

Iowa Autism Council Meeting

Final Meeting Minutes – November 4, 2020

Meeting minutes taken by Beth Buehler-Sapp and Wendy Trotter

Present: Andrew Beer, Angela Burke Boston, Beth Buehler-Sapp, Carrie Elser, Connie Fanselow, Michelle Grant, Erika Hertel, Evelyn Horton, Bill Kallestad, Andrea Keith, Betsy Lenzmeier, Cheryl Mulligan, Nicholas Nopoulos, Matthew O'Brien, Caleb Primrose, Blake Stephenson, and Wendy Trotter

Absent: Michael Zehr

Guest: Rachell Swanson-Holm

Erika Hertel, Co-Chair, brought the Zoom meeting to order at 10:03 am. Council members took time to introduce themselves. Council members reviewed the minutes from the September 9, 2020 meeting. Edits were suggested and made. Caleb Primrose 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.

Guest Presentation:

Rachell Swanson-Holm, Iowa's *Learn the Signs. Act Early. (LSAE)* Ambassador, shared that CHSC was recently awarded a \$94,000 AUCD (Association of University Centers on Disability) grant called *Support for Early Childhood State Systems through the Act Early Network to support Recovery and Build Resiliency Skills, Behaviors and Resources of Children, Families, and Communities*. This is a one-year grant (September 1, 2020 – August 31, 2021) that charges recipients to look at their state's Act Early systems and how they are building resiliency and supports for families.

Rachell is leading a stakeholder task team to develop a needs assessment taking into consideration COVID-19 barriers and solutions. Erika also serves on this task team.

They are currently seeking stakeholder feedback and are focusing on 4 key steps:

- Parent engaged developmental monitoring
- Screening for developmental disability and autism
- Referrals for diagnostic evaluations and services
- Receiving services

The project requires them to identify high reach, statewide programs that are willing to embed LSAE materials/supports into their programming. CHSC has identified three key targeted statewide programs: WIC, Child Care Resource and Referral Network, and 1st Five.

The overall goal is to see the age of identification decrease – it is currently approximately 4 years of age. They are also intentionally thinking about how they can sustain these efforts beyond the one year grant.

The LSAE materials are available in English and Spanish – and there may be additional languages that can be accessed via other states.

Rachell also shared an update on the *Innovations in Care Coordination Grant* that the Division of Child and Community Health was awarded about a year ago. Rachell and Erika support some of the initiatives which were put in place as a result of this grant to bolster the Regional Autism Assistance Program (RAP).

For this grant, RAP has been hosting the Iowa Autism Learning Community webinar series, which has specifically been targeted to primary care providers around the state who serve children with developmental disabilities, including autism. Topics to date include:

- Autism 101
- Interventions to support children on the spectrum
- Services provided by RAP and LSAE
- Feeding issues
- Sensory processing issues
- Behavior concerns

The sixth webinar in the series is November 18, 2020 at noon, with Mary Roberts and Todd Kopelman speaking on Evaluation and Behavior Management of Severe Self Injurious Behaviors. This series is also appropriate for parents, other providers, and anyone with an interest in developmental disabilities and ASD. The webinars are being recorded.

This grant also allows for placing Family Navigators within Primary Care practices to assist families in finding resources and services.

Strategic Plan:

Updates on progress on the Strategic Plan were provided:

Focus Area A (Get a Good Start)

- Erika Hertel reported the following:
 - The Iowa Regional Autism Assistance Program (RAP) is offering an Autism Basics Webinar Series with Kelly Pelzel, PhD. The webinars are aimed at families with newly diagnosed children. Sessions include: *What is Autism?*, *Autism Interventions*, *Challenging Behavior*, and *Educational Programming*. The webinars will be held on Tuesdays, October 20 - November 10, 2020, from 12:00 – 1:00 pm. Foster parents can earn one hour of group credit for each webinar. Sessions are recorded.
- Wendy Trotter gave an update on the Autism Navigator project:
 - Cohort 6 in the Autism Navigator project is underway. Autism Navigator is an online course designed to help early interventionists better recognize the early warning signs of ASD and to learn to work collaboratively with families to identify priority outcomes for treatment to help prevent the cascading effect ASD can have on development and learning. The course focuses on the evidence-based practice of coaching caregivers to embed intervention strategies in everyday routines and activities.

- For the Iowa Autism Navigator project, we ask cohort participants to agree to a 2-year commitment: Year 1 = Training tier where they complete the online course; Year 2 = Implementation Tier where they work to implement what they've learned into practice.
- Additional professional development activities to support learning are provided via a regional *Autism Navigator (AN) Learner Community* within each AEA, as well as 2 additional statewide workshops.

