

## **Alabama Interagency Autism Coordinating Council (AIACC)**

**Monday, April 19, 2021**

**Zoom**

The AIACC met on Monday, April 19, 2021, via Zoom (due to COVID-19 meeting capacity restrictions). The meeting was called to order by State Autism Coordinator Anna McConnell. Also in attendance were Council members: Commissioner Jane Elizabeth Burdeshaw, Robert Caldwell, Suzanne Dowling, Megan Everett, Dr. Erich Grommet, Dr. Heather Jones, Melanie Jones, , Dr. Sarah O’Kelley, Dr. Justin Schwartz, and Chris Stewart. The following proxies were in attendance as well: Karen Watkins-Smith for Stephanie Azar, Malissa Valdes-Hubert for Commissioner Boswell, and Jake Schieber for Lucian Cronkite. Also in attendance was Anna McConnell, State Autism Coordinator.

The minutes from January 2021 were unanimously approved.

*Lead Agency Comments:* Malissa Valdes-Hubert noted that it is Autism Acceptance Month. She also noted the use of [Alabama Family Central](#) as a hub for families to connect to public and private resource options. She also noted that the social media post from the AL Dept of Mental Health with the highest engagement was about the Office of Autism Services. If anyone has questions or needs for resources, there is a submission form on the ADMH website to submit directly.

The minutes from the January 25, 2020 meeting were approved and adopted.

*State Coordinator Announcements:* Some Council members will be rolling off the AIACC in September. Vacancy announcements will be posted on the website and sent out via e-news.

*New Business:*

*0-5 Subcommittee:* Sarah O’Kelley noted that the group had identified opportunities for systems to collaborate and exemplified the group accordingly. For example, Infant and Early Childhood Mental Health Consultants have been added to the group. The next steps for the group include expanding to reach childcare centers, especially working toward that transition at three years old. Mary Beth Vick is collaborating with the group on an EI Project to help children who are known to have or are suspected of having ASD. The project has started off focusing on identified autism interventions appropriate for this age group and includes coaching and technical assistance. Rural outreach has been a new facet of

the group, working with the MCHAT with follow-up interview, which will move kids into appropriate interventions more quickly. A data plan is in place for these activities.

*6-13 Subcommittee:* Heather Jones noted that the focus of the committee's work has been shared resources. The group met with Eilsabeth Newell from ALSDE about the Autism Academy. It will not be held at the MEGA conference as planned but will be delivered in a different way. It would be helpful to have someone from the 0-5 committee to discuss transition to school.

*14-20 Subcommittee:* Erich Grommet reported that the group is currently building the website for resources, which should be available in July. The current project includes identifying transition resources for students, families, schools, and providers to allow for the transition from childhood to adulthood. If anyone has submissions to add to this listing, please share with Dr. Grommet. Anna McConnell noted that the group of children who were reflected in the 1 in 88 prevalence statistic (who were eight years old in 2008 [per CDC data](#)) are now 21 years old. These individuals will likely need continued support as they make their way into adulthood.

*Diagnostics and Health:* Justin Schwartz noted that a focus on workforce related to diagnostics has been a primary focus of discussion. The workforce is not equipped for the surges in demand for services for adults and young adults. The group is continuing to advocate for systems to fit the needs of those with ASD. Some examples of this include access to vaccinations for the DD population, including ASD, and telehealth impacts on those with ASD and their families (looking at ways this was and was not successful). With increased screening, there is increased need for evaluations and referrals for diagnostics. Dr. Schwartz also referenced that he presented to Grand Rounds regarding the ID and ASD populations and needs. There are disparities in care accentuated because of diagnostic and treatment delays. The group is looking into systems building in current infrastructures.

*Public Awareness:* Melanie Jones reported this committee is trying to provide informational materials to pediatricians in underserved areas. Autism Friendly is waiting on web finalization.

Melanie Jones reported that the ASA and group continues to work on Autism Friendly Alabama. The website is in development. Once it is developed, the site will be sent out for further review. More committee members are needed.

*Funding and Finance:* It was reported that the licensure board maintains a list of active licenses for LBA and LABA providers on their website: <https://mh.alabama.gov/alabama-behavior-analyst-licensure->

[board/](#). An increase of funding for RAN has been requested in the DMH budget, but was not included in the Governor's budget.

