

2016



Mississippi Autism Advisory Committee

2016 REPORT TO LEGISLATURE

Dear Legislators,

The Mississippi Autism Advisory Committee (“MAAC”) is pleased to present our annual report to the Mississippi Legislature for 2016. This document outlines the struggles faced by Mississippi families living with autism spectrum disorder (“ASD”) and makes a single, crucial recommendation in hopes of easing the burdens they face.

Autism spectrum disorder now constitutes a public health crisis in Mississippi and our nation as a whole. Data from the Centers for Disease Control shows a steady increase in the prevalence of ASD with 1 in 68 children being affected.¹ Children diagnosed with ASD need access to specialized services as quickly as possible. Getting access to these services or even knowing where to look and who to ask about these services can be confusing and frustrating for parents. There are several state agencies providing services related to ASD along with countless private businesses. Parents must make quick, informed decisions about early intervention, education, specialized therapy, transition to adulthood, employment, independent living, etc. In Mississippi these families are essentially on their own. There is no public entity dedicated to helping people understand the services available for individuals living with ASD.

The MAAC recommends the establishment of a statewide Office of Autism Services. An Office of Autism Services is an innovative approach intended to help individuals and families face the challenges listed above by providing information about resources and services for people with ASD in Mississippi.

On behalf of individuals with autism spectrum disorder, their families, and professionals who work with them, the Mississippi Autism Advisory Committee would like to thank you for the opportunity to recommend improvements to the services and quality of life available to Mississippians living with ASD.

Sincerely,

Lisa Bryant, M.Ed.
Co-Chairperson

Phillips Strickland, JD
Co-Chairperson

Mississippi Autism Advisory Committee

¹ Centers of Disease Control and Prevention. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *Morbidity and Mortality Weekly Report. Surveillance Summaries*. 2016; 65(3):1-23. Available online: <http://www.cdc.gov/mmwr/volumes/65/ss/ss6503a1.htm>.

Committee's Purpose and Work

The Mississippi Autism Advisory Committee was created by House Bill 1125² (2011 Regular Session) as the Legislature recognized an urgent need for strategies on how to best identify, treat, educate, accommodate and employ individuals with autism spectrum disorder and assist their families.

The MAAC's mission is "to study, make recommendations and develop a strategic plan on how best to educate and train students with ASD to maximize their potential productivity within the workforce ... and to develop an annual plan" outlining these strategies. The MAAC is tasked with writing a report to the legislature outlining any roadblocks to creating meaningful progress in the areas of mental health, education, medical and employment for individuals with ASD and their families.

The MAAC met six times this year and heard from parents of children diagnosed with ASD. The Committee also heard from providers who care for these children concerning the need for ASD specific treatment and services starting from early childhood and extending through adulthood. Based on these meetings and testimonies, the committee has chosen to focus this report on one strategic recommendation as set forth below.

Understanding Autism

Autism spectrum disorder is a general term for a group of complex disorders of brain development. They include autism, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger syndrome.³ With the May 2013 publication of the Diagnostic and Statistical Manual of Mental Disorders, these autism subtypes merged into one umbrella diagnosis of ASD.⁴ ASD can be associated with attention issues, difficulties in social interactions, motor coordination problems, as well as physical health issues such as sleep, gastrointestinal disturbances, and epilepsy. However some individuals with ASD excel in visual skills, music, math and art.

ASD appears to have its roots in very early brain development. The most obvious signs and symptoms of autism tend to emerge between 2 and 3 years of age. Unfortunately, many children with Autism are not diagnosed until much later.⁵ Studies have shown that children receiving early intensive intervention can greatly increase their educational and vocational outcomes. As indicated below, the prevalence of ASD diagnosis has increased by 6-15% each year from 2002 to 2010.

Table 1 provides an overview of the increase in Autism Prevalence as identified by the Autism and Developmental Disabilities Monitoring Network.

