

Alabama Interagency Autism Coordinating Council (AIACC)

Monday, October 16, 2023

Alabama Industrial Training Institute (AIDT), 1 Technology Court, Montgomery, AL 36116

The AIACC met on Monday, October 16, 2023, at the Alabama Industrial Training Institute at 1 Technology Court, Montgomery, AL 36116. The meeting was called to order by Dr. Erich Grommet. Also in attendance were Council members: Heather Jones, Sarah O'Kelley, Justin Schwartz. The following proxies were in attendance as well: Bennett Emfinger for Stephanie Azar, Beverly Johnson for Kimberly Boswell, Sonia Cleckler for Jane Elizabeth Burdeshaw, Wendi Glass for Dennis Gilliam, Chenique Jeffress for Melanie Jones, Elisabeth Newell for Eric Mackey, and Holli Cawthorne for Darryle Powell.

Dr. Grommet called the Council to order and welcomed participants.

Lead Agency Comments:

Beverly Johnson presented on behalf of Alabama Department of Mental Health. She reported that Certified Community Behavioral Health Centers (CCBHCs) are designed to meet needs of individuals served and ADMH continues to work toward CCBHC implementation. ADMH also has a grant for suicide prevention called the Zero Suicide grant (partnering with ViTAL) and another 988 Improvement Grant. 988 is a phone number callers can reach out to instead of 911 mental health needs for those in crisis or just need someone to talk with. 988 provides referrals and services. 988 rolled out in July 2022, and within first year, 50k contacts came from Alabama alone. ADMH also provides and participates in Mental Health First Aid. There are some offerings from local universities and other individuals. Trainings help recognize signs and symptoms of mental health needs and teaches participants how to listen attentively and how to engage. The method taught is Question, Persuade, Refer (QPR), which has more flexibility for time – in 1- or 2-hour blocks for training. The training teaches participants how to ask questions and what are appropriate questions. Trainings free statewide. Can be virtual or in person.

The goal is for CCBHCs to be statewide. Currently there are CCBHC pilots in North Alabama at WellStone, the other at AltaPointe in Mobile. They are considered Phase 1/Tier 1 providers while the state continues to apply for a demonstration project. Those entities were picked because those 2 locations already had CCBHC grants and were more defined.

Ms. Johnson reported that as of October 1, 2023, she is the new Director of Child and Family Services, under the division of Mental Health and Substance Use – Autism Services and the AIACC will fall under this new unit. Autism, Infant and Early Childhood Mental Health, Mental Illness for adolescents, Prevention for Substance Use, and children's Developmental Disabilities will fall under this new unit to ensure the effective coordination of services to meet needs of children and their families. The first joint initiative is occurring today in Mobile, working with school system on Governor's Turnaround List. A question from the audience asked about plans for outreach to Hispanic community. Ms. Johnson responded that as in Prevention, health disparities and equity will be broken out within Child and Family Services.

Approval of Minutes:

Motion for the approval of minutes was offered by Heather Jones and seconded by Elisabeth Newell.

State Coordinator Comments:

Anna McConnell reported that AIACC applications have been received. There will likely be a reopening of application opportunities until vacancies are filled. There was also a meeting regarding service needs for adults with Autism that was held recently. The University of Missouri-Kansas City's Charting the LifeCourse facilitated the work that has been done (environmental scans, key informant interviews, focus groups, and recently a day long workgroup session). A summary of responses was developed. Dr. Sarah Ryan, as chair of the Adult Subcommittee will be point person for this work. There were questions about Community Support Services going into homes. These are services not through the waiver for transition. Questions from Dr. Grommett regarding RBTs being included in the PBS services. Melanie Bald said that Robyn McQueen and Dr. Eliza Belle are working on restructuring the CSS teams. The goal is to intervene earlier, especially when there is nowhere to go. It was reported that ADMH was looking at rules regarding that funding. It was noted by Dr. Grommett that regulations and licensure don't match because of timing of legislation, updates, etc. outdated addresses.

