

2015



Mississippi Autism Advisory Committee

2015 REPORT TO LEGISLATURE

MISSISSIPPI AUTISM ADVISORY COMMITTEE REPORT

Dear Legislators,

Thank you for your support of the Mississippi Autism Advisory Committee (MAAC) during the 2015 legislative session. The passing of HB 885 provides insurance benefits covering treatment services for many individuals diagnosed with autism spectrum disorder. In furtherance of the work of the MAAC, we are pleased to submit this, the 2015 MAAC Report detailing our findings and recommendations for the 2016 legislative session.

Our report outlines the current struggles faced by an ever-rising autism population in our state and recommends the establishment of an Office of Autism Services. The MAAC membership considers this a critical step needed to address the autism crisis in Mississippi.

The dramatic growth in the number of children affected by autism spectrum disorder (ASD) now constitutes a public health crisis in Mississippi and our nation as a whole. An estimated 10,743 Mississippi children have been diagnosed with autism spectrum disorder – an increase from 1 in 500 children to 1 in 68 within the last decade. Current data from the National Health Interview shows an increase in prevalence as high as 1 in 45 when parents were asked about their child's autism diagnosis.¹⁻³ Statistics from the Mississippi Department of Education show a 563% rise in the number of public school children with autism in the past ten years. Throughout the state of Mississippi, families and systems of care are struggling to meet the needs of individuals with ASD across their life span.

ASD is a biomedical disorder that impairs a person's ability to communicate and socialize. It is characterized by restricted and repetitive behaviors. It typically appears within the first three years of life and can range from mild to severe. There is no known cause and no known cure.

It can cost as much as \$3.2 million to care for an individual with autism across their lifespan.⁴ Early and intensive therapy can improve ASD treatment outcomes. Forty-Two states, the District of Columbia, and the US Virgin Islands have enacted insurance coverage mandates for ASD treatment, and Mississippi is NOW one of those states. Coverage will result in significant long-term cost savings to health care and educational systems.

The number of students with ASD in public schools has increased dramatically. Most teachers do not receive training on ASD prior to entering the school system, as many teacher preparation programs contain little to no autism related curriculum. There is one institution of higher learning in Mississippi offering a specialty program or degree in the area of Autism. One of the few bright spots in the training of professionals to work with the ASD population is through a collaborative effort of The Mississippi Department of Education and the University of Southern Mississippi.⁵

The Mississippi Public Health Institute collaborated with the Mississippi Department of Health to submit a grant to the Centers of Disease Control and Prevention (CDC) to be a part of the Autism and Developmental Disabilities Monitoring Network (ADDM). Results from the ADDM studies help identify the prevalence of autism spectrum disorder (the 1 child out of 68 affected by autism spectrum disorder). MAAC was asked to write a letter of support for this grant proposal and many members of the MAAC helped the state agencies they represent contribute to this grant application. The grant application submitted by the Mississippi Public Health Institute and the Mississippi Department of Health received a good grant score (90 out of 100), but one of the major weaknesses of the grant application was our state's inexperience in accessing data from multiple educational and clinical sources.⁶ Despite a good grant score, Mississippi did not win this award.

To address the challenges outlined above the MAAC recommends the establishment of a statewide Office of Autism Services

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

Sincerely,

Dr. Sherry Ponder, PhD,
Co-Chairperson

Dr. Kimberly Stringer, MD,
Co-Chairperson

Mississippi Autism Advisory Committee

UNDERSTANDING AUTISM

Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. They include autism, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger syndrome. With the May 2013 publication of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), these autism subtypes merged into one umbrella diagnosis of ASD.

ASD can be associated with difficulties in social interactions, motor coordination and attention and physical health issues such as sleep, gastrointestinal disturbances, and epilepsy. Some persons with ASD excel in visual skills, music, math and art.

ASD appears to have its roots in very early brain development. However, the most obvious signs of autism and symptoms of autism tend to emerge between 2 and 3 years of age. Unfortunately, many of our children with Autism are not diagnosed until much later. Studies have shown that children receiving early intensive intervention can greatly increase their educational and vocational outcomes.

Did you know...

- Autism now affects 1 in 68 children and 1 in 42 in boys.⁷
- Government autism statistics suggest that prevalence rates have increased 10 to 17 percent annually in recent years.
- Autism is the fastest-growing serious developmental disability in the U.S.
- Autism costs a family \$69,000 a year on average.⁸
- Boys are nearly five times more likely than girls to have autism.⁷
- There is no medical detection or cure for autism
- There is no autism specific degree granting training toward licensure in Mississippi.