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

- Erika shared that:
 - Child Health Specialty Clinics continues hiring process for:
 - ARNPs for Decorah-Oelwein and Spencer
 - FN (Family Navigators) for Creston and Iowa City
- Wendy gave an update on the SEE-KS project:
 - As a result of an RFP in which the Department of Education sought a vendor to provide a multi-year plan to build capacity to support social emotional engagement across multi-tiered system of supports within the State of Iowa's Specially Designed Instruction (SDI) Framework, a contract was awarded to Emily Rubin with Communication Crossroads for her Social-Emotional Engagement – Knowledge and Skills (SEE-KS) framework.
 - SEE-KS is a professional learning approach designed to fuel learner engagement, both in the children and young people that we support, as well as their educators and service providers. The focus is on increasing engagement by fostering initiation, independence, and investment within classroom instruction. Current neuroscience is shared as a means to illustrate the importance of positive and healthy social connections as a fuel for learning. Within a universal design for learning framework, instructional design for learner engagement is enhanced by ensuring all learners have access to curriculum and are engaged in their learning regardless of their developmental level of social, language, and executive functioning skills.
 - At the school level, an internal core team of general and special educational teachers are identified with the idea that they will help mentor and share these strategies with their colleagues. Either onsite or via web-based telehealth, teachers will review video recordings of their classroom lessons to see what they are already doing to foster engagement and identify opportunities to increase student engagement; they will also observe each other's classes in action. These freely accessible tools within the SEE-KS framework enable us to measure engagement, engage in teacher to teacher mentorship, and identify opportunities for further social emotional engagement and growth in their students. Both general and special educators serving diverse learners from preschool through 12th grade will benefit from these instructional practices and mentorship techniques.
 - The pilot of this project was to begin last April with Grant Wood AEA and Washington Elementary School in the Mt. Vernon school district, but was put on hold due to the pandemic. We hope to launch the pilot again this January (of 2021).
- Wendy also shared that the Iowa Department of Education announced updated [Iowa Social-Emotional Learning Competencies](#) for fall 2020, and has a new designated webpage for [Social-Emotional Learning](#).

- SEL has been demonstrated to increase students' academic performance and create a more positive learning environment. Schools are being asked to consider social-emotional-behavioral health (SEBH) in concert with Iowa's Academic Standards (e.g., literacy and mathematics). To support schools in these efforts, the Department worked closely with a broad group of stakeholders to develop Iowa's Social Emotional Learning Competencies. For Iowa schools, use of these competencies is voluntary and not required.
- Based on research and recommendations from stakeholders, the decision was made to use the [CASEL SEL framework](#) as the focus for providing SEL resources in Iowa. The CASEL framework identifies five broad and interrelated competencies that comprise SEL: Self-awareness, Self-management, Social awareness, Relationship skills, and Responsible decision making. The Iowa Social-Emotional Learning Competencies are organized around these five competency areas to include: Learning Targets, Developmental Indicators, Adult Examples for Instruction, and Learner Examples for each competency area across 4 grade bands, K-2nd, 3rd-5th, 6th-8th, and 9th-12th.
- Autism Support Program (ASP) – Connie Fanselow reported that there have been very few changes. She does not yet have the numbers calculated for this 2020 fiscal year, but she anticipates a decrease. They are seeing a few more applications coming in.

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

- Erika reported that RAP is partnering with the Iowa City Autism Community and the University of Iowa Stead Family Children's Hospital Autism Center to offer a workshop series. The second session is coming up this month.
 - Autism Workshop Series: Introduction to Mindfulness for Caregivers with presenter Christine Allen, LISW.
 - Saturday, November 14, 2020 at 1–2 PM
 - Registration required, cost \$3: <https://www.eventbrite.com/.../mindfulness-for-caregivers>.
 - Funds generated by this event will help pay for Sensory Kit distribution to students learning at home this year. Scholarships are available if the fee is a hardship. Email Dina: iowadina@yahoo.com

Focus Area D (Successfully Transition to Adult Life)

- Iowa Vocational Rehabilitation Services (IVRS) Update – Andrea shared that IVRS is still moving forward with their Autism Advisory Team. They have their next meeting in December where they have invited a BCBA from Autism Speaks to give their advisory team an intro to ABA training. They hope to then come up with ideas and information on how they can combine vocational barriers with use of ABA techniques or knowledge, that can then be disseminated out to field staff. The goal of the team is to create resources and tools to better serve clients on the spectrum.
- Erika reported that the *2020 Caregiver Retreat & Transition Conference* changed to the *Transition to Adulthood Webinar Series* with sessions on transition related topics. This is sponsored by the Iowa DD Council, University of Iowa Center for Disabilities and Development, Division of Child and Community Health, Child Health Specialty Clinics (CHSC), and the Iowa Regional Autism Assistance Program (RAP).

- *Transition to Adulthood Webinar Series for Families of Youth with Special Health Care Needs* (8 sessions)
- Presenters vary depending on session.
- October 9 – November 20, 2020
- Fridays, 12:00 – 1:00 pm; and Friday 12/20 from 7:00 – 9:00 pm.
- Register at: <https://register.gotowebinar.com/rt/5131915955829810960>
- Carrie shared that they just got the approval to create an Ability Inclusion Network at University of Northern Iowa. The focus is on life enjoyment for individuals with differing abilities. There will be interdisciplinary participation across all their colleges to create recreational opportunities for students (like swimming, canoeing, music, dancing, etc.).

