

ALABAMA INTERAGENCY AUTISM COORDINATING COUNCIL



2015

Annual Report

Autism Spectrum Disorder is a developmental disability that causes substantial impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASD have unusual ways of learning, paying attention, and reacting to different sensations. The thinking and learning abilities of people with ASD can vary from gifted to severely challenged. ASD begins before the age of 3 and lasts throughout the life of a person with the disorder. (Act 2009-295)

The Alabama Interagency Autism Coordinating Council, created by the Alabama Autism Support Act of 2009 (Act #2009-295), is charged with meeting the urgent and substantial need to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system of care (SOC) for individuals with Autism Spectrum Disorder (ASD) and their families.

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Foreword: Autism in Alabama

The Alabama Interagency Autism Coordinating Council (AIACC) *2015 Annual Report* provides updates on progress toward achieving goals set out in our charge, mission, and *2014-2017 AIACC Strategic Plan*.

In 2014, the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network released updated prevalence rates, citing that 1 in 68 children are identified as having an ASD. The prevalence rate increased even more when describing the male population – 1 in 42 boys are identified as having an ASD. That is five times the rate of ASD in girls.¹

According to CDC prevalence rates for ASD, there could be as many as 71,000 people with ASD living in Alabama.² No matter what the rate may be, all Alabamians with ASD need a System of Care with appropriate and accessible supports and services. This is not possible without funding – funding for insurance coverage (public and private), services (public and private), and Regional Autism Centers.

The *Journal of Autism and Developmental Disorders* recently published findings that by 2025, the costs related to ASD will reach \$461 billion.³ Families in this state cannot afford the growing costs – and Alabama will not be able to afford the imminent costs if action is not taken now. Alabama can combat these rising costs by providing services and supports to those with ASD. Here are some key activities that can head off the much larger potential future costs:

- **Require that private insurance plans cover ASD services, including Applied Behavior Analysis.** Alabama is one of seven states that does not have mandated insurance coverage for people with ASD.
- **Require that public insurance plans (Alabama Medicaid's EPSDT program) cover Applied Behavior Analysis (ABA).** The Centers for Medicare and Medicaid Services (CMS) issued two pieces of guidance in 2014 that pointed to the validity of and encouraged the inclusion ABA therapy in accessible service offerings.⁴
- **Expand waivers to include developmental disabilities and consider a waiver that is autism-specific.** Alabama is one of eight states that do not include Developmental Disabilities (DD) as a qualifying condition to receive specified waiver services. Alabama is one of 17 states that do not include Autism as a qualifying condition in any of the waivers it currently offers. Thirteen states currently offer an autism-specific waiver.
- **Provide funding for Regional Autism Centers.** Act 2009-592 allowed for the creation of Regional Autism Centers when funding was made available through the Legislature. Care coordination for families, as well as training, technical assistance and consultation for service professionals and educators would contribute to the needed resources and fill the gaps for those with ASD.

The wave of youth that have higher rates of ASD are now becoming adults. An earlier and smaller investment in the lives of those with ASD can yield enormous savings over the lifetime.

¹ CDC's *Autism and Developmental Disabilities Monitoring (ADDM) Network*, <http://www.cdc.gov/ncbddd/autism/data.html>

² U.S. Census Bureau: *State and County QuickFacts*, <http://quickfacts.census.gov/qfd/states/01000.html>

³ J. Paul Leigh, Juan Du. *Brief Report: Forecasting the Economic Burden of Autism in 2015 and 2025 in the United States*. *Journal of Autism and Developmental Disorders*, 2015; DOI: [10.1007/s10803-015-2521-7](https://doi.org/10.1007/s10803-015-2521-7).

⁴ <https://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf> and <https://www.medicaid.gov/federal-policy-guidance/downloads/faq-09-24-2014.pdf>

About the AIACC

HISTORY

Alabama Autism Task Force

On March 20, 2007, Representative Cam Ward and Lieutenant Governor Jim Folsom, Jr. announced the formation of the Alabama Autism Task Force (AATF). House Joint Resolution 23 was passed by the Alabama Legislature on March 8, 2007 and signed into law by Governor Bob Riley shortly afterwards. The AATF reviewed the state's response to the increased incidence of ASD.

The AATF was comprised of advocates, state officials, educators, physicians, and members of the academic community to recommend ways to improve the treatment of autism in Alabama. Representative Ward and Lt. Governor Folsom served as Chairmen for the AATF, which held its first meeting on June 17, 2008. The final meeting of the AATF was held on January 22, 2009.

The AATF was composed of 27 appointed members and a number of volunteers, and was organized into the following Subcommittees: Diagnosis and Early Screening, Intervention Services (0-5), Intervention Services (6-21), Intervention Services (Adult), Health Care, Ad Hoc (Regional Center Development), Systems of Care, and Financial Impact.

