## Alabama Interagency Autism Coordinating Council (AIACC) Monday, January 9, 2017 Alabama Industrial Development Training Center

The AIACC met on Monday, January 9, 2017, at the Alabama Industrial Development Training Center. The meeting was called to order by Co-Chair, Greg Carlson. Also in attendance were Council members: Fred Biasini, Brooke Bowles, Jane Elizabeth Burdeshaw, Megan Everett, Cam Ward, and Karen Willis, and Anna McConnell, State Autism Coordinator. Joining via phone due to icy weather conditions were: Robert Caldwell, Whitney Meade, and Todd Tomerlin. The following proxies were in attendance as well: Russell Green on behalf of Stephanie Azar, Sabrina Franks on behalf of Nancy Buckner, Bama Hager on behalf of Melanie Jones, Vera Hendrix on behalf of John Mascia, Laurie Eldrige-Auffant on behalf of Thomas Miller, Justin Schwartz on behalf of Myriam Peralta, Courtney Tarver on behalf of Jim Perdue, and Tina Sanders on behalf of Michael Sentance.

The minutes from the October 17, 2016 meeting were approved and adopted.

Lead Agency Comments: Department of Mental Health Associate Commissioner Courtney
Tarver reported that discussions are still ongoing between the State and Alabama Disabilities
Advocacy Program and the Center for Public Representation regarding a complaint about
EPSDT issues for children who are Medicaid-eligible. Mr. Tarver also reported that the Executive
Committee of the AIACC met in December to discuss the draft of a bill that would provide ABA
therapy to children with Autism. We expect this will be filed in the upcoming legislative session.
The question was raised if any other states have had a similar bill which used state dollars to
provide therapy rather than insurance. This current draft of the bill would fund state agencies to
do similar activities rather than through an insurance mandate. There are ongoing discussions
regarding the best delivery system and adequate funding to meet needs.

State Coordinator Comments: Anna McConnell said that the Alabama Autism Provider Network (AAPN) bill be meeting immediately after the AIACC meeting. There is a public meeting portion. Contact Sarah O'Kelley for questions. Upcoming meeting dates have been set: April 10, July 10, and October 16, 2017. The AAPN will also be holding meetings immediately after the AIACC meetings on these dates as well.

Bylaws/Membership Committee Comments: Sarah Ryan reported that the Parent of an Adult with ASD position had been filled. Suzanne Dowling has been Governor-appointed. She is from Tuscaloosa.

Accessibility Committee Comments: Brooke Bowles announced the Certification Training in Community Based Services, with support from the DD Council. This training has previously been offered, and resulted in Flourish of Cullman, a new service provider for young adults with ASD and other DDs. This year, the DD funded training will be opened to parents and 2 other trainings (targeting schools or other providers) will be opened to providers and will be fee-based. More information can be found through contacting <a href="mailto:bowles@triumphservices.org">bowles@triumphservices.org</a>. A collaboration with ADRS and ALSDE to provide transition service in Autauga, Elmore, and Montgomery counties specifically for students with ASD. The AL Autism Providers Network will be a good vehicle to improving accessibility. The committee will work toward making sure all providers know how to access services, particularly from DMH, ALSDE, ADRS, and private pay. During the AAPN meeting in the afternoon, Brooke Bowles and Joe Carter will provide a presentation "Autism 101 – What Is?" There is expectation that the Regional Autism Networks will work closely with the AAPN to learn from each other how best to navigate services.

Funding and Finance Committee comments: Greg Carlson noted that the potential repeal of the ACA probably will impact how children and adult with ASD receive services, including ABA therapy. The committee will also be watching with the Essential Health Benefits will look like if a repeal or replacement occurs. The Treasury has responsibility for the ABLE accounts, and has chosen to use Nebraska's savings plan. Contact Treasurer Boozer's office with questions about these accounts. The Federal Employee's Insurance Program now allows for ABA therapy to be covered beginning January 1, 2017. Autism Speaks is trying to come up with a template for helping federal employees review the 15 or so available plans for best coverage for a family. Most plans require a pre-approval for assessments and continued provision of ABA therapy. For RCOs, some boards and groups have discontinued meetings, as some RCOs have withdrawn. Glenwood has submitted preliminary applications to RCOs for a crisis center, expanded assessment and diagnostics, and provide integrated care within a pediatric practice. The deadline for provider applications for special projects funding is January 29 for Centene. Anna asked Greg about the recently released CMS guidance reiterating requirements of managed care regarding EPSDT benefits. Tami Waters described the issued guidance as saying that providers (whether fee-for-service or managed care) must cover EPSDT services, and are giving direction to state Medicaid agencies on how they can be clear with managed care