COMMITTEE'S PURPOSE AND WORK

The Mississippi Autism Advisory Committee was created by House Bill 1125 (2011 Regular Session) because the “Legislature recognizes that strategies for how to best identify, treat, educate, accommodate and employ individuals with autism and assist their families are urgently needed in our state.”

The mission established for this committee is “to study, make recommendations and develop a strategic plan on how best to educate and train students with autism or ASD to maximize their potential productivity within the workforce ... and to develop an annual plan” outlining these strategies. This is the fifth report of this committee and there was a 2007 report from a previous task force that was legislatively created and authorized.

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

KEY FINDINGS ON ASD SERVICES

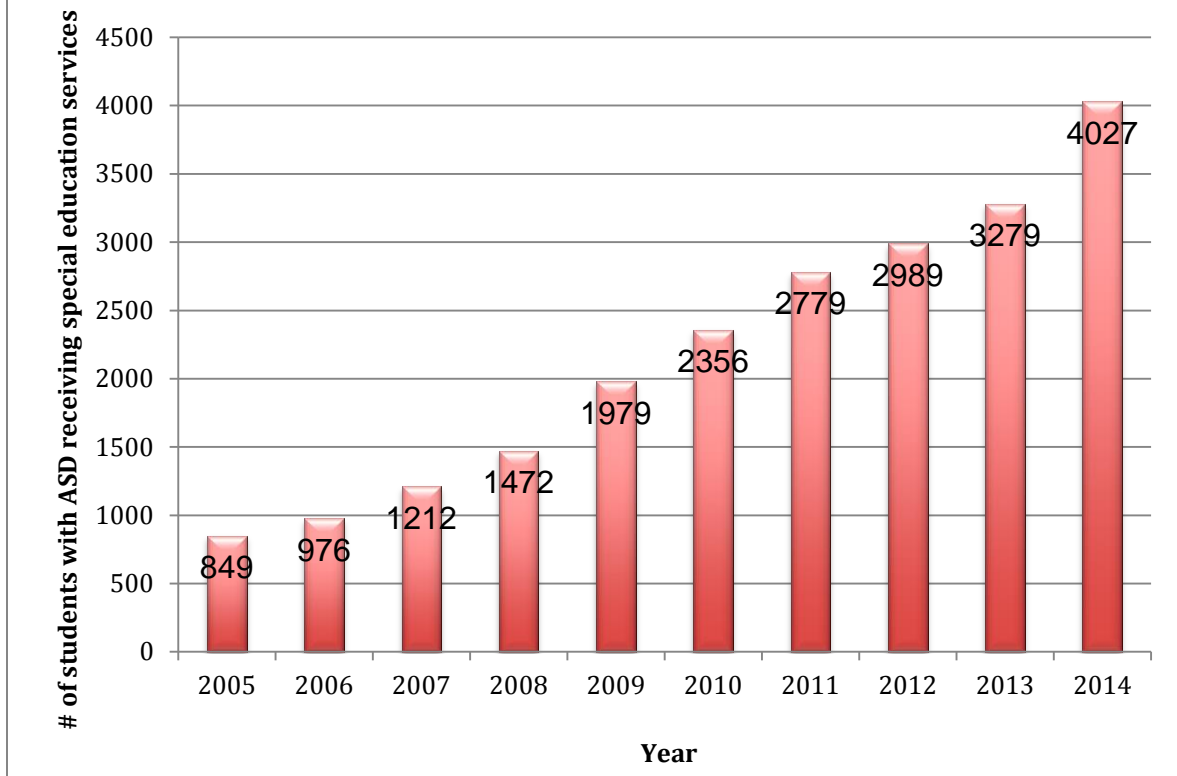
The following section provides key findings on the services provided by major state agencies that work with and provide services to our increasing population of individuals with ASD and their families and improvements needed in these agencies:

MISSISSIPPI DEPARTMENT OF EDUCATION

- The Mississippi Department of Education identified 4027 children, ages 3-21, with the educational ruling of Autism in 2014. That number reflects an increase of 748 children identified in 2013.
- The explosion in the number of children diagnosed with Autism has created a huge demand for trained professionals to work with the Autism population.
- The lack of a trained work force to assist those with Autism is one of the biggest issues reported by both parents and teachers.
- Some services currently exist to support this population but they are scattered, disconnected and inconsistent from one part of the state to the next.
- The State Department of Education has supported the development of a training program in conjunction with the Department of Curriculum and Instruction at the University of Southern Mississippi. This program was described in the 2013 MAAC Report.⁵
- The MDE has recently added an autism instructional specialist.

