

Alabama Interagency Autism Coordinating Council (AIACC)

Monday, April 10, 2017

Alabama Industrial Development Training Center

The AIACC met on Monday, April 10, 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: Brooke Bowles, Jane Elizabeth Burdeshaw, Robert Caldwell, Lucian Cronkite, Sally Davis, Suzanne Dowling, Megan Everett, Doris Hill, Myra Jones, Sara Ryan, Jim Perdue, and Karen Willis, and Anna McConnell, State Autism Coordinator. The following proxies were in attendance as well: Sarah O'Kelley on behalf of Fred Biasini, Bama Hager on behalf of Melanie Jones, Vera Hendrix on behalf of John Mascia, Justin Schwartz on behalf of Myriam Peralta, Dianna Tullier on behalf of Jean Ross, and Tina Sanders on behalf of Michael Sentence.

The minutes from the January 9, 2017 meeting were approved and adopted.

Greg Carlson provided a legislative update from Sen. Cam Ward. Funding for Regional Autism Networks was added for the two remaining locations. The Autism Insurance Bill is projected to get a vote in committee on Wednesday (in the House Insurance Committee, chaired by Kerry Rich). Bama Hager provided an update on the bill. HB284 requires coverage of Applied Behavior Analysis (ABA) therapy by health insurances, which is like 45 other states' laws requiring the coverage of Autism and ABA therapy. Bama expressed appreciation to Rep. Rich and other legislators moving the bill. Bama is hopeful that the bill will move out of committee favorably and then go to the House floor for a vote. Comm. Perdue said that he believes Alabama will eventually be one of those states covering ASD. There are two bills in this session. The Governor asked Sen. Gerald Allen, Sen. Cam Ward, and Comm. Perdue to try to come to a compromise bill (SB57). That bill produced by Senator Allen included age and dollar caps (\$40,000) and used funds from the ETF. Many asked why insurance wasn't covering this. Comm. Perdue expects HB284 to get out of committee, but there is still a long way to go until the Governor's desk. Bama noted that the best way to support the bill is to identify your representative and senator (using the AL Legislature website) and their contact information – contact your legislator specifically asking them to support HB284 and those with ASD in their district. The vote on Wednesday is a public vote – 10:30 a.m. in Room 410. Everyone is welcome. Anyone with BCBAs connected to their organization need to make sure that they are advocating as well since it relates to their profession. Comm. Perdue further explained the legislative process and warned that there may not be enough time to deal with amendments. Grassroots advocacy and contacting your legislators is imperative and naming the bill in your discussion is important.

Comm. Perdue has included autism in his talking points during town hall meetings. He also addressed the ADAP complaint regarding EPSDT services for children. Half of the children in Alabama are on Medicaid, and the courts in other states have upheld complaints that services must be delivered. If Alabama does not respond to the complaint, this may go to court as well. Currently, there is \$11.5 million in the Education Trust Fund (under DMH, but intended to cover Medicaid costs for services for ASD, SED, and IDD) designated as a response to this complaint, but must be approved by the legislature.

Anna McConnell announced that the AIACC will be convening a group to update the strategic plan since the current one runs 2014-2017. If you are interested in participating, contact Anna. The Alabama Autism Provider Network (AAPN) will meet immediately after the AIACC meeting. The public portion of the meeting will be the first part of the meeting, and the private business meeting will be last. Brooke Bowles announced, as part of the Accessibility Committee update and in relation to the AAPN, that it is vitally important for providers to know the available resources so that the correct information can be given to families who call. The public presentation last quarter was a presentation on Accessibility in Alabama based on funding sources. Today, the AAPN will host a panel for best practices for those with ASD.

New Business:

Bylaws Committee: Sarah Ryan reported that the Governor appointed Council members are all appointed for two consecutive terms of three years each. Several members are coming up on their second term: Karen Willis, Sally Davis, Brooke Bowles, Whitney Meade, and Lucian Cronkite. If you are interested in continuing in your second term, let Anna McConnell know as reappointment letters may be needed. Sarah Ryan introduced Suzanne Dowling, a new member to the AIACC, filling a position as a parent of an adult on the Autism Spectrum. Suzanne is from Tuscaloosa and has a 25-year-old son with ASD. She has always been active and involved in the autism community since his diagnosis. Her son is currently employed and active in his community.