within contracts. There are three different suggestions regarding language that clarifies what requirements are. Greg noted that the contract he had seen did articulate EPSDT requirements well. Potential implications of the EPSDT requirements may not be fully understood yet. Sen. Ward noted that during the upcoming session, Medicaid will be a major factor in budget. The AL General Fund is about \$1.8 billion, and has remained roughly the same for the last 15 years. In 2008, there were about \$480 million to Medicaid in AL. This year, the legislature appropriated just under \$800 million. Next year, the figure will be close to \$1 billion. The General Fund budget is not growing. Other states around the country are dealing with similar growth. Due to AL's tax structure, even if you tried to increase property taxes, corporate income taxes, or personal income taxes (would be a vote of the people), under our constitution, that money would be earmarked for the Education Trust Fund (ETF). To continue to pay for the increase in Medicaid, you would have to take it out of the ETF. Changes on the federal level to Medicaid are still unseen, but for the next 2 years, Medicaid will be the biggest reform/impact that will be seen. Nationally, healthcare costs in the country are increasing and are looking to ways to cut back in other areas to afford Medicaid costs. Next year will be the first time where Medicaid will be close to \$1 billion when the state General Fund budget is \$1.8 billion. The entire healthcare community, including autism, must face these challenges over time.

Senator Ward addressed priority legislation – funding for Regional Autism Networks (RANs) and autism therapy coverage. Last year was the first time the RANs were funded. There is potential to build on that again as the education budget continues to grow. Insurance is the biggest issue for people with autism and service providers. The challenge in the legislature is creating a new government run healthcare entity when Medicaid is struggling with funding. The other alternative is mandating insurance coverage.

Russell Green asked about the role of schools in treatment of ASD and behavioral therapy. How would the legislature view that?

Sen. Ward responded by noting the growth of costs, even if initially the costs are relatively small. It is too simplistic to say that an insurance program would be the only avenue. Schools, private providers, and others will need to all participate in service delivery. The issue again comes down to creating another government run insurance program when Medicaid isn't fully funded. That is the debate he foresees. This is not an insurance program, but still covering costs of what insurance would cover.

Russell Green noted the importance of schools in the treatment of children with ASD, since children are already present and spent much time in the school setting.

Sen. Ward noted that adults or students who are homeschooled may miss out on the entitlements delivered by the school system.

Bama Hager said that most parents in the state will say that they will take ABA coverage in whatever form – whether education or private insurance. However, in 45 states, the medical condition of ASD is covered by private insurance and it is a different approach. She could see that some parents would be troubled by thinking that treatment would be delivered by schools; it would be slippery slope, because there are no other medical conditions treated by schools in that way.

Fred Biasini noted that insurance providers won't cover treatment because they say it is the school's responsibility – ADHD and learning disability. If the school makes a referral, the insurance companies won't pay for a diagnosis. In the past, the school system would pay for it as a  $2^{nd}$  or  $3^{rd}$  opinion, but that could potentially be a similar thing.

Sarah O'Kelley noted that ASD is a multi-setting condition, because generalization is an issue in intervention. They may do well in a school setting, but when they leave, they don't make the same gains. Those skills may not transfer into employment, the community, or other settings. It is a multi-setting and multi-modal approach in treatment. She said she understands the budgetary standpoint and that we must be creative.

Greg Carlson noted that the AMA has identified ABA as an intervention, along with the billing codes, so calling it "educational" in nature would be difficult.

Whitney Meade said that educational law only says what is "appropriate", not the clinical model of treatment to "fix" the condition.

Sen. Ward said that insurance has continued to be an issue. Changes in Medicaid is dictated by the federal regulations, and states must match funds in order to provide Medicaid services. Commissioner Perdue has been adamant in coming up with a solution to at least get us started. One challenge is whatever insurance solution is put forward would not be universal – it will not cover everyone, and that is not just talking about age caps. There is a finite amount of money, so some will get covered initially and some will not. Like the Regional Autism Networks, we start smaller and work our way out.

