

Alabama Interagency Autism Coordinating Council (AIACC)

Monday, July 13, 2015

Alabama Industrial Development Training Center

The AIACC met on Monday, July 13, 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, Doris Hill, Melanie Jones, Becky Nordgren, Sarah Ryan, Todd Tomerlin, and Karen Willis. The following proxies were in attendance as well: Russell Green on behalf of Stephanie Azar, Susan Goldthwaite on behalf of Thomas Bice, David Savage on behalf of Cary Boswell, Rosalind Butts on behalf of Brooke Bowles, Erin Wofford on behalf of Nancy Buckner, Hanes Swingle on behalf of Miriam Peralta, Courtney Tarver on behalf of Jim Perdue, Julie Henthorne on behalf of Jeana Ross and Dawn Ellis on behalf of Don Williamson.

In reference to the Special Session which is starting today, Becky Nordgren stated some items that are not ready as they have not passed through the Legislative Fiscal Office. Today the session will be short and should begin in earnest the second week of August.

In Chairperson's comments, Greg Carlson shared his disappointment with the General Fund Budget not being passed. If it isn't passed and funded at an adequate level, the work being done by Medicaid on the Regional Care Organizations (RCOs) will be adversely impacted. In addition, cuts to agencies, could be detrimental. Medicaid and Mental Health are two of the biggest agencies that would be affected. There have been rallies held throughout the state to garner publicity regarding the need for funding.

Courtney Tarver of AL Department of Mental Health adds that the department has some money from the Education Trust Fund (ETF) which is level funded, however, there is no budget yet in the General Fund. For planning purposes the Department is currently issuing contracts hoping they will be level funded. If they get the additional, desperately needed, revenue, contracts can be amended up. If there are are cuts, they'll have to amend them down.

Greg mentioned that in regards to AIACC if the General Fund was passed, there was going to be a cut to the council by one quarter. The hope is that can get restored. Few funds are allotted to the council, as most of the work is done by volunteers. Regional Center funding was not included in the Special Education Trust Fund budget so there may be some news for the General Fund.

Anna wanted to make the committee aware that DMH has a new commissioner. Mr. Tarver shared that Jim Perdue, former Probate Judge of Crenshaw County has begun serving in this capacity. During his time as a Judge, Commissioner Perdue served as legislative liaison, and was recently appointed to the Advisory Board of Trustees, for the Department. He served as President of the Mental Health Center that serves Crenshaw and surrounding counties, and worked on the Health Care Board in his area. He has "hit the ground running", and has been absorbed with budget issues. He is a very caring person and committed to serving others. Mr. Tarver stated the Department is glad to have him.

Anna gave an update about the BCBA Licensure Board. There was one thing they had to amend and that has been done. They are still working on details, so applications are not yet available. They will make an announcement once applications are available. Mr. Tarver added that he has met with them and there may still need to be a couple of amendments to the legislation, Unfortunately, that won't happen until the next regular session of the legislature, so it will be a little while longer. They will be beginning to look at regulations in the meantime, but some additions to the statute may be necessary. They will know more after next meeting.

Accessibility Committee Report:

The Accessibility Committee of the AIACC Strategic Plan has the goal to advocate for increased choice among and access to quality services and supports for people with ASD and their families.

Members of the Accessibility Committee met in April to discuss how to best inform families and individuals about services in Alabama. The information needs to be concise and available across the state. We agreed that the Autism Society of Alabama is the best channel for this communication.

On July 17th, the Autism Society of Alabama is having a Network Leaders Conference. This is a group of about 30 leaders who are the autism advocates and Autism Society contacts in their hometowns. They take information from the meeting back to their local communities. Thirty-three towns in Alabama have ASA Network Support Groups.

Joe Carter from Glenwood, Inc. and Brooke Bowles from Triumph Services will present to this group on how to access services in Alabama across the lifespan. The focus of the presentation will be on services offered through the Department of Mental Health, the Department of Rehabilitation Services, the Department of Education, and Private Pay. There will also be an emphasis on entitlement versus eligibility.

The Accessibility Committee also continues to work with the Alabama Autism Providers Network in developing a comprehensive listing of all individuals or agencies providing any level of support to people on the autism spectrum.

Accountability Workgroup Report:

Per Anna, the Accountability Workgroup has been looking at ways to support the Standards of Practice work that has been done. They are also synthesizing some of the new information that has come out. For instance, the National Professional Development Center on Autism put out some recommendations late last year. In addition, the National Autism Center recently released a Phase II to some of their recommendations.

Funding Committee Report:

Per Greg Carlson, the Funding Committee hasn't met yet, but has been able to come up with the figure that Senator Ward needed for the prototype budget for the Senate. They are also looking at how services get funded, other than through the legislature. A big component of that funding is the EPSDT program and how that is progressing nationally. This program is moving forward, and will be discussed more fully in Russell Green's report from Medicaid.

