

# Iowa Autism Council Meeting

Final Meeting Minutes – September 13, 2017

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

**Present:** James Curry, Angela Burke Boston, Andrea Keith, Brandon Reese Arkland, Wendy Trotter, Rik Shannon, Sean Peterson, and Beth Buehler-Sapp.

**Absent:** Matthew O'Brien, Connie Faneslow, Erika Hertel, Angela Logsdon, Christine Bowker, Jeanne Kerkoff, Nicholas Nopoulos, Peggy Swails, and Chris Kliewer.

**On Zoom:** Jenny Phan and Steve Muller

The meeting was called to order at 10:15am. Members and guests introduced themselves.

The council reviewed and voted on the minutes from the June 14, 2017 meeting. Edits were suggested and made. James Curry made a motion to approve the minutes as corrected and Sean Peterson seconded the motion. Minutes approved.

## **Strategic Plan Update:**

**Focus Area A** (Get a Good Start) –

**Strategy 2** (...timely screenings and comprehensive diagnostic evaluations...):

- Wendy Trotter gave an update regarding the Autism Navigator for Iowa's Early ACCESS Providers statewide project.
  - The Autism Navigator® courses are 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 has a focus on recognizing the early warning signs of ASD in toddlers as well as focusing on the evidence based practice of coaching caregivers to embed intervention strategies in everyday routines and activities. (Naturalistic Developmental Behavioral Interventions – NDBI)
  - The course includes a screening tool to help identify toddlers at risk to ensure a more timely referral to diagnostic evaluation.
  - Wendy Trotter shared the year-end report of the project and related evaluation data:
    - Cohort 1-Year 2 participants = 40
    - Cohort 2-year 1 participants = 57
    - Team Leads = 9
    - Mastery Course = 7
    - Primary Care Course = 3 AEAs
  - Course Evaluation Data – A sampling of evaluation results from Cohort 2 participants regarding the Autism Navigator Course. Each question begins with, “As a result of completing this unit, I am...”
    - More confident in my ability to recognize early signs of ASD:
      - Strongly Agree = 45%

- Agree = 50%
- Neutral = 2%
- Disagree = 0%
- Strongly Disagree = 0%
- More confident in my knowledge of how ASD impacts a child's development and learning:
  - Strongly Agree = 27%
  - Agree = 68%
  - Neutral = 3%
  - Disagree = 0%
  - Strongly Disagree = 2%
- More confident in coaching families to use intervention strategies/supports within everyday activities/routines:
  - Strongly Agree = 33%
  - Agree = 58%
  - Neutral = 3%
  - Disagree = 2%
  - Strongly Disagree = 2%
  - Not applicable = 2%
- Would you recommend Autism Navigator to a friend or colleague:
  - Yes = 98%
  - No = 2%
- Plans for Year 3 (2017-19):
  - Cohort 3: Offering up to 10 seats per region for Knowledge and Skills course for "Cohort 3 – Training Year"
  - Renewal Seats: All past participants (Cohort 1 and Cohort 2) will have a renewal seat in the Knowledge and Skills course to assist with implementation of strategies learned – "Implementation Year"
  - Mastery Course Seats: Offering up to 5 seats per region for those Cohort 1 and 2 participants who would like to dive deeper and hone their skills/practice
  - Primary Care Course Seats: Offering 4-5 seats per region to train service coordinators or to share with community partners
  - Will again be asking for all participants and administrators to sign and return project agreement forms
  - Will continue to tweak the implementation plan to define expectations, as well as to develop/define role for future "internal coach" or "regional specialist" to support scale-up and sustainability
  - Will continue to foster collaboration across AEAs and with community partners/agencies

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

**Strategy 3** (Increase access to high quality services throughout the lifespan):

- Wendy Trotter updated the Council on work happening related to statewide educational services and supports. An ASD Supports Design Team has been meeting (both in person and via Zoom) focusing on:

- Through collaborative efforts between the DE, AEA, LEA, and Parents, we are developing a statewide framework to provide tools, supports and learning for school personnel and families to ensure learners with ASD receive effective instruction and support so they successfully graduate high school ready for college and/or career and live independent and interdependent lives within their community.
- The ASD Supports Design Team has developed a Vision/Guiding Principles and Theory of Action document to provide structure to this work.
  - **Vision:** Learners with Autism Spectrum Disorder (ASD) will be engaged in school and community acquiring skills so that they successfully graduate from high school ready for college and/or career and live independent and interdependent lives within their community.
  - **Process:** Establish and support an ongoing statewide system of supports to school personnel in order to provide effective tiered supports for learners with ASD, including effective specially designed instruction.
  - **Guiding Principles:**
    - We believe learners with ASD are...
      - General education students first
      - Individuals with unique characteristics, abilities and interests
      - Deserving of a rigorous and relevant individualized program
      - Contributing members of society
    - We believe effective practice and instruction...
      - Uses a team-based approach and engagement of families
      - Is evidence-based, informed by research and data, and accountable to federal and state policy and standards
      - Provides access to social opportunities to develop social skills and relationships
- The team has now begun to dive deeper into the identified strands of action to develop logic models and action plans to move the work forward. Hope to have materials and processes developed this year to allow for usability site implementation in the 2018-19 school year.