Each Subcommittee reviewed data gathered through the Alabama Autism Needs Assessment, which was conducted in conjunction with the AATF's activities. Recommendations were given based on current identified needs and available research.⁵

Alabama Autism Collaborative Group

The Alabama Autism Collaborative Group (AACG) received a grant from the Alabama Council for Developmental Disabilities (ACDD) to conduct a statewide Autism Needs Assessment in order to guide the recommendations of the AATF. The AACG conducted a thorough literature review to determine current best practices, seven community and family forums, in person and online surveys of parents and service providers, and key informant interviews. The Needs Assessment was conducted between September 2007 and May 2008.⁶

Alabama Interagency Autism Coordinating Council

The AIACC was created to carry out the work of the AATF once it dissolved in 2009. The AIACC, secured by the Alabama Autism Support Act of 2009 (Act #2009-295), is charged with meeting the urgent and substantial need to develop a statewide, comprehensive, coordinated, multidisciplinary, interagency system of care (SOC) for individuals with Autism Spectrum Disorder (ASD) and their families.⁷

⁵ *Alabama Autism Task Force: Final Report to the Governor and Legislature, January 2009*, http://autism.alabama.gov/Documents/Autism_Task_Force_Final_Report.pdf

⁶ *Statewide Autism Needs Assessment: Final Report, June 2008*, Alabama Autism Collaborative Group, http://autism.alabama.gov/Documents/Autism_Needs_%20Assessment_Full_Report.pdf

⁷ *Alabama Autism Support Act (Act 2009-295)*, http://autism.alabama.gov/Documents/Legislation/ACT_num_09-0295_HB0041.pdf

Recommendations from the AIACC are to be derived from scientifically based research and nationally recognized best practices. The AIACC is also to ensure interagency collaboration, public participation, and mutual sharing of information to facilitate policy decisions and the implementation of a plan for a comprehensive statewide system of care to individuals with ASD.

The AIACC is to develop a long-term plan and steps toward creation and implementation of a comprehensive system of care. The plan is to address: identification barriers such as duplicative or fragmented policies which may require modification; the development of a coordinated program of services; a comprehensive fiscal review, analysis and recommendations for state spending on programs and services for ASD; and the identification of annual action steps toward implementation.

MEMBERSHIP

The AIACC is composed of the following members:

Governor appointed members include⁸:

Karen Amos
Brooke Bowles
Greg Carlson, Co-Chair
Lucian Cronkite
Sally Davis
Joshua Heard
Doris Hill, Ph.D.
Mitchell Lord
Whitney Meade, Ph.D.
Sarah Ryan, Ph.D.
Todd Tomerlin
Karen Willis

Senate Appointee: Cam Ward, Chair

House Appointee: Becky Nordgren

The chief executive officer or a representative from each of the following state agencies:

Alabama Council on Developmental Disabilities
Alabama Department of Early Childhood Education
Alabama Department of Education
Alabama Department of Human Resources
Alabama Department of Insurance
Alabama Department of Mental Health⁹
Alabama Department of Public Health
Alabama Department of Rehabilitation Services
Alabama Institute for Deaf and Blind
Alabama Medicaid Agency
American Academy of Pediatrics – Alabama Chapter
Autism Society of Alabama
University Center of Excellence in Developmental Disabilities Education, Research, and Service

⁸ Governor appointed membership includes: three adults with ASD, three parents of children with ASD, five service providers, and one health insurance representative.

⁹ The Alabama Department of Mental Health is the lead agency for the AIACC.

Year in Review

LEGISLATIVE REVIEW

Relevant Legislation

Act 2015-442, the Achieving a Better Life Experience (ABLE) Act was passed during the 2015 legislative session. Senate Bill 226 was signed into law on June 9, 2015. The ABLE Act allows for a savings account for individuals with disabilities (occurring before the age of 26) that will not count as a “resource” for SSI and Medicaid (current resource limits are \$2,000). This account will offer an option for savings and gifts and prevent disqualification from needed services. “Qualified disability expenses” paid by the ABLE account are currently being defined. It is expected that the program will be available at the end of 2016.¹⁰

Act 2014-163 established the Alabama Behavior Analyst Licensing Board within the Division of Developmental Disabilities of the Alabama Department of Mental Health. This board is charged with regulating the practice of behavior analysts in Alabama. Legislative revisions are needed to allow for proper spending authority and governance before this Board can become fully operational. It is anticipated that the necessary updates will be made during the 2016 session.

Act 2014-344 authorized the Alabama Department of Public Health to issue a certification card to persons with autism spectrum disorder to be presented with a person’s driver’s license to law enforcement as necessary. Identification cards are now available at County Health Departments. A social story was developed and shared by partner organizations to provide training and support on use of the card.

Budget

Total state dollars allocated to support the mission and recommendations of the AIACC \$123,900. This is level funding from the previous year. Funding is allocated in both the State General Fund (\$60,000) and the Education Trust Fund (\$63,900).

GENERAL UPDATES

The University of Alabama at Birmingham prepared a Cost Estimate Proposal for Regional Autism Centers to help with planning. The Centers, based on the Florida Center for Autism and Related Disabilities (CARD) model, has been our guide since 2009. Act 2009-592 (see Appendix A) authorized the establishment of Regional Autism Centers when funding from the legislature was appropriated. A request for funding in 2015 was not successful. Another request for funding will be made in 2016. The AIACC continues to request \$100,000 per Regional Autism Center – five total, for a combined cost of \$500,000. The five proposed Regional Autism Centers would be housed at The University of Alabama at Birmingham, the University of South Alabama, Auburn University, The University of Alabama, and the University of Alabama in Huntsville. Autism programs are already in existence in these universities, and the funding would help to further direct outreach and training. Each Regional Autism Center will provide: 1) staff with expertise in Autism Spectrum Disorder; 2) individual and direct family assistance in the home, community, and school; 3) technical assistance and consultation services; 4) professional training programs; and 5) public education programs. These activities would provide support to existing service providers, train new service providers, and relieve some of

¹⁰ Information about how to access ABLE accounts is available at the ABLE National Resource Center, <http://www.ablenrc.org/>.

the burden that families and service providers carry when caring for those with ASD in a state that provides minimal services for the ASD and DD diagnoses. Providing a small amount of funding to create these centers will be a cost-saving measure in the long-term, by giving needed supports at an earlier age and before crises arise.

