified as having ASD:

- 2016 - 264
- 2017 - 266
- 2018 - 248
- 2019 - 215

Vocational/Technical Programs

Number of individuals identified as having ASD:

- 2016 - 161
- 2017 - 170
- 2018 - 134
- 2019 - 102

4 Year Programs

Number of individuals identified as having ASD:

- 2016 - 231
- 2017 - 259
- 2018 - 254
- 2019 - 226

Matt reported that Kelly Pelzel is working on pulling together data from the University of Iowa Autism Center. He hopes to be able to share the data at the November meeting.

Additional programs in the state that are making an impact:

- UI REACH (University of Iowa - Realizing Educational and Career Hopes) – a comprehensive transition program for students ages 18-25 years old with intellectual, cognitive and learning disabilities. UI REACH offers an integrated college experience in a caring and structured environment.
- DMACC STRIVE Academy - a STRIVE Academy - an educational program offered through DMACC in partnership with school districts, parents, and students, students ages 18-21 with transitional needs and an IEP (Individualized Education Program) learn to live as independently as possible. STRIVE Academy helps students:
 - Grow work-ready skills in a classroom setting.
 - Get on-the-job experience.
 - Gain independent living know-how
- ASK Program at Kirkwood Community College - The ASK program at Kirkwood is a support program for students with autism spectrum disorder. The ASK program is an extra layer of support in addition to the academic accommodations for students with high functioning autism spectrum disorder, including Asperger's syndrome or pervasive developmental disorder-NOS, and other related disabilities. ASK staff work with students to create an individualized plan for each student by integrating Kirkwood resources, community partnerships and research-based interventions.

Additional data will be shared at the November meeting.

Review Goals for 2019/Identify 2020 Priorities:

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 discussed which of those to continue for the 2020 Priorities in the 2019 legislative report:

- Council members discussed continuing all identified 2019 priorities, with updated language and adding additional priority of developing a task team to begin working on the next Strategic Plan that will begin in 2021.
- Rik asked if the Council has ever considered adding a legislative priority regarding establishing a funding stream for adult services. He stated the Developmental Disabilities (DD) Council has a priority that urges establishing a stable, long-term funding stream to expand access to services. He will send the DD Council priorities report to Wendy for an example of wording.

Wendy reminded the Council that the 2019 legislative report needs to be completed by the November meeting so that the Council can review and vote on the final draft. She will send last year's report to the co-chairs for them to reference when drafting this year's report.

Next meeting is scheduled for Wednesday, November 13, 2019.

Christine Bowker made a motion to adjourn the meeting.

Erika Hertel seconded the motion.

Meeting adjourned at 1:30pm.