Public Awareness Report:

Melanie Jones provided handouts to the group regarding the Autism Friendly Alabama campaign. Meetings regarding this project are currently occurring by email. The distribution list now stands at around 100 people, up from the original 15. Some of their goals have already been met in making Alabama more autism friendly. Recently, the Birmingham Barons baseball team held an Autism Awareness Night. The Autism Society, Triumph Services and other service providers were involved. The response was great.

Also, sensory movies are being offered throughout the state of Alabama. There has been good feedback from personal experiences with these events.

Another effort that is going a long way to make Alabama more autism friendly is First Responder trainings. Currently they are scheduled in Mobile, Birmingham, Auburn and Montgomery.

One of the goals that has not been met is producing the Autism Friendly decal which will be awarded to businesses who complete training and are designated as Autism Friendly zones. Melanie is currently working with the University of Missouri to get information on how they currently conduct this type of training.

In addition to these efforts toward Public Awareness is the work being done on the Autism I.D. Sarah O'Kelley has had a group of Psychiatry and Speech Language trainees as well as faculty at the Sparks Clinic work on a draft Social Story to help people understand ways to use the Autism I.D. card. She has shared the draft with the Council, and it will be available for comments on the website. Sarah will be open to suggestions during and after the meeting. She will also glad to discuss comments via email. She is available at sokelley@uab.edu.

A possible issue was recently brought to their attention when a parent submitted an application for an I.D. card, to the Sparks Clinic, where their child's diagnosis was originally made. However, the clinician that made the original diagnosis is no longer on staff there. The application appears to indicate the person who made the diagnosis should sign. In fact, information on the Department of Public Health's website states more generally that "a health care provider" must verify the person is on the spectrum. In order to reduce confusion it is being suggested that applicants include the instructions from DPH so the provider will understand what it is they are signing. It would also be helpful to include the signature and diagnosis pages from reports of original diagnosis. Sarah is still working with DPH on clarification.

Also, on the subject of the I.D. cards, Anna thanked Karen Willis, Council Member, for doing a great job in a media interview about the I.D. Card and how/when it could be helpful.

Regional Networks Report

Fred Biasini stated that the group got together and brainstormed, as well as gathered info for Senator Ward on initial costs that will be required. The initial thought is the cost of the centers should be in the millions, but to at least start off with \$100,000 each for up to five centers. They will be working with the University of Alabama, the University of Alabama at Birmingham, the University of Alabama at Huntsville, Auburn University and the University of South Alabama. They are still unsure about funding for the initial first year, but they are preparing, with the small amount of funding that was left in the AIACC budget, to gather information through each of the universities. They will identify resources, do family interviews, possibly hold community forums and survey service providers to get an idea of what kind of instruments/screening they are doing and the results. A list of questions has been developed, and they will be working on those, hoping to get all that information by January.

Chairperson Carlson took a break from updates and the minutes from the April 13, 2015 meeting were approved and adopted.

Member Updates:

Anna wanted to share that the Act Early Alabama information will be available on the [AIACC website](#). They are currently working with UCEDD and Sparks to have it on their website as well.

Susan Goldthwaite had no updates to share on behalf of the Department of Education. In response to Greg's question, she stated there will be no changes to code at this time.

Melanie Jones of the Autism Society shared the Autism Shines Gala will be at the Marriott in Birmingham, August 22nd.

Dr. Swingle of the University of South Alabama shared they are starting a study with the University of Texas in Houston. They will be looking at environmental pollutants that may be associated with autism. They will be studying thirty elements in particular to include dioxin, BPH, phthalates and others that could potentially be causing the rise in the number of cases of autism.

Greg recognized Karen Willis, who has been active in self-advocacy work since the last Council meeting.

Russell Green of Medicaid also congratulated Karen on an excellent job with the Media.

Russell said he has been asked how Medicaid will handle the new Applied Behavior Analyst services. On behalf of the agency, Russell states that Medicaid will treat all children, regardless of condition, based on medical necessity. In reference to Autism, these services typically include occupational therapy, speech therapy and physical therapy, as well as the basic components of ABA in assessments and testing provided by psychologists and allied mental health professionals. These services will be covered, as is federally mandated.

As of this date, as no applications for ABA have been received, there has been no opportunity to put a procedure in place. If such requests comes in, they will be sent to Russell.

In reference to the Regional Care Organizations, agency officials met with CMS officials to discuss the 1115 waiver. If approved by CMS, things can move forward with the RCOs. However, the budgetary impact will significantly affect the progress. The agency is cautious and waiting to see what happens with that.

In reference to program funding, this varies depending on services involved. Shares are paid by various groups, and there is a division of federal and state funds.

Anna pointed out that Russell did not mention ABA when listing the types of services that would be covered. His response is that the determination would be made on a case by case basis, following receipt of documentation such as doctor's orders, care plans, needs assessments, etc. In response to Anna's question he stated there has currently been no response made to CMS regarding ABA coverage under EPSDT.

Mr. Tarver added that in the two Waivers that DMH currently operates, for intellectual disability services, if an individual has autism co-occurring with ID, there is behavior therapy at three levels in the ID Waiver and LAH Waivers that were modified somewhat at renewal. Some of those services are required to be performed by a BCBA.

