

Iowa Autism Council Meeting

Final Minutes – September 12, 2018

Meeting minutes taken by Beth Buehler-Sapp

Present: Caleb Primrose, James Curry, Nicholos Nopoulos, Evelyn Horton, Jane Brown, Connie Fanselow, Christine Bowker, Erika Hertel, Jenny Phan, Rik Shannon, Wendy Trotter and Beth Buehler-Sapp

Absent: Matthew O'Brien, Andrea Keith, Chris Kliewer, and Jeanne Kerkoff

Call-In: Angela Burke-Boston and Angela Logsdon

James Curry, Co-Chair brought the meeting to order and the members present went around the room and gave introductions of themselves and their roles on the council. Caleb Primrose, Co-Chair, had organized a guest speaker for this morning but that person had to cancel.

The council members reviewed the minutes for the June 13, 2018 meeting. Edits were suggested and made. Christine Bowker made a motion to approve the minutes and Jane Brown seconded the motion. A vote was taken by voting council members to approve the minutes. Minutes approved.

Wendy Trotter mentioned that the next scheduled Iowa Autism Council Meeting is scheduled for November 14, 2018; however, she will be out of state so asked if the Council would like to move the date to November 7, 2018 or would they prefer to find a substitute facilitator? The members present and on the call-in had no objections to changing the date. Consensus was made to move the November meeting to November 7, 2018. James Curry asked that the meeting RSVP announcement be sent out a bit earlier for that meeting to give members more notice to respond.

Strategic Plan Update:

Focus Area A (Get a Good Start) –

Strategy 1 (Expand and intensify public awareness of the early signs of ASD and educate the public on the benefits of early identification):

- Wendy Trotter reported that the Autism Navigator Project for Iowa's Early ACCESS providers, through the Department of Education, has completed their third year and will begin year four this fall. Early Access is the early intervention system for 0-3 year olds in Iowa. For the last three years, we have been utilizing the Autism Navigator online courses to help our providers better recognize those early red flags and those early warning signs of social communication delays and autism, to be able to make referrals for diagnostic evaluations and sooner, and to better identify the most effective priority outcomes for intervention to make the biggest impact they can, as soon as they can. We have been approved, actually have done an RFP, but each year we have to get that contract approved, the money has to be there. As we move into year four, we hope to begin to train a few providers to become regional trainers to assist with scale-up and sustainability.

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

Strategy 3 & 4 (3 – Increase access to high quality services.../ 4 – Ensure equal access to high quality and timely services across the state regardless of geographic location):

- Wendy Trotter updated the Council on work happening related to statewide educational services and supports. The ASD Supports Design Team has been meeting for the last year and a half to develop a more consistent statewide approach to providing supports to districts for use of evidence-based practices for students with ASD. They have been working on developing a tiered system of supports for school personnel to assist them in their knowledge and use of evidence-based practices. They have also been carefully integrating this work with other statewide initiatives (such as Specially Designed Instruction and Social Emotional Learning competencies) so as to not overburden school personnel with too many initiatives. The team intends to begin with a focus on social engagement and hopes to develop a training package to roll out first with a few pilot schools/districts or usability sites and then modify and tweak until ready for statewide rollout.

James Curry asked about the practical use of the Strategic Plan. Is the plan intended to be a tool that families can use or is it mostly a tool for providers? What is the end goal for the plan?

Wendy Trotter responded that her understanding is that the Strategic Plan is more of a State System plan to give guidance to systems and organizations as to what areas they need to be focusing on as they begin to develop work statewide. She stated, “For example, at the Iowa Department of Education, when I’m looking at priorities for state efforts related to supports and services for individuals with ASD, it will be important that any projects or initiatives chosen align with what was identified as priority areas and focus areas in the strategic plan. So I look at it more as a guide rather than as a resource tool. A guide for those providing services and identifying projects or initiatives to ensure that anything they are focusing on is aligned with the strategic plan. And if it’s not aligned, then it may not be the right initiative.”

Angela Logsdon stated that she agrees with Wendy, and shared her personal story of how services have been over the years for her children. She then asked how the plan is being disseminated. How are we getting the information out to the providers, organizations and families in the state? How do we share it more broadly?

James Curry asked if there is a way to track whether various state initiatives are actively attempting to align their practices and recommendations with what’s been outlined as the goals for the state? Do we have any data or feedback about that?

Wendy Trotter reminded the council that the strategic plan was actually put together by a task team sponsored by RAP because RAP had a federal grant that required the development of a strategic plan, and then voted on and endorsed by the Council. She added that she knows that RAP and CHSC have included the Strategic Plan on their website, and that the Department of Education added it to the Council webpage, but asked if RAP has been promoting it or sharing it in other capacities?

Erika Hertel shared that all the CHSC regional centers have copies on hand, and that they take copies with them to share whenever they engage in outreach opportunities. She added that they have a lot of

extra copies that she would be willing to give to anyone who would like some to help get them dispersed. She shared the value of parent voice and how effective parents can be in advocating for change, so if parents can share the plan with organizations and providers across the state it really could make a huge impact. She added the other benefit of referencing the strategic plan is to remind everyone of all the focus areas and stages of life that need to be focused on. For example, she shared that she is a parent of a son with ASD who just graduated from college and is now moving on to the next step of employment, so making sure we aren't forgetting what is needed for people at different stages of their lifespan. We can't all be focused on "Get a good start". We know we're making baby steps toward improvement but there are still gaps in every one of these areas all over the state so it's just a constant reminder of what we still need to be working on to keep the plan moving forward.