² HB 1125, An Act to Create The Mississippi Autism Advisory Committee, Available online: <http://billstatus.ls.state.ms.us/documents/2011/pdf/HB/1100-1199/HB1125SG.pdf>

³ Centers for Disease Control and Prevention, Facts about ASD, Available online: <http://www.cdc.gov/ncbddd/autism/facts.html>

⁴ Centers for Disease Control and Prevention, ASD Diagnostic Criteria, Available online: <http://www.cdc.gov/ncbddd/autism/hcp-dsm.html>

⁵ J Am Acad Child Adolesc Psychiatry. 2012 Mar; 51(3):249-260.e25. doi: 10.1016/j.jaac.2011.12.009. Epub 2012 Feb 3. Available online: <http://www.ncbi.nlm.nih.gov/pubmed/22365461>

**Table 1. Identified Prevalence of Autism Spectrum Disorder
ADDM Network 2000-2012
Combing Data from All Sites⁶**

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children...
2000	1992	6	6.7 (4.5–9.9)	1 in 150
2002	1994	14	6.6 (3.3–10.6)	1 in 150
2004	1996	8	8.0 (4.6–9.8)	1 in 125
2006	1998	11	9.0 (4.2–12.1)	1 in 110
2008	2000	14	11.3 (4.8–21.2)	1 in 88
2010	2002	11	14.7 (5.7–21.9)	1 in 68
2012	2004	11	14.6 (8.2–24.6)	1 in 68

Did you know...

- ASD now affects 1 in 68 children and 1 in 42 boys.⁷
- Boys are nearly five times more likely than girls to have ASD.⁸
- A majority of ASD-related costs in the U.S. are in adult services – \$175-196 billion, compared to \$61-66 billion for children.⁹
- ASD costs a family \$69,000 a year on average.¹⁰
- Key findings show that ASD is the fourth most prevalent diagnosis in children aged three (3) to seventeen (17) years.¹¹
- 70% of children with ASD have one comorbid developmental or psychiatric condition.¹²

⁶ Centers for Disease Control, Autism Spectrum Disorder Data and Statistics, Available online: <http://www.cdc.gov/ncbddd/autism/data.html>

⁷ Christensen DL, Baio J, Braun KV, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *MMWR Surveill Summ* 2016; 65(No. SS-3)(No. SS-3):1–23.

DOI: <http://dx.doi.org/10.15585/mmwr.ss6503a1>

⁸ *Id.*

⁹ Buescher AS, Cidav Z, Knapp M, Mandell DS. Costs of Autism Spectrum Disorders in the United Kingdom and the United States. *JAMA Pediatr.* 2014; 168(8):721-728. doi:10.1001/jamapediatrics.2014.210.

¹⁰ *Id.*

¹¹ Centers for Disease Control, Children’s Mental Health, Available online:

<http://www.cdc.gov/childrensmentalhealth/data.html>

¹² *Lancet.* 2014 Mar 8; 383(9920):896-910. doi: 10.1016/S0140-6736(13)61539-1. Epub 2013 Sep 26. Available online: <http://www.ncbi.nlm.nih.gov/pubmed/24074734>

Recommendation

1. **The MAAC recommends that the Mississippi Legislature pass legislation creating an Office of Autism Services. This entity shall coordinate ASD efforts among primary agencies that serve Mississippi’s population of children and adults with ASD and their families.**

Rationale for a Mississippi Office of Autism Services

The MAAC is made up of professionals working in the field of mental health, parents of children diagnosed with ASD, and employees of state agencies that currently provide services to support individuals with ASD and their families. Every year since its inception, this committee has made the recommendation to the legislature in one form or another to create an office of autism services.

Several state agencies currently provide services related to ASD, however these services are scattered and inconsistent from one part of the state to the next. Committee members regularly hear from people looking for information on both public and private ASD service providers. Parents and families of Mississippians diagnosed with ASD are struggling to understand the services available to them, how to access these services, and where to start. These challenges are not unique to Mississippi.¹³ In 2008, the Missouri Legislature established an Office of Autism Services to “provide leadership in program development for children and adults with autism spectrum disorders, to include establishment of program standards and coordination of program capacity.”¹⁴ Similar to Mississippi, Missouri families reported confusion and frustration when faced with navigating the seemingly endless maze of services from the medical, educational, and community provider fields. An Office of Autism Services is an innovative approach intended to help ease this process by providing information about ASD resources and services to the people Mississippi.

