



Mississippi Autism Advisory Committee

Report to the Legislature

July 2014

MISSISSIPPI AUTISM ADVISORY COMMITTEE REPORT

Dear Legislators,

We are pleased to submit the 2014 report from the Mississippi Autism Advisory Committee detailing our findings and recommendations.

The dramatic growth in the number of children affected by autism spectrum disorders (ASD) now constitutes a public health crisis. An estimated prevalence of 10,980 Mississippi children have autism spectrum disorder – an increase from 1 in 500 children to 1 in 68 within the last decade.^{1,2} Statistics from the Mississippi Department of Education show a 563% rise in the number of public school children with ASD in the past 11 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.

Autism Spectrum Disorder (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 ASD across their lifespan.³ If the state's children currently living with ASD do not overcome their challenges by the time they reach adulthood, it could cost Mississippi taxpayers more than 35 billion dollars over the next 50 years. We know early and intensive therapy can improve outcomes. Even though ASD is a biomedical brain disorder, insurance companies routinely exclude coverage for ASD. Thirty-seven states, the District of Columbia, and the US Virgin Islands have enacted autism insurance reform laws to ensure necessary treatment is provided.⁴ Mississippi is NOT 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 ASD related curriculum. There are also no institutions for higher learning in Mississippi offering a specialty program or degree in the area of ASD. 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

Our report focuses on two key recommendations that have been the long-term recommendations since the creation of this committee through House Bill 1125 (2011 Regular Session). This is not an exhaustive list of remedies but will lay the critical foundation needed to address the ASD crisis in Mississippi.

On behalf of individuals with autism spectrum disorder, their families, and the professionals who work with them, the Mississippi Autism Advisory Committee stands ready to assist in the implementation of these recommendations.

Thank you for the opportunity to serve and recommend improvements to services and the quality of life for our children, adults, and family members with ASD.

Sincerely,

Dr. Sherry Ponder, Co-Chairperson

Dr. Kimberlly Stringer, Co-Chairperson

Mississippi Autism Advisory Committee

UNDERSTANDING AUTISM

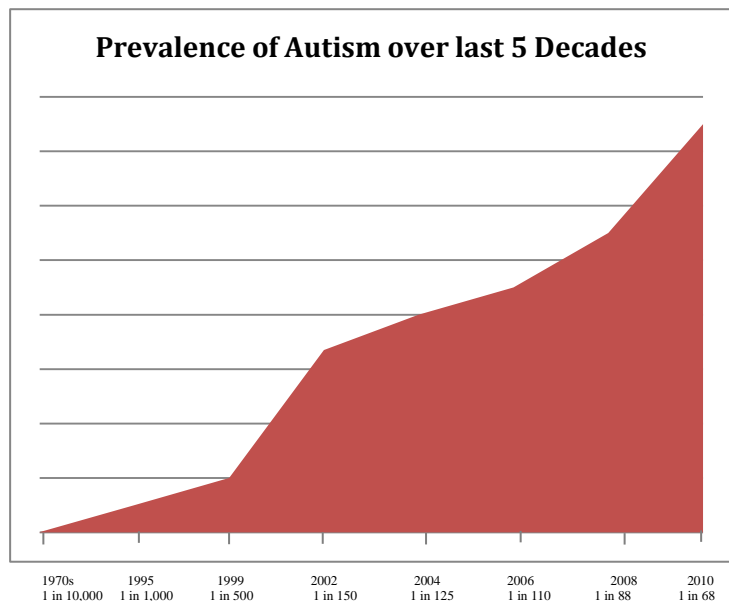
Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. They include autism pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger syndrome. With the May 2013 publication of the Diagnostic and Statistical Manual 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 ASD and symptoms of ASD tend to emerge between 2 and 3 years of age. Unfortunately, many of our children with ASD 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...

- ASD now affects 1 in 68 children and 1 in 42 in boys.¹
- 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.
- ASD costs a family \$60,000 a year on average.
- Boys are nearly five times more likely than girls to have ASD.¹
- There is no medical detection or cure for autism.
- There is no staff person at any state agency whose primary responsibility is to coordinate either training for professional working with persons with ASD or services for persons with ASD.
- There are no ASD specific training programs or certifications at any of our public university and college institutions.