*Regional Autism Network (RAN)*: Lizzie Taylor reported for the RANs collectively as the RAN Annual Conference had been recently held in February. Prior to that meeting, a Qualtrics survey was sent to Constituency Board members to assist in identifying priority issues. Twenty-six completed the survey and the top two priority areas were: 1) Access to Services and 2) Services for Adults. The issues and possible solutions were discussed in small groups via Zoom. Results were presented and are listed below:

### Regional Autism Network Constituency Board Survey Data

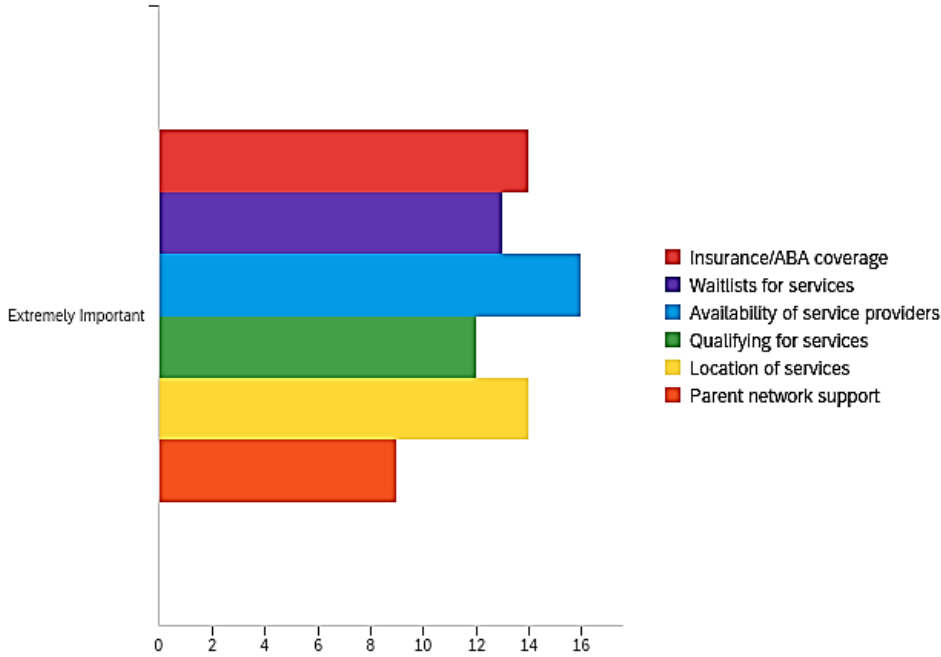
Out of the six issues we asked the board members to rate, the issues of Access to Services and Services for Adults were tied and yielded the highest number of results. Out of 26 responses, 16 members, on both topics, responded with "extremely important". Below is a table of each issue under Access to Services and Services for adults, organized according to their rating.

<b>Access to Services</b>	Availability of Providers
	Insurance/ABA Coverage
	Location of Services
	Waitlists for Services
	Qualifying for Services
	Parent Network Support
<b>Services for Adults</b>	Independent Living
	Employment
	Social Opportunities
	Residential Placement
	Coordination of Long-Term Care
	ASD Evaluation for Adults
	Guardianship
	Waiver

Below are tables and charts representing the percentage of respondents that rated "extremely important" on the above issues.