An Office of Autism Services (“OAS”) is needed to identify gaps in autism-related services and to facilitate the development of a state-wide strategic plan to improve and expand effective services and resources for individuals with ASD and their families.

A major goal of the OAS will be identifying, developing and coordinating services throughout the state and to form interagency agreements with entities/agencies providing services and training to individuals with ASD and related disorders, and their families. The OAS would also work with the MAAC at each committee meeting.

Primary agencies in Mississippi that serve individuals with ASD include the Department of Education, Department of Mental Health, Department of Rehabilitation Services, Department of Health, and the Institutions of Higher Learning. These and other various public agencies work to treat individuals with ASD from the time of their diagnosis until adulthood.¹⁵ Although these agencies each work with individuals affected by ASD, there is lack of communication between the agencies as to what services are

¹³ See Appendix A

¹⁴ Missouri Office of Autism website, <http://dmh.mo.gov/dd/autism/>

¹⁵ See Appendix B

provided and who qualifies for those services, and a lack of coordination of care between the agencies and families. The OAS will work to develop and maintain linkages among these state agencies.

Expected Organization and Goals of the Office of Autism Services

The MAAC recommends the creation of an Office of Autism Services within the Mississippi Governor's Office. The Office of Autism Services should consist of an Autism Coordinator, an administrative assistant and two qualified staff members to serve the northern and southern regions of the state.

The expectations and goals of the Office of Autism Services are as follows:

- Develop and maintain various mediums for distributing information and resources related to ASD such as a website, toll-free phone number, and contact information for key assisters at various state agencies.
- Design and annually update a Mississippi Autism Services Handbook that combines information about how to navigate the medical, educational, and community services in Mississippi with information in the form of credible websites and relevant telephone contact numbers.
- Provide an integrated support system for families of children with ASD by facilitating communication with state agencies providing ASD-related services.
- Coordinate with state agencies providing ASD-related services to track, identify, and assist individuals diagnosed with ASD.
- Establish an ASD Network of state and national experts to assist the OAS in identifying promising practices and model programming.
- Organize and coordinate a comprehensive program of outreach, involving the dissemination of information on Mississippi ASD resources to families, service providers, and local communities.
- Develop a social media campaign (Facebook, Twitter, Instagram) to communicate about ASD and other related disabilities throughout the state.
- Ensure that a link to the OAS webpage is available on the websites of all state agencies providing ASD related services.
- Plan, coordinate and facilitate regional and statewide training programs for ASD assessment teams, general educators, para educators, parents and local communities.
- Act as liaison to the MAAC and provide reports to the committee at each of the six annual meetings.
- Assist school districts with initial ASD assessment information and scheduling, or referral to regional ASD teams when needed.
- Be an active member of Special Education Advisory Council Standing Committee on ASD.
- Work with the Mississippi Department of Rehabilitative Services to develop an adequate pool of qualified personnel to work with individuals with ASD.

Estimated Budget:

The Committee estimates an initial funding amount of \$1,500,000. This includes an estimate of start-up costs, including: equipment and fixtures, programmatic expenditures, and costs related to staffing such as salaries and benefits. It is estimated that 80% of the requested funds will be allocated to services and programs with the remaining 20% being spent on supplies and payroll related costs.

Conclusion

The number of Mississippians diagnosed with autism spectrum disorder is growing and the need for change is clear. State agencies and other concerned parties will need to work now and in the future to develop new programs that provide the flexibility, training, and level of support that will allow persons with ASD to live and work in their communities. This will require innovative approaches and models of support that are both effective and cost efficient.

