

Alabama Interagency Autism Coordinating Council (AIACC)

Monday, April 18, 2022

Zoom

The AIACC met on Monday, April 18, 2022, via Zoom (due to COVID-19 meeting capacity restrictions). The meeting was called to order by Dr. Erich Grommet. Also in attendance were Council members: Commissioner Jane Elizabeth Burdeshaw, Robert Caldwell, Tametria Conner, Dr. Erich Grommet, Dr. Heather Jones, Dr. Sarah O'Kelley, Dr. Justin Schwartz, and Chris Stewart. The following proxies were in attendance as well: Elizabeth Huckabee for Commissioner Stephanie Azar, Elisabeth Newell for State Superintendent Eric Mackey, Wendi Glass for John Mascia, Asia Sticka for Dr. Whitney Meade, and Yada Horace for Commissioner Ridling. Also in attendance was Anna McConnell, State Autism Coordinator.

The minutes from January 2022 were unanimously approved.

Dr. Grommet welcomed the Council and extended an invite to anyone joining the forum for the first time to introduce themselves. Ms. Kelly Odom was invited to join the AIACC meeting. Ms. Odom is a mother of two children with Autism and she is a passionate advocate for them and is enthusiastic and ready to assist however she can.

Ms. Beth Huckabee with the Alabama Medicaid Agency also greeted the forum.

Lead Agency Comments and State Coordinator Announcements:

Ms. McConnell noted that there are some opportunities for public comment again for the Community Waiver Program. ADAP has sent out some of the opportunities for public comments throughout several counties. They are also providing the opportunity in some of community mental health centers. They're updating models, CBHC along with other broader mental health models. There will be more information regarding the models later.

In the State Coordinator announcements, Ms. McConnell noted that a group would be convening to review the applications for the Council, she also noted some changes in the timeline for the council members. Council members who are approaching the end of their respective terms, but not officially ended were encouraged to stay. However, if that is no longer possible the members were encouraged to let Ms. McConnell know so the position could be filled prior to the member's term completion. Ms. McConnell was hopeful to hear back from those members soon. The group will convene for further discussion and review.

New Business:

0-5 Subcommittee:

Dr. O'Kelley reminded the forum of her work group's focus, which is taking a deeper look at the systems of care and how children and families are being supported through those early years. The work group

has convened intermittently, but she noted there's a lot of progress happening behind the scenes! Dr. O'Kelley also reminded the council of the different components, which include one group that has been heavily focused on encouraging evidence-based strategies within the Early Intervention system for children with known or suspected Autism, and Dr. Andy Barber and Dr. Kimberly Tomeny have led this initiative along with the screening components. The pilot initiative within four Early Intervention programs in the State has also been a focal point for almost a year. Routine screening of children who are referred to EI for Autism spectrum disorders. The goal is to identify children who need Autism specific interventions and get them on the pathway for diagnosis. The other component has been transitioning from Early Interventions support C services to part B services. There is also a subgroup moving forward on collecting information about that process and taking some information that's been acquired already and putting that into practice. Dr. O'Kelley also noted that a small team of individuals meet every other week along with the Early Intervention professionals, that meet weekly with the pilot programs.

Ms. Wendy Pittard shared her ASD Screening dashboard overview for the pilot program. The pilot program has been able to serve 258 cases in less than a year within the four Early Intervention programs. The dashboard provided a breakdown by gender (71% male and 29% female), race (54% Caucasian, 36% African American and 2 to 4 percent were made up of the Hispanic and Asian population respectively), financial information (insurance coverage; most cases were Medicaid eligible children following those covered under private insurance, All Kids, and no insurance coverage). The dashboard also included data for age at the time of EI referral and age at initial M-CHAT-R, average M-CHAT-R score, male/female and M-CHAT-R pass/fail rate, and referrals for ASD diagnosis evaluation.

6-13 Subcommittee:

Dr. Heather Jones noted that her work group has continued to meet monthly. Their focus has been supporting the State Department of Education's Autism Academy. The Autism Academy has launched and is online and through the State Department of Education. A survey that has been sent to each expert that could provide presentations or resources to add to the Autism Academy. It will also assist with providing information for teachers and what they would be looking for as it relates to training and resources

Ms. Elizabeth Newell shared that the survey would help them identify what the teachers know, are unaware of, what they'd like to know, and implementing the resources to help reach that objective goal. So far there have been 81 respondents. Ms. Newell shared an overview of her data related to Learner Development and Individual Learning Differences, Learning Environment, Curricular Content Knowledge, Assessment (Alabama Educational Eligibility and State Assessments), Assessment (Behavior), and Instructional Planning and Strategies.