From UCEDD, Sarah O'Kelley and Fred Biasini will be attending the Autism Cares Meeting in Washington. This will be a great information sharing opportunity for professionals from across the country.

Per Mr. Tarver, there is much going on in the Department of Mental Health. One of the biggest is the ID Waiver Renewal through CMS. This has been completed and the program has been approved for another five years. Since that time DMH, and Medicaid have had to update data systems to bill the services being phased in. A large part of those services relate to employment of the people that DMH serves. A number of services have been re-defined to help build a more flexible, integrated day of activity for people who are preparing to work, are working, or, are not working. Individuals will be provided more community-based experiences that help people under the waiver service package get more access to the broader community. Providers are shifting toward incorporating new services into individualized plans. Getting the waiver renewed was challenging in that just last year in March, CMS promulgated a new home and community-based service rule that gives a more detailed definition of what home and community-based really means.

The Living at Home waiver currently serves about 1/10th of the people the ID waiver serves. The LAH Waiver is currently up for renewal, and once complete will be put out for public comments prior to being submitted to CMS. There are fewer changes in this waiver, and they have been matched to the services in the new ID waiver. Rate restructuring analysis is happening. Other agencies and stakeholders are involved and there has been technical assistance from the US Labor department.

Next up will be to finish the ACT II waiver which will serve a broader developmentally delayed population, who are currently in nursing homes, as they are moved into home and community-based care.

Mr. Carlson shared that Glenwood has recently joined the Healthy General Fund Partnership which was started by ARISE, AARP, Children's first, AAP... all the disability groups including The Disability Leadership Coalition, in order to assist legislators with the task of developing the general fund budget. Anyone interested is welcome to join.

Presentations:

Parents as Teachers: Heather Johnson spoke on behalf of *Parents as Teachers*. Heather previously interned with Autism Society and now works with UCP of Greater Birmingham. *Parents as Teachers* serves Jefferson, Blount, and Cullman counties. Forty-four counties across the state have this home visiting program. It is free of cost to families and participation is voluntary. They serve the age group birth to kindergarten entry. The program focuses on families with children who are diagnosed with, suspected of having, or at risk of having Developmental Disabilities. They often work with Early Intervention programs, and can still serve, even after Early Intervention services end, to help transition into kindergarten to prevent any gap in services. This is a valuable program in that the early years of a child's life are critical for optimal development. Parents are a child's first and most influential teacher. Curriculum used by *Parents as Teachers* has been around for over thirty years. The program aims to partner, reflect, and facilitate with the families. Visits are usually every other week, but can be more or less often, as needed. Typically, visits last about an hour, and focus on three main things. One of which is parent/child interaction with a pre-planned activity or game. There is also a development center parenting component in which they spend time talking to parents about what to expect from the child. Lastly they discuss family well-being. They spend a lot of time getting to know the family and what their needs are, and connecting them to the resources needed.

The main goal is to increase the parent's knowledge of their child's emerging development and what is age-appropriate development, to improve the parent capacity and their parenting practices, as well as their parent-child relationship, and provide early detection for developmental delays and health issues.

ABLE Act: Chris Stewart, President/CEO of ARC of Jefferson County shared an update regarding the ABLE (Achieving a Better Life Experience) Act. This act is basically a 529 account for people with disabilities. It is governed under section 529A of the Internal Revenue Code. Mr. Stewart is of the opinion that the ABLE accounts probably won't take the place of the Special Needs Trust, as the Special Needs Trust adds more flexibility and gives individuals a better option. The ABLE legislation is modeled on the 529 plan for individuals going to college. It will pay for qualified expenses, including education, housing, transportation, employment training and support, assistive technology and personal support services, health, financial management and administrative services,

legal fees, burial expenses and other expenses the Secretary of the Treasury promulgates.

One important point to note is in the case of individuals dependent on SSI, money from the ABLE account used to pay for housing, rent, or food will be deducted from SSI, as stated in the code. The annual contribution limit of the account is equal to the annual gift tax exclusion (currently \$14,000/year) and can grow to any size. If the account exceeds \$100,000, the individual will begin to lose SSI and Medicaid benefits.

The account can be funded anyway a 529 account can, except it must be done in the state of Alabama, if the person is a resident in Alabama. It cannot be funded through legal action or a will process. Contributions are not tax deductible, but growth is tax free.

Alabama is one of the first states to pass this legislation, and it should be especially good for persons who cannot afford the Special Needs Trust. The account must be in the disabled individual's name and they are the owner of the account. While the regulations are not done yet, accounts can be set up beginning January 2016.

Announcements:

ARC of Jefferson County has announced their *Wings for ASD* program at the airport. This program will allow children and young adults with ASD an opportunity to experience the airport as if they were taking a flight. They will go through security, and board a plane that will taxi around the airport before returning them to the gate to deplane. The first event will be September 26th at 4:00. Such events, which are part of a national program, will be held two times a year. Airport employees will receive training, and the whole event will be Autism friendly. The link for registration will be made available.

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

Next meeting: Monday, October 19, 2015.

Recording Secretary

C. S. Weldon