

Iowa Autism Council Meeting

Approved Final Minutes – June 14, 2017

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

Present: Matthew O'Brien, James Curry, Erika Hertel, Angela Burke Boston, Andrea Keith, Brandon Reese Arkland, Wendy Trotter, Connie Fanselow, Angela Logsdon, Jenny Phan, Rik Shannon, Christine Bowker, Jeanne Kerkhoff, Nicholas Nopoulos, Sean Peterson, Sean Casey, and Beth Buehler-Sapp.

Absent: Steve Muller, Theresa Croonquist, Peggy Swails, and Chris Kliwer.

Guests: Kristen Wayson CHSC,
Mary Carstens, Green Hills AEA,
Melanie Van Dyk, Green Hills AEA
Valerie Schmidt, Driver for Christine Bowker

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

The council reviewed and voted on the minutes from the March 8, 2017 meeting. Edits were suggested and made. James Curry made a motion to approve the minutes as corrected and Christine Bowker seconded the motion. Minutes approved.

Presentation - Regional Autism Clinic of Iowa (RAC-I)

Mary Carstens and Melanie VanDyke, from Green Hills AEA presented on the Regional Autism Clinic of Iowa (RAC-I) which is a collaborative partnership between Child Health Specialty Clinics (CHSC) and Green Hills AEA to provide access to diagnostic services for ASD in rural Iowa.

Highlights from the presentation are below:

Iowa

- Rural state with shortage of providers
- Need clinicians, specialists, and services
- 79 of Iowa's 99 counties are rural
- 72 counties have at least one medically underserved area

Identification of Needs

- CHSC – medical
 - Trained all Nurse Practitioners in STAT
 - Regional Autism Program (RAP)
 - RAP Family Navigator
 - Organized screening tools
- GHAEA - educational
 - Autism Resource Team
 - Behavior teams
 - Staff trained in Autism Diagnostic Observation Schedule, Second Edition (ADOS-2)
 - Added additional screeners

Goal: Provide Gap-Filling Services

- Both agencies identified who needed to be evaluated for ASD
- Problem – getting the diagnosis for ASD
 - Gateway to additional services
- CHSC and Green Hills AEA formed an innovative partnership in 2015

Team Consult Approach

- Referral from Primary Care Provider, AEA, teachers, parent
- CHSC completes
 - Comprehensive history
 - Physical
 - Developmental screening
 - Autism screening
 - Cognitive screening
- AEA
 - Observation of child in the school setting
 - Sensory/speech assessments
 - Autism Resource Team
 - Autism screenings
 - Behavioral testing if needed

Next Steps

- Determine need for ADOS testing
 - Refer to Regional Autism Clinic – Iowa (RAC-I)
- ADOS testing in collaboration
 - CHSC sees child
 - AEA performs testing
 - All review testing results
- CHSC NPs review video as team with child psychiatrist
 - Case review
 - Discussion of findings
 - Review considered treatment plan
 - AEA participates as able

RAC-I Team Consult

- AEA and CHSC meets with family
 - Review all screenings and ADOS results
 - Provide diagnosis
 - Determine treatment plan
 - Provide handouts
 - Make referrals as needed
 - Plan for transitions as needed
 - School/AEA participants invited
 - Family Navigator provides peer to peer and care coordination

Treatment Plan

- Nurse Practitioner
 - Referral to speech, Occupational Therapy (OT), behavior, cognitive testing

- Applied Behavioral Analysis (ABA)
- Follow up and monitor progress
- AEA
 - School based services – speech, OT, behavior, social skills
 - Autism Resource Team
 - Possible special education services
 - Connect to autism email list serve and parent support group
- RAP Family Navigator
 - Follow up calls
 - Follow up resources
 - Assist with SSI application/waivers/diapers/travel reimbursement

Parents Feel

- Love the team approach
- Appreciate school being represented
- Feel “heard” and valued
- Enjoy that they are part of the planning/collaboration
- Recognize they have a team to approach if problems result
- Feel support for now and the future
- They have a VOICE

Total Referrals to RAC-I (March 2016-March 2017)

- Approximately 100
 - Total ADOS tested: 28%
 - Total Diagnosed: 18%

Total ADOS completed: 28

- Total Diagnosed: 18
- Percent Diagnosed: 64%
- Total Ruled out: 6
- Monitor/Repeat Testing: 4
- Other diagnosis given: *ADHD, FAS, Mental Delay, Expressive Language Disorder, Environmental, Anxiety*

James Curry asked if this program will be replicated in other regions?

