

Alabama Interagency Autism Coordinating Council (AIACC)

Monday, April 13, 2015

Alabama Industrial Development Training Center

The AIACC met on Tuesday, January 27th, 2015, 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, Lucian Cronkite, Sally Davis, Joshua Heard, Doris Hill, Elmyra Jones, Whitney Meade, Sarah Ryan, and Karen Willis. The following proxies were in attendance as well: Russell Green on behalf of Stephanie Azar, Lisa Highfield on behalf of Thomas Bice, David Savage on behalf of Cary Boswell, Erin Wofford on behalf of Nancy Buckner, Bama Hager on behalf of Melanie Jones, Christy Atkinson on behalf of John Mascia, Hanes Swingle on behalf of Miriam Peralta, and Dawn Ellis on behalf of Don Williamson.

The meeting was called to order by Co-Chairman Carlson.

The minutes from the January 27, 2015 meeting were approved and adopted.

Mr. Carlson mentioned a story shown on NBC's Dateline regarding a Florida family's experiences with transitioning an individual into adult services. Time permitting, there will be further discussion on the subject during this meeting.

Mr. Carlson's Comments regarding the Legislature: The Governor's Budget is a recommendation from the Governor's office based on the passage of tax bills that would increase the General Fund by about \$500 Million and would level-fund state agencies which operate off General Fund monies. This budget would also meet requirements for Medicaid and Prison Systems. Additional dollars would be needed to fund Senator Ward's bill on prison reform.

Senator Orr sent a letter to State Agencies asking each to consider what it would be like to incur a 15% to 30 % cut in the General Fund. For the Department of Mental Health, it would mean discontinuation of 1000 slots on the ID waiver. There is a question as to whether this would be legal. These cuts would result in more inpatient commitments but with nowhere to commit since the state hospitals are closed.

Medicaid Reform is progressing. However, Dr. Williamson did advise the legislature that if the cuts go through as proposed, even though only 3%, they would halt the waiver application for

Medicaid Reform/Regional Care Organizations (RCOs), and discontinue optional services. RCOs have been developed, and proposals for Health Homes have been awarded to six of the RCOs in the state, which began April 1st. At this time, the RCOs continue to meet and are active.

Per Fred Biasini, Governor Bentley has said that he would veto any budget that drastically cuts state budgets.

Anna McConnell shared the State Coordinator's Comments: The Annual Report has been completed and is included in members' packets. It includes general updates of the funding status and legislative issues. The Annual Report also includes the Strategic Plan, which has seen a lot of progress this year. Also Auburn University at Montgomery is offering a Certified Public Management course. Heather Goggin and Karen Coffy are present, representing the course. They will be partnering with the Autism Council in exploring ways to help with autism issues, particularly in the funding realm and in service issues as well. There will be a presentation in August at the Capitol.

Anna also expressed her thanks to the committees for all their hard work, and looks forward to hearing the updates.

Whitney Meade of the Accountability Committee stated they have been focusing most of their efforts in helping Anna establish a good body of research for Evidence Based Practice. Therefore, they have been putting most of their effort into doing their own literature reviews to ensure there is a robust body of research to support the identified strategies.

Bama Folsom Hager is reporting for Melanie Jones regarding Special Projects. The Public Awareness Committee has done a great deal of work. She was able to garner responses from parents to the survey regarding places in the community they would like to see more Autism friendly. Bama will give an update on those results later.

Funding and Finance Committee update from Greg Carlson: The minutes of the committee meeting have been included in Members' packets. One thing that was discussed is what is available for children and the best way to get that information into some format to allow families to better understand what is available to them, as well as what they can expect through the lifetime. First of all, they were attempting to come up with a proposal for the legislature for the funding of the five regional centers that would be university based. In the meantime, Senator

Ward has met with the budget committee chairs about including an amount in the Education Trust Fund to kick start those programs.

Fred Biasini added that in the Executive Committee Meeting Senator Ward proposed starting with two centers, but Anna, Greg and Fred counter-proposed starting with five. He then went to the Budget Committee chairs and talked to them about starting with a set amount of \$500,000 or \$100,000 for each possible pilot or planning center (five total).

Greg added that there has been some work in determining the Universities' interest and if they would be able to leverage those dollars if awarded to their institutions. Five have responded that they are very interested.

The Funding and Finance Committee currently has a working document, developed in conjunction with UAB for the purpose of establishing a budget for the regional centers.

