

Alabama Interagency Autism Coordinating Council (AIACC)

Monday, January 11, 2016

Alabama Industrial Development Training Center

The AIACC met on Monday, January 11, 2016, at the Alabama Industrial Development Training Center. The meeting was called to order by Chair, Senator Cam Ward. Also in attendance were Council members: Brooke Bowles, Greg Carlson, Doris Hill, Myra Jones, Melanie Jones, Whitney Meade, Commissioner Jim Perdue, Sarah Ryan, Todd Tomerlin and Karen Willis. The following proxies were in attendance as well: Russell Green on behalf of Stephanie Azar, Sarah O'Kelley on behalf of Fred Biasini, Karen Jenkins on behalf of Cary Boswell, Sandra Mack on behalf of Nancy Buckner, Vera Hendrix on behalf of John Mascia, Laurie Eldridge-Auffant on behalf of Thomas Miller, and Hanes Swingle on behalf of Miriam Peralta.

The minutes from the October 19, 2015 meeting were approved and adopted.

Senator Ward opened the meeting with his comments. There has been much attention in the national and state news regarding the presidential campaign. Senator Ward finds it refreshing to see the candidates speak about various issues, and points out the plans of Secretary Clinton, as well as that of Governor Kasich, both mention Autism and the need for better services and insurance coverage around the country. Senator Ward feels anytime there is a discussion about ASD on a national stage it is healthy for the cause. This forum may bring to the attention of more State Legislators the importance and how vital the issue is.

Senator Ward serves on the General Fund Budget Committee. While autism services, to whatever degree they exist, come out of both budgets, to a large degree it is expected the General Fund should be used. This will be a challenge again this year, as the General Fund will be short. Accounts which provide funding to the General Fund Budget don't grow very much, therefore, the budget continues to shrink as expenses continue to increase. Discussions will be beginning this week and the legislature goes into session on February 2nd. We expect no additional new programs from the General Fund budget.

Members of the committee and reps from the University of South Alabama and the University of Alabama at Birmingham are very receptive to the idea of Regional Centers. The Law was established in 2009 to create the framework for regional centers, and we are ready to try the first two. There is a possibility of opportunities to secure the funding necessary.

Anna McConnell, State Coordinator shared that the Annual Report is due the 10th legislative day of each session, which will be March 3rd. As soon as that is written and submitted she'll make it available electronically, posted on the website and sent via e-news.

For each of the Strategic Plan goals, there is an associated committee. Persons interested in serving on a committee, were given an opportunity to sign up via a sheet at the back of the room, and provided copies of the Strategic Plan Objectives.

In New Business, Brook Bowles spoke on behalf of the Accessibility Committee. They are focused on increasing choice and access to services for people on the spectrum. She is recruiting members for the committee and would love to have a Co-chair to work collaboratively with her. She also wanted to remind everyone that she and Joe Carter put together an Accessibility 101 presentation for the state of Alabama. They outline what is available throughout the lifespan and who funds each service. Brooke, Joe and Autism Society of Alabama have the presentation available upon request. She asked that it please be used to share with families, at any stage in their lives, to help them access services.

Accountability Committee – Whitney Meade is currently working on some things that have to come to fruition before they can move forward. She is also looking for members to join her committee.

Funding Committee – Greg Carlson states while they have not met as a committee, he does have an update on some of the issues that are being discussed. Autism Speaks had their Legal Summit in Mobile in November, which was well attended. Initiatives addressed included insurance, both private & public. There are many efforts to improve coverage and access to services as well as working on approval for services such as ABA. Persons who attended the conference and who would like to join the funding committee can let Greg know.

They are currently working on funding sources for Regional Centers, including a proposal that could leverage dollars from the University level to match money that might be forthcoming from the legislature. There may also be potential dollars that would be available in October 2016, assuming the waiver is approved. As Mr. Carlson understands, the waiver is close to being approved. Disability Leadership Coalition has a representative on the Citizen's Advisory

Committee, as does ARISE. One of those individuals has been on the Board of Directors for each of the RCOs.

Russell Green of Medicaid addressed the possibility the Waiver might not be approved. It is his opinion the leadership is not ready to go down that path. The most recent thing heard is that CMS is close to approval, however it is hard to say exactly what that means at this point. It is expected that if the Waiver is approved, it will give Alabama the opportunity to move forward with setting up the managed care model.