While waiting for funding of Regional Autism Centers, the proposed Center sites began work on Regional Autism Assessments. The information gathered in the assessments will provide updates to the 2009 Autism Needs Assessment and provide an opportunity for Center planning. One of the primary objectives of the Assessments is to gather information about service providers in the community, as coordination of resources is a vital component of a system of care and care coordination. These Assessments will be completed in April 2016.

The AIACC Executive Committee met in early 2015. Among the discussion topics was the need for ASD insurance coverage (both public and private) and the funding of the Autism Regional Centers. One particular focus of discussion was coverage of ABA therapy in the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program administered by Alabama Medicaid. It was reported that a funding increase was needed in order to cover ABA therapies, even if it was deemed to be “medically necessary” by a qualified medical provider.

STRATEGIC PLAN PROGRESS

The AIACC updated the Strategic Plan to cover years 2014-2017. See Appendix B for full plan progress and activities. The targeted goals/committees are:

Accountability: To promote evidence-based, high quality, cost effective models and best practices that provide supports to persons with ASD and their families.

Highlights: Screening, assessment, referral, and treatment information provided to 14 pediatric medical offices with training on how to use the materials. Learn the Signs. Act Early. materials from the Centers for Disease Control and Prevention and added Alabama-specific materials from Act Early Alabama were provided. More trainings and material distribution are planned in conjunction with Help Me Grow’s statewide expansion.

Public Awareness: To raise public awareness of issues and needs affecting persons with ASD and their families.

Highlights: First responder trainings were held across state. The Online Autism Resource Directory (in partnership with the Autism Society of Alabama) is in the process of being updated, using information gathered through Regional Autism Assessments. A Transition Roadmap was developed and will be available for distribution in 2016. Educational opportunities and conferences were made available throughout the state.

Funding: To identify and promote opportunities for diversified public and private partnerships that expand needed funding.

Highlights: Continued work and requests for legislative funding of Regional Autism Centers are being made. Public and private insurance coverage remains a topic that merits continued education and awareness of community members and legislators.

Accessibility: To advocate for increased choice among and access to quality services and supports for people with ASD and their families.

Highlights: Statewide Network Group leaders were trained on how to maneuver existing system of care to help other families. Also, the Alabama Department of Rehabilitation Services, Vocational Rehabilitation (VR) is beginning a pilot program in their Birmingham office to identify and train a liaison specifically for individuals with ASD. Upon the pilot project's success, an autism-specific liaison will be identified in all VR offices statewide.

Regional Centers: To develop and coordinate necessary resources that allow for the creation of Regional Centers/Networks (through Act 2009-592, see Appendix A).

Highlights: Cost estimates for Regional Autism Centers were developed by the University of Alabama at Birmingham. Regional Autism Assessments are currently in process to inform the work of Regional Autism Centers and to identify strengths and challenges in each region. The committee continues to pursue a legislative line item to support Center development.

BARRIERS

People with Autism in Alabama face many barriers. Families in Alabama quickly find out that a diagnosis of autism does not qualify a person for services or coverage for services. The only state agencies that include ASD as an eligible diagnosis for services is the Alabama State Department of Education (ALSDE) and the Alabama Department of Rehabilitation Services – Early Intervention (EI) program; however, by the time a diagnosis is made, most children are older than age 3, which is the cutoff of the EI program's eligibility. Often, a number of medically necessary therapies are prescribed by a diagnosing physician and/or team, and these therapies are typically not available through ALSDE or EI in the dosage prescribed. Typical interventions are Speech and Language Therapy, Occupational Therapy, and Behavioral Therapy – namely Applied Behavior Analysis (ABA), among others depending on the individual needs.

In order for people with ASD to access needed services beyond what is offered by state agencies (a number of other state agencies may offer services to individuals with ASD, but this is not based on their ASD diagnosis, but rather other eligibility criteria), private insurance and private funds are utilized. Insurance coverage for ASD in Alabama is severely lacking. Alabama is one of 43 states without mandated private insurance coverage that includes ABA therapy. While some speech therapy and occupational therapy is usually covered by insurance, the dosage prescribed and needed is typically not adequately covered. Families often pay out of pocket to access the full number of visits required for their loved one. In the realm of ABA therapy, insurance coverage is not accessible. Only those who have Tricare or those who work for a company who have chosen to offer ABA coverage are able to access coverage. In 2012, a mandatory offering bill was passed by the Alabama Legislature, which required an autism coverage package to be offered to companies to purchase. This has not resulted in any coverage for those with ASD to date. Mandated insurance coverage in Alabama is necessary and would incur minimal costs – the cost projections is \$0.26 per member per month in additional premiums.¹¹ Lack of coverage pushes families to the point of crisis, which could lead to hospitalizations, residential care, loss of wages and jobs, just to name a few, when early access to therapies could have provided the needed supports and skills before any crisis situation arose.