Response: That depends on what the administration from other AEAs is willing to support.

Sean Casey stated, “A relationship with CHSC would benefit all parts of the state.” (referring to the AEA/CHSC partnership)

Jeanne Kerkhoff, a new council member, shared her concerns regarding the lack of services and coordination of services in rural areas. She shared her personal story and struggles with accessing services for her son.

Sean Casey asked Jeanne if the Behavior Team from her AEA had evaluated her son?

Jeanne stated she was not aware that there was a behavior team and that she will contact her AEA and will pursue this option.

Matt O'Brien said, "It's great you are a part of this group to help you become more aware of what is available to you; but we also benefit from hearing your perspective and helping us as a council to see the challenges families are facing in rural areas of our state."

Council members discussed the various stumbling blocks for accessing services in the state, including, diagnosis and treatment issues and limited availability of service providers.

Brandon Arkland stated that perhaps having the new centrally located program for training BCBA's starting this fall at Drake University will help with the shortage of service providers. The next big challenge will be trying to keep some of the graduates in Iowa to benefit our state's needs.

Legislative Updates

Insurance Reform

- HF 215 was passed and signed into law. This legislation states that health insurance plans regulated by the state insurance commission will now be required to pay for Applied Behavior Analysis (ABA) for children/youth with autism. This applies to any non-self-funded plans renewed or issued after January 1, 2018.
- The Division of Mental Health and Disability Services will soon be revising the ASP administrative rules to align with this new legislation so they will be in effect by January 1, 2018.

Health and Human Services Appropriations – HF653 (report from Connie Fanselow, DHS)

- \$950,000 to be credited to the autism support program fund
 - o \$25,000 of that to be used for Mercy Dubuque – was not used last year and will not be contracted for FY18
 - o \$25,000 of that to be used for Four Oaks Summer program – are in the process of extending their contract, they have told us this will be last year for their program
- the Governor vetoed \$202,000 for Drake University to establish remote learning sites and maximize outreach and enrollment in its master's program in applied behavioral analysis (ABA) which effectively takes the appropriation down to \$748,000
 - o his stated reason was that the funding would be redundant and unnecessary because the Dept. of Ed. Has already awarded funding to Drake for establishing the program and because of the BCBA grants program
 - o veto specifies that the \$202,000 reverts to the General Fund
- potentially we will have \$700,000 to spend on ASP services for FY18

Autism Support Program (ASP)

Connie Fanselow provided the following update on ASP:

- Continue to receive 2 to 3 applications per month
- Main reason for denial is income over the limit
- Attrition due to several reasons:
 - o Obtaining Medicaid coverage or Waiver slot
 - o Reaching 24 month or \$72,000 expense limits
 - o Obtaining private insurance coverage
 - o A few removed at parent's decision – make adequate progress or didn't think they were benefiting

- Maximum number actively being served has been 21
 - o March was 17
 - o April was 15
- Carrying 12 kids on eligibility list who have been approved for services but for whom no service plans have been submitted:
 - o 3 from prior to January 1, 2017
 - o 6 have been approved more than 3 months
 - o 3 approved in the last three months
 - o Try to follow up with families and find out what is preventing them from getting served
- Through April, the FY17 expenditures total about \$405,000
- Expect FY17 total to be about \$480,000

Matt O'Brien told the group that there is a new list of approved providers. Current approved providers include: The Homestead, The Pier Center for Autism, The University of Nebraska (Pottawattamie County families), Behavior Care Specialists (Rock Valley), and Hills & Dales (Dubuque).

With the new insurance reform legislation, there was discussion about modifying the ASP program as we move forward that will allow it to function more like a "fill in the gaps" program to help families cover what insurance does not (i.e., co-insurance, co-pays, deductible).

BCBA Education Grant Program

Connie Fanselow talked with Megan Hartwig, the contact for the BCBA grant at IDPH, and reported the following updates:

- IDPH does not yet have a date of the next round of RFPs, although they had planned to offer them for students enrolling in the fall
- They are still not finished executing the first round of contracts from the December RFP
- IDPH has adopted a change to the BCBA Grants program administrative rules
 - o effective July 12, 2017
 - o eliminates the language that limits the length of the contract to a four year period
 - o will make the length of the contract flexible
- BCBA education grant program was allowed to keep the money currently in the fund (\$500,000 total), but no new monies were appropriated
- 12 applicants received awards
 - o Still finalizing some of the contracts
 - o Should have plenty of funds
- Applicants only need apply one time – they map out their plan when applying
- Awarded applicants are required to repay the grant if they do not honor their contract
- Grant pays 50% of tuition (does not cover fees)
- Underwhelming response could be due to minimal coverage of tuition

Sean Casey suggested the council recommend the tuition reimbursement be increased to 100% of cost and to strike the language about having to demonstrate financial need. That may increase interest in the program.