New Business:

Ages 0-5

Dr. Sarah O'Kelley noted that the group has expanded – it's a subcommittee with 2 workgroups and affiliated projects. The group is looking at best practice guidelines for Birth-3 and those at risk of ASD and eligibility for services across systems. Dr. O'Kelley co-chairs with Dr. Kimberly Tomeny at UA. There are 2 workgroups: 1) focused on childcare, led by Stephanie Waters (0-5 before entering school system), and 2) focused on Part B with school-based services and trying to support that across the state. The childcare group has gathered information on priorities needs reported from community and have priority areas: 1) how to talk with parents if suspect ASD, 2) training how to support kids in classroom with range of challenges and welcoming environment 3) better understanding of EI system and how to connect families. They discussed a virtual roundtable with RAN Family Navigators. Childcare preparation will be discussed at the next meeting Oct 30 at 10 am. The Part B Transition group met in late August and is wanting to bring more stakeholders into the group. The group is discussing how to align different models of interventions. This group is focusing on helping families better understand transition process and be better advocates for transition. There is a transition session at the EI Conference this week. The Birth-5 meeting will be Nov 16 at 1 pm via Zoom. Early Intervention has invested in autism specific screening and intervention. There are 7 intervention sites across the state who are actively using MCHAT with follow-up interview at point of entry into EI and the re-eval (6 months). Across those 7 sites, 400+ kids screened. 270+ kids need further evaluation for evaluation. There is a time lag for getting evaluations. Of those with positive screenings and referred for evaluation, 80% received ASD dx and others got another developmental disability diagnosis. Only 3 of those children previously entered the system with an ASD diagnosis. The group is looking at how to equip EI providers to support ASD needs in their family centered approaches. Twelve mentors are trained in best practice for young children with ASD – we are currently in the third cohort. The hope is they will coach other providers who to implement interventions. Seven of these have achieved fidelity. The next step is for UAB to look at deidentified MCHAT data and how to maximize identifying kids with ASD to not overload the evaluation clinics. EI has obtained funding for this work. The question is sustainability to make this part of standard procedure for the system and/or look at additional funding for expansion.

Dr. Grommet asked if any kids have been deferred a diagnosis to wait and see at future growth. Dr. O'Kelley said there was likely fewer than 5 kids in this scenario. The group is trying to identify if there are counties where you are more likely to lose families in process, as well as things are going well. Priority referral clinics are asked to see the kids in 3-6 months. Most kids with ASD in EI are not being referred to EI until they are usually 24-36 months. The goal is to get the diagnosis established before they age out of EI. Maria Sahonic asked where Hispanic families could be evaluated for a diagnosis. Many families can't receive services because they haven't received a diagnosis. Some families have gone to Florida for evaluations. Dr. Grommet noted that this could be mitigated through interpreters. Could still do a diagnosis and use interpreter. Dr. O'Kelley noted there are not enough providers for the demand of ASD diagnoses in general, and with any barriers, the access is even harder. Sarah Bailey noted in regard to Early Intervention, other states serve ages Birth – Five instead of Alabama's Birth to Three. She also noted that reimbursement rates were low – for example, Tennessee's hourly rate is 3x the amount of EI workers in Alabama. Dr. O'Kelley noted this should be discussed in the committee meeting.

Ages 6-13

Dr. Jones noted that representatives for service providers and agencies participate in the committee (ALSDE, RAN, Sparks, AIDB, etc.). The committee's focus is on training and support for teachers and how to support and work with ALSDE for current trainings. In 2022 the RIC/RAN workshops were conducted and continue to be utilized. Dr. Ryan has done workshops for how to implement psychotherapy for those with ASD. In addition, ALSDE partnered with PCG to provide trainings for teachers. The group shared conferences, trainings, and workshops to support teachers, families, students. The committee also worked on task analysis and resources available for teachers for skill building. The committee meets 2nd Tuesday of the month around 1 pm. The time may change. If interested in joining, contact hjones@pelhamcityschools.org.

Ages 14-21/Transition:

Dr. Grommet noted that transition is supposed to start at age 14, and preferably earlier. It can be difficult to picture a child's life and prepare for adulthood earlier, especially when there are difficulties being faced in the present. The committee meets the first Monday of the month via zoom and is working on three items: 1) Developing a response to the state's response to public comment on the CWP asking the state to come in line with what most states provide – example group homes for adults with ASD. The response did not address the ASD specific issues. 2) Getting Spanish language resources on the website and the spreadsheet, and 3) Development/distribution of a flyer that was included in the 2023 Autism Conference to direct families to the website/group. The QR code was useful. Next step panel discussion to have representatives of state agencies, nonprofits, those who provide or consume those services. Maria Sahonic noted that many people of transition age are at home or out of school (adults) and need social skills training. How should we address this age group? Some are on waitlists. Some must go to Birmingham for services. Information for resources do not seem to be getting to families. Dr. Grommet noted that there are fewer home and community providers now after COVID. It impacts all waitlists.