Melanie Jones of the Public Awareness Committee shared they are continuing to make good progress thanks to the work of the Autism Society. They are making progress with Regions Bank becoming the first Autism Friendly Bank in the state of Alabama.

The Autism Society is helping fund a Sensory Room at Camp ASCCA. They are continuing to provide sensory movies statewide. They are also continuing to update materials in one library in each of the 67 counties. They are Partnering with the Barons and Service Providers across the state to plan an outing that will be sensory friendly for May 1. Legislative day is scheduled for March 15th.

Sarah O'Kelley spoke on behalf of the Regional Centers Committee which are dependent on the status of funding. The five universities involved are pulling information and doing assessments in an on-going effort. The goal for the upcoming year is to move in this direction of establishing the centers. The location of the two centers that will receive funding will depend on the money available, and additional centers will be added over time.

Sarah Ryan of the Bylaws Committee stated there are currently two positions open. The positions are the Parent of a child 18 years or younger with ASD and a Self-advocate with ASD 19 years of age or older. The committee will be meeting in March to review applications and fill those seats.

The BCBA licensing board has been communicating with the Legislative Reference Service to submit necessary changes to the past bill. Rules and Regulations will be developed after that filing. October 1, 2016 is still the target date to be able to license these individuals.

As part of Regional Assessment updates Anna asked for anyone from the universities who would want to highlight what they've been doing to let her know. In conjunction with that, there is a

family survey, almost exactly the same as the one done in 2008-2009 with the Needs Assessment, which can be found on the website of the Autism Council. Regional Assessments continue to be conducted.

Member updates:

Russell Green of Medicaid clarified that Medicaid will recognize Board Certified Behavioral Analysts and Board Certified Assistant Behavioral Analysts as "Allied Health Professionals". As Allied Health Professionals, these categories are not eligible for enrollment as providers. This category will be similar to other Allied Health Professionals, for example, Licensed Professional Counselors who must work with a psychologist, the psychologist being the actual Medicaid provider. So the services performed by the BCBAs and BCABAs under the auspices of the psychologist, listed in the psychologist chapter of the provider manual, would be billed by the psychologist. The individual Allied Professional will not be able to bill directly. As for the RCOs, they will have some flexibility, as the services are actually going to be billed by the RCO, and not the performing provider. When asked if the BCBAs would be able to direct bill after the licensure in October, Mr. Green stated he is not in a position to answer that question at this time. More discussion is needed. Also, individuals who have had difficulties with the portal have probably encountered them due to the restriction of these categories not being authorized as providers.

Commissioner Perdue's initial comments include that he is excited to serve with such a fine group of people. As a former Probate Judge and Businessman, he feels he brings a different point of view to the table. He already has a great working relationship with Senator Ward, having served as the Legislative Liaison for Probate Judges.

His initial impression of the Council is that it is well organized and currently in a great place. His chief concern is the October 1 deadline for RCOs. There are more questions right now than answers, and the Commissioner thinks it would be optimistic to say they will be ready by October 1. This concerns him because the deadline was put in legislatively and the only way it could be changed would also be through the legislature. He doesn't want the Council to be in the position of jumping into something they are not ready for. As there will be some overlap with the Community Mental Health Centers and the RCOs, there is some serious concern about the path among those MHCs.

Optimistically speaking, we are on the doorstep of treating children with autism prior to reaching the first grade. If insurance law could be tweaked a little, which could happen this session, so funds would be made available through a premium increase, (using the term "shall" instead of "may"), the rest of the goals could be met more easily.

Regions Bank has gained some recognition by serving as the financial institution as part of an intermediary. We need to make sure those businesses like this and others can be shown as partners with this group. We need to recruit them whether it's the Bar Association or hospitals, or whatever. We need to give them an opportunity to shine with us.

Overall, Commissioner Perdue feels it is a privilege to be on this Council. Autism is one of the most aggressive yet treatable disabilities that we face.

Chair Person Ward suggests if you look at health care in general, not just Mental Health or Developmental Disabilities, health care in general, across the whole country has never been as "fluid" as it is right now. The Legislature is dealing with tweaks which need to be made to the RCOs, deadlines in particular, and the issue of funding. Funding is always an issue and all that is in flux right now. Rural Hospitals are currently engaged in a serious battle because of the Medicaid Expansion debate. While there are pluses and minuses on both sides, Medicaid Expansion will always be debated. Senator Ward feels we are closer to seeing it happen, than not. Insurance regulations are the same way, and there is a lot of concern and anguish, particularly for rural providers, with an increased demand for rural services. One of the biggest issues is the source of funding for individual services, but this could also provide an opportunity to help increase services. The next six to seven months should be telling.