Sean Casey also reported that Drake will be the only BCBA program in the state. Briar Cliff is closing their program, and the program at University of Iowa fell through.

Regional Autism Assistance Program (RAP)

Erika Hertel reported that the RAP program in Iowa City has posted for a family navigator position. She also reported that four CHSC staff are going to Rhode Island to participate in a State Public Health Autism Resource Center (SPHARC) State Grantee Peer-to-Peer Exchange Activity June 20-21st, 2017 in Warwick, Rhode Island. They will be hosted by the Rhode Island State Autism Grantee team who will share how they leveraged different partners, addressed challenges around funding and sustainability, established buy-in to effectively integrate Family Navigators in the community, developed tools for Family Navigators to help them determine their role with families, and much more through interactive discussion with the RI team and peers, presentations, and a parent panel. It will also provide a space for participating states to engage and develop action plans related to Family Navigation while receiving real-time feedback and resources to help address a need and/or improve a program.

Iowa Vocational Rehabilitation Services (IVRS)

Andrea Keith provided information about IVRS – visit website for more information:

[Iowa Vocational Rehabilitation Services website](#)

The mission of IVRS is “to work for and with individuals who have disabilities to achieve their employment, independence and economic goals.” IVRS provides a number of services and supports – Andrea discussed the following points:

- There is no age limit
- For High School students, IVRS offers pre-employment transition services (as indicated in WIOA legislation):
 - Assist with job exploration – what’s involved in a job
 - Virtual job shadow to decrease anxiety (will video a particular job so student can see it)
 - Work-based learning opportunities – depends on school and community partnerships
 - Counseling to assist with developing plan for future – help them navigate their path: college or career or training
 - Assist with workplace readiness skills (i.e., social skills, self-advocacy)
 - Offer both individualized and group sessions
 - Encourage clients to reach back to them to check in and talk about any struggles or obstacles they’ve encountered – how can IVRS help?
 - Have funds available to assist with many aspects of vocation and vocation prep (e.g. tuition, interview clothes, transportation, etc.)

Strategic Plan Update:

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

Focus Area A (Get a Good Start) –

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

- Wendy Trotter reported that Cohort 2 of the Autism Navigator® PD project has completed Year 1 (Training Tier). Both Cohort 1 and 2 had opportunity to attend a 2 day workshop in May with Dr. Amy Wetherby and Dr. Juliann Woods (developers of Autism Navigator®)
- 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.

Review of IAC goals:

Matt O'Brien reviewed progress on the following goals that were identified by the Council for 2017.

1. Insurance Reform – legislation passed
2. ASP – funded, but appropriations were cut – will have approximately \$700,000 to spend on ASP services for FY18
3. Statewide Transition Plan for Compliance with federal home and community-based services (HCBS) – do not know the status; will defer to next meeting.
4. Iowa Strategic Plan – continue to see progress in some focus areas. Need to determine what/if any progress happening in other focus areas
5. Minimum wage vs. reimbursement rate floor – no updates
6. Reduction of wait times associated with HCBS Waiver Program –
 - DHS quarterly report that addresses this issue – see page 80 of [Iowa Department of Human Services Quarterly Report](#)
 - There is currently a waitlist for waiver services
 - No new money appropriated
 - There are 3 waivers in Iowa:
 - Intellectual Disability (ID) waiver
 - Mental Health (MH) waiver
 - Health and Disability waiver
 - No ASD waiver in Iowa Department of Education
 - Services vary based on type of waiver (caps, length of time, supported community living, respite, transportation, etc.)
 - With new DSM-5 there have been changes to diagnosis of intellectual disability – used to be very rigid IQ measure (75 or below), but have shifted to allow for a focus on adaptive behavior. So individuals who have an IQ of above 75, but score low on adaptive behavior can now qualify

Brandon Arkland mentioned inviting legislators to a meeting and give a presentation to share the needs of our state.

Matt suggested we could also share our strategic plan with them to illustrate where we are now and what we still need to do. Matt also suggested that perhaps we invite representatives from Drake's new BCBA program to our next meeting so they gain a better understanding of the needs of our state.

Matt O'Brien made a motion to adjourn the meeting. James Curry seconded the motion. Meeting adjourned at 3:00pm.