- For insured Mississippians, most policies especially private insurance policies refuse to offer coverage or provide very limited coverage for habilitative and behavioral autism services.

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 fourth 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. The committee has worked with professional organizations to conduct surveys about how they serve individuals with ASD. Plans are being finalized to conduct additional hearings this year and conduct additional surveys from stakeholders.

This committee heard from both parents and providers the need for services from early childhood through adulthood. This committee has chosen to focus this report on our most important and critical recommendations.

RECOMMENDATIONS

1. THE COMMITTEE RECOMMENDS THAT THE MISSISSIPPI LEGISLATURE PASS LEGISLATION MANDATING COVERAGE OF EVIDENCE-BASED ASD SERVICES BY PRIVATE AND PUBLIC INSURANCE PROVIDERS.

Rationale:

Issue 1: There is a need for health insurance coverage in our state that includes medically necessary and appropriate comprehensive services and treatments/interventions for individuals with ASD.

Key Findings:

- Autism spectrum disorder (ASD) is a biomedical disorder. There is currently no cure for ASD. Rather, ASD treatment is focused on controlling or diminishing symptoms and associated impairments. In this way it does not differ from other chronic medical disorders whose treatment is covered routinely by health insurance, including hypertension, diabetes, renal failure, and asthma.

- Insurance companies providing coverage in our state routinely exclude coverage of some treatments for ASD particularly those that involve communication and behavioral treatments.
- Insurance exclusion for ASD results in financial hardship for some families as they are forced to pay for therapies and treatments excluded solely on the basis of their child's disability. These are families who in many cases already have reduced resources because one parent has been forced to give up their job to care for their child.
- 37 states have enacted autism insurance reform laws to ensure that citizens with ASD receive necessary medical and behavioral treatment.⁴ Mississippi is NOT one of those states.
- In the 2014 Legislative session, House Bill 542 (2014 Regular Session) which supports ASD insurance coverage for state and school employees was passed, but provides no coverage and by Senate action referred to a study group. MAAC is working on an ASD Evidence-Based Report to present to the study group, the State and School Employees Health Insurance Management Board, in the fall of 2014.
- House Bill 542 (2014 Regular Session) also does not provide coverage to others who do not have state and school employee insurance.
- Many people with ASD go without medical and behavioral treatment due to financial reasons.

Costs: (for private insurance) According to a report issued from Autism Speaks in March of 2012. . .

- "Autism insurance reform laws have been in effect for at least one year in 15 states. Twelve of these states require coverage for members of their state employee health plan.
- Claims data is available from the first year of implementation in 5 states (i.e., SC, IL, FL, AZ and KY).

The first year costs of coverage range from \$0.09 per member per month (PMPM) to \$0.30 PMPM. The average first year cost of coverage is \$0.15 PMPM.
- Claims data is available from the second year of implementation in 5 states (i.e., SC, IL, LA, FL and AZ). The second year costs of coverage range from \$0.10 PMPM to \$0.43 PMPM. The average second year cost of coverage is \$0.31 PMPM.
- Minnesota has not enacted autism insurance reform. However as a result of a settlement of litigation against Blue Cross and Blue Shield of Minnesota, they have been required to cover unlimited treatment for ASD since 2001. After 6 years, the premium impact on the commercial market resulting from unlimited coverage for ASD was \$0.83 PMPM.

- Fiscal notes were prepared for the legislatures in 5 of the states where Autism Speaks obtained claims data. These cost projections were prepared for fiscal or calendar years that correspond to available claims data in 3 states. Fiscal projections overestimated the actual cost of autism insurance reform by 293% to 1,261%.¹⁶

Costs: (for public insurance)

- Implementation of an ASD specific Medicaid waiver will cost \$1,000,000. This would provide approximately 200 waiver slots at an estimated \$20,000/person with Mississippi providing \$1,000,000 in funding and approximately \$3,000,000 in matching dollars provided from the federal level for a total of approximately \$4,000,000.

