

ALABAMA INTERAGENCY AUTISM COORDINATING COUNCIL



2014

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) *2014 Annual Report* provides updates on progress toward achieving goals set out in our *2014-2017 AIACC Strategic Plan*, which is based on recommendations from the *Alabama Autism Needs Assessment*, the Alabama State Autism Task Force, and past progress in the *2011-2013 AIACC Strategic Plan*. These reports may be accessed at www.autism.alabama.gov.

The CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network released their most recent prevalence rates, citing that 1 in 68 children are identified as having an ASD. The prevalence rate increases 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

In Alabama, the prevalence rates are vastly different. The total prevalence rate for Alabama is 1 in 175, with rates of 1 in 114 for boys and 1 in 417 for girls. The average age of first diagnosis is 4 years, 3 months for ASD, and for higher functioning ASD, the average age of diagnosis is 6 years. ASD can reliably be diagnosed at age 2 and sometimes earlier.² The vast differences in the national and Alabama-specific prevalence rates are probably due to a number of systemic issues.

One potential reason to consider for the varying prevalence rates is Alabama's lack of an accessible and comprehensive System of Care for those with ASD. Children may be identified late (once they reach the school system) or may be misdiagnosed or undiagnosed. It is very difficult to determine the number of individuals with ASD served by state systems, since ASD is not a qualifying primary diagnosis for some state services and is often not collected. Information from national data and the vast number of family, advocate, and provider reports tells us there many more Alabamians with ASD than currently have access to services. Further development of the System of Care for those with ASD would mean a better quality of life for those individuals and family caregivers, as well as a cost savings for Alabama, because intervening early and appropriately can lead to better outcomes and less intensive supports later in life.

According to the Alabama and national ASD prevalence rates, there are between 28,000 and 71,000 people with ASD living in Alabama.³ No matter what the number 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.

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

² CDC's *Community Report on Autism 2014*, http://www.cdc.gov/ncbddd/autism/states/comm_report_autism_2014.pdf

³ U.S. Census Bureau: *State and County QuickFacts*, <http://quickfacts.census.gov/qfd/states/01000.html>

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.⁴

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 2008.⁵

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.⁶

⁴ Alabama Autism Task Force: Final Report to the Governor and Legislature, January 2009, http://autism.alabama.gov/Documents/Autism_Task_Force_Final_Report.pdf

⁵ Statewide Autism Needs Assessment: Final Report, June 2008, Alabama Autism Collaborative Group, http://autism.alabama.gov/Documents/Autism_Needs_%20Assessment_Full_Report.pdf

⁶ 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 include:

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 Children's Affairs
Alabama Department of Education
Alabama Department of Human Resources
Alabama Department of Insurance
Alabama Department of Mental Health⁷
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

⁷ The Alabama Department of Mental Health is the lead agency for the AIACC.

Year in Review

LEGISLATIVE REVIEW

Relevant Legislation

The United States Congress passed the Autism Collaboration, Accountability, Research, Education, and Supports (CARES) Act in 2014. It reauthorized the Combating Autism Act of 2011. The Act sets aside \$47 million to fund research and federal and state initiatives to improve the system of care for those with ASD.

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. In order for many insurance companies to recognize service providers for reimbursement purposes, they must be licensed. A national certification group oversees the designation of Board Certified Behavior Analysts, and the state licensure allows for the recognition and proper reimbursement of these certified professionals in Alabama.

Act 2014-344 authorizes 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.

Senate Joint Resolution 117 encouraged the AIACC to include assistance to individuals with neurodevelopmental disorders within the scope of its mission. The AIACC mission statement, which has been in place since 2010, states:

"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."

The "associated conditions" in the mission includes the "neurodevelopmental disorders" that are articulated in the Senate Joint Resolution. The AIACC will continue its mission to serve those with ASD and associated conditions, which includes neurodevelopmental disorders. The spectrum is so vast and varied in Autism, that improving a system of care for this population invariably improves the system of care for others with related disorders.

Budget

Total state dollars allocated to support the mission and recommendations of the AIACC in 2013 amounted to \$100,468. In 2014, the amount of support increased to \$123,900. This came from both the State General Fund (\$60,000) and the Education Trust Fund (\$63,900).