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

On June 15, 2017, RAP received notification that IDPH was going to eliminate funding for RAP effective July 1, 2017. Peggy Swails sent out a notice via email to council members and other community and agency partners. The following information was contained in the email:

Below is a summary of activities impacted by the elimination of IDPH-RAP funding, These cuts not only affect the direct services RAP has provided to families through the CHSC Regional Centers (enhanced care coordination efforts through RAP Family Navigators (FNs) and RNs), the elimination of funding also affects indirect activities that have assisted with enhancing Iowa's system of care for children and youth with Autism Spectrum Disorder (ASD) and their families. All of these activities are deemed important, but will no longer be able to be sustained without additional funding.

- RAP has a contract for FY18 with the Iowa Department of Education (IDOE - \$154,972), which was established in 1990

- Peggy Swails shifted .05 full-time equivalent (FTE) from the IDPH-RAP to the IDOE contract. Peggy will continue to serve in the capacity of Program Manager at .95 FTE (.05 FTE is paid through ILEND).
- Kelly Pelzel (UICH-CDD/Autism Center) has a .05 FTE appointment on this contract. Kelly will continue providing technical assistant and serve as a consultant (formerly provided by Scott Lindgren – who has retired)
- Letters (see attached) will be sent by July 31<sup>st</sup> to all families served by RAP (including Iowa City and Des Moines)
- Letters (see attached) will be sent by July 31<sup>st</sup> to statewide key stakeholders, and community partners (including the Iowa Autism Council, RAP Expert Panel Committee)
- Elimination of RAP Program Coordinator position (Erika Hertel - .90 FTE), effective July 31, 2017
  - Erika served a very valuable role, having the parent perspective enhanced her capacity to support the statewide RAP teams. She will be greatly missed as we made a great team.
- Elimination of RAP Family Navigator position in the Des Moines metro area (Clementine Karl - .50 FTE), effective July 31, 2017
  - This FN served as the only CHSC/RAP staff member in the Des Moines metro area and provided services to over 70 families.
  - Those families will be triaged to FNs located in other CHSC regional centers (Fort Dodge, Carroll, Mason City, Spencer, and Ottumwa).
  - Referrals from the Des Moines metro area had increased significantly over the last 18 months once this role was established. Clementine participated in several outreach activities to build relationships with community providers. We will miss having the presence of an FN in the Des Moines area.
- Elimination of RAP Family Navigator position from Creston, effective July 31, 2017
  - The FN who works for the Creston CHSC Regional Center will absorb these families into her caseload
- Reduction of the FTE for CHSC RNs from 4 hours to 2 hours weekly in all of the CHSC regional centers
- Outreach efforts to increase awareness on the Autism Support Program (ASP) will not be sustained
  - Although the number of applications received over the past year have increased, without funding for outreach efforts to raise awareness on ASP, the number of families who could benefit from this resource will most likely decrease.
- RAP's social media outlets (Facebook and Twitter) may not be as active due to staffing cuts. RAP also had a Pinterest account that will no longer be sustained.
- Reduction in RAP FNs in the statewide network. Hours reduced from 8 hours to 4 hours per week – funding for these 4 hours per week will be covered from other sources for 6 months.
- Strategies being developed for data capturing activities (both in the electronic medical record [EPIC] and spreadsheets)

- Will need to demonstrate negative impact and outcomes, for both indirect and direct services to families
  - Some anticipated negative outcomes include:
    - Increase in response time to referrals/FN consults
    - Decrease in the number of contacts FNs are able to make to families
    - Reduced Outreach and social media efforts
    - Limited opportunities for professional development for staff
    - Decrease in the number of applications made to the Autism Support Program
- Professional Development opportunities are no longer available
  - The IDPH RAP contract provided some monies for professional development opportunities so RAP staff could attend educational conferences, such as the ASI conferences held throughout the year
- Initiatives and activities planned for 2017-18 with the IDPH-RAP contract that will *most likely* not happen:
  - Assure that 75% of families applying for the ASP were connected with a FN. This deliverable for the IDPH – RAP contract had always been met. Most often, a RAP FN had assisted families with the application process.
    - We will no longer be able to commit to this standard, reducing FN access to underserved populations.
  - RAP Expert Panel – It has not yet been determined whether these quarterly meetings will occur or not due to reduced staffing and the necessity to prioritize activities (e.g. capturing data).

James Curry made a recommendation that the council consider making re-funding of RAP a priority area in the legislative report. Brandon Arkland agreed and suggested perhaps the council should make it a goal.

Sean Peterson shared that the RAP Expert Panel will continue to exist and help coordinate efforts when/where they can. Sean also stated that he hadn't even considered the issue of how RAP helped raise awareness of the Autism Support Program (ASP) and helped link families to this funding source. This will hurt Iowa families.

James Curry suggested the Council and RAP Expert Panel draft a joint statement to ask for reinstated funding for RAP.

Council member discussion continued on this topic and centered around where this funding should be housed – ultimately decided it makes most sense to keep it with a medical-based entity like IDPH.