The committee is also trying to identify all the potential coverage areas for kids and adults with Autism. They have determined there is a lot of information on what could be available and not quite as much about what is currently available. They have also done some research into what a waiver for Medicaid waiver would cost the state.

Russell Green of Medicaid did not have the numbers at hand but seemed to recall that the initial estimates for State Match needed to cover ABA therapy under EPSDT was around \$130 Million, so clearly a large percentage would come from Federal funds as well. After further study, the number was reduced to a State Match of \$32 million needed. Medicaid continues to review, and it is all contingent on what comes out of the legislature. He doesn't have any data on how much support there is for an Autism Waiver. He thinks if the legislature finds a way to fund it clearly Medicaid will implement it.

This past week they received an inquiry from someone that asked if Medicaid would provide ABA services for a 5 year old child. In accordance with EPSDT guidelines, and the Medicaid State Plan, those children will have to be provided those services. So Medicaid is crafting its response now, in effect to say, whatever services are needed by children, irrespective of ABA per se not being covered, those services will be provided to those children. Even if it is on a case by case basis until everything gets in place. Essentially, Medicaid is not going to deny a child services because legally, it cannot.

Other issues the Funding Committee is working on:

- IDEA – Discussion of what services are available for children – meeting further with Education
- Tricare - Currently identifying issues with billing/payments and will bring in someone to address
- Federal Employee Insurance Coverage – Federal Employees are technically covered for autism services; however, coverage specifics are determined on a state by state basis. Plans are in the works to approach the Office of Personnel Management to request this coverage be extended to federal employees in Alabama.

Brooke Bowles gave an update from the Accessibility Committee – They are trying to increase funding and improve services for people on the autism spectrum. They are considering how to help individuals with ASD access services and have a choice among what is currently available. Their activities include developing a comprehensive list of all public and privately funded individuals or groups who work with autism. This is not a list of sources they necessarily endorse or have evaluated. They just want to present the information. It would be up to the individual to determine if the provider is a good fit for them. It is believed there are more services available than they may currently be aware of.

Also, Brooke and Anna met with Commissioner Boswell from the Department of Rehab Services. He has agreed to pilot an ASD Liaison for the Birmingham ADRS office. If successful, he will consider having a liaison in every ADRS office in the state. This would mean persons with a diagnosis of ASD, or history of autism would automatically go to the liaison instead of a counselor potentially less familiar with ASD and based on zip code. Dr. Boswell allowed the Accessibility group to make recommendations of who would be good counselor in the Birmingham office and also to train the counselor.

There was also a small group meeting this morning to brainstorm and share information on how to get services when a person receives an ASD diagnosis or when transitioning. Typically the go-to would be the local chapter of the Autism Society. Therefore, to improve accessibility, training will be provided to all the chapters of the ASA on publicly funded services. Then Chapters will provide information to the families on how the services look and give recommendations if they are having trouble accessing services.

Fred Biasini spoke about the Regional Care Centers. One of the mandates for the centers is that they provide some level of care coordination for families to find/access services. Regional Care Centers, or Regional Network Centers would involve having experts in Autism at each location.

The four areas each center would be responsible for are:

- Individual and direct family assistance in the home, community, and school – this could also be a care coordination model(modeled after the CARD Network in Florida);
- professional training, including pre-service and in-service training;
- technical assistance/consultation;
- public education.

Though the proposal included a need of \$1.2 million per center, 1/3 of the funding is from the state. The remainder is from grants, local resources, school systems, etc. Senator Ward felt it would not be possible to get \$1.2 million, so instead he proposed starting two pilots with \$300,000 total. He suggested they be at the University of Alabama Birmingham and the University of South Alabama. Greg, Anna and Fred counter-proposed five pilots, one in each of the Regional Care Networks. They suggested starting the five pilots at \$500,000 each and that they be located at the University of Alabama, the University of Alabama at Birmingham, the University of Alabama at Huntsville, the University of South Alabama, and Auburn University. Initially these centers would provide basic services (training, care coordination, etc. as outlined in the original legislation), but would eventually expand their capacity and have more community partnerships, with the possibility of more centers in the future. They then asked the people at those universities with autism services if they would be interested in these programs. All five said they would be. The Universities were asked to come up with a tentative budget. Some gave a budget for around \$100,000. They then began to piece together what they could actually accomplish with \$100,000. It was decided they would have to implement, to some degree, all four of those mandated services, but they would target or identify one or two areas of need for their area to focus on. For example, Dr. Swingle proposed a couple of things for USA. Increased adult services and more collaboration with schools systems.

