

# Mississippi Autism Advisory Committee

2020 REPORT TO LEGISLATURE

Dear Legislators,

The Mississippi Autism Advisory Committee (MAAC) is pleased to present the following report to the Mississippi Legislature. This report outlines the struggles faced by Mississippi families living with autism spectrum disorder (ASD) and outline several key areas in need of immediate reform.

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 54 children being affected. 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, and other needs. In Mississippi, these families are essentially on their own. There is no public entity dedicated to helping people understand the services available for people living with ASD.

As part of this report, the MAAC recommends expanding access to training related to educational methods for children with ASD, implementing a public school pilot program to reduce wandering, and the establishment of a statewide Office of Autism Services (OAS). An Office of Autism Services is an innovative approach intended to help individuals and families overcome the challenges listed above by providing information about resources and services for people with ASD in Mississippi.

On behalf of people with ASD, their families, and professionals who work with them, the MAAC 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,

Melody Madaris, Co-Chairperson Phillips Strickland, JD Co-Chairperson

Mississippi Autism Advisory Committee

<sup>&</sup>lt;sup>1</sup> 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, 2016. Available online: <a href="https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm?scid=ss6904a1">https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm?scid=ss6904a1</a> w.

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### **Committee's Purpose and Work**

The Mississippi Autism Advisory Committee (MAAC) was created by House Bill 1125<sup>2</sup> (2011 Regular Session) as the Legislature recognized an urgent need for strategies on how to best identify, treat, educate, accommodate and employ people with Autism Spectrum Disorder (ASD) 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 people with ASD and their families.

The MAAC met six times this year. Based on these meetings and testimonies received within, the committee has chosen to focus this report the included strategic recommendations as set forth below.

### Advisory Committee Recommendations to the Legislature

Based on currently available data, the MAAC recommends the following to the Mississippi State Legislature:

- 1) The MAAC recommends that the Mississippi Legislature pass legislation that requires public school districts to conduct annual in-service training on Autism Spectrum Disorders and related evidence based interventions and education.
- 2) The MAAC recommends that the Mississippi Legislature pass legislation creating an Office of Autism Services (OAS). This entity shall coordinate ASD efforts among primary agencies that serve Mississippi's population of children and adults with ASD and their families.
- 3) The MAAC recommends implementing a pilot program in at least one Mississippi school district to reduce the risk of injury and death relating to the wandering characteristics of some individuals with autism and other disabilities.

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

### Rationale for School District Wide Training Related to Autism Spectrum Disorders

Data collected by MAAC over the years has supported the growing number of individuals identified with Autism Spectrum Disorder within Mississippi (see Table 1). It has also been documented that many individuals are not diagnosed until they are already school-age and enrolled in the Mississippi public schools.

Further information received has revealed that the majority of school districts in Mississippi do not provide ongoing training on Autism Spectrum Disorder, despite the growing numbers. While some teachers may have exposure to children with autism or have received training in the past there is no process to ensure that they have received ongoing training for the advances related to treatment advances and interventions strategies with this increasing population of students with ASD.

MAAC is recommending that the legislature support a bill, similar to the current statutes related to suicide prevention training and active shooter response, requiring the annual exposure to inservices/trainings, live or online module based, related to behavior interventions and educational programming that are usable with children with Autism Spectrum Disorder and/or related Developmental Disabilities for all public school employees. MAAC believes that this would increase the possibility of public school employees feeling competent and feeling able to respond proactively to the needs of individuals with ASD. This would also decrease ongoing difficulties related to suspensions and significant disciplinary referrals with this population.

### 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 people 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.<sup>3</sup> In 2008, the Missouri Legislature established an Office of Autism Services (OAS) 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." 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 OAS is an innovative approach intended to help ease this process by providing information about ASD resources and services to the people of Mississippi.

<sup>&</sup>lt;sup>3</sup> See Appendix A

<sup>&</sup>lt;sup>28</sup> Missouri Office of Autism Services website, <a href="http://dmh.mo.gov/dd/autism/">http://dmh.mo.gov/dd/autism/</a>

An OAS is needed to identify gaps in autism-related services and to facilitate the implementation of a state-wide strategic plan to improve and expand effective services and resources for people 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 people 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 people 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 people with ASD from the time of their diagnosis until adulthood. <sup>5</sup>Although these agencies each work with people affected by ASD, there is lack of communication between the agencies as to what services are 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 or Lt. Governor's Office. The OAS should consist of an Autism Coordinator, an administrative assistant and two qualified staff members to serve the northern, central, and southern regions of the state.