GENERAL UPDATES

The University of Alabama at Birmingham led the Strategic Planning Committee in the update process. The 2014-2017 AIACC Strategic Plan was completed during the summer of 2014 (see Appendix A for a copy of the updated plan). In order to better accomplish the goals and objectives of the updated Strategic Plan, the AIACC Committee structure changed. Committees will begin meeting late 2014 and early 2015, with a

committee report due at each quarterly AIACC meeting. The new AIACC Committee Structure is represented here:



The University of Alabama at Birmingham was tasked with estimating of the cost of a fully operational Autism Regional Center, based on the Florida Center for Autism and Related Disabilities (CARD) model that has been our guide since 2009. These cost estimates should be available by early 2015 and used to request funds and plan for the Autism Regional Centers. The legislation that allows for the creation of Autism Regional Centers is in Appendix B.

The AIACC Executive Committee will meet in early 2015 in order to convene closer to the start of the legislative session. It is anticipated that they will discuss insurance coverage (both public and private) and the funding of the Autism Regional Centers.

Four AIACC members completed their second term on the AIACC and new members were appointed to fill these vacancies. Members who completed their second term of service were: Jerimie Goike; Bama Hager, PhD; Hanes Swingle, MD; and Kathy Welch, CCC-SLP. New AIACC members include: Brooke Bowles; Lucian Cronkite; Sally Davis; Whitney Meade, PhD; and Karen Willis. Ms. Cronkite joined the AIACC as the first representative of a private health insurance carrier who addresses medical/health policy – this position had been vacant for over a year.

PLAN PROGRESS

The AIACC updated the Strategic Plan to cover years 2014-2017. The targeted goals are:

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

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

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

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

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

Each committee will be developing an action plan to address the various goals and objectives.

Further exploration of other planning and implementation opportunities are being investigated as potential options, including grant opportunities made possible by the Autism CARES Act, which was renewed in 2014 (formerly the Combating Autism Act).

BARRIERS

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.⁸ Many of these facets are being prepared and developed and collaborations formed; however, funding is the key ingredient for the creation of an Autism Regional Center, which will aid in the development of a System of Care for individuals with ASD.

In a recent review of Medicaid's Section 1915 (c) Home and Community Based Waivers in the United States, 32 states include Autism as a qualifying condition to receive specified waiver services. Forty-three states (and Washington, D.C.) include Developmental Disabilities (DD) as a qualifying condition to receive specified waiver services. Of the seven remaining states without a waiver available to those with DD, three states do not have the 1915 (c) waiver, meaning that only four states in the US with the 1915 (c) waiver do not have DD services included. Alabama is one of these four states with a 1915 (c) waiver that does not specify Developmental Disabilities as a qualifying condition, and it is one of the 18 states to not include Autism as a qualifying condition in any of the waivers it currently offers.

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.

Insurance coverage continues to be problematic in Alabama. Although Alabama legislation has made an optional private autism coverage plan available to medium sized companies, it is limited in scope and most companies do not purchase it. As of 2014, Autism Speaks reported that 39 states had enacted insurance reform laws; Alabama is not one of these states.⁹ In addition, access to insurance coverage for Applied

⁸ Act 2009-592, http://autism.alabama.gov/Documents/Legislation/ACT_num_09-0592_HB0615.pdf

⁹ Autism Speaks, <https://www.autismspeaks.org/state-initiatives>

Behavioral Analysis for federal employees in Alabama must be addressed at the state level before progress can be made on this issue. The Centers for Medicare and Medicaid Services (CMS) issued guidance regarding ASD on two different occasions during 2014. The guidance addressed the issue of ABA therapy and its coverage under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit when it is deemed “medically necessary” and under waivers. Some states have submitted state plan amendments while others have made changes due to litigation regarding the inclusion of ABA therapy in Medicaid and EPSDT benefits. The Alabama Medicaid Agency is reviewing its policies and state plan regarding this issue and a determination is expected in 2015 for next steps.

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 providers are necessary to meet the demand for timely services. Retention and rural programs need to be developed.

Conclusion

It is anticipated that a number of the barriers described above will begin to be addressed more thoroughly in 2015. 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, beginning work on the *2014-2017 AIACC Strategic Plan* through its restructured committees, and completing the Standards of Practice recommendations are priority activities for the AIACC.