Another option would be to get additional funding to bring in more partners in the regions. Conclusively, all five universities were asked for a budget, a budget narrative & a plan for addressing the four areas, by June 1, at which time funding should be known.

Bama Folsom Hager gave the update for Melanie Jones of the Public Awareness Committee. Per Bama, Melanie reports they are currently focused on the Autism Friendly campaign for the state of Alabama. The campaign has been developed to assist businesses in becoming more autism friendly. They will focus on training videos, a sort of "Autism 101" for business employees. They will also show businesses how they can get involved in the Autism Friendly project and the steps for each business to get underway. They would like to see Recreation Centers, YMCAs, Banks, Health Clubs, Grocery Stores, (any place where families go everyday) to get involved in this statewide effort. A logo has been designed, and participating businesses will have the option to display the designation on their door/window. The group is currently on track to bring this project to fruition and is using information supplied by parents as to where to first focus their attention.

Bama also spoke about the ABLE Act, which has passed federally, as a tax-free savings account created for families with an individual who was disabled before the age of 26. Each state now has to pass their own ABLE Act. Bama believes Alabama will be one of the first states to pass and that it will happen this session. The ASA will make sure to keep everyone updated through social media.

The Able Act behaves like a 529A account. Parents may contribute up to \$14,000 per year which can then be used by an adult later in life for anything that they might wish to spend it on. There are some rules about what it can be used for. The rules are fairly generous, and include use for education, living expenses, travel, etc. Also, in Alabama, adults who are receiving some income can place those dollars into their 529A account, as well. This could allow individuals to earn more than the current caps, without losing benefits, by direct-depositing the overages into the ABLE account. The account will have a max of \$100,000. Many families will choose to have a Special Needs Trust in addition to an ABLE account. Katherine Barr is a great resource for questions. She may be contacted at kbarr@sirote.com or 205-930-5147. Also, Christ Stewart of the ARC of Jefferson County has said he would be available to speak on the subject after the Act passes. The ABLE Act Bills are HB274 and SB226.

Lucian Cronkite, LCSW, CPM is the manager of the Autism program for New Directions Behavioral Health. New Directions is partnered with Blue Cross Blue Shield of Alabama to manage behavioral health benefits for subscribers. They have been in business for 20 years and they are partnered with six other Blue Cross programs across the country.

Ms. Cronkite's background includes her experience as the Principal Director of the Challenger School at Northwest Alabama Mental Health Center. The program was partnered with the Fayette County Board of Education and the Mental Health Center. They had children in grades from Kindergarten to High School. Services provided were considered day treatment and will be billed to Medicaid. Ms. Cronkite's experience in Mental Health spans 38 years, during which she developed behavioral management systems in hospitals as well as helped teachers develop management systems at the Challenger School.

New Directions has a team located in the Blue Cross office operating as Case Managers for Mental Health in/outpatient services. They have BCBA's on staff who perform all reviews. In other states, they have worked on education of using new codes and medical policies. They are available for consultation and case management and refer parents and siblings for counseling, as well as remain current on available resources. They review and approve services, but do not provide direct services.

Ms. Cronkite asked that any questions be directed to Anna, or to her at lcronkite@ndbh.com, and she will respond at a later time.

Member Updates include Greg's announcement of Glenwood's lecture up in Birmingham, featuring Brenda Smith-Myles on April 15th.

Autism Society of Alabama, for Autism Awareness month, is sponsoring walks and 5k runs throughout the state during the month. The Autism Conference will be May 8th in Mobile and will focus on teachers. The Autism ID Cards process is moving forward. The Alabama Department of Public Health is completing the application process. Applications will be available to families at any local Public Health Offices. First Responder Training has been requested and has started throughout the state in response to the Autism ID Card. Dustin Chandler who is a Disability Advocate throughout the state will perform those trainings. He has been trained by an internationally known first responder trainer, Dennis Debbaudt. May 3rd will be Autism Day at the Barons. There will be representation from across the state. This will provide an opportunity for individuals with autism to enjoy a baseball game without all the sensory stimulation, as well as educate the public and highlight the successes of those with ASD. Tickets will be \$5, it is a Sunday afternoon game and the Barons will be facing Chattanooga.

Myra Jones with the Alabama Council on Developmental Disabilities shared that the A-APSE/ACDD conference will be in Mobile, June 17-19. Sue Sorenson will be one of the keynote speakers, and is the Deputy Secretary of the Office of Education and Rehabilitation Services, as well as the parent of an Adult with ASD.