Jane Brown – I feel like from a perspective of care coordination there's additional opportunity for us to take the strategic plan and do internal training and education with staff. So if there's an electronic copy of this, that's definitely a good way for me to share it with my group and make sure that they read it cover to cover and understand it.

Jenny Phan – I have a family navigator with RAP and she and I are in constant communication. She's always sending me information about seminars/trainings that I can attend, but a copy of the strategic plan was not in any of her communications. Are other family navigators sending out copies of the strategic plan to the families they serve? If not, can this be something they do?

Erika Hertel - Yes, definitely, that's a good plan. Thank you.

Evelyn Horton – We should also be sharing it with providers too. My company's been involved with the development of the strategic plan from the beginning, but I don't know that everybody else is as familiar with it as we are and would use it as a guide to see if what they are focusing on fits with where the state wants to go. Having this plan in hand could also spur somebody else to do something new and innovative as well.

James Curry – So this plan is currently slated to go until 2021, so what happens after that?

Wendy Trotter – As we approach 2021, we can bring a committee or task team back together to evaluate progress and identify new focus areas for Iowa for the next five years, or however long they choose.

James Curry – So when it is time to re-evaluate the plan, is there some sort of data that can be used to determine success and help identify new focus areas?

Nicholos Noupoulos – There are a number of project management/strategic tools that we could use to really hone in and quantify the goals and the strategies that we put into place and then we can go back and really see how everything played out. I'm envisioning at least 3 tools that we could use to do just that.

Wendy Trotter – Yes, it will be important to gather data so that we can implement data-based decisions moving forward. We as a council do not have access to data, but many of us have access to data through our own individual workplaces. Or we know who to contact to get relevant data.

Jane Brown – I agree, I think that this is going to be a question of how do we measure success and figuring out what that is, and then think about where we get the data in order to be able to validate it.
James Curry – I know that a lot of focus has been on early identification and access to services in the early years, but as you mentioned Erika, moving forward we are going to need to be sure we are also focusing on adult supports and services.

Jenny Phan – Autism Speaks is very focused right now on transition and adult supports. At the last Autism Law Summit that was a major topic. Their next conference is coming up next month in San Antonio. There are going to be 50 states represented at the conference so if you want to hear about how other states have been successful, that's a really good conference to go to. I know Josh Cobbs was talking about working on an initiative focusing on adult supports/services since the last conference. I think he's had a few set-backs, but he is like highly motivated so he's also a good connection. He's here in Iowa, and is a previous council member, and he needs help.

Connie Fanselow – I think if you're sharing this strategic plan with a provider, the provider may look at it and say "Ok, so what does that mean for me?" So I think that if somebody could (and even if it's us) put together a little one page cover sheet that says "To providers: Here's what you can do" or "Here's what we hope you'll get out of this", or for parents, "Here's what you can do, Here's what we hope you'll get out of this". Give specific information o the different populations you would share it with. I think there are a lot of plans of various kinds going around and most people do just kind of look at them and go ok I don't know what that means to me. Yes it sounds good but I don't know how to relate to it or what to do about it.

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:

- They now have two new Family Navigators to serve the Cedar Rapids/Iowa City corridor area.
- There will also be an additional Family Navigator to serve the counties of Story, Marshall, and Tama.
- RAP will be focusing on education and advocacy training.
- They continue to have an expert panel that advises RAP and collaborates with other community partners to help move the strategic plan forward.

Autism Support Program (ASP) Update:

Connie Fanselow reported:

- FY18 closed – spent just under \$358,000
- Have had more applications come in recently –
 - June – 5
 - July – 2
 - August – 3
- With the new insurance law in effect, starting to see a few more applications where they have some insurance coverage so do not qualify for ASP
 - However, some of these families have a very high co-pay and/or deductible; or their private insurer does not have an in network provider

- It would require a change in legislation for these folks to be able to access ASP funds
- New provider for ASP:
 - One Vision (formerly Opportunity Village)
- Now have a contract with Tanager Place for skill building groups:
 - Social skills groups meet during the school year
 - For middle school and high school aged participants
 - Meet 2 times per week

Priorities for 2019:

The Council began discussing what priorities should be the focus for 2019. The following priorities were identified:

1. ASP – Continue funding for ASP. Modify code to increase accessibility to funds. Continue to fund the BCBA education grant.
2. Telehealth Coverage – for services related to ASD (e.g. ABA)
3. Continued implementation of the Strategic Plan – with emphasis on transition/adult supports and services.

Next meeting is scheduled for Wednesday, November 7, 2018. (Rescheduled from November 14, 2018.)

Jane Brown made a motion to adjourn the meeting.

Evelyn Horton seconded the motion.

Meeting adjourned at 2:00 pm.