Establishing an Office of Autism Services will lay a critical foundation for providing early access to care for persons diagnosed with ASD, which will lead to long-term savings for affected families and the state of Mississippi.

Appendix A

How does Mississippi Compare to other Southern States with Autism Services?

States similar to Mississippi in size and resources have developed ways to coordinate ASD-related services. The best examples are Missouri and South Carolina. Missouri was a pioneer of coordinated ASD services. Families affected by ASD found a champion in the Governor's wife and a state legislator to create five (5) Missouri Autism Projects in the 1990s. The Missouri Autism Project, which consisted of five (5) regions, provided ASD-specific family support (e.g. assessment, parent training, advocacy, behavioral therapy, respite) and assisted in skill development of individuals with ASD. Missouri subsequently created an Office of Autism in 2008 under the Missouri Department of Mental Health and Division of Developmental Disabilities. Missouri's Office of Autism consists of a Director, coordinator, project specialist, and administrative support assistant. Besides overseeing home and community waivers, The Missouri Office of Autism has created state guidelines that now help to coordinate the five (5) Missouri Autism Projects, manage the autism spectrum disorder interagency committees, and maintain a website that provides information about statewide projects involving ASD.

South Carolina, Tennessee, Arkansas, and Louisiana have excellent websites that families can utilize to obtain information about services for individuals with ASD and other related-disabilities. The majority of these websites have been developed and maintained through state funding. For families that don't have internet access, states such as South Carolina have 1-800 numbers to additional access to these services. Mississippi can greatly improve access to services and treatments by establishing a central entity to provide parents with updated information about ASD-related services.

Table 2: Brief Overview of ASD-Related Services by Neighboring States

State	State Autism Committee with Stakeholders from different state agencies	Mandated Autism Insurance reform that includes ABA Therapy	Coordinated Autism Services within Depts. of Mental Health, Education, and Vocational Rehab.	Parents receiving information about Autism Services from central state agency or nonprofit.	Statewide Autism Research Collaborative
Mississippi	Yes	Yes	No	Partial	No
Alabama	Yes	No	Partial	Partial	No
Arkansas	No	Yes	Partial	Yes	Yes
Georgia	Partial	Yes	No	No	Partial
Louisiana	No	Yes	Partial	Yes	No
Missouri	Yes	Yes	Yes	Partial	No
S. Carolina	No	Yes	Yes	Yes	No
Tennessee	No	No	No	Yes	No

Appendix B

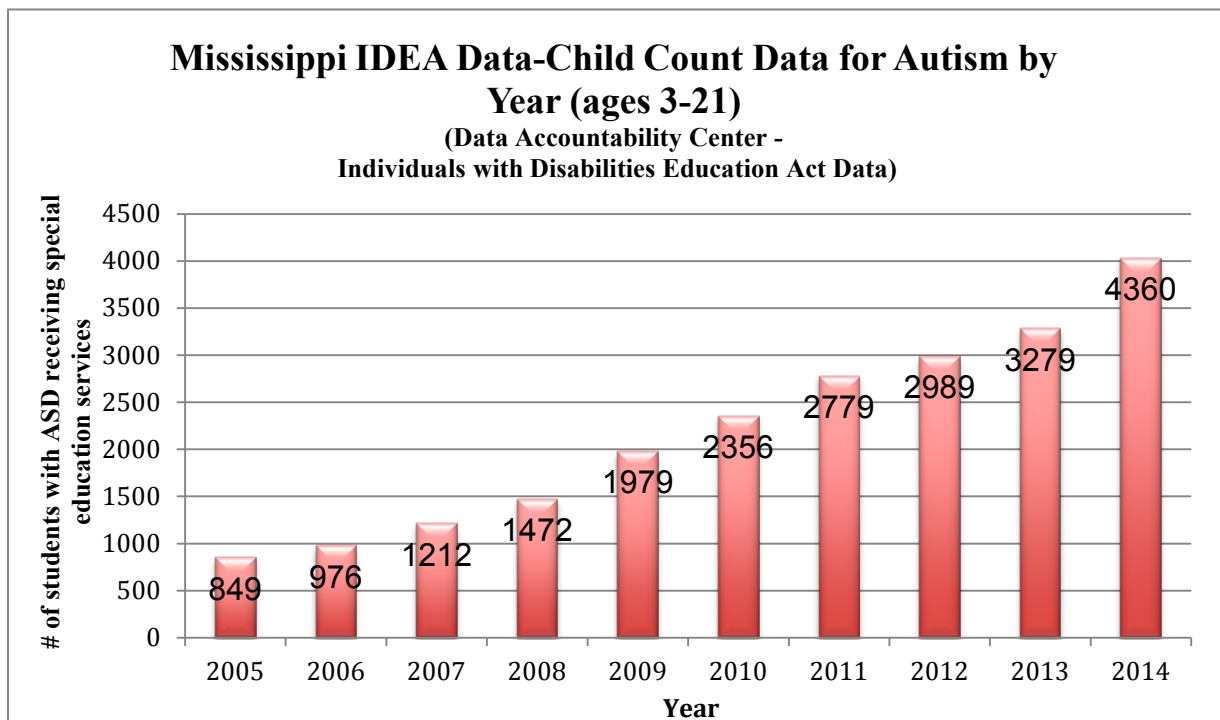
Key Findings on ASD Services provided by Mississippi State Agencies