Adults:

Dr. Ryan noted that adults receive the least amount of funding and there are lots of barriers. The ability to obtain services depends on knowing what words to say when you call providers. The group is working on a task analysis for families/individuals to guide them through what to say to whom. In some cases, autism is used as reason they can't access services. Autism doesn't fall into ID or mental health, and someone can have needs in both and more categories. Many in the mental health community are trained in kids, not adults. If providers aren't taking adults with ASD, we need to ask if they feel capacitated. Dr. Ryan worked with the RAN to provide a 4-hour training to 200+ mental health practitioners to effectively provide psychotherapy to individuals with ASD. This training was provided in 5 different regions of the state. Eighty percent of participants had no prior training in ASD, so hopefully this helped expand access. The training was about how to adapt what they already know how to do and broaden it to apply to adults with ASD. The sessions were recorded and should be released to the public soon. At the end of it, there was discussion of perceived barriers – funding was most. The idea of primary diagnosis as access to services is often a barrier. Community Mental Health Centers say they don't serve ASD. Medicaid doesn't cover mental health care for adults. Nancy Anderson said the Certified Community Behavioral Health Centers (CCBHC) construct should address that.

Diagnostics and Health:

Dr. O'Kelley reported on behalf of Dr. Justin Schwartz. The subcommittee is working toward building capacity for those practitioners who are already seeing patients, so that diagnostics can be offered without having to go to specialists. There are many new members and still looking for more. Diagnostics and Health is a broad topic and more members are needed. The subcommittee is working on: 1) looking at diagnostic models of care involving primary care providers (who can diagnose, how, and what is quickest method). Where would they be best served (primary care or comprehensive clinic) 2) insurance requirements for diagnostic evaluations to include what components are needed to access ASD specific services 3) continued training (ECHO) 4) looking at regional reimbursement rates and look at parity with other states and consider how to keep those we train based on rates. 5) The public comment period on revised rules for the federal section 504 of Rehab Act and in access to healthcare for those with disabilities. The group is working to compile information from stakeholders to submit. The rule is making clearer that access to healthcare falls under 504 – to include physical equipment, interpreting, choices for types of treatment, etc.

The state initiative with CRS that has been occurring over the last year and more is designed to empower existing clinics within CRS to do autism diagnostics, using interdisciplinary teams to serve kids. Dr. O'Kelley and Dr. Schwartz provided guidance to this project. There are two in Tuscaloosa and Homewood. Huntsville and Mobile will be soon with another one coming next year. Some of those kids being seen at the CRS clinics are from the EI pilot. There are monthly tele-education calls and presentations on ASD diagnostics with case presentations. Fifty-four providers in CRS participated in the last meeting. The subcommittee's work is to empower those with the skill set.

Sonia Cleckler from ADRS noted that the goal is to have the autism clinics in all 13 offices. The primary barrier is physicians who have the training and want to be part of the clinic. It's a staff capacity issue – the offices want to do it, but need a full team.

RAN Updates

Dr. Hill noted that Auburn was continuing the work from the ACDD grant that supported H-TRAN, outreach and training for the Hispanic community.

Sarah Bailey, RAN Director from the University of Alabama in Huntsville noted that the RAN had worked with Regional In-Service Centers, which serve educators, and provided trainings on practical tips and tools for kids with ASD. Links to presentation on [RAN page](#) on the ADMH website. Dr. Linda Reaves provided one of the presentations. University of South Alabama's RAN welcomes two new faculty members, Sarah Shank and Jordan Albright. University of Alabama at Birmingham's RAN reached 687 people through various events and activities, including Community Education Workshops. UAH welcomes two new staff and new Family Navigator, Linda Ware. They have also been able to present to different groups within the university, to include counseling, kinesiology, and aerospace faculty. UAH RAN was able to attend school mental health fairs. Auburn's HTRAN provided three trainings this quarter with simultaneous interpretation and is available on the YouTube channel. Presentations were made for the AU School of Nursing and various conferences. The University of Alabama RAN welcomes new Director Cynthia Ellis. The UA RAN is now housed at the College of Community Health Sciences.

Announcements and Updates

Dr. Heather Jones noted that the Alabama Behavior Analyst Licensure Board has been reviewing information on where licensees are located (usually around major cities and ABA programs). Currently total 62% of counties with at least 1 licensee. More information about the Board is available at <https://mh.alabama.gov/alabama-behavior-analyst-licensure-board/>.

The University of Missouri – Kansas City's Charting the LifeCourse has been parting with the adult subcommittee to gather information to inform a gap analysis and to assess needs and preferences. Jenny Wilson and Meghan Lamarche and led a discussion about this work. Slides are included.