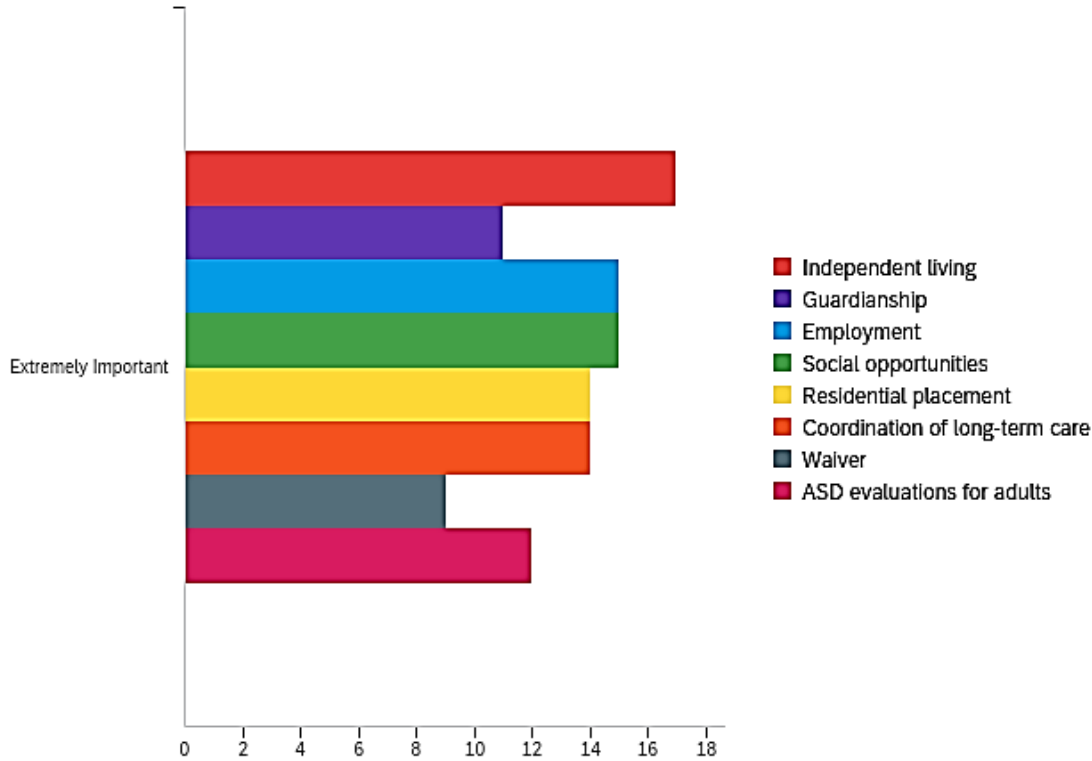
#### Access to Services

Availability of service providers	70%	16	23
Insurance/ABA coverage	61%	14	23
Location of services	61%	14	23
Waitlists for services	57%	13	23
Qualifying for services	52%	12	23
Parent network support	45%	9	20



### Services to Adults

Independent living	77.27%	17	22
Guardianship	50.00%	11	22
Employment	68.18%	15	22
Social opportunities	68.18%	15	22
Residential placement	63.64%	14	22
Coordination of long-term care	63.64%	14	22
Waiver	40.91%	9	22
ASD evaluations for adults	54.55%	12	22



### Regional Autism Network Conference Overview of Themes

Data below were collected from 17 Regional Autism Network constituency board members at the Regional Autism Network Annual Conference on February 23<sup>rd</sup>, 2021. The questions for this listening session were designed to add open-ended responses to the survey questions to understand the board members perspective and experiences on issues related to availability of services providers, barriers to access, independent living, and types of services needed for adults with ASD.

Themes	Sub-Themes	Topic Areas
Access to services	<b>Availability of Providers</b>	Competition and incentives, government knowledge and support, location of providers, reimbursement rates
	<b>Barriers to Access</b>	Cost of care, insurance, knowledge of services, out of state services, provider knowledge, system navigation, transportation, waitlist and workforce shortage
Services for Adults	<b>Independent Living</b>	Appropriate jobs and compensation, community inclusion, daily living skills, financial management, housing, insurance and SSI, limited providers, long-term planning, medical care, post-secondary education, service qualifications,

	transportation
<b>Types of Services</b>	Day-hab programs, High school outreach, job/peer/life coaching, limited after high school, role of parent, waiver

## Definitions Access to Services

### Availability of Providers

- **Competition and Incentives** – Other states are more competitive with compensation and incentivize people to move to their state after graduation. Alabama does not offer anything to encourage people to stay and practice in Alabama, especially in the rural parts of the state.
- **Government Knowledge and Support** – The legislators have limited knowledge of the workforce issue in Alabama and are not invested in the ASD community to provide financial support.
- **Location of Providers** – Service providers are primarily located in the larger metropolitan areas of the state and few are spread out across rural communities
- **Reimbursement Rates** – Reimbursement rates for services in Alabama are low and difficult to navigate. This causes providers to move out of state where reimbursement rates are more competitive or only accept private pay clients.

### Barriers to Access

- **Cost of Care** – ABA therapy was specifically referenced. Not all interventions are covered by insurance and not all employers opt in for ABA therapy coverage with private insurance.
- Insurance
- **Knowledge of Services** – Parents/caregivers do not know what services/providers are available. Parents/caregivers also do not know how to locate quality services/providers.
- **Out of State Services** – Families that live on the border of the state will go out of state to access services.
- **Provider Knowledge** – Many professionals (physician, EI, etc.) lack knowledge about early signs of ASD, behaviors associated with ASD, and/or evidence-based services for the population.
- **System Navigation** – Navigating the system and knowing what services to access for certain issues is difficult, specifically for families of newly diagnosed children.
- **Transportation** - Finding transportation to the services located in the larger metropolitan regions can be difficult.
- **Waitlist and Workforce Shortage** -There are limited providers, or providers are relocating to other cities/states. The limited providers across the state causes long waitlists at the agencies that are providing services to the ASD population.