Sarah O'Kelly is speaking on behalf of the UAB Civitan Sparks Clinic, home to the UCEDD and LEND grants. The big update right now is the four-year competitive renewal which is due in February. They are currently working on that and requests for Letters of Support will be sent out soon.

Upcoming events to highlight:

- The Autism Conference will be February 26th in Tuscaloosa. Speakers will include Amy Van Hecke from Marquette University. Dr. Van Hecke does EED/MRI research looking at the impact of intervention, particularly social skills interventions, with individuals on the Autism Spectrum; Cathy Pratt from Indiana will be talking about creating an inclusive environment across the school; Micah Mazurek who is a psychologist at University of

Missouri, will speak on anxiety and interventions for anxiety. Breakout sessions will include: Janet Shouse, Vanderbilt University, who is the parent advisor to a parent intervention program; Scott Parks from Spanish Fort High School will be talking about Project Reach and Project Outreach and will also bring a number of students to the conference. The conference will close out the day with a panel of Alabama-focused self-advocates with the assistance of John Miller a national Autism Self-Advocate facilitating.

- The Sparks Clinic and LEND grant will co-sponsor the Simpson-Ramsey lecture held at UAB in conjunction with neuro-biology and neuro-science. This will be a 2-day event, April 21 & 22. The focus of the symposium is to bring together speakers from basic science to clinical science and highlight the transitional aspects.

Bama Hager shared that she attended, along with many other advocates, the Autism Law Summit in Mobile. Alabama is one of the last seven states that do not have mandated insurance coverage for Autism treatment. There are advocates throughout the state who are willing to help looking closely at what other states have done to improve coverage for autism services without legislation. This does not mean we won't go forward with legislation, if we have to, for insurance reform, but we are looking at a few states that have better coverage without having to pass an autism law. Bama asked for volunteers who would like to be an advocate for autism insurance reform.

In addition this month, Autism Society will be kicking off a social media campaign called #autismmatters. They will be collecting photos from families, individuals, or children holding a sign with a #autismmatters on it. The photos will then be delivered to legislators. This could be a fun event for families, school groups, or communities, as the persons pictured don't have to be directly affected by autism.

Brooke Bowles spoke for Triumph Services, which provides community- based support to adults in the Birmingham area. Triumph is looking to open a new office in Montgomery. At this point they are trying to meet with collaborators and partners, so she would like suggestions of anyone she needs to talk to that would support Triumph Services in Montgomery. Also, Brooke is looking for 5-7 parents or professionals in any region in Alabama, other than Birmingham, to come spend a week with Triumph in late June to learn how to do what they do. It's called Certification in Community-based Services. It is funded by the DD council and will be an exciting opportunity to

learn how to provide community-based services and take that knowledge back to regions that perhaps do not have services available.

Dr. Hanes Swingle spoke for the University of South Alabama. Dr. David Grooms, Dr. Kim Zlomke, head of Child Psychology, and others are working with 20-plus graduate students who are pursuing their Ph.D., or Masters in Psychology, and are now being incorporated into Primary Care, the Department of Pediatrics and Specialty Clinics. This means there will be a psychologist in training working with families. They will be doing primary mental health services right at the point where the families come in and will reduce that barrier of having to go to the Psychology Clinic to get care. There is intense interest in working in the ASD Clinic. This has the potential to increase the amount of services the clinic can provide.

They are also conducting epidemiology study with the University of Texas by examining toxins that may be a contributing factor in the rise in Autism. The pilot study calls for thirty children with ASD and thirty controls. Thirty children with ASD were enrolled in the first two months, however, they are still trying to recruit controls between 2-8 years of age that do not have autism and live around the gulf. Interested parties should contact Dr. Swingle or Amy Mitchell for more information on the study.

Myra Jones with the Developmental Disabilities Council states they are excited to be working with Brooke on the Certification in Community-based Services project, and hopes to be working with the Autism Society on First Responders Training. The Council has a small fund for the purposes of supporting self-advocates in attending meetings. This can be helpful in helping persons attend board meetings, or conferences or workshops, or to support speakers at trainings.

