

Iowa Autism Council Meeting

Final Meeting Minutes – March 10, 2021

Meeting minutes taken by Beth Buehler-Sapp and Wendy Trotter

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

Absent: Carrie Elser, Matthew O'Brien, Michael Zehr

Caleb Primrose, 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 November 4, 2020 meeting. Edits were suggested and made. Erika Hertel made a motion to approve the minutes as edited, and Nicholas Nopoulos seconded the motion. A vote was taken by voting council members to approve the minutes as edited. Minutes approved.

Council Membership Update:

Wendy Trotter shared updates regarding Council membership. The following individuals have terms ending in May: Erika Hertel, Evelyn Horton, Cheryl Mulligan, Jenny Phan (vacant), and Caleb Primrose. Caleb, Evelyn and Cheryl have renewed their terms. Jenny Phan's vacant position has been filled by the Governor's office by Wendy Andersen. The Council now has two vacancies, both for a person or a family member of a person with autism. Erika Hertel will continue to serve on the Council as a non-voting member as a representative of Child Health Specialty Clinics. Wendy shared that if anyone knows of someone who may be interested in serving on the Council, to apply via the website: <https://talentbank.iowa.gov/board-detail/32d8461f-45f6-44b4-af2d-008ff27228d2>

Wendy shared that we need to nominate and vote on Chair and Co-Chair positions for the 2021-22 term. Caleb Primrose and Michelle Grant were both nominated. Wendy stated for the nominees to think about their willingness to serve, and for the Council to think about any additional nominees and we will bring it to a vote later in the meeting.

Wendy shared that she updated the Iowa Autism Council Bylaws with current contact information and included the document in the Council's Google folder.

Strategic Plan:

Wendy Trotter mentioned that the Strategic Plan for Iowa expires at the end of this year and a new one will be needed starting in 2022. Erika, Evelyn and Wendy will re-convene their Strategic Plan task team and determine next steps for pulling together a stakeholder group to develop the next Strategic Plan.

Updates on progress on the current Strategic Plan were provided:

Focus Area A (Get a Good Start)

- Erika Hertel reported the following:

- Staff Updates for Iowa Regional Autism Assistance Program (RAP) who work with RAP teams:
 - We hired a new ARNP at Spencer, Megan VanOtterloo. This position in northwest Iowa has been vacant for some time and this is an area where we really have some need.
 - We also hired Danielle Wendell as the new ARNP in Oelwein and Decorah. Danielle will split her time between those two regional centers.
- Both of the new ARNPs will be taking the STAT training. We did find out from the maker of the STAT training that they've had some glitches with some on-line access for some of the things needed for the training so they are doing updates and can't work on the training right now. There's no access to that until it is fixed which will hopefully be completed by April. The ARNPs will be providing Autism Screenings in those regional centers including the STAT screening once they are trained.
- Danielle and Megan will also take the Autism Navigator for Primary Care Providers course. I also put a request out to our other clinical staff to see if there was more interest. We have had quite a few trained and we did have three additional ARNPs that said they were interested in doing taking the course.
- Wendy Trotter gave an update on the Autism Navigator project:
 - In January, Cohort 6 of the Autism Navigator project attended the "January Face-to-Face Workshop which is a virtual learning event. Every year, this workshop includes the topic of how to engage in those difficult conversations with families when you are sharing your concerns for their child. In that learning, there is a clear message of ensuring that even though you may be sharing news that their child is developmentally delayed or exhibiting signs of autism, that it is critical to also give the families hope for their child's future in your messaging. This year in particular, that message of hope rang out for many of the participants. I think given the current state of the world, that part of the presentation just hit home more this year. I think one positive thing that may come from this difficult year is the increased awareness of mental health/wellness and the need to provide positive messaging and hope.
 - The Autism Navigator Spring Workshop that will include both Cohort 5 and Cohort 6 participants will take place in May 2021. In the past we have always brought in the developers of Autism Navigator, Dr. Amy Wetherby and Dr. Juliann Woods, to lead the spring workshop. This year we decided to tackle it ourselves and a few of our Autism Navigator Team Leads will lead the learning in this workshop. I am excited for this opportunity for some of our Team Leads to step up and share what they have learned with others across the state.