Hanes Swingle shared that Dr. Stephanie Anderson is present for the meeting. Public speaking events upcoming, include a local radio interview, and speaking with the Masons later in the week. Also, the local Autism Chapter honored them by keeping the proclamation of Autism Awareness month in their clinic. In addition, they were featured on the *Med School Watercooler*, a university publication, highlighting Light It Up Blue.

Per Lisa Highfield, Department of Education, they are currently working on several projects involving pilot sites across the state spanning preschool level to preparing students with autism for college. She will be able to share more on this in the future.

Sonia Clecker from ADRS shared that ADRS and CRS will be co-hosting a pediatric feeding seminar from June 11th – 13th. This is a three day feeding course that looks at sensory and behavioral issues, and a fourth day on June 14th, that will include a several-hour specialty course regarding feeding a child on the autism spectrum. Attendance the first three days is required for the specialty course on day four.

Sally Davis shared with the group that she has been working a lot with the Autism Resource Foundation in Huntsville, and they are putting together sensory programs with the Space and Rocket Center.

Doris Hill of Auburn University asked if anyone has any information to contribute regarding the Needs Assessments for the Regional Centers to please get in touch with her.

Joshua Heard, Council Member, and Secretary of the SGA Disability Services at AUM shared information regarding a Movie Event on campus titled "Adam". This movie and event is an effort to spread Autism Awareness, and they will also be distributing Autism Awareness Bracelets during the event.

Sarah Ryan of the University of Alabama shared that Tuscaloosa will be having their Autism Walk this Saturday at Central High School.

Whitney Meade reported that Camp Autism Smiles is coming up in two weeks. They have over 45 volunteers, most are education pre-services teachers that will get their first real live experience with working with the family as a whole unit.

Fred Biasini shared that the Simpson Ramsey Symposium will be this Thursday and will focus on transition. They will have Erin Reihle, who created Project Search, and Heidi Menendez, who runs a program similar to Horizons/Triumph on the University of Cincinnati campus. Students get an actual on-site campus experience and certificates of attendance. The symposium will focus on education, employment and health issues: the whole transition process.

Greg Carlson finished up the meeting with a discussion of the Dateline Program, featuring two young men who each turned 21 and were suddenly faced with no services. An open discussion followed regarding the transition process in Alabama. Federally, transition is supposed to start at least by age 16. The IEP team creates the transition plan. There are 7 current Project SEARCH sites, and some students work with Triumph Services. Many work with VR – DOE is hoping to do more collaboration with VR for seamless transition. College bound students are also receiving attention and work is being done at DOE to address those hurdles. DOE mentioned that there were a lot of things in the works with different agencies currently. Issues also arise in regard to teaching parents about services – moving from an entitlement to an eligibility service structure, and planning for post-school life. There is a post-school survey to see where students are, but it is massive undertaking and difficult to carry out effectively. It was noted that there was data that showed that as little as 4% of individuals with ASD that went through VR actually ended up in employment (not specifically competitive employment). The data also showed that when parents were involved rather than just the school system and VR, that the employment rate was higher. The IEP team begins transition planning; at age 18 the VR counselor is invited to IEP meetings for transition planning. This does not necessarily mean that VR will do own assessments – and VR can have less time due to capacity. VR operates on referral. It was noted that there is a national initiative for Employment First, driven by an interagency coalition; there is a subject matter expert (Alan Bergman) that is working with the AL and there is work being done on braided funding. It was stopped legislatively because of concerns from those with sheltered workshops. Workforce Reinvestment Act requires a percentage (15% that must be spent by Sept 30) of VR funds for pre-vocational training (for students in schools, etc.). It also limits use of sheltered workshops. It focuses on seamless transition of services. Nationally, about 17-18% with ID and 25% with ASD are gainfully employed. This is a huge unemployment rate for a group that

could have more independence. There are a number of AL companies that successfully employ people with disabilities. Would carrying out the transition plans at age 16 reduce the lifetime cost of care for those with ASD? There needs to be stronger partnerships between VR and DOE. Transition programs for some students is minimal. There is a page/form from DOE that is used to determine goals based on individual assessments (i.e. long term goal, and yearly goals to achieve long term). Expectations for people with disabilities and ASD need to be elevated beyond "canned" expectations of baggers and janitorial. Students are to be involved in IEP meetings, and their interests are to be taken into account during transition planning. Training and funding are some key areas that could address these issues. The Employment First initiative should make significant progress forward.

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

Next meeting: Monday, July 13, 2015.

Recording Secretary

C. S. Weldon