Accountability Committee: Anna McConnell noted that Anne Brisendine, a doctoral student at the UAB School of Public Health has been working with the UAB Regional Autism Network and will be helping to finish pulling the Standards of Practice together in a more easy-to-read format. The Standards will be distributed to the state, guiding providers and families in identifying best practices in Alabama – most effective treatments for appropriate populations.

Funding and Finance Committee: Greg Carlson announced that the additional funding for 2 more Regional Autism Networks is currently in the ETF budget. It is anticipated that other coverages will be coming online soon as well.

Public Awareness Committee: Bama Hager provided the update on behalf of Melanie Jones and the Autism Society of Alabama. She stated that the RAN funding was a big deal for Alabama – allowing the addition of UA and UAH. Current RAN sites are Auburn University, University of Alabama at Birmingham, and University of South Alabama. We are still awaiting final confirmation that it will remain in the budget. On the ASA webpage, there is an option to enroll in receiving email updates, particularly regarding HB284. There are currently 33 ASA support groups throughout the state – they are listed on the website. Regions Bank will kick off their autism-friendly campaign in all 1600 branches during April 2017. ASA and Regions partnered in this project, but it will be shown in other states as well. Signage indicating they are autism friendly will be in each branch, and there will be a sensory pack for families to use if needed. All associates are trained to work with adults and children with ASD. There are plans to continue the partnership through communicating banking packages specifically to the ASD population and provide user-friendly banking products. The First Responder trainings are ongoing. Dustin Chandler continues to work with the ASA in providing trainings. There are autism-friendly baseball games in Mobile and Birmingham, as well as in Montgomery. The sound is reduced as much as possible in the ball park. On May 5, the Mobile Autism Conference will be held. Amy Mitchell announced that the Conference is co-sponsored by the USA RAN and the ASA, and it is designed for educators, service providers, and parents. Anna McConnell announced that Sesame Street introduced a new character with ASD – Julia. Also, Laura Klinger, who used to direct the UA Autism Clinic and is the TEACCH Director, contributed to the work on this character. Greg Carlson noted the prevalence of autism in news – that parents have stepped up and made the issue known and promoting acceptance.

Regional Autism Networks: Sarah O'Kelley announced that the additional funding was secured for remaining RAN sites, allowing the state to be fully covered. The first 3 that were funded were still covering the portions of the state where there was not RAN coverage, and that the universities were already doing some of the work informally. For the 3 RANs currently operating, the Constituency Boards were recently approved. Those Boards should be having their first meetings very soon, and the Boards will guide the networks. USA Update: Amy Mitchell announced that the USA RAN is co-sponsoring the conference on Friday. USA is thrilled to start plugging into the advice of the Constituency Board. All RANs just submitted 2nd Quarter reports; USA almost doubled the number of calls received, and all but one of the counties covered called the RAN (indicating that word is spreading). AU Update: Doris Hill announced that the existing RANs meeting monthly via phone to discuss data collection, resources, and feedback on progress. The number of calls for professionals and families increased. Doris found that getting out in other counties was improved by speaking at conferences, like the AU Transition Conference, that have broader reach in the community. Doris also attended the Montgomery County Public School Resource Fair – she could meet with parents and add more professionals to the resource directory. UAB Update: Lizzie Griffith announced that UAB has been receiving more calls from