The following section provides key findings on the services provided by major state agencies in Mississippi that work with and provide services to our increasing population of individuals with ASD and their families:

MISSISSIPPI DEPARTMENT OF EDUCATION

- The Mississippi Department of Education (“MDE”) identified 4360 children, ages 3-21, with the educational ruling of Autism in 2014. That number reflects an increase of 1,081 children identified in 2013.
- This increase has created a huge demand for trained professionals to work with the Autism population.
- As a result, the MDE supports the development of a teacher training program in conjunction with the Department of Curriculum and Instruction at the University of Southern Mississippi.
- The MDE added an autism instructional specialist in 2014 to increase support through training and technical assistance. The MDE has trained approximately 928 teachers and related service providers through conferences, training and institutes during the 2015-2016 school year.

Table 3: Mississippi Dept. of Education Autism Child Count Data, 2005-2014



MISSISSIPPI DEPARTMENT OF HEALTH

- Infants and toddlers who have a diagnosis of ASD or who do not have a diagnosis but exhibit significant delays are eligible for early intervention services via the Mississippi First Steps Early Intervention Program.
- Unfortunately, many young children in Mississippi have difficulty gaining access to early intervention services due to delays in diagnosis and/or referrals for service.
 - According to the Centers for Disease Control (CDC), ASD can sometimes be detected at eighteen (18) months or younger. By age two (2), a diagnosis by an experienced professional can be considered very reliable. However, many children do not receive a final diagnosis until three (3) to five (5) years of age. This delay means that children with ASD might not get the intensive early intervention they need.
- Over the 2015-2016 program year, the Mississippi First Steps Early Intervention Program identified and serviced 122 children with a diagnosis of ASD, who are undergoing additional evaluation for ASD, or who were suspected of ASD, but had not yet received a diagnosis of ASD.
- Eligible families are provided a Service Coordinator who assists with the development of an Individualized Family Service Plan (IFSP) and linked to medical, educational, and developmental services as needed.
- Eligible children will be provided a plan including steps and services to transition to school and/or community-based services upon exiting early intervention by three (3) years of age.
- The Mississippi First Steps Early Intervention Program provides family-centered developmental supports and services to families and caregivers to enhance their child's development through early learning opportunities embedded in their daily routines and activities.
- Increased use of developmental screenings at critical points can improve identification. CDC recommendations include ensuring all children are, "screened specifically for ASD during regular well-child doctor visits at eighteen (18) and twenty-four (24) months," and provided additional screening, if a child is at high risk for ASD (e.g. sister, brother, or other family member with an ASD) or if behaviors sometimes associated with ASD are present."
- When the Mississippi Autism Task Force surveyed Mississippi pediatricians in 2007, very few pediatricians screened for ASD. When MAAC surveyed Mississippi pediatricians in 2013 only 30% of pediatricians were screening children for ASD.
- Improving the education of health care professionals and allied health-care professionals, in addition to identifying and eliminating other barriers faced by these professionals in screening for ASD can increase referrals to the Mississippi First Steps Early Intervention Program.