The expectations and goals of the OAS are as follows:

- Adopt, implement, and regularly assess the progress of a statewide ASD strategic plan.
- 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 contacts 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 people 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.

<sup>&</sup>lt;sup>5</sup> See Appendix B

- 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.
- Work with the Mississippi Department of Rehabilitation Services to develop an adequate pool of qualified personnel to work with people with ASD.

# Rationale for implementing a pilot program to reduce the risk of injury and death relating to the wandering characteristics of some individuals with autism and other disabilities

On March 23, 2018, the United States Congress passed bipartisan legislation to help families locate missing loved ones with autism and related conditions. Kevin and Avonte's Law, named in honor of two boys with autism who perished after wandering from safety, supports training for caregivers to prevent and respond to instances of wandering. This bill makes resources available to deploy the use of technology to help unite missing family members before tragedy occurs and provides resources for education and training to help prevent a vulnerable family member's disappearance or, in the event he or she goes missing, take immediate action to return that endangered family member to safety.

The MAAC was approached by Mr. George Stewart, a teacher in the Jackson Public School District and a parent of a child with special needs. Mr. Stewart worked with Representative Christopher M. Bell to draft House Bill 490<sup>8</sup> in an effort to implement state-wide protections in Mississippi similar to those found in *Kevin and Avonte's Law*. However, HB 490 died in Committee without a vote.

The MAAC recommends the adoption of a pilot program based on the provisions of HB 490 that will implement some or all of the protections found in the bill, including but not limited to: the installation of security cameras and door alarms at entrance and exit doors, and the implementation of training on student safety protocols for school personnel. The pilot program should provide resources that will help the school district build a better working relationship with local law enforcement agencies, first responders, schools, clinicians and the public.

https://www.judiciary.senate.gov/imo/media/doc/Kevin%20and%20Avonte,%2011-03-17,%20One-pager.pdf

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<sup>&</sup>lt;sup>6</sup> See: <u>https://nationalautismassociation.org/kevin-avontes-law-has-passed/</u>

<sup>&</sup>lt;sup>7</sup> A summary of the bill can be found here:

<sup>&</sup>lt;sup>8</sup> See: http://billstatus.ls.state.ms.us/documents/2020/pdf/HB/0400-0499/HB0490IN.pdf

# Conclusion

The number of Mississippians diagnosed with ASD 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.

Providing ongoing training to public school employees, implementing safeguards at our schools, and 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.

### **Understanding Autism**

Autism Spectrum Disorder (ASD) is a diagnostic term for a group of complex disorders of brain development. Previously, these disorders have been labeled in multiple ways, including Autistic disorder, Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), and Asperger Disorder. With the May 2013 publication of the Diagnostic and Statistical Manual of Mental Disorders, these autism subtypes merged into one umbrella diagnosis of ASD. ASD can be associated with attention issues, difficulties in social interactions, language disorders, motor coordination problems, as well as physical health issues such as sleep, gastrointestinal disturbances, and epilepsy. However, some people 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 two and three years of age. Unfortunately, many children with autism are not diagnosed until much later. Recent data has revealed that fewer than a fifth of Mississippi children ages 6 and younger are screened for developmental and behavioral disorders, the lowest rate in the nation, reflecting half of the national average of 30.8 percent.

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 continued to increase each year.

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

Table 1. Identified Prevalence of Autism Spectrum Disorder ADDM Network 2000-2014 Combining Data from All Sites<sup>12</sup>

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

<sup>&</sup>lt;sup>9</sup> Centers for Disease Control and Prevention, Facts about ASD, Available online: <a href="http://www.cdc.gov/ncbddd/autism/facts.html">http://www.cdc.gov/ncbddd/autism/facts.html</a>

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<sup>&</sup>lt;sup>10</sup> Centers for Disease Control and Prevention, ASD Diagnostic Criteria, Available online: http://www.cdc.gov/ncbddd/autism/hcp-dsm.html

<sup>&</sup>lt;sup>11</sup> 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: <a href="http://www.ncbi.nlm.nih.gov/pubmed/22365461">http://www.ncbi.nlm.nih.gov/pubmed/22365461</a>

<sup>&</sup>lt;sup>12</sup> Centers for Disease Control, Autism Spectrum Disorder Data and Statistics, Available online: http://www.cdc.gov/ncbddd/autism/data.html

2016	2008	11	(13.1 – 29.3) <b>18.5</b> (18.0 -19.1)	1 in 54
2014	2006	11	16.8	1 in 59
2012	2504		(8.2 - 24.6)	1 111 00
2012	2004	11	14.6	1 in 68
			(5.7 - 21.9)	
2010	2002	11	14.7	1 in 68
			(5.7 - 21.9)	
2008	2000	14	11.3	1 in 88
			(4.2 - 12.1)	
2006	1998	11	9.0	1 in 110