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

- Erika shared that CHSC has hired Joy Kim as the Family Navigator for RAP for Iowa City, and Amanda Woods is the new Family Navigator in Creston. The two new Family Navigators will complete the Autism Navigator JumpStart to Coaching course.
- Wendy gave an update on the SEE-KS project:
 - Background information as a reminder:
 - 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. 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.
- As shared at our November meeting, we were hoping our pilot (which was originally set to launch in April and was postponed due to the pandemic) would start in January; however, they had to postpone again because they were still just a little overwhelmed with all that was happening in their schools with the pandemic. Everyone's a little overwhelmed right now. Teachers, schools, districts, and families are just trying to keep it all together right now with all of the challenges that have been placed on them over the past year. We are hoping that we can get something up and running in the fall of 2021. We will give you more information as it becomes available.
- Social-Emotional Learning (SEL) - Wendy also shared that the Iowa Department of Education is pulling together a few task teams to begin developing modules related to Social-Emotional Learning: Foundations of SEL and SEL Assessment. These task teams are just beginning, so she will report updates as they become available.
- Wendy also shared that she will be meeting with a colleague at the Department regarding literacy supports for individuals with ASD. The Department has had a lot of work happening around Specially Designed Instruction with a focus on K-6 literacy. But now we have the opportunity to introduce reading comprehension supports to this work; and in particular, a focus on the types of reading comprehension supports that benefit neuro-diverse learners. She will provide updates as the work progresses.
- Autism Support Program (ASP) –
 - Connie Fanselow reported that since the beginning of the year she's approved approximately 10 applications. One month last fall there were only 3 kids actively being served, and now it's up to 15 or 16 kids that are either eligible or have a service authorization in place. This is a promising uptick, and it's hopeful that more families will start utilizing the program this year. Utilization of the program has been down this last year which is probably due to COVID. She had been getting more applications in recently and all have been approved so far.
 - Connie also shared that she is hoping that some of the proposed changes to the program are considered; in particular flexibility in the eligibility requirements so that they could serve some of the families who are caught in that gap between being able to use insurance benefits and not being able to afford it. Connie stated that Marissa Eyenson, Division Administrator and Theresa Armstrong, Bureau Chief had a meeting with a few legislators and shared the information that Connie had put together about what the gaps were and the possible solutions to addressing these gaps. She does not have any feedback to report as of yet about whether they're seriously moving it

forward, but we do know that they got all of the information that they needed. If Legislators have a number of their constituents contacting them in support of the proposed changes, there's a much better chance that they will do something about it.

- There is an updated provider list now available.
- She is also in the process of updating the application form and parent packet and hopes to send out the new versions next week for folks to begin using.
- There was a request for an application in Spanish, so Connie is working with Erika Hertel and CHSC to have an application translated into Spanish.
- Evelyn Horton shared that Balance Autism was finally able to open their doors at the Coralville location at the end of January.

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

- Erika reported that RAP is continuing to offer a number of trainings/webinars:
 - We're providing some trainings around safety and behavior for families with Marc Hines who works in the University of Iowa Mental Health and Intellectual Disabilities Clinic. This training is aimed at helping families learn strategies to deal with behaviors and how they can deescalate and deal with a situation in an appropriate way and prevent it from becoming a crisis. The first training was in Fort Dodge on February 18th, and there is another one coming up in Creston on March 18th. There are still openings if you know of anyone who would be interested in attending this training and is willing to drive to Creston. It is an all-day training, 9:00am – 3:00pm with a lunch break. We had really good feedback from the first training in February, but it wasn't heavily attended due to the weather and COVID. Right now masks are required for safety and we are making sure we have room to allow for adequate social distancing. We are moving forward with caution knowing the classes might be small. The training is free but it is only for families of someone on the spectrum. The training will present modules one and two but if there is additional interest, Mark may return to these areas to present modules three and four.
 - We also have an Autism Community Webinar, Supporting Infant and Early Childhood Mental Health in Iowa and the guest speakers for that are Rhonda Rairden-Nelson, a project director for Project Launch, and Alyssa Caldwell. The target audience for this is really Primary Care Providers but anyone is welcome to attend. CME and IBC credit are available. There is no cost. They will identify the principles of Infant and Early Childhood Mental Health, recognize and describe the impact of trauma on development, and recall current initiatives to support infant and early childhood mental health in Iowa. This is on March 31st from 12-1 and will be held virtually. Erika will e-mail the flyer for this out to the council members.
 - We will also be offering the Autism Basics Webinar Series we do with Kelly Pelzel again. This we do twice a year for newly diagnosed parents. Anyone is welcome to attend these and they are approved for foster parent credit which seems to be fairly popular as well. There are four webinars:
 - What is Autism?
 - Autism Interventions
 - Challenging Behavior
 - Educational Programming

These webinars are one a week on Tuesdays at noon. New this session, we were approached by Kris Steinmetz from the Autism Society of Iowa about adding a discussion session on what it's like to have a family member with autism; so the Autism Society of Iowa will be co-hosting a fifth session which will specifically focus on what it's like to have a family member with autism which will include an opportunity for more discussion and questions and answers for parents. It's kind of an exciting add-on opportunity for more parents because the first sessions are more educational.