¹¹ Annual Report to the Missouri Legislature: Insurance Coverage for Autism Treatment and Applied Behavior Analysis, Statistics Section; Department of Insurance, Financial Institutions, and Professional Registration. February 1, 2015.

Although Medicaid is the single largest health insurer for children, and autism is the fastest growing developmental disability in the United States, there is no public health insurance coverage of ABA therapy in Alabama. Medicaid covers 47% of Alabama children.¹² ABA coverage under Alabama Medicaid's EPSDT program faces a number of barriers: 1) funding, 2) Board Certified Behavior Analysts (BCBAs) are listed as "Allied Mental Health providers" and cannot enroll as Alabama Medicaid providers, 3) BCBAs must be supervised by and bill through a Medicaid-approved psychologist if any billing were to take place (this is not common practice and would continue to prevent access to treatment), and 4) there are no appropriate billing codes in the Alabama Medicaid system that fit the ABA service category. In order for changes to occur that will benefit children with ASD and their families and that will reduce the lifespan costs incurred to the state and to individual families, a conscious and purposeful effort to include ABA coverage in Alabama's EPSDT program must take place. This has been done in a number of other states and been supported by decisions in federal law.

It is important to note that because ABA coverage is so lacking in Alabama, there is a dire shortage of providers. A recent survey found that 75% of trained ABA providers graduating from one of the two state universities training Board Certified Behavior Analysts (BCBAs), those trained in ABA therapy delivery, move out of state and remain out of state as many as four years after graduation and most do not return. BCBAs in Alabama must rely on private pay and Tricare clients and usually have practices in city centers or military bases – these kinds of practices are inaccessible to those in rural locations or who are already struggling financially, which many families with children with ASD do.

In a recent review of Medicaid's Section Home and Community Based Waivers in the United States, 33 states include Autism as a qualifying condition to receive specified waiver services. Forty-two states (and Washington, D.C.) include Developmental Disabilities (DD) as a qualifying condition to receive specified waiver services. Alabama is one of the eight remaining states without a waiver available to those with DD, and we are one of 17 states without ASD listed as a qualifying condition to access a waiver. Thirteen states nationwide have an autism-specific waiver.

Due to the many reimbursement issues in Alabama for ASD services, diagnosticians and treatment providers are few and far between in Alabama. Waiting lists can be as long as a year to receive a diagnostic evaluation. In a largely rural state, most ASD providers are located in Alabama's urban centers, namely Birmingham, Huntsville, Mobile, Montgomery, and Tuscaloosa. Although services exist in other cities as well, the number of providers is very few if they exist at all. More insurance coverage to reimburse and keep providers in our state is necessary to meet the demand for necessary and timely services.

Since ASD is not a qualifying condition for a number of state services publicly funded services in Alabama, it is not tracked in those systems. Typically, only the primary diagnosis (qualifying condition) is tracked, so if those being served happen to also have ASD, there is no way to count them. We need to know how many people have ASD in Alabama and how many are currently being served under other eligibility criteria, and we need to have appropriate services to match the needs specific to ASD.

The need for funding for Regional Centers for ASD and related disabilities is great. Regional Centers will provide: staff with expertise in ASD; individual and direct family assistance in the home, community, and school; technical assistance and consultation; professional training programs; and public education programs.¹³ Many of these facets are being prepared and developed and collaborations formed; however,

¹² https://www.aap.org/en-us/Documents/federaladvocacy_medicaidfactsheet_alabama.pdf and <https://www.autismspeaks.org/what-autism/facts-about-autism>.

¹³ Act 2009-592, http://autism.alabama.gov/Documents/Legislation/ACT_num_09-0592_HB0615.pdf

legislative support and funding is necessary for the creation of an Autism Regional Center, which will aid in the development of a System of Care for individuals with ASD.

The AIACC hopes that progress can be made during 2016 on removing some of these persistent and problematic barriers.

Conclusion

It is anticipated that a number of the barriers described above will begin to be addressed more thoroughly in 2016. The AIACC has made significant steps toward crafting a System of Care that will benefit individuals affected by ASD and their families, as well as those providing services. While there is much left to be done, the cooperation among agencies and individuals has made the process more efficient. Obtaining funding for Autism Regional Centers, continuing work on the *2014-2017 AIACC Strategic Plan*, and obtaining insurance coverage options for ASD are priority activities for the AIACC.

Regional Autism Centers Legislation

APPENDIX A

The establishment of the Regional Autism Centers (Act 2009-592) is one of the most critical elements of the statewide system of care. The legislation outlines the basic requirements of the centers. It is the hope of the AIACC to see five centers strategically placed around the state.

REGIONAL AUTISM CENTERS LEGISLATION (ACT 2009-592)

Establishment of regional autism centers; constituency board; rules and regulations.

(a)(1) There is established in determined geographic regions of the state one or more autism centers whose purpose is to provide nonresidential resource and training services for persons of all ages and of all levels of intellectual functioning who have any of the following:

a. Autism.

b. A pervasive developmental disorder that is not otherwise specified.

c. As determined by the Alabama Interagency Autism Coordinating Council, other disability populations which may receive benefit from the services and activities of the regional centers.