#### Did you know:

- Based on the National Survey of Children's Health (2016-2017), it is estimated that approximately 13,379 children (ages 3-17) are currently diagnosed with Autism or Autism Spectrum Disorder in Mississippi.<sup>13</sup>
- ASD now affects 1 in 54 children<sup>14</sup>
- ASD is 4.3 times more prevalent in boys than girls<sup>15</sup>
- A majority of ASD-related costs in the U.S. are in adult services \$175-196 billion, compared to \$61-66 billion for children. <sup>16</sup>
- ASD costs a family \$69,000 a year on average. 17
- Key findings show that ASD is the fourth most prevalent diagnosis in children aged three (3) to seventeen (17) years. 18
- 70% of children with ASD have one comorbid developmental or psychiatric condition. 19

15 *Id*.

<sup>&</sup>lt;sup>13</sup> Available online: https://www.childhealthdata.org/browse/survey/results?q=5383&r=26

<sup>&</sup>lt;sup>14</sup> See: https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm?s cid=ss6904a1 w

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.
 Id

<sup>&</sup>lt;sup>18</sup> Centers for Disease Control, Children's Mental Health, Available online: <a href="http://www.cdc.gov/childrensmentalhealth/data.html">http://www.cdc.gov/childrensmentalhealth/data.html</a>

<sup>&</sup>lt;sup>19</sup> 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

### History of Mississippi Legislative Actions Related to Autism

The following section contains a non-exhaustive list of recent actions taken by the Mississippi Legislature concerning Autism Spectrum Disorder.

### 2007 - HB 1267 - Caring for Mississippi Individuals with Autism Task Force

During the 2007 session the Mississippi Legislature passed HB 1267<sup>20</sup> establishing the Caring for Mississippi Individuals with Autism Task Force. This task force was formed to:

- Review the best practices of other states with regard to educational, medical and early intervention services provided to people diagnosed with autism or ASD,
- Review the standard of services provided by local Mississippi school districts and early
  intervention programs to people diagnosed with autism or ASD, identify any additional
  potential funding sources for school districts, and identify guidelines for measurable
  educational and instructional goals that can be used by members of the education
  community for serving children with autism or ASD,
- Assess the medical availability of services currently provided for early screening, diagnosis and treatment of autism and ASD and provide recommendations for enhancing medical services,
- Identify the role of higher education in developing a workforce in Mississippi possessing the skills necessary to assist people with autism or ASD in medical, educational, and vocational efforts or in providing additional services associated with autism or ASD,
- Evaluate and identify any and all additional relevant information and make legislative recommendations regarding the development and implementation of a continuum of educational and medical services for people with autism or ASD, and
- File a report with those standing committees of the Mississippi State Legislature and with those state agencies having jurisdiction over specific recommendations of the task force, not later than December 1, 2007.

In December 2007 the Task Force issued their report containing a variety of recommendations related to workforce training, medical treatment, early intervention, educational practices, and infrastructure changes.

### 2011 - HB 1125 – Mississippi Autism Advisory Committee

As stated above, the Mississippi Autism Advisory Committee was created by House Bill 1125 (2011 Regular Session) as the Legislature recognized an urgent need for strategies on how to best identify, treat, educate, accommodate and employ people with ASD and assist their

<sup>&</sup>lt;sup>20</sup> The bill text can be found online at: <a href="http://billstatus.ls.state.ms.us/documents/2007/pdf/HB/1200-1299/HB1267SG.pdf">http://billstatus.ls.state.ms.us/documents/2007/pdf/HB/1200-1299/HB1267SG.pdf</a>

families.<sup>21</sup>

# 2014 - HB 542 - State and School Employees Health Insurance Management Board Task Force

HB 542<sup>22</sup> requires the State and School Employees Health Insurance Management Board ("Board") to review and study "whether to expand coverage currently provided for the treatment of autism spectrum disorders under the State and School Employees Health Insurance Plan ("Plan").<sup>23</sup>" In December of 2014 the State and School Employees Health Insurance Management Board released their study entitled "Evaluation of Health Insurance Coverage for the Treatment of Autism Spectrum Disorders.<sup>24</sup>" This report listed a variety of services already covered by the Plan but noted that Applied Behavior Analysis (ABA) based therapy was not a covered benefit.<sup>25</sup> The Board commissioned an independent study to conduct an evidence-based evaluation of selected treatments and risk assessment methods for