Focus Area D (Successfully Transition to Adult Life)

- Iowa Vocational Rehabilitation Services (IVRS) Update –
 - Andrea Keith shared an update on the work of IVRS's Autism Advisory Team. It's a new advisory team and we are trying to find our footing and trying to figure out how best to serve our agency. We're starting with what we call an Autism Huddle where we've invited all of our VR staff to meet on particular days to discuss some issues or concerns they're having with placing individuals with autism or just struggling with anything related to a job candidate with autism.
 - We are also currently in the process of creating a presentation for our Statewide Summer Conference that is for all VR staff. Our trainer for VR says the number one request they receive for training is for information on how to best serve individuals that we are working with that have autism. We're really trying to focus on providing our staff tangible information/supports that they can take back and implement in order to better assist individuals with autism.
 - Also, the benefits specialist, Suzie Paulsen, at VR has really broadened her work schedule to offer Zoom webinars in the evenings for parents related to benefits. She has one that's called "Parents of Superstars" and one that's called "Young Iowa Entrepreneurs". She takes a poll at the beginning of the Parents of Superstars webinar to learn more about the group of parents in attendance and what they want to talk about. A lot of them are things related to Social Security, Guardianship, Medicaid, Medicare, and parent choice information. We're really trying to get as much information about those topics to parents as soon as possible; particularly during the age 18 redetermination phase for social security. Andrea will send out information about these webinars to the Council.

Betsy Lenzmeier asked if these presentations were ever provided to the managed care organization (MCO) case managers because many do not seem to know much about what is available? Andrea said she will let Suzie know there could possibly be a need to share this information with the MCOs.

Blake Stephenson asked if these webinars ever covered 529 savings plans and ABLE Accounts? Andrea responded, "She has had speakers that have addressed those. She takes polls and then if there is something that requires bringing in another speaker, she'll then have another session. I know that with those ABLE Accounts there is a lot of misinformation out there. I know she did have a speaker recently come in and talk about ABLE Accounts." Andrea also shared that there have been times in the past where a family participating may be knowledgeable on a topic and Suzie will invite them to lead a session. For example, one time there was a financial planner who was participating in the webinars and he gave a great presentation to the families in the program that was very eye opening.

- Another thing IVRS is focusing on is working closely with Autism Speaks and a local business, Lee Container in Centerville, Iowa, who are collaborating to build a business model around hiring individuals with autism. The focus is on both what the business needs to do to make their environment appropriate to support staff with autism, as well as training their staff to know how to effectively work with and support their co-workers with autism. They're also creating training modules for individuals with autism to train them what is needed and expected of them when working in a factory setting. I have yet to look at those. We're getting a training on that today from Autism Speaks and I will provide some more feedback at our next meeting. Apparently, the modules will also be beneficial for individuals who may not work in a factory setting. They are also creating different modules for other employees and VR staff so I'm excited to learn more about that. Lee Container is hoping this model can be reproduced in any business so they have made it their goal to really hone in on a model that hopefully can be duplicated statewide.

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

- Erika shared that all of the RAP Family Navigators are either working toward obtaining or renewing their Family Peer Support Specialist credential, a new credential in Iowa as of 2019. It involves a family peer support specialist training and they have to attend a Mental Health First Aid or a Youth Mental Health First Aid training as well. They also have to have a certain amount of hours on the job and work supervision to get that certification. It requires renewal every two years.

Legislative Update:

Evelyn shared that there has been some ups and downs related to Medicaid coverage for telehealth. The Governor's proclamation in February did not include telehealth, and a lot of families were scrambling to figure out what to do; but then the Governor added it back in in the most recent proclamation, so it's been a challenging few months. The next proclamation is scheduled for April 4th, so we will have to see if telehealth is still included. It's been very challenging going 30 days by 30 days to know if we will be able to continue to use telehealth.

The Council revisited the topic of nominations for Chair and Co-Chair. Caleb Primrose and Michelle Grant accepted the Chair and Co-Chair nominations respectively. No other nominations were submitted. The Council voted and named Caleb and Michelle to the positions.

Next meeting is scheduled for Wednesday, June 9, 2021. Wendy will send out a meeting reminder several weeks prior. At that time a determination will have been made as to whether the June 9th meeting will be via Zoom or in-person.

Michelle Grant made a motion to adjourn the meeting.

Nicholos Nopoulos seconded the motion.

Meeting adjourned at 12:00 pm.