(2) Each center shall be operationally and fiscally independent, and provide evidence-based services within its geographical region of the state. Service delivery shall be consistent for all centers. Each center shall coordinate services within and between state and local agencies and school districts but may not duplicate services provided by those agencies or school districts. The respective locations and service areas of the centers shall be recommended by the Alabama Interagency Autism Coordinating Council and selected by the Governor, the Lieutenant Governor, and Speaker of the House of Representatives.

(b)(1) There is established for each center a constituency board, which shall work collaboratively with the center. Each board shall consist of no fewer than six members, each of whom is either an individual who is, or a member of a family that includes, a person who has a disability that is described in subsection (a).

(2)a. The Governor, the Lieutenant Governor, and Speaker of the House of Representatives shall select the members for the board from a list that has been developed by the Alabama Interagency Autism Coordinating Council and other relevant constituency groups that represent persons who have sensory impairments as described in subsection (a). The Governor, the Lieutenant Governor, and Speaker of the House of Representatives shall appoint members who reflect the racial, gender, geographic, urban/rural, and economic diversity of the state.

b. As representatives of the center's constituencies, these boards shall meet quarterly with the staff of each of the centers to provide advice on policies, priorities, and activities. Each board shall submit to the Alabama Interagency Autism Coordinating Council an annual report that evaluates the activities and accomplishments of its center during the year.

(c) To promote statewide planning and coordination, a conference shall be held annually for staff from each of the centers and representatives from each center's constituency board. The purpose of the conference shall be to facilitate coordination, networking, cross-training, and feedback among the staffs and constituency boards of the centers.

(d) Each center shall provide the following:

(1) A staff that has expertise in autism and related disabilities.

(2) Individual and direct family assistance in the home, community, and school. A center's assistance may not supplant other responsibilities of state and local agencies, and each school district shall be responsible for providing an appropriate education program for clients of a center who are school age, inclusive of preschool special education.

(3) Technical assistance and consultation services, including specific intervention and assistance for a client of the center, the family of the client, and the school district, and any other services that are appropriate.

(4) Professional training programs that include developing, providing, and evaluating preservice and inservice training in state-of-the-art practices for personnel who work with the populations served by the centers and their families.

(5) Public education programs to increase awareness of the public about autism and autistic-related disabilities.

(e) The number of regional centers shall be determined by the Alabama Interagency Autism Coordinating Council, and where possible, the centers shall be based on the campuses of state universities and colleges which provide a proposal for a center to the Alabama Interagency Autism Coordinating Council.

(f) The Alabama Interagency Autism Coordinating Council and the regional autism centers shall adopt the necessary rules to implement and administer this section.

(g) The provisions of this section shall become operative only when funds are appropriated by the Legislature through a line item appropriation.

(Act 2009-592, p. 1748, §1.)

Strategic Plan

APPENDIX B

The 2014-2017 AIACC Strategic Plan¹⁴ guides the work of the AIACC. A committee is assigned to each of the five goals.

Mission Statement

The Alabama Interagency Autism Coordinating Council guides a collaborative effort to facilitate a lifelong system of care and support for persons with Autism Spectrum Disorder or associated conditions and their families, so that they may enjoy a meaningful and successful life.

Values Statement

We believe that a successful system of care will provide innovative best practices services for individuals with ASD and their families. These services should be accessible to families across the state of Alabama, provide person and family centered services, and promote meaningful public awareness and community integration and inclusion. We value a system of care that is responsive to the current sense of urgency, is accountable for providing best practice services, that includes collaborative partnerships, and offers hope to families and service providers across the state.

PERSON AND FAMILY CENTERED. We respect and value the uniqueness of all individuals. The system of care and support that will serve those with an Autism Spectrum Disorder (ASD) is based upon the individual's distinctive strengths, abilities, interests and choices. We recognize when given the opportunity, each person can make a unique contribution to their family, community and society. They individual's needs drive their unique program.

SENSE OF URGENCY. Due to the overwhelming necessity for quality services and knowledgeable, reputable providers, our focus will be on the steps we can take to respond rapidly, efficiently, and effectively to the immediate and life-long needs and challenges of people living with an ASD and their families.

PARTNERSHIPS IN ACTION. We promote improved public awareness and understanding of those living with an ASD and advocate for public policy and funding that expands medial, therapeutic, educational, vocational, recreational, social, and residential options.

SPIRIT OF COLLABORATION. Cooperative partnerships will be created between those living with an ASD and their families and those agencies, organizations and professionals which serve them. These partnerships will encourage collaboration and lead to an enhanced and more efficient service delivery to their clients. We value partnerships founded on honesty, integrity and mutual respect. We will treat all interested parties with respect, listen to diverse views with open minds, discuss submitted public comments and foster discussions where participants can comfortably offer opposing opinions.

ACCOUNTABILITY. We will pursue innovative best practices of the highest quality for each individual to protect the safety and advance the interests of people affected by an ASD. We will promote a SMART (Specific,

¹⁴ 2014-2017 Alabama Interagency Autism Coordinating Council Strategic Plan, http://autism.alabama.gov/Documents/AIACC_Strategic_Plan.pdf

Measureable, Achievable, Realistic, and Time-specific) structure for service delivery. This structure will be aligned with the needs of each individual with an ASD and their family. Methods will be used to evaluate and determine the success of service delivery. Services will be adjusted as necessary to promote meaningful and successful lives for those living with an ASD.