MISSISSIPPI DEPARTMENT OF MENTAL HEALTH

- In FY 2015, the Department of Mental Health's certified community mental health agencies served approximately 97,530 (unduplicated) individuals with serious mental illness, serious emotional disturbance and intellectual/developmental disabilities. Persons diagnosed with ASD are reflected within this number under the developmental disabilities category.
- The true number of individuals with ASD that are being served remains unknown because only one state agency – the Mississippi Department of Education – tracks this population and only for children, ages three (3) to twenty-one (21), who have an educational ruling of autism.

- In 2012, Boswell Regional Center (BRC) operated by the Department of Mental Health, established the Division of Autism Services to provide supports to persons with an Autism Spectrum Disorder (ASD) and to develop and offer a training curriculum, at no cost, to families, professionals and communities throughout Mississippi.
- The Autism Training Initiative began in 2012 and is designed to build capacity in Mississippi to provide evidence-based, lifespan services and supports to individuals with ASD and their families based on the premise that individuals with autism are included in all settings. Since February 2014, 42 trainings have been offered throughout the entire state with 1512 attendees to date. This number is continuously increasing. On September 11, 2015, a conference titled: Creating Your Own Path: Successful Transitions for Persons with Autism was held with 180 participants, 38 of which were family or persons with ASD. The second annual conference was held on September 8, 2016.

MISSISSIPPI DEPT. OF REHABILITATION SERVICES - Office of Vocational Rehabilitation

- State vocational rehabilitation agencies are one of the most important sources of employment services for individuals with ASD and other disabilities.
- The following chart reflects the number of individuals with ASD that the office of Vocational Rehabilitation served from FY 2014 until June 2016:

FY	Number Served	Funds spent
2014	226	\$328,828.49
2015	249	\$481,040.38
2016	240	\$525,843.84

- Mississippi Department of Rehabilitation Services (MDRS) has a program coordinator for Autism whose duties include:
 - Providing field staff updated information regarding ASD.
 - Coordinating training for field staff on matters related to ASD.
 - Coordinating services provided for individuals with autism through private organizations such as TEAAM Autism.
 - Working with Vocational Rehabilitation Counselors who are requesting other services for client with ASD.
 - Working closely with the Supported Employment Program Coordinator regarding individuals with ASD by participating in Personal Care Planning (PCP) meetings along with the Counselor, client and family.
- Mississippi Department of Rehabilitation Services Office of Vocational Rehabilitation recognizes the importance of emphasizing the strengths and contributions that many of the clients with ASD can offer businesses. Individual characteristics such as punctuality, attention to detail, consistency, reliability, or good visual-spatial or mechanical skills can make these individuals more attractive to employers. Vocational Rehabilitation

counselors utilize different tools in seeking employment options for clients with ASD; they include but are not limited to:

- Person-Centered Planning (PCP): where an action plan is developed to provide directions in employment by identifying client desires, dreams and employment goals.
- Customized Employment (CE): Includes discovery, profile portfolio, resume, and negotiation with employers and job placement.

INSTITUTIONS OF HIGHER LEARNING

- The University of Southern Mississippi, Mississippi State University and the University of Mississippi now offer courses that have been approved by the Behavior Analyst Certification Board as meeting the requirements for behavior analyst licensure.

Committee Membership by Appointment

We would like to thank the following Mississippi Autism Advisory Committee Members for their time and commitment in creating this report:

MEMBER	APPOINTED BY
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With invaluable assistance provided by the MS Department of Mental Health staff: Faye Foster, Bureau of Intellectual and Developmental Disabilities; and Lisa Henick, Director, Special Projects.