What We Hope to Achieve Today

- Understanding current state in Alabama related to autism services
 - Vision
 - Needed supports
 - What's happening now
 - Considerations for program



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Purpose of Listening Sessions

- Alabama Office of Autism Services is exploring the addition of adult services
 - They have asked UMKC to facilitate information gathering and to develop strategic recommendations
- Why?
 - We know there is a "service cliff" - services end at age 21 for most
 - We know adult with autism have unmet needs
- The goal of these sessions is to provide feedback that will inform the design of a future adult autism services program

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Starting with a Vision for Adults with Autism in AL

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What does a good life look like for the person? What about their family members?

What life experiences would be included in the vision?

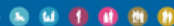
What outcomes would be desired?

Feedback included:

- Housing
- Satisfaction with career
- Access to healthcare
- Social networks
- Job coaches
- Extracurricular opportunities
- Autonomy
- Transportation

What We Don't Want

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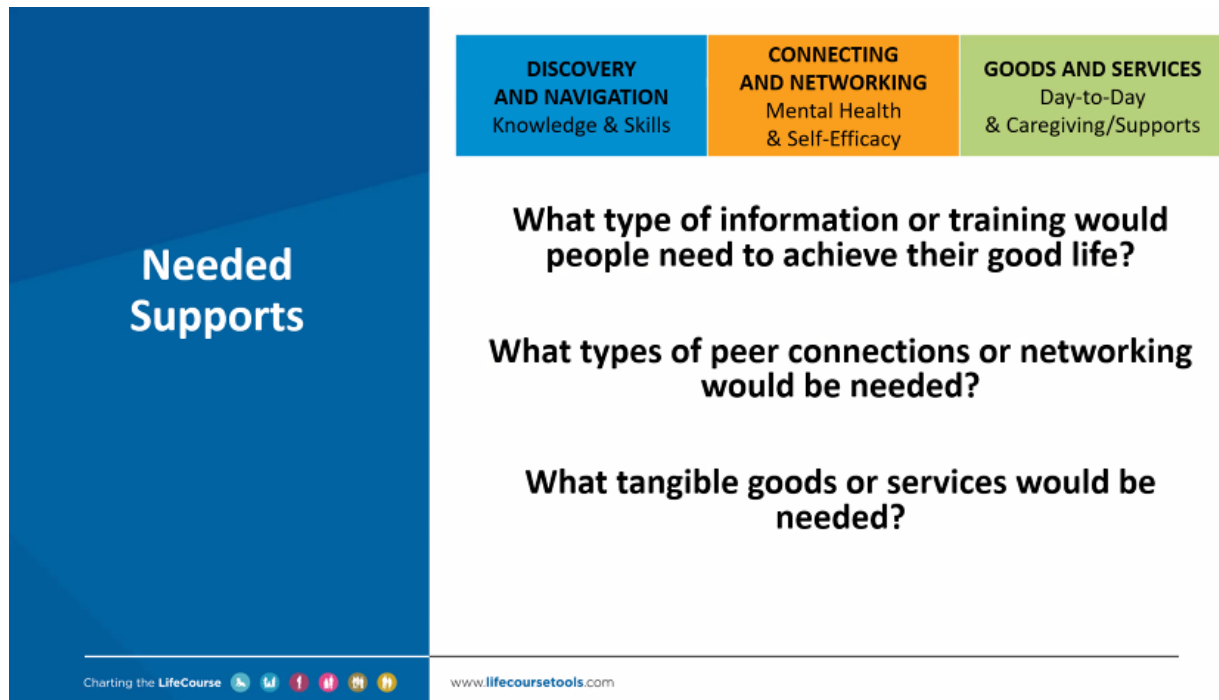
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What do you want to avoid happening?

What would a bad life look like?

Feedback included:

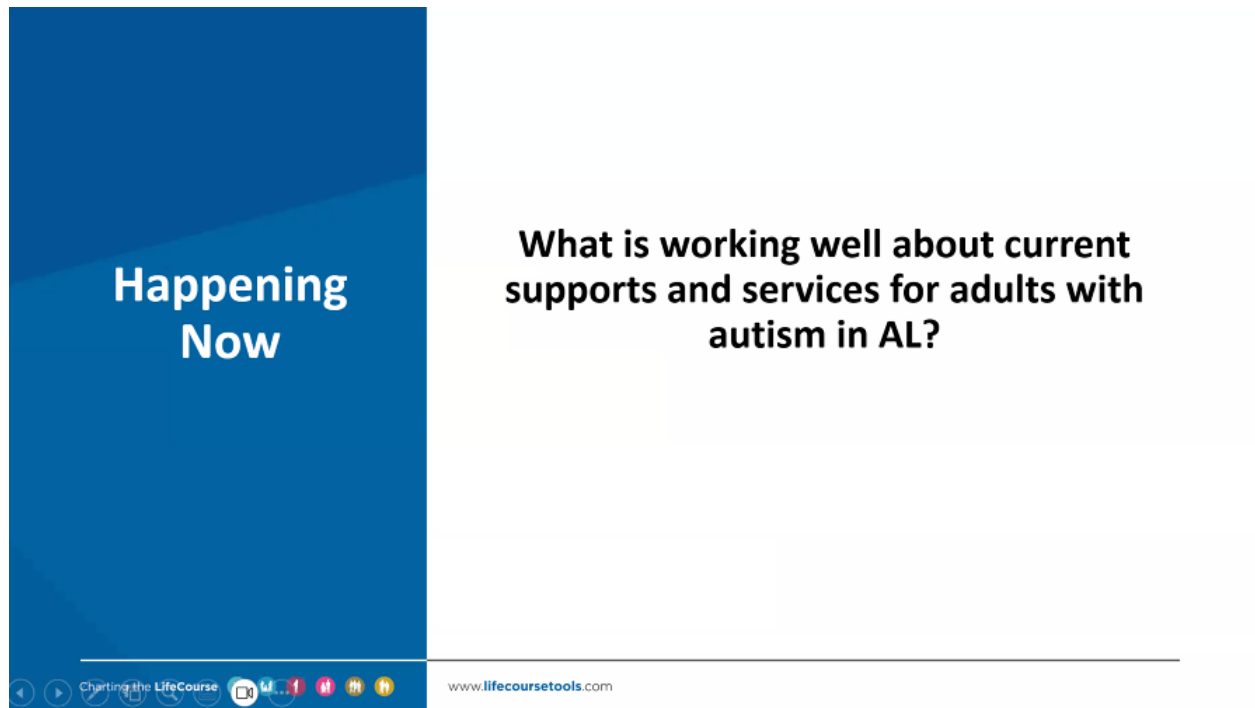
- Sedentary lifestyle with no planning after
- Isolation
- Mental health issues (poor MH)
- Underemployment
- Navigating complicated systems while parenting child with disabilities
- Hunger
- Housing
- Aging issues – especially family caregivers (assisted living, nursing homes for eviction) – evicted due to behavior



Feedback included:

- Independent living skills
- Social development
- Self-advocacy
- Transportation
- Funding for communication and network among supports
- Expand existing services to include with and without ID and access to nonprofits – leverage existing services
- Care coordination
- Avoiding silos
- Help Me Grow (HMG) goes to age 8 – could there be a “help me launch, or help me adult”? Help me engage?
- HMG works because there are resources. There must be some resources to refer to. Funding existing services and expanding access allowances.
- How to advocate for something not as popular to advocate for (consider HIV funding).
- Infrastructure coming out different than in other sessions – how to stand up and maintain the good things that are happening. What would they be and what would they support. Where would it come together? When you point to other populations, they had a

movement. What is the movement for adult services and what infrastructure supports that?



Happening Now

What is working well about current supports and services for adults with autism in AL?

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Feedback included:

- RAN is going well. Need more RAN and need for adults.
- Private groups to include the Exceptional Foundation (internships for universities) for ASD and ID (Braveheart engaged with social work). More connections to engage. Many nonprofits to do it specific areas (Glenwood, Triumph). Many are doing work with adults but can only do so much with funding and staffing. AAPN going well where providers can discuss barriers. The groups that do exist try to get together and improve.
- Coordinating the services (Triumph). Working with ADRS – funding to provide psychologist and licensed counselor while in work program with ADRS. Underlying reasons why not getting a job not being addressed (depression, anxiety, etc.). There is no one to pick up the funding for groups with capacity to do services and groups with experience in working with ASD. They are having to pay other groups to help wrap around services. May consider grants in AL for adult services and hire a grant writer. However, there is so much competition especially when competing with groups that serve young kids. Don't see successes and milestones (speaking, not speaking).
- Barrier and a strength – professionals and providers with the experience are here, but they are working with kids or need opportunity for expansion.
- ADRS as long as intellectually able to receive services. Need to look at other models (Rutgers has adult services). Everyone is capable of doing something.

The meeting was adjourned at 12:11 p.m.

Next meeting: Monday, January 22, 2024

Recording Secretary: Anna McConnell