James Curry asked if we could amend ASP to include more funding for RAP. Could we reach out to legislators who have been allies for this program before?

Sean Peterson added that we really need to amend the ASP to be more inclusive.

Steve Muller suggested that the council focus on the needs that are now going to be unmet due to the defunding of RAP instead of focusing on reinstating funds. He asked if there were any other agencies or organizations that could provide what RAP was providing. This may be a better way to

address the challenges that defunding RAP has created, rather than demanding funds be reinstated. Council members agreed.

**Autism Support Program (ASP)** - Connie Fanselow was not present to provide an update on ASP.

Steve Muller explained that there may be an unintended consequence of the insurance reform. Some families who qualified for ASP, and did not have to go through co-pay/deductible/co-insurance process, will now have to go through co-pay/deductible/co-insurance with this new insurance legislation. This additional costs may be too cost prohibitive for families resulting in them having to cease services.

Council discussed modifying ASP to allow it to function more like a “fill in the gap” program to offer financial assistance to families to cover what insurance does not (i.e., co-pay, deductible, co-insurance).

### **BCBA Education Grant Program**

James Curry asked if the council should ask for the rules of the BCBA grant to be modified to cover 100% of tuition. (Currently only covers 50% tuition.)

Sean Peterson stated that the biggest challenge right now with the BCBA education grant is that IDPH failed to issue an RFP in time for fall applicants. Concerned about how this will impact Drake’s brand new BCBA program. Drake lost out on funds that were vetoed by the Governor to help establish the program because it was deemed redundant with other contracts (specifically the BCBA education grant), but now new students enrolling this fall cannot access these grant funds. Iowa has already lost one program in the state (Briar Cliff), we don’t want to see a second program die due to lack of funding.

Council members discussed whether we should include this concern in the legislative report.

Steve Muller stated we are not asking for more money, just that the established program is implemented as it was intended. We need to urge IDPH to green light the RFP and ensure the funds are accessible.

Sean Peterson suggested the council draft a letter to reach out to IDPH to urge them to post an RFP as soon as possible to allow applicants to apply for funds for the Fall 2017 – Spring 2018 school year. Sean motioned to draft a letter. James Curry seconded. Motion passed.

Sean Peterson will draft a letter and send around to council members via email for input and consensus before sending to IDPH.

### **Iowa Vocational Rehabilitation Services (IVRS)**

Andrea Keith reported:

- Pre-employment transition services initiative is still a focus for VR for students ages 14 and up who qualify
- Encourage schools to address these skills earlier than 14
- Focus is on skills for employment but, for students with ASD there is also a goal to decrease anxiety related to the “unknowns” when it comes to work or job.

## **Additional Discussion**

Wendy Trotter reminded the council that the next council meeting is November 8, 2017. Also, the council needs to draft the year-end legislative report before the November meeting so council can vote to approve and submit the final draft by mid November.

Sean Peterson shared that the Iowa Association for Behavior Analysis (IaABA) is pushing for licensure in this state for BCBA's. The importance of licensure is for consumer protection. There are other entities that claim they are certifying "Behavior Analysts" that do not adhere to the same level of qualifications as the Behavior Analyst Certification Board (BACB). Sean suggested the council consider recommending licensure tied to BACB standards for credentialing for consumer protection.

Jenny Phan asked Steve Muller to clarify his statement about insurance premiums increasing as a result of insurance reform. Sean Peterson clarified that it was not the premiums increasing that was the unintended consequence, but challenges with families now having to pay high deductibles, co-pays or co-insurance that they didn't have to pay before when they qualified for ASP making services too cost prohibitive.

## **Iowa Autism Council Goals/Priorities for 2018:**

Council members discussed possible priority areas for 2018 to include in the legislative report.

James suggested that Matt O'Brien (chair) and Brandon Arkland (co-chair) could go back through minutes of meetings this year to look for themes.

Sean Peterson wondered if we could encourage replication of the successful collaborative program between Green Hills AEA and CHSC, the Regional Autism Clinic of Iowa, as a goal for the council. Council discussed this idea at length and decided the best approach at this time may be to highlight the program as a success and for the state to investigate ways to replicate the model in other underserved areas.

Other successes that were suggested to be highlighted in the report include:

- Insurance reform
- Movement on the strategic plan:
  - The positive impact RAP had
  - Positive statistics from the ASP
  - Department of Education's Autism Navigator initiative for early intervention providers
  - Department of Education's ASD Supports Design Team work
  - The Learn the Signs Act Early ambassador
  - BCBA education grant

Areas of focus/concern:

- Continue to fund ASP
  - Monitor unintended consequences of insurance reform and consider modifying ASP to provide "fill in the gap" coverage for families who cannot afford their deductible or co-pay/co-insurance, as well as those who do not have insurance coverage
- Concerns regarding funding cuts to RAP and the services they were providing that are now not being met

- Investigate innovative ways to improve access to diagnostic services, like the Regional Autism Clinic of Iowa model.

Brandon Arkland made a motion to adjourn the meeting. Sean Peterson seconded the motion. Meeting adjourned at 2:00pm.