professionals this quarter. She announced that Anne Brisendine has been working with her to pursue IRB approval for the RAN database. This would allow for structure and guidance for how we collect information to help callers. If there are specific questions that need to be asked and included in this IRB approval request (i.e. insurance status), let Anne or Lizzie know. At the Alabama Autism Conference, a Training Needs Survey was distributed. This will be distributed to the AIACC and RAN Constituency Boards and others to get input on what topics or target populations need to be prioritized. The RANs have held off on the professional training and public education pieces, because there needs to be input from the Constituency Boards and data to guide activities. Sarah O'Kelley noted that in the university context, if you are collecting any kind of data, it's a good idea to go ahead and look at IRB. That will protect the data and make sure it is used well. Once there is aggregate data, it can guide practice and service efforts, and puts us in better positions as individual organizations and as larger connected groups to seek additional funding sources. As someone who works with data a lot, it seems like this is a great opportunity for using this information for the greater good. We are asking how we can use this data to increase the power and outreach that we have. If you have additional questions about the database, please feel free to talk with Sarah. The RAN reports have shown an increase in number of calls and contacts. The calls are not only coming from families, but also professionals, who see the RAN as a way to enhance their care for people on the Autism Spectrum. Growing resources and continuing contacts and networking with existing resources in the areas covered by the RAN (not just in areas with "more services" than the outer-lying areas). Anna McConnell noted that state agencies struggle with data regarding ASD because it is typically not the mechanism or primary diagnosis that allows an individual to be served. For state agencies, in particular, please let us know what information would help inform the work that you do, as well as knowing a training mechanism is coming into place. We hope to partner with state agencies for training and sharing of information and referring families to appropriate resources. Bringing universities in through the RAN brings academic and clinical aspects more integrated into the system of care that is being developed, along with service providers, advocacy organizations and the RAN. It has been 10 years since the Task Force and last Needs Assessment, and while the data system will not take the place of the Needs Assessment, it can still inform the work that we do. Sarah noted that one of the findings of the Task Force was that even though there are existing Center/Network models in other states, they don't quite fit the needs and structure in Alabama. We are currently in that process and seeing results, which is nice.

Anna McConnell provided a report from Paige McKerchar regarding the Behavior Analyst Licensing Board, saying that the Board will begin accepting applications in June, no later than July. That would mean by the next fiscal year there should be licensure fully in place. Board Certified Behavior Analysts

(BCBAs) are already nationally board certified and the licensure would be a function of reimbursement issues for Alabama. The application is not available yet, but will be by June/July.

Member Updates:

Tina Sanders from ALSDE announced MEGA Conference July 10-14 in Mobile. Registration is available online.

Robert Caldwell noted that Autism Legislative Day was an opportunity to meet with legislators, specifically Slade Blackwell and Speaker McCutcheon's offices. He attended the Autism Walk and is a member of TAG (Triumph Advocacy Group), and is the Regional Autism Network Constituency Board for UAB.

Karen Willis also attended and participated in Autism Legislative Day. She announced that she is applying for a service dog. Bama Hager noted that her experiences in that application process may be able to inform other families as they pursue this as well.

Justin Schwartz announced Project ECHO. It recently received IRB approval, and is currently in active recruitment phase (using flyers and ads to primary care providers in AL). The anticipated start date is early June. AIACC members and attendees are encouraged to help spread the word. Also, a resolution was passed by the American Medical Association which was introduced by the American Academy of Pediatrics. The resolution focuses on the inclusion of developmental disabilities in curriculum for undergraduate, graduate, and continuing medical education. He noted that this is encouraging that it was formally adopted, since education in developmental disabilities is not something that there is ready access to, especially as we look to make lifespan care as good as possible. The resolution is one way to state the commitment to increased attention to curriculum development inclusion of DD. This can be used as a charge to make sure this attention to developmental disabilities is something that is truly included in education and practice.

Myra Jones noted that the Alabama Council on Developmental Disabilities is also working with Dustin Chandler on the First Responders Training. ACDD is also working with the ARC of Jefferson County on Wings for Autism project. The Saturday training needed to be postponed due to weather, but it is a real-life practice opportunity for the process of flying (getting a ticket, loading, taxi-ing, and in some places takeoff and landing, although not currently in AL). That partnership will continue through the next year. The ACDD has three requests for proposal available on their website (acdd.org)– for self-advocate support, employment, and community inclusion. The funding is up to \$75,000.