HOPE. Although ASD can be an isolating and involved experience, we will encourage hope for the ASD community by endorsing our values on each and every service provider, agency and organization that touches them. We will also promote education for family members and those living with an ASD, so that they will be knowledgeable in what the possibilities are for their lives.

Goals

An integrated and overarching guiding principle of the AIACC is to cultivate an environment of understanding, communication, collaboration and consensus building among Council membership that extends to the ASD community. There are five goals of the AIACC’s work, and the goals and specific activities to support them are listed below.

GOAL 1: ACCOUNTABILITY

Promote evidence-based, high quality, cost effective models and best practices that provide supports to persons with ASD and their families.

Measurement Key:

0=Not Met – no progress: no endorsements, no trainings, no meetings, no reviews no website postings, no provider updates

1=Partially Met – some progress: 1-2 endorsements, trainings, meetings, reviews, website postings and/or provider updates related to effective models and current best practices

2=Mostly Met- much progress: 3-4 endorsements, trainings, meetings, reviews, website postings, and/or provider updates

3=Completely Met/Sustaining – totally satisfactory progress: 5 or more endorsements, trainings, meetings, reviews website postings, and/or provider updates

Objective	Completion Date	Measurement	Responsible Party
Support Universal Screening and Surveillance for ASD and Developmental Disabilities.			
Actively endorse American Academy of Pediatrics (AAP) recommendation that all primary care pediatric health care practitioners provide universal screening and surveillance for developmental delays/disabilities and ASDs.	December 2017	1- Screening and referral materials provided to 14 pediatrician offices (along with training) in partnership with Help Me Grow (HMG).	Accountability Committee

Encourage wide distribution of educational materials on early warning signs of ASD and appropriate referrals. For example, <i>Learn the Signs. Act Early.(LTSAE)</i> , <i>Birth to Five: Watch Me Thrive</i> .	December 2017	1- Distribution of LTSAE materials by Children’s Rehabilitation Service (CRS) representative to Bullock, Pike, and Montgomery Counties (in partnership with Public Awareness committee); LTSAE distributed to 14 pediatrician offices through HMG. HMG statewide expansion is pending and will include this information to pediatric offices through the state.	Accountability and Public Awareness Committees
Foster and advocate for the use of ASD–specific and developmental screenings in all appropriate early childhood settings for early identification and referral of at-risk children.	December 2017	0	Accountability Committee
Endorse evidence-based, best practices that people with ASD will receive in their home communities.			
Advocate for service providers to use ASD-specific best practice screening tools, interventions and services.	December 2017	1- Materials, screeners, and training provided by HMG to 14 pediatricians and ongoing info to service providers and families	Accountability Committee
Promote policies and procedures that support an educated and trained multidisciplinary workforce.	December 2017	0	Accountability Committee

Regularly review best practice and evidence-based treatment, evaluation, assessment, and diagnostic criteria.	December 2017	1- Assisting with identification of best practices and citations for Standards of Practice, Birth-School age	Accountability and Standards of Practice Committees
Disseminate best practice and evidence-based findings (including frequent updates from national resources). For example, the Autism and Developmental Disabilities Monitoring (ADDM) Network, National Professional Development Center on Autism (NPDC), and other relevant data.	December 2017	1- 2014 ADDM report distributed; current research updates distributed to AIACC e-news list (approximately 450 people)	Accountability and Public Awareness Committees

GOAL 2: PUBLIC AWARENESS

Raise Public Awareness of issues and needs affecting persons with ASD and their families.

Key: 0=Not Met – no progress: no educational events, no dissemination of data and/or research findings, no support for trainings and policies for first responders, no distribution of educational materials, no promotion of transition activities, no resource directory creation or maintenance

1=Partially Met – some progress: 1-2 of the above activities to promote awareness

2=Mostly Met – much progress: 3-4 events or activities related to public awareness

3=Completely Met/Sustaining – totally satisfactory progress: 5 or more events or activities related to public awareness for ASD

Objective	Completion Date	Measurement	Responsible Party
Support the education of service providers and the public about needs across the lifespan through strategic and collaborative partnerships.			
Advocate for educating service providers and the public about needs affecting persons with ASD and their families across the lifespan.	December 2017	3- Autism friendly (Regions Bank, museum in Mobile, Camp ASCCA sensory rooms and tools); sensory movies; Barons game; lending library expansion; exhibitor	Public Awareness Committee

		opportunities; conferences	
Coordinate and disseminate evidence-based and best practice findings and relevant data identified by the Accountability and Standards of Practice Committees.	December 2017	1- Healthcare provider toolkits to pediatricians through HMG	Public Awareness Committee
Support partnerships among AIACC, law enforcement and the Autism Society of Alabama to continue existing safety training on ASD for law enforcement and other emergency responders.	December 2017	3- Safety trainings (Birmingham, Cullman, Mobile, Auburn); Project Lifesaver expansion; Safety Net project	Public Awareness Committee
Encourage a statewide policy which requires all law enforcement and emergency responders to receive ongoing ASD training.	December 2017	1- Following legislation in other states and nationally regarding training requirements and autism. Discussions with AG's office and others regarding benefits of training.	Public Awareness Committee
Support the education of service providers and the public about ASD interventions and next steps.			
Promote wide distribution of educational materials related to ASD signs, services and follow-up action steps to reduce age of first diagnosis. For example, <i>Learn the Signs. Act Early.</i>	December 2017	1- Distribution of LTSAE materials by CRS parent representative to Bullock, Pike, and Montgomery counties; Healthcare provider toolkit and training distributed; LTSAE website accessible via AIACC homepage	Public Awareness Committee