14-20 Subcommittee:

Dr. Erich Grommet's subcommittee has met twice since our last meeting, in February and March. There have been a lot of activities geared towards updating the website. There are still a few updates that haven't yet been made, but the committee has voted to make those changes and they will be completed

soon. One noted addition will be the presentation slides related to transition processes in the school system by Ms. Alicia Hodge. Ms. Hodge is an administrator for Special Education Services at the Alabama Department of Education. Dr. Grommet also noted with the guidance of Marie Gutierrez, who is the Family Navigator with Auburn University, Regional Autism Network (RAN); the committee will create a Spanish language tab for their website. Ms. Gutierrez provided vital information for this process, and the committee will also pull from other sources like the Organization for Autism Research already translated their transition guidebook, which is an incredibly useful free resource. The Spanish language version will be added to the website. Also posted to the website will be, the public comment submitted to the Alabama Intellectual Disabilities, Home and Community Service, Community Waiver program. The core issue highlighted; many states allow community waiver based on a diagnosis of ASD, but Alabama requires a diagnosis of Intellectual Disability that could be problematic. For a few reasons; one, there are individuals who would benefit from the waiver just because of the impairment associated with Autism Spectrum Disorder separate and apart from intellectual disability, and another issue is that there are many individuals in Alabama who have a diagnosis of Autism and qualify for a diagnosis of Intellectual Disability, but because it was never made when they were children, they don't fully meet all the criteria. The committee's public comment is asking for an expansion to allow individuals with an Autism diagnosis only to access these services. The committee's third and final activity is beginning the preparation on a presentation related to transition resources for autistic Alabamians. for the Auburn Transition Conference in April, 2,023. Dr. Grommet thanked members of his committee for their diligence to the group's efforts.

21+ Subcommittee:

Dr. Sarah Ryan noted a few issues with the Medicaid waiver program. Issues like assessing IQ and individuals with autism and making the assumption that they have an intellectual disability. The reality of this is that in some cases the individual may not have an intellectual disability, however, in some cases individuals are being denied and they do have an intellectual disability, but their Autism diagnosis becomes the focal point. The committee has noted barriers to accessing both medical care and mental health care, especially with primary care and psychiatric services. The committee has spoken the adolescent transition medicine group at UAB, who have experienced similar issues.

The committee is working to understand why a lot of providers are declining adults with various forms of medical diagnosis but in this case specifically Autism. Dr. Ryan stated that her committee would like to conduct a survey to both primary care offices and psychiatric providers to hear from them what barriers they might be experiencing and potentially create solutions with assistance from the RAN for those areas. The committee has been diligently trying to collect information for providers and resources who serve adults on the spectrum, this would also be a feature on the survey...identifying providers that are open to serving adults with Autism. The committee meets every fourth Wednesday of every month, at the next meeting they work to finalize the survey.

Diagnostics and Health:

Dr. Justin Schwartz noted the subcommittee has met monthly since calendar year 2020. The committee is very happy to have new additions, Yada Horace and Beth Huckabee. There have been significant discussions about insurance related issues. In addition, a lot of focus has been placed on troubleshooting these things related to insurance, that relate to diagnosis and health. Also, the committee continues to discuss ways to provide their input for many of the current projects going on related to diagnosis, screening, and pilot projects; both in early intervention as well as Children's Rehabilitation Services and their Autism Diagnostic Clinic.

Dr. Schwartz also noted discussions about ways to support primary care providers in their identification of Autism and getting some checklists so that those are ongoing topics of discussion. The committee has received various input from community providers, and they are working to set up details for various models of how clinics are structured to support new diagnosis.

Stephanie Anderson mentioned that she and her clinic uses the speech language pathologist to aid in diagnosis. Dr. Schwartz stated, he would like to make sure that they were being reimbursed adequately, the committee is working on that issue, and they've discussed some of the things related to the systems in place especially for mental health care for individuals with Autism across the lifespan.

The team has also encountered some barriers; unfamiliarity with Autism in many realms, as well many communities' private mental health practitioners either take a limited range of insurances or don't take insurance at all. Dr. Schwartz noted that it will take a concerted effort to figure out how to address this issue. Discussions related to some of the incentives and disincentives for community mental health centers in to accept individuals with Autism have been held by the committee and they ready, willing, and able to provide technical assistance and ongoing support for any practitioners. Dr. Schwartz noted it would be a necessary component of any initiative to try to increase the workforce for mental health care for individuals with Autism.

Dr. Schwartz also noted, for the community going forward he'd like to discuss with the committee an emerging issue in recent legislation that was passed in the state of Alabama related to LGBTQ care, particularly related to the health care of individuals identifying as transgender or gender diverse. This is an issue Dr. Schwartz believes deserves our committee and council's attention because when we talk about any legislation that affects health care for individuals who are transgender or who identify as gender diverse or individuals who are experiencing gender dysphoria; those who are identifying as transgender are three to six times more likely to have a diagnosis of Autism Spectrum Disorder. This finding is based on some literature that we know that's been collected robustly through various data sources and was recently published. There is some worry about the effects of the recent legislation and how it affects the entire population of internal individuals that we're tasks to serve on this council and on this committee.

There is strong evidence that supports gender affirming environmental support and gender affirming medical care reduces mental health outcomes that are negative in a substantial amount of people. Dr. Schwartz welcomes discussions among council and committee members, on ways to advocate for and support the health care initiative for individuals directly affected by the legislation's ruling.