2. THE COMMITTEE RECOMMENDS THE MISSISSIPPI LEGISLATURE PASS LEGISLATION CREATING THREE AUTISM SPECTRUM DISORDER POSITIONS (PINS AND FUNDING) TO COORDINATE ASD STATEWIDE EFFORTS. ONE ASD STAFF MEMBER IS TO BE LOCATED AT THE MS DEPARTMENT OF EDUCATION, ONE AT THE MS DEPARTMENT OF MENTAL HEALTH AND ONE AT THE MS DEPARTMENT OF REHABILITATION SERVICES.

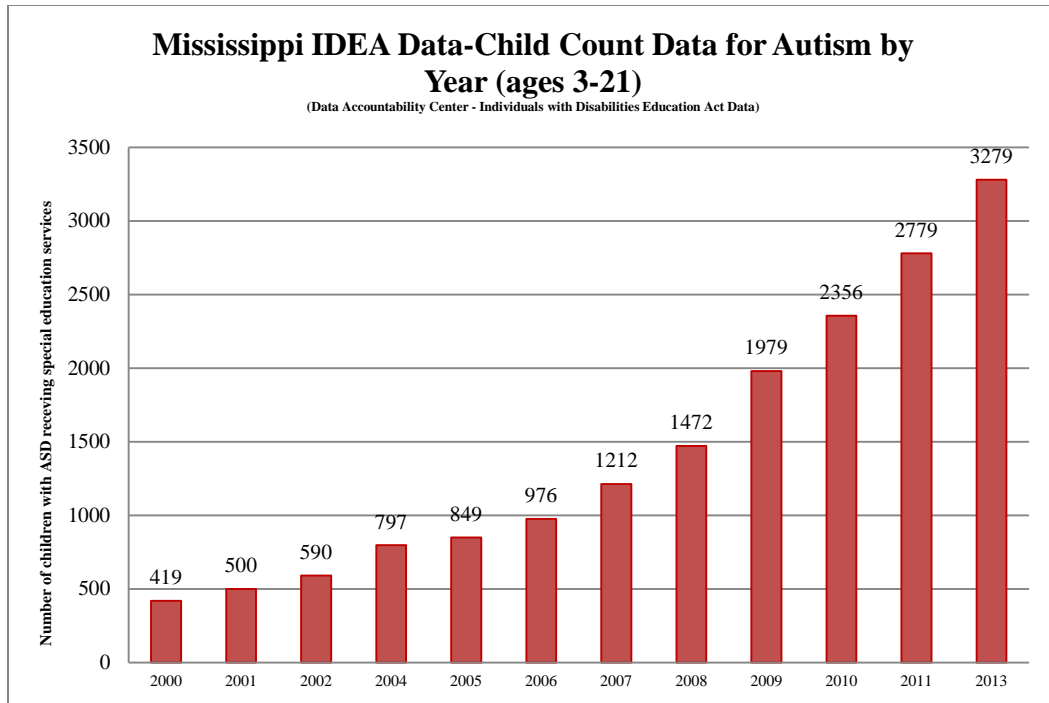
Rationale

Issue 2.1: Appropriate educational instruction for children with ASD and training for professionals working with those with ASD.

With the increase in the population of students with ASD, both parents and teachers are requesting that more training opportunities for professionals be provided. Persons holding this position would also work with the Mississippi Autism Advisory Committee at each committee meeting.

Key Findings:

- The Mississippi Department of Education identified 3279 children (ages 3-21) with the educational ruling of Autism in 2013. The numbers reflect a 683% increase from 13 years ago, a 170% increase from 5 years ago and a 39% increase from 3 years ago.