Strategic Plan

APPENDIX A

The 2014-2017 AIACC Strategic Plan¹⁰ will guide the work of the AIACC. Corresponding committees to each goal have been formed. Progress updates are anticipated at the end of 2014 and beginning in 2015.

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,

¹⁰ 2014-2017 Alabama Interagency Autism Coordinating Council Strategic Plan, http://autism.alabama.gov/Documents/AIACC_Strategic_Plan.pdf

Measurable, 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 2016		Accountability Committee
Encourage wide distribution of educational materials on early warning signs of ASD and appropriate referrals. For example,	December 2017		Accountability and Public Awareness Committees

<i>Learn the Signs. Act Early., Birth to Five: Watch Me Thrive.</i>			
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 2016		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 2016		Accountability Committee
Promote policies and procedures that support an educated and trained multidisciplinary workforce.	December 2016		Accountability Committee
Regularly review best practice and evidence-based treatment, evaluation, assessment, and diagnostic criteria.	December 2016		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 2016		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		Public Awareness Committee
Coordinate and disseminate evidence-based and best practice findings and relevant data identified by the Accountability and Standards of Practice Committees.	December 2017		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		Public Awareness Committee
Encourage a statewide policy which requires all law enforcement and emergency responders to receive ongoing ASD training.	December 2017		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		Public Awareness Committee
Promote awareness of transition, vocational and post-secondary opportunities and supports for youth and adults with ASD.	December 2017		Public Awareness Committee
Create and maintain an online resource directory of ASD services.			
Create online resource directory for autism services in Alabama.	June 2015		Public Awareness Committee
Maintain accurate and up-to-date data regarding available services in Alabama.	September 2015		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		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		Funding and Finance Committee
Explore opportunities to consult with insurers regarding outcome metrics, quality indicators and utilization indicators of service effectiveness.	December 2017		Funding & Finance and Standards of Practice Committees
Support access to diagnostic evaluations.			
Identify and address barriers to diagnostic evaluations.	December 2017		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		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		Funding and Finance Committee
Explore options for improved coverage for persons with ASD in the current and future Medicaid program. For example, an autism-	December 2017		Funding and Finance Committee

specific waiver to include individuals without Intellectual Disability.			
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		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		Funding and Finance Committee
Advocate for ASD diagnosis to be included in Medicaid Regional Care Organizations.	December 2017		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		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		Funding and Finance Committee
Support funding of Regional Autism Networks.			
Perform cost analysis to determine cost per Regional Autism Network.	February 2015		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		Funding & Finance Committee
Develop funding flow recommendations for the Regional Autism Networks Committee to consider during Request for Proposal development.	May 2015		Funding & Finance and Regional Networks Committees
Determine reporting requirements for each Regional Autism Network in regard to funding.	May 2015		Funding & Finance Committee

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		Accessibility and Public Awareness Committees
Advocate for increased access to diagnostic evaluations, treatment, and supports across the lifespan.	December 2017		Accessibility Committee
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		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		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	December 2017		Accessibility Committee

and work issues earlier in the youth's schooling.			
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GOAL 5

Develop and coordinate necessary resources that allow for the creation of Regional Autism Networks. (See Appendix B 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		Regional Network and Funding & Finance Committees
Identify process and develop Request for Proposal.	March 2015		Regional Network Committee
Support submission of budget request to legislature.	March 2015		Regional Network and Funding and Finance Committees
Identify contact in each region submitting response to Request for Proposal.	October 2015		Regional Network Committee
Develop annual reporting requirements for Regional Autism Networks.	October 2015		Regional Network Committee
Share information about Regional Autism Networks as it becomes available.	Ongoing (pending allocation of funding for Regional Autism Networks)		Regional Network Committee
Assure public awareness/education	Ongoing (pending		Regional Network

campaign is in place in conjunction with the development of the regional centers	allocation of funding for Regional Autism Networks)		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		Regional Network Committee
Encourage university officials to increase university-based degree and certificate programs that provide ASD specific training	December 2017		Regional Network Committee

Regional Autism Centers Legislation

APPENDIX B

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 as a starting point for

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.)