Mississippi IDEA Data-Child Count Data for Autism by Year (ages 3-21)

(Data Accountability Center -
Individuals with Disabilities Education Act Data)



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.⁹ However, many children do not receive a final diagnosis until three (3) to five (5) years of age.¹ This delay means that children with ASD might not get the intensive early intervention they need.

- Over the 2014-2015 program year the Mississippi First Steps Early Intervention Program identified and serviced over 120 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.”¹⁰
- When the Mississippi Autism Task Force surveyed Mississippi pediatricians in 2007, very few pediatricians screened for ASD.¹¹ 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 2012, the Department of Mental Health’s certified community mental health agencies served approximately 220,000 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, twenty trainings have been offered throughout the entire state with 1123 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.
- With the passage of HB 885, the number of certified behavioral analysts, behavioral analyst assistants, and registered behavioral technicians will need to grow in order to offer applied behavioral analysis therapy.
- So far, the University of Southern Mississippi and Mississippi State are the only universities in this state offering training for Masters Level Psychology with emphasis in Applied Behavioral Analysis. With the creation of these programs, these institutions will need funding to recruit faculty. Other universities and community colleges also need funding to hire faculty to train behavioral analysts and registered behavioral technicians who can treat the behaviors associated with ASD.
- To determine the prevalence rate of ASD in adults, a research project was conducted in England. In general, they found that an estimated prevalence of ASD in adults approximates the current estimates of ASD in prevalence in children at 1.1%¹²
- Boys are four times more likely than girls to have Autism and there is a higher prevalence of ASD among men¹²
- Key findings show that Autism is the 5th most prevalent diagnosis in children aged three (3) to seventeen (17) years:
 - Attention Deficit Hyperactivity Disorder (6.8%)
 - Behavioral or conduct problems (3.5%)
 - Anxiety (3%)
 - Depression (2.1%)
 - Autism Spectrum Disorder (1.1%)¹³
- 70% of children with autism spectrum disorder have 1 comorbid or co-existing developmental or psychiatric condition:
 - Intellectual Disability (~45%)
 - Attention Deficit Hyperactivity Disorder (28-48%)
 - Depression (12-70%)
 - Anxiety (42-56%)
 - Self-Injurious behaviors (≤50%)
 - Suicidal Ideation or Attempt (11-14%)¹⁴

Some services currently exist to support individuals with ASD and their families, but they are scattered and inconsistent from one part of the state to the next. The rate of ASD in Mississippi has risen and yet we have little available data to understand the scope of this problem. Therefore, a full-time position and funding for an Autism Coordinator is needed to track this population through available data systems, to identify gaps of autism-related services and to facilitate the development of a state-wide strategic plan to improve and expand effective services/resources for individuals with ASD and their families.

Many people with ASD have the potential to hold full time employment. However, the committee, through their professional experiences and through public meetings realizes that as the population of autism increases, vocational training for this population must expand if we are to get and keep this population in the workforce.

DEPARTMENT OF REHABILITATION SERVICES

- For youth with ASD, 34.7% attended college.¹⁵
- 32.5% of individuals with ASD have worked for pay and 47.7% have worked in the last two years (employment research and reports; Autism NOW Center. <http://autismnow.org>).
- 54% percent of young adults with ASD have never worked for pay outside the home since leaving high school, which is the lowest rate, compared to adults with other disabilities.¹⁶
- More than 50% of youth who had left high school in the past 2 years had no participation in employment or education.¹⁵
- 20% of youth with ASD worked full-time (>35hrs/wk).¹⁶
- Adults with ASD who came from households with higher incomes (an indicator of more services received), had better conversational skills, and functional skills were able to have higher paying jobs.¹⁶
- The total mean cost of vocational rehabilitation services for transitioned-aged adults with ASD was \$1, 085 per person in Mississippi versus the total cost for an adult to be placed in Intermediate Care Facility in 2012-2013 was \$125, 037.44 per person per year.¹⁷
- State vocational rehabilitation agencies are one of the most important sources of employment services for individuals with autism spectrum disorder and other disabilities, and the number of people with autism spectrum disorder seeking these services has risen steadily. The number who exited vocational rehabilitation services more than tripled between 2003 and 2008. In 2008, 5,344 individuals with autism spectrum disorder completed vocational rehabilitation services.¹⁸

- In 2009, 59% of people with autism spectrum disorder gained employment after receiving vocational rehabilitation services compared to people with any types of disabilities (56%).¹⁸
- The Mississippi Department of Rehabilitation Services has a Program Coordinator for Autism whose duties include:
 - Providing field staff updated information regarding ASD
 - Coordinating training for field staff
 - Coordinate services provided for individuals with autism through private providers such as TEAAM
 - Works closely with Supported Employment Program Coordinator regarding individuals with ASD by assisting with Personal Care Planning (PCP) meetings in working with Counselor, client, and family.