## Services for Adults

### Independent Living

- **Appropriate Jobs and Compensation** – Adults expressed they often feel underemployed and under paid. Many adults hold college degrees and are unable to find employment outside of the retail industry.
- **Community Inclusion** – There are lack of social groups, outlets, or recreational options available to adults with ASD. Loneliness for adults on the spectrum is a big issue. They seek out community, but it is often difficult to find.

- **Daily Living Skills** – Parents/caregivers expressed concern about their children living independently but not knowing how to manage their home or take care of themselves. Adults expressed similar concerns.
- **Financial Management** – Adults need support with managing their finances, learning how to save money so they're able to live independently. This will support their endeavors to have their own home and purchase a car.
- **Housing** – Parents/caregivers are concerned if there is a safe place for their child to live and often state they do not want their children homeless or in jail. Adults want to live independently in their own home but navigating the steps to achieve that independent are difficult.
- **Insurance and SSI** – Social security usually denied, and if approved, is not enough to support an adult. Additionally, insurance for adults is difficult to access if they are not employed.
- **Limited Providers** – Providers for adults with ASD are limited to VR. More adult services through other state agencies are needed.
- **Long-Term Planning** – Parents/caregivers worry about what will happen to their children when they are gone. Adults are also concerned about how they will support themselves and live independently without their caregiver's financial support, especially if they do not have a trust established.
- **Medical Care** – Primary care physicians have few interactions with adults with ASD and are not equipped to manage their care.
- **Post-Secondary Education** – Supports in post-secondary education settings are needed for adults with ASD that do not qualify or do not have the finances to enroll in one of the "niche" programs on college campuses
- **Service Qualifications** – Behavioral challenges that are consistent with ASD often preclude access to services.
- **Transportation** – Transportation for adults that are unable to drive is difficult because there is no reliable system in Alabama. A caregiver may not be able to take them where they need, which makes it difficult to hold a steady job.

### Types of Services

- **Day-Hab Programs** -Few of these programs are available, and those that are available are hard to access.
- **High School Outreach** – Adults wish they had support during their high school years to help figured out career and post—secondary education paths and opportunities. Parents/caregivers noted involving more high school personnel, such as school counselors, will providers students with ASD more support as they transition to adulthood.
- **Job/Peer/Life Coaching** – These three services are essential for adults to thrive in adulthood. Parents/caregivers and adults noted they have goals they want to accomplish but need support in reaching those goals.
- **Limited after High School** – Finding an agency after high school is difficult. Adults noted they received support during high school but were "on their own" following graduation.
- **Role of Parent** – Finding an agency that will serve a child with ASD after high school is difficult. Parents/caregivers noted those that are available have limited follow through, leaving it up to the parent to act as the service provider for every aspect of adult life.
- **Waiver** – The waitlist for the waiver is extremely long and the waiver is not helpful for the ASD population. Parents/caregivers discussed other waiver options, such as the Katie Beckett waiver.

## Appendix A

### Regional Autism Network Conference Listening Session Questions

- 1) What are 3 examples of barriers to access to care that you or the community you interact with have experienced?

- 2) Thinking about the highest rated topic under access to services, what is the primary reason you think "availability of providers" is an issue? What do you think has led to the limited service providers across Alabama?
- 3) When you think of services for adults, what types of services do you typically think of?
- 4) Thinking about the highest rated topic under services for adults, what is the primary reason you think "independent living" is an issue in Alabama? What types of "independent living" services would you like for your child and others in your community?

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*Other Announcements:*

Chris Stewart noted that the ARC of Central Alabama has an independent living program and has three openings for anyone who is looking for subsidized housing (not services).

Maria Sahonic noted that an apartment or subsidized housing is hard to get and asked how that was accessible. There are local and federal grants that can be used, as reported by Mr. Stewart. The state has not funded this housing.

Commissioner Burdeshaw noted that the Independent Living Centers has tried to advocate for more programs and services from the AL Legislature in the past.

Sarah O'Kelley noted that there is federal funding increasing access to vaccines for the IDD population.

Maria Sahonic noted that the Auburn RAN has applied for and been granted funding from the ACDD for a Hispanic outreach grant for those with DD.

Erich Grommet noted that if there is interest in ASL and ASD, there is someone on faculty at Troy who may be of assistance.

Melanie Jones reported that the ASA continues to share [CARE Binders](#) with parents – this is place for documents and resources to be in one place and comes with information to get the recipient started. Applications are available online to receive the binder.



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

Next meeting: Monday, July 19, 2021

Recording Secretary

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A. McConnell

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