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

- No updates

Legislative Report:

The 2020 legislative report is due December 1, 2020. The Council reviewed the priorities identified in last year's legislative report to help guide identification of priorities for 2021.

Priorities identified in the 2019 report for 2020 included:

1. Funding of the Autism Support Program (ASP). The Council recommends continued support for this valuable and cost-effective program, and asks the legislature to consider making the following modifications:
 - Change eligibility criteria to allow for flexible funding options. – The Council suggests that the eligibility standards for ASP be expanded to add individuals with private insurance coverage that have an Applied Behavioral Analysis (ABA) benefit requiring out-of-pocket costs, and allow ASP funds to be used to help “fill the gap” between the cost of ABA and the insurance benefit by reimbursing families for high co-pays and/or deductibles that are spent for ABA services.
 - Increase flexibility in program benefit limits. – Allow flexibility in the program limits on the number of months and total funding available per child. No additional program funding would be needed, rather legislation to allow exceptions to the time and funding limitations when ASP program funds are available would provide greater flexibility in meeting the needs of children with autism at a critical time in their development.

Council members wish to continue this priority for 2021.

2. Maintenance of the BCBA Education Grant to build provider capacity in Iowa. Through the ASP legislation, \$250,000 has been allocated to assist students in meeting the financial obligations associated with completing an educational program in applied behavior analysis to become a Board Certified Behavior Analyst (BCBA). The Council recommends that the ASP funding be maintained and continue to include the scholarship fund to be used for the BCBA program.

Matt O'Brien shared that the University of Iowa now offers a BCBA program. It is not a degree program, but provides the courses needed to be able to sit for the BCBA certificate exam.

Also, the fourth RFP has gone out. Melana Hammond is now the contact person for the grant.

Council members wish to continue this priority for 2021.

3. Implementation of the *Iowa Strategic Plan – 2016-2021: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families*. The Council recommends continued implementation of the *Iowa Strategic Plan* to systematically move Iowa forward in maintaining optimal services and supports for individuals with autism spectrum disorder (ASD) and their families; empowering them to have meaningful and successful lives in their communities. The *Strategic Plan* identifies the following areas of focus in order to build the state infrastructure for comprehensive, lifespan supports:
 - 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

Council will continue this priority.

4. Funding for the Regional Autism Assistance Program (RAP) to support families and strengthen early identification of ASD. RAP provides services and supports that are instrumental in meeting the goals of the *Iowa Strategic Plan*.

Council will continue this priority.

5. Increase statewide access to ABA treatment through telehealth models. The council recommends legislative action to support telehealth service provision to reach all individuals with ASD in the State of Iowa who are in need of ABA and other therapies, including the following actions:
 - Clarification of state rules and regulations to indicate that qualified health service providers may provide telehealth services using a clinic-to-home model.
 - Review of the Iowa Medicaid Enterprise interpretation of ABA codes for the inclusion of telehealth and/or inquiry to the Centers for Medicare & Medicaid Services (CMS) for guidance on this issue.

It was discussed that we should tweak this priority for 2021 and share how successful the clinic-to-home model that has been allowed due to COVID has been for families. The flexibility that has been allowed due to COVID has greatly increased access to services for families, and we would like to continue that flexibility and build on it to continue to support families.

Council will tweak this priority for 2021. Matt will help with the language for this priority.

6. Support of the Legislative Priorities established by the Iowa Developmental Disabilities Council. The Council recommends and supports the *Legislative Priorities* established by the Iowa DD Council to ensure all children and adults in Iowa with developmental disabilities (which includes ASD) have access to high quality services and supports that promote a life in the community.
 - Establish a stable, long-term funding stream for the Regional MHDS system that supports the vision of the MH/DS redesign and growth of a system that expands access to services for Iowans with developmental disabilities and brain injuries.
 - Adequately fund and administer a state Medicaid program that ensures access to an array of services for Iowans with developmental disabilities.
 - Implement development of a statewide Children's Mental Health system that continues the recommendations from the Children's System State Board Strategic Plan submitted to the General Assembly on November 15, 2018.
 - Expand the availability, knowledge, skills and compensation of professionals, paraprofessionals and direct support workers to build community capacity and ensure access to a comprehensive system of mental health and disability services.

Council will continue this priority.

Michelle asked if there would be a place in the legislative report to discuss language barriers that exist in Iowa and adversely impact access to services and supports. She mentioned that Storm Lake alone has 26 languages spoken at the high school, so when looking at Iowa as a whole, this has to be a widespread issue. Erika suggested that we include accessibility as a focus area in the updated strategic plan.

Erika and Caleb will begin drafting the 2020 legislative report and will send the draft out for feedback. Erika asked that any council member that agreed to assist with language for the 2020 report, to please have those to her by Friday, 11/13/2020.

Next meeting is scheduled for Wednesday, March 10, 2021.

Cheryl Mulligan made a motion to adjourn the meeting.

Andrew Beer seconded the motion.

Meeting adjourned at 12:45pm.