Promote awareness of transition, vocational and post-secondary opportunities and supports for youth and adults with ASD.	December 2017	1- Roadmap to Transition (ASA and ADAP); camp for older kids; Triumph training for VR autism liaison (Accessibility Committee)	Public Awareness Committee
Create and maintain an online resource directory of ASD services.			
Create online resource directory for autism services in Alabama.	June 2015	2-Resource directory being populated (last revision coming in April 2016)	Public Awareness Committee
Maintain accurate and up-to-date data regarding available services in Alabama.	September 2015	2 -partnering with AIACC Regional Assessment locations to complete directory – to be completed summer 2016	Public Awareness Committee

GOAL 3: FUNDING

Identify and promote opportunities for diversified public and private partnerships that expand needed funding.

- Key: 0= Not Met – no progress: no strategies to increase insurance coverage, opportunities for diagnostic evaluations, waivers and support services and/or state spending and support
- 1=Partially Met – some progress: 1-2 opportunities or strategies (as described above) identified and/or promoted
- 2= Mostly Met – much progress: 3-4 opportunities or strategies identified and/or promoted
- 3=Completely Met/Sustaining – totally satisfactory progress: 5 or more opportunities or strategies for funding expansion were identified and/or promoted

Objective	Completion Date	Measurement	Responsible Party
Utilize multiple strategies to focus on the various sources of Insurance (private, public, employer funded, privately funded) to increase appropriate levels of coverage and			

reimbursements for ASD specific treatments such as Applied Behavior Analysis therapy, occupational therapy, speech-language, and other related services.			
Advocate for parity in insurance coverage for comprehensive array of services for Alabamians with ASD.	December 2017	1	Funding and Finance Committee
Support a national platform that 3rd party insurance should cover screening, evaluations, and therapies as part of basic plans.	December 2017	1	Funding and Finance Committee
Explore opportunities to consult with insurers regarding outcome metrics, quality indicators and utilization indicators of service effectiveness.	December 2017	1- Developmental screenings in RCO outcome measures	Funding & Finance and Standards of Practice Committees
Support access to diagnostic evaluations.			
Identify and address barriers to diagnostic evaluations.	December 2017	1	Funding and Finance and Accessibility Workgroups
Examine and capitalize on existing opportunities in the Medicaid and Education fields (such as the mental health pilots in the Montgomery schools). (Potential Partners: Alabama Arise and Disability Leadership Coalition).	December 2017	1- Discussion ongoing	Funding and Finance Committee
Advocate for expanded and improved waivers and supports for persons with ASD.			
Engage with Alabama Medicaid to advocate for the healthcare needs of individuals with ASD and Developmental Disabilities (Potential Partner: Medicaid Regional Care Organizations).	December 2017	1- Meetings with AL Medicaid and national information shared; discussion ongoing	Funding and Finance Committee
Explore options for improved coverage for persons with ASD in the current and future Medicaid program. For example, an autism-specific waiver to include individuals without Intellectual Disability.	December 2017	1- Met with AMA to discuss EPSDT and waiver issues related to ABA therapy	Funding and Finance Committee
Collaborate with state agencies to identify new models for the use of waiver services for the ASD population. (Potential Partners: Alabama Department of Mental Health, Alabama Department of Public Health, Alabama Department of Rehabilitation Services).	December 2017	1- Met with DMH re: Autism Waiver; exploring use/benefit of DD waiver	Funding and Finance Committee
Advocate for state spending and support for those with ASD.			

Determine funding needs to achieve goals of the AIACC, including the Regional Autism Networks, and recommend ways to include ASD in budget considerations of the Executive and Legislative Branches for publicly funded services.	December 2017	1- Continuing to request funds for 5 regional centers, at \$100K per center	Funding and Finance Committee
Advocate for ASD diagnosis to be included in Medicaid Regional Care Organizations.	December 2017	1- Disabilities Leadership Coalition representatives on RCOs	Funding and Finance Committee
Advocate for more coordination and sharing of human and financial resources to address the issues of people with ASD across the lifespan.	December 2017	1- Collaboration discussions held during committee/council meetings	Funding and Finance Committee
Advocate for an autism database that may be used to know how many in Alabama are affected by ASD for service and budget planning purposes.	December 2017	0	Funding and Finance Committee
Support funding of Regional Autism Networks.			
Perform cost analysis to determine cost per Regional Autism Network.	February 2015	3- Study completed	Funding & Finance Committee
Advocate for a line item in the Alabama budget for at least two Regional Autism Network locations, with more to be added in subsequent years.	December 2015	2- Up to 5 pilot locations proposed; Request made in 2015 for \$500k but request was denied. Funding for 2-3 centers will be requested in 2016.	Funding & Finance Committee
Develop funding flow recommendations for the Regional Autism Networks Committee to consider during Request for Proposal development.	May 2015	1- In progress; extended due to continued request for Regional Autism Center funding	Funding & Finance and Regional Networks Committees
Determine reporting requirements for each Regional Autism Network in regard to funding.	May 2015	1- In progress; extended due to continued request	Funding & Finance Committee

		for Regional Autism Center funding	
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GOAL 4: ACCESSIBILITY

Advocate for increased choice among and access to quality services and supports for people with ASD and their families.