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 our increasing population of children and adults with ASD and their families. The MAAC recommends a staff consisting of a statewide Autism Coordinator, two staff members to serve the northern and southern regions of the state, and an Administrative Assistant. It is further recommended that the office be a part of the Governor's staff.

Rationale for a State Office of Autism Services

A major goal of this office 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 Autism Coordinator would also work with the Mississippi Autism Advisory Committee at each committee meeting.

Primary agencies in Mississippi who serve individuals with ASD includes the Department of Education, Department of Mental Health, Department of Rehabilitation Services, Department of Health, Institutions of Higher Learning and other various public agencies that work in treating individuals diagnosed with ASD from the time of their diagnosis until adulthood. Although these agencies each work with individuals affected by ASD, there is a major disconnect among the agencies as to what services are provided, who qualifies for those services, and the coordination of care between the servicing agencies and families. Another major responsibility of the Office of Autism will be to develop and maintain linkages among service providers.

Expected Organization and Goals of the Office of Autism Services

The MAAC recommends the creation of an Office of Autism Services within the Mississippi's 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 an Office of Autism Services website, toll-free phone number, and contact information for key assisters at various state agencies.

- Design and update annually a Mississippi Autism Services Handbook that combines information about how to navigate the medical, educational, and community services that presently exist in Mississippi with resource 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 Office of Autism Services in identifying promising practices and model programming.
- Organize and coordinate a comprehensive program of outreach, involving dissemination of information on Mississippi ASD resources to families, staff, and communities.
- Develop a social media campaign (Facebook, Twitter, Instagram) to communicate about autism and other related disabilities throughout the state.
- Ensure that a link to the Office of Autism Services webpage is available on the websites of all state agencies providing ASD related services.
- Facilitate an increase in the number of individuals in our state that are trained to work with people with ASD by planning, coordinating and delivering regional and statewide training and/or staff development for ASD assessment teams, general educators, para educators, parents and community.
- 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 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.

Recommended Budget:

We propose an initial funding amount of \$1,500,000. This funding request represents 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 with autism is growing exponentially and the need for change is clear. This report outlines many of the gaps in our system of care for persons living with ASD. Establishing an Office of Autism Services will require minimal funding and will lay a critical foundation for providing early access to care for persons diagnosed with ASD, which will in turn mean huge long-term savings for our state. More importantly, the implementation of this recommendation will mean the difference between a life of dependence or independence for many Mississippi children, youth and adults living with autism.

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.

Mississippi must make a commitment to its citizens living with autism spectrum disorder by creating the infrastructure to allow them the same freedoms afforded other Mississippians – the freedom to live, work, learn and play in their own homes, schools and communities.

APPENDIX

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

States similar to Mississippi in size and resources have developed ways to coordinate autism services. The best examples are Missouri and South Carolina. Missouri was actually a pioneer of coordinated autism services. Families affected by autism were able to find a champion in the Governor's wife and a state legislator to create five (5) Missouri Autism Projects in the 1990s.^{19 20} The Missouri Autism Project, which consists of five (5) regions including three (3) rural areas in the state, that provides autism-specific family supports (e.g. assessment, parent training, advocacy, behavioral therapy, respite) and assist in skill development of individuals with ASD. From the work of the Missouri Autism Projects, Missouri was lead to create 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 helps coordinates the five (5) Missouri Autism Projects, manage the autism interagency committees, and maintain a website that provides information about statewide projects involving autism.¹⁹

South Carolina, Tennessee, Arkansas, and Louisiana have excellent websites that families can utilize to receive information about services from individuals with autism and other related-disabilities. Most of these websites universities or non-profit organizations have received state funding to develop and maintain. Mississippi does have a website of resources for individuals with disabilities but it desperately needs be updated and maintained. There are also families who don't have Internet access who need to be able to call and the get answer to their questions. South Carolina's Office of Autism does provide a 1-800 number to get information about their services. If Mississippi was able to have a central agency which was able to provide parents with updated information about autism services this would greatly improve access to services and treatments.

Table 1: Brief Overview of Autism 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 departments of Mental Health, Education, and Vocational Rehabilitation	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
South Carolina	No	Yes	Yes	Yes	No
Tennessee	No	No	No	Yes	No

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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:

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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.