Dianne Tullier noted there is a new staff member of the AL Dept of Early Childhood Education, Dallas Rabig, State Coordinator of the Infant Early Childhood Mental Health Consultation. Dallas will coordinate efforts through technical assistance to communities and consultation services in early

childhood systems of care, support building of capacity within early childhood workforce to address social and emotional development and mental health problems in early childhood, coordinate the endorsement efforts of First Five Alabama. Through First Five Alabama, early childhood providers from all domains can seek endorsement, which is a credential of sort that helps others in that field identify what competency standards and professional needs in infant and early childhood mental health. There are 4 categories that identify various professional standing (for example: teachers, coaches, early interventionists, speech therapists, occupational therapists, physical therapists, and case managers may become endorsed at levels 1 and 2 based on education and experience). Most mental health clinicians may be endorsed at levels 3 and 4 as clinical providers, researchers, policy advocates, and mentors based on years of experience and education. There will be more information rolling out regarding the endorsement process at the PDI Summit in May and at various conferences around the state. There will be statewide dissemination of the process soon. First Five Alabama will be working on a systematic way to get the information out to the rest of the state as well as a meeting on May 19. The application process for endorsements is expected to open later this year for endorsements in 2018. There is a cohort currently going through the endorsement process. This is still a new process and something that will be able to help move forward Infant Early Childhood Mental Health. This is related to Project Launch, where a consultant is able to go into daycares, schools, etc. to trouble shoot behavior issues (which could be for a child with ASD).

Megan Everett said that she went to the Sibshops training in March in Milwaukee to become a trained provider. She is in Birmingham, and will let us know of the dates when that will begin.

Tina Sanders of the ALSDE reiterated that there are still contracts with Glenwood and the Learning Tree for evaluations and consultations. A recent survey to LEAs have said they are very pleased with these contracts. There were 300 autism evaluations and 200 consultations working with students with behavioral needs in the classroom.

Commissioner Burdeshaw noted that ADRS has a partnership with ALSDE. The Vocational Rehabilitation program is not under the Workforce Innovation Opportunity Act (WIOA), and regulations have been provided within the past year. ADRS is working with providers to expend 15% of federal allotment in VR program on pre-employment transition services (Pre-ETS). In the past, VR could begin serving those children at age 16. Now, with WIOA, they can begin serving children at age 14, as well as those who are potentially eligible for services and not yet declared eligible. That opens a window of opportunity for serving those who could benefit from the services. One way of achieving these activities is through the jointly funded pre-employment program transition specialists who are across the state. VR staff also went out in January and February to meet with all LEAs to come up with individualized plans for each school system on how to provide those pre-employment transition services. It opens the door for many things with providers, like additional job exploration training in summertime, serving kids who

need services over a longer period of time in order to go to work, or additional college prep programs to help those who can and want to go to college or technical training to learn to self advocate. If you have questions, contact ADRS/VR and help spread the word to families that these services are available and available at a younger age.

Brooke Bowles said that Triumph has started those services at Huffman High School and Homewood High School in Birmingham, and a transition program specific to ASD in Montgomery's tri-county area. Triumph has been able to go into the schools and do things like social skills training, financial literacy, transportation 101, job tries, and career exploration. The schools have been very welcoming, and this is a great program.

Sarah O'Kelley announced April 19 is the Glenwood Endowed Lecture (speaker is Dr. Cheryl McNeil talking about Parent Child Interaction Therapy), and April 20 is the Simpson Ramsey Neurodevelopmental Symposium (a collaboration between Civitan-Sparks and LEND program and the Department of Neurobiology). The Alabama Autism Conference was very well attended. The planning committee will be meeting soon – let Sarah O'Kelley know if you have any suggestions for next year's conference.

Dr. Abbie Baxter and Dr. Dennis Campbell provided a presentation on PASSAGE USA, a post-secondary educational experience for students with ID (http://www.usouthal.edu/colleges/ceps/passage/resources/pusa_pamphlet.pdf). This program is now offered at University of South Alabama.

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

Next meeting: Monday, July 10, 2017

Recording Secretary

A. McConnell

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