- This explosion in the number of children diagnosed with ASD has created a huge demand for trained professionals to work with the ASD population.
- No Mississippi college or university offers ASD specific certifications or degrees requiring most training to come from the Mississippi Department of Education.
- The lack of a trained work force to assist those with ASD was one of the biggest issues reported at the public meetings 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 Mississippi Department of Mental Health and Boswell Regional Center provides a free Autism Statewide Training Initiative to educate families and people working with individuals with autism spectrum disorders about evidence-based services and supports to individuals with ASD across the lifespan. More information about the Autism Statewide Training Initiative can be found on the following website:
<http://www.brc.ms.gov/Pages/autismtraining.aspx>.⁷

Issue 2.2: Appropriate mental health services and coordination of services for people with autism is needed.

A major goal of this position will be identifying, developing and coordinating services regionally throughout the state; and to form interagency agreements with entities/agencies providing services and training to individuals with ASD, who work with individuals with ASD and assist in the development of a strategic plan. Persons holding this position would also work with the Mississippi Autism Advisory Committee at each committee meeting.

Key Findings:

- In FY 2013, the Department of Mental Health's certified community mental health agencies served approximately 200,000 (down from 220,000 in FY 2012) individuals with serious mental illness, serious emotional disturbance and intellectual/developmental disabilities.
- The true number of individuals with ASD served remains unknown because only one state agency – the MS Department of Education – tracks this population, but only for children who have an educational ruling of autism.
- 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%.⁸
- Key findings show that ASD is the 5th most prevalent diagnosis in children aged 3-17 years:
 - Attention Deficit Hyperactivity Disorder (6.8%)
 - Behavioral or Conduct Problems (3.5%)
 - Anxiety (3%)
 - Depression (2.1%)
 - Autism Spectrum Disorders (1.1%)⁹
- 70% of children with ASD have 1 comorbid 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%)¹⁰

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 very little available data to understand the scope of this problem. Therefore, a full-time position and funding for an ASD Coordinator is needed at the Department of Mental Health to track this population through available data systems, to identify gaps in ASD-related services and to facilitate the development of a state-wide strategic plan to improve and expand effective services/resources for individuals with ASD.

Issue 2.3: Vocational Employment for People with ASD

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 must expand to obtain and maintain employment. Expertise must be developed within the state vocational rehabilitation programs. The person holding this position would also work with the Mississippi Autism Advisory Committee at each committee meeting.

Key Findings: In reviewing the US employment of young adults with ASD in the community:

- For youth with an ASD, 34.7% had attended college¹¹
- Fifty-Four (54) percent of young adults with ASD have ever worked for pay outside the home since leaving high school which is the lowest rate compared to adults with other disabilities¹²
- More than 50% of youth who had left high school in the past 2 years had no participation in employment or education¹¹
- One-fifth of youth with ASD worked full-time (>35 hours per week)¹²
- Adults with ASD who came from households with higher incomes (an indicator of more services received), better conversational skills, and functional skills were able to have higher paying jobs¹²
- 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. ¹³
- State vocational rehabilitation agencies are one of the most important sources of employment services for individuals with ASD and other disabilities, and the number of people with ASD seeking vocational rehabilitation services has risen steadily. The number who exited vocational rehabilitation services more than tripled between 2003 and 2008. In 2008, 5,344 individuals with ASD completed vocational rehabilitation services.¹⁴
- In 2009, 59% of people with ASD gained employment after receiving vocational rehabilitation services compared to people with any types of disabilities (56%).¹⁴

CONCLUSION

The number of Mississippians with ASD is growing exponentially and yet service systems in the state are not growing nearly as quickly. The strategies recommended in this report require minimal financial investments and will lay a critical foundation, which will in turn mean huge long-term savings for Mississippi. More importantly, the implementation of these strategies will mean the difference between a life of dependence or independence for many Mississippi children, youth and adults living with ASD.

The need for change is clear. The work outlined in this report illustrates that we have many gaps in our system of care. One extreme challenge is the number of youth with ASD who are reaching adulthood. 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 to persons with ASD to live and work in their communities, using the most cost effective means possible. This will require innovative approaches and models of support. In addition, for change to be successful, individuals with ASD and their families must play a critical role in all aspects of the process.

This state must make a commitment to Mississippians living with ASD by creating the infrastructure to allow them the same freedoms afforded other citizens – the freedom to live, work, learn and play in their own homes, schools and communities

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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:

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