Key: 0=Not Met – no progress: no collaborations with state partners to communicate services and/or transition issues, no supports for a coordinated system of care or more flexible eligibility criteria

1=Partially Met- some progress: 1-2 collaborations or opportunities for supporting increased access and choice

2=Mostly Met – much progress: 3-4 collaborations or support opportunities

3=Completely Met/Sustaining – totally satisfactory progress: 5 or more collaborations or support opportunities for increasing access and choice of services and supports

Objective	Completion Date	Measurement	Responsible Party
Advocate for increased choice among and access to quality services and supports for persons and families within ASD community-based systems of care.			
Collaborate with state partners to identify and communicate local and state services available to children, youth and adults.	December 2017	1- AAPN and ASA putting together comprehensive list of public and private providers	Accessibility and Public Awareness Committees
Advocate for increased access to diagnostic evaluations, treatment, and supports across the lifespan.	December 2017	1- Meeting with service providers and members of funding committee in April 2015; pursuing insurance reform to increase access; Joe Carter and Brooke Bowles developed Accessibility Presentation on state mental health, education, private pay, and rehabilitation	Accessibility Committee

		funded services in July 2015	
Encourage publicly-funded service systems to allow people with ASD to access services under more flexible eligibility criteria. For example, account for social-emotional, adaptive, and functional deficits as well as communication, academic and cognitive.	December 2017	1- Met with ADRS to discuss services and available possible collaborations to improve service delivery to people with ASD. Received approval for Autism Liaison for Birmingham office – recruiting for the Birmingham office is currently underway	Accessibility Committee
Encourage and support a coordinated system of intervention and care for transition age students that include the person with ASD, parents, mentors and support agencies and that addresses transition issues, job training and coaching, college support, daily living skills, communication and social skills.	December 2017	0- Need a way to understand current standard of care. Also need to look at WIOA funding for transition services through ADRS	Accessibility Committee
Collaborate with Alabama State Department of Education's Autism team and others to identify youth and young adults transitioning from school in order to address training and work issues earlier in the youth's schooling.	December 2017	0- See above	Accessibility Committee

GOAL 5: REGIONAL CENTERS

Develop and coordinate necessary resources that allow for the creation of Regional Autism Networks. (See Appendix A for legislation outlining requirements of Regional Autism Networks.)

Regional Networks/System Support - Phase 1 – (Initial steps: 1-Establish budget (cost analysis) for budget request to legislature, 2-Identify process and develop RFP, 3-Support submission of budget request to legislature, 4-Identify contact in each region submitting response to RFP, 5- Develop annual reporting requirements for Regional Autism Networks)

Key: 0=Not Met-No initial steps taken

1=Partially Met-1-2 initial steps completed or initiated

2=Mostly Met – 3-4 initial steps completed or initiated

3=Completely Met/Sustaining – totally satisfactory progress: All 5 initial steps completed or initiated to be completed within an appropriate time frame.

Objective	Completion Date	Measurement	Responsible Party
Advocate for, promote, and encourage the establishment of four to six Regional Autism Networks in accordance with Act 2009-592.			
Support the cost analysis conducted by the Funding and Finance Committee to determine the amount of a budget request to state legislature.	December 2014	3- Budget proposal is complete and will be used as a guide when planning for Regional Centers' current and future funding needs	Regional Network and Funding & Finance Committees
Identify process and develop Request for Proposal.	March 2015	2- Process started – budget proposals received; desired sites identified (UAB, USA, AU, UA, UAH)	Regional Network Committee
Support submission of budget request to legislature.	March 2015	3- Request made in 2015 unsuccessfully; seeking support again in 2016	Regional Network and Funding and Finance Committees
Identify contact in each region submitting response to Request for Proposal.	October 2015	3- Regional contacts identified	Regional Network Committee
Develop annual reporting requirements for Regional Autism Networks.	October 2015	1- This has been initiated through the proposed identification of resources and initial report	Regional Network Committee
Share information about Regional Autism Networks as it becomes available.	Ongoing (pending allocation of funding for	1- This will begin with the reports for the RAC's on the	Regional Network Committee

	Regional Autism Networks)	initial resource survey that will be made available on a website yet to be determined.	
Assure public awareness/education campaign is in place in conjunction with the development of the regional centers	Ongoing (pending allocation of funding for Regional Autism Networks)	0	Regional Network Committee
Support an increase the number of qualified and competent ASD trained professionals, personnel, and providers.			
Support programs and policies designed to increase the number of qualified and competent ASD trained professionals, personnel, and providers.	December 2017	0	Regional Network Committee
Encourage university officials to increase university-based degree and certificate programs that provide ASD specific training	December 2017	0	Regional Network Committee

Alabama Interagency Autism Coordinating Council

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