Public Awareness Committee: Bama Hager introduced Angel Loewen and Michelle McDaniel from the Mobile Autism Society of Alabama office. They reported on activities in South AL. Angel said that they have been expanding their community outreach and sensory friendly activities (Toys R Us, movies, visiting Santa at the Mall and Bass Pro Shop, Exploreum IMAX, etc.). Angel said that whenever they have approached businesses in the community, they have been eager to help coordinate these kinds of activities. ASA is looking at putting together Care Binders for families that can give more information to families whose child has just received a diagnosis. Often when families call, there is so much information given to them, if it was in one

place and could be mailed to families, it would be helpful. These would be tailored for local communities. Michelle discussed the new program, SibShops, which is a program for siblings of children with special needs. They are getting ready for their 2<sup>nd</sup> event. There are not enough services for children with ASD and other special needs, but beyond that, there aren't services out there for siblings. Sibshops includes fun activities, games, and talk about what it's like to have a sibling with special needs. They try to include an older youth who is a sibling so they can get a network going. Michelle is currently the only facilitator in the state.

Bama Hager reported that the Autism Society of Alabama is hosting Autism Legislative Day is Tuesday, March 7, from 10-3 pm. There is a rally at the Statehouse at noon.

Sen. Ward said Autism Legislative Day is very effective and one of the most important things done as a community, because legislators see people from their communities coming into town. Lawmakers may not otherwise have contact with people with ASD and their families, and this is a good tool to reach out with.

Brooke Bowles mentioned that this advocacy opportunity is empowering for adults on the spectrum.

Bama also reported that Autism Awareness Month is in April, as well as walks around the state. Autism Friendly has grown tremendously, and businesses want to know how they can be more autism friendly. Regions Bank presented at the last AIACC meeting about their Autism Friendly program, and their leadership has helped the efforts around the state. There are now lots of sensory activities around the state, and this will continue to be a focus for ASA moving forward. The Transition Roadmap is online at the ASA website. It walks families through the transition process specific to Alabama. It is 90% constructed, and was developed by Caroline Gomez. First Responder trainings are continually being offered. Sarah O'Kelley announced that the Alabama Autism Conference will be held February 24 (last Friday of February each year). This year, we will be focusing on challenges that aren't necessarily specific to the ASD diagnostic criteria, but are related issues – like sleep, difficult behaviors, and rethinking school environments to support everyone who may need supports. Scholarships are available. The conference includes speakers who highlight current research and connect to practical implementation across settings.

Anna McConnell reported that the AIACC is working with the ASA to build up the resource directory. The Regional Autism Assessments will help to inform and populate the Resource Directory. Service providers can register themselves on the ASA Resource Directory tab. Anna McConnell noted that Paige McKerchar, who is key to developing the State Licensing Board for Behavior Analysts, projected that the beginning acceptance date for applications is mid-April. The rules and regulations will need to go through a comment period. Sen. Ward

noted that Dr. McKerchar has been working toward getting the licensure board up and running from the beginning and thanked her for her service.

Russell Green asked if in April license for BCBAs would be issued. Sen. Ward said "yes", and also gave some background on licensure. BCBAs are already Nationally Board Certified, and the state licensure is primarily used for insurance companies.

Regional Autism Network Committee & Presentation: Fred Biasini provided an update on the Regional Autism Networks (RANs) during a presentation on the current activities of the RANs. The RANs are currently located at the University of Alabama at Birmingham (Lizzie Griffith, Coordinator), University of South Alabama (Amy Mitchell, Coordinator), and Auburn University (Doris Hill, Coordinator). They began October 1, and we hope to have more RAN locations in the future at UA and UAH. Each RAN is tasked with providing 1) staff with expertise in Autism, 2) assistance to individuals and families, 3) technical assistance and consultation, 4) professional training, and 5) public education. Each RAN site is accomplishing these tasks differently due to the varying resources at each location. Reports on number of contacts and impact measurements are being collected and submitted to the Council.

The meeting was adjourned at 12:00 p.m.

Next meeting: Monday, April 11, 2017

Recording Secretary

A. McConnell