Whitney Meade of the University of Alabama in Huntsville announced that in December their first group of Masters students, who have specializations in autism, graduated. The program is fully operational now and turning out graduates. They currently have a nice group that is working on core courses and will be heading into the autism courses. They are also looking for more students to increase the number of individuals who have a degree in autism. Scholarship money is available. The program is open to teachers who do not have a Master's degree and would like to pursue one. They are also offering a certificate program, for general education teachers who want to know more but already have a Master's degree. This is a route to take some course work for professional development and helps with renewal of a teaching certificate without being strapped into getting another degree.

Camp Autism Smiles will occur in April. The dates for families are April 16th and 17th. The dates for volunteers are April 15-17. The application will be on the Camp Autism Smiles Facebook page in early February. This is a family-based camp which will provide activities all day Saturday for the children to give parents some respite time. Sunday will be structured so volunteers are providing support to the families so they can access camp activities as a family unit. They are currently seeking volunteers 18 years of age and older, as the number of families able to attend is directly in proportion to the number of volunteers available.

Also, she has a grant funded to look at educational services for kids who are special needs and involved in the justice system, to have a better idea of what special education services look like for those that are incarcerated.

Todd Tomerlin spoke about Wings for Autism – in this program, persons on the spectrum and family members are able to go through the process of going to the airport and checking in for a flight, boarding the plane and taxiing the runway. The plane does not take off, but it is a wonderful chance for individuals to experience the process. The ARC of Birmingham has already gone through this and it was well received. Plans are for an event in Mobile on February 20th and also coming up in Huntsville. Any questions may be directed to Todd Tomerlin, or the Autism Society of Alabama.

Bama Folsom Hager share an Education update on the Administrative Code. She, along with Dustin Chandler, Todd Tomerlin and Whitney Meade attended a meeting with the Alabama State Department of Education, regarding the proposed changes to the current Administrative Code. Also in attendance were Special Education Leaders and a several parents. In addition to the efforts of the Autism Society of Alabama, they are monitoring the ongoing review of the proposed changes. Once those changes are submitted to the Board of Education, there could be a series of hearing regarding the changes, most of which deal with the processing of I.E.P.s, due process and the statute of limitations. Concerns should be directed to your State Board of Education representative, whose name may be found on their website by searching by zip code.

One concern in particular is that parents may not realize if they choose to allow their child to participate in the graduation ceremony and receive a "regular" diploma, they are giving away their right to continued education, and that individual will not be eligible to receive services

again until they reach the age of 21. There is, however, a process by which the child can participate in the program, but not actually receive a diploma, however many parents may not be aware of this.

Dustin Chandler is the President and Co-founder of Interaction Advisory Group, (IAG), which provides Autism training for First Responders. The group is focused on contact with persons with Autism and has the goal of promoting acceptance and awareness for all disorders in developmental disabilities.

Mr. Chandler has a law enforcement background as a police officer working streets for almost a decade. Most of his career was spent on nightshift patrol, dealing with Vice Operations, including street crime, involving drugs, prostitution and street violence. He also served with the U.S. Marshall's Service during Operation Falcon, which is a fugitive roundup, held every year.

Dustin is also the parent of a child with special need. He has a five year old daughter who has multiple disabilities, including ASD. She is not ambulatory or verbal. With his professional background and personal experience, he has a lot of empathy for both first responders and the parents. While he knows the parent's point of view and what they want the police officers to know, he also knows how police officers think

The training is called R.E.A.C.T.: Recognition and Evaluation of Autism Contact Training. The responders are taught to recognize and adapt to a situation with the goal of a better outcome. The training doesn't go into a clinical explanation of what autism is, but it does give them a brief overview and the knowledge of how to deal with an individual with Autism. The primary goal of the training is to give the responders tool to keep the officer, citizens and the individual safe.

School Resource Officers need this training, as well, to help children with ASD in the school system. This decade alone, half a million children with Autism will enter adulthood and increase the incidences of these individuals coming into contact with first responders. This training gives those responders the tools necessary to deal with the situations that might arise.

IAG is currently working on strategic partnerships to become capable of providing remote webinar training that could, potentially, be conducted world-wide. More information is available on the organization website at www.interactionadvisorygroup.com/, or they may be contacted by phone at 205-447-7998.

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

Next meeting: Monday, April 11, 2016.

Recording Secretary

C. S. Weldon

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