Public Awareness:

Ms. Melanie Jones was not able to attend. Ms. McConnell shared from an email: There were no major updates from the committee report. The Autism Friendly Alabama site is still under construction.

Regional Autism Network (RAN):

Ms. Allison Davis, Region II RAN Director noted that Region I will host a luncheon learn on May 16th which will be held at the Enrichment Center. Region I is also reformatting their newsletter for the calendar of events to make it accessible and easier to share, they are also contacting all schools in the region to alert them of this update. Region I also attended the Community Connections meeting, and they were able to promote the RAN and meet other service providers. They also attended a mental health wellness event.

Region II were asked to join a Hispanic outreach event with a team of parents who are working without grant funding, but they are very active. Region II was able to assist with passing out 80 resource bags, some which included Spanish materials related to Autism. The Region II RAN committee is currently planning an informational for a potty-training workshop that's going to be in person on June 25th. They are also working to plan a babysitter and respite care training that will be offered free to parents and caregivers in the area. Ms. Davis noted the annual Autism Conference, was in February. Region II has also reached out to one of our regional libraries and connected with one the student groups on campus and collected 2,000 dollars. The committee is working along Sunny Chambliss who is a RAN constituency board member, to use those funds to create autism resources, the students present them with a check.

Region III has had 108 requests for direct assistance and technical assistance from individuals. There is a critical need for diagnostic services for all ages, including adults. Also, an increase in need for mental health services, social opportunities for adolescents and young adults, and summer program. Region III has set a goal to make an in-person visit to each of the 9 counties in the region. They also have established a partnership with the regional in-service centers across Alabama, and they are going to provide summer autism training series for teachers across the state. They're going to be offering four zoom trainings to teachers statewide in June and July, and they're going to cover topics that reflect the needs that were expressed by the teachers.

Region IV are continuing to see very large number of Spanish-speaking families from across the State. They have conducted several trainings for pharmacy and social work, pre-service, professionals. They also included trainings on sexuality and disability as well as alternatives to guardianship. Region IV has attended several resource fairs and vaccine events, and they've recently hosted a hybrid Constituency Board meeting. Chenique Jeffress and Varina Mead were named the new chair and co-chair for Region IV. Maria Guterres, one of the family navigators, and several advocates, were interviewed by La Haifa which radio station about autism and developmental disabilities. Maria was also awarded the Commitment to Inclusion and Diversity Award by the Auburn University College of Education at their yearly awards luncheon.

Region V has been working on outreach services to their underserved counties and collaborating with new providers and increasing the amount of collaboration they have with previous providers. Many students in the region are now beginning to receive increases in services or services that were not in place before, and they're still making referrals to organizations that can provide services. The hope is to

empower the caregivers, and not necessarily, and not enable them. They have ongoing community education workshops and luncheon events for the remainder of the year. They have been an active participant of Echo Autism, and the providers have expressed their appreciation for sharing didactics and gaining information to help in their roles. Finally, they participated in a vaccination event in Georgiana, Alabama, and the participants were able to learn about the brands, and that was well received there.

Funding and Finance Updates:

Dr. Erich Grommet presented on behalf of Dr. Kenneth Atkins, Chairman of the Alabama Behavioral and Analyst Licensure Board. It was noted that since the last meeting a total of 41 licenses have been issued. This includes both licensed behavior analysts and license assistant behavior analysts. That brings the total in Alabama to 467 active license behavior analysts and the license assistant behavior analysts. There were no changes in the total number of counties with at least one licensee. License behavior analysts or license assistant behavior analysts remains at 60, 1.2% or 41 out of 67 counties. The counties with the highest number of licensed behavior analysts license and assistant behavior analysts are as follows: Jefferson with 61, Madison with 40, Lee with 30, Mobile with 27, Shelby with 26, Calhoun with 21, Baldwin with 20, Houston with 14, and Montgomery with 12, and then there's no other counties that are in the double digits.

Ms. Anna McConnell added, ADMH Office of Autism Services that provides services to individuals from birth through age 20. OAS has 20 different providers with 78 trained individual staff members with those providers. Ms. McConnell noted that there a few Intensive Care Coordinator positions open. We are excited about the growth happening within the program. We have internal providers that are coming on board. We have also formed relationships with private providers who may not be interested in enrolling as a Medicaid provider, or a DMH provider, but still provides services to a group, and so, just like the RAN and Autism Society we make referrals to whatever resources are out there.

Member Updates:

Dr. O'Kelley noted her training program has worked to increase access to the COVID vaccine and reduce vaccine hesitancy. This Thursday the committee will host its annual Simpson Ramsey Symposium, which is focused on neuro development. It's a completely free virtual event. The keynote speaker is from Kansas, is talking about self-determination in intellectual disabilities as well as autism, spectrum disorders. Dr. Percy will discuss his large body of work and red syndrome, as well as one of our former trainees, who is a speech, language, pathologist, but also the parent of a child, with a rare genetic disorder. Everyone is invited to join us!

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

Next meeting: Monday, July, 2022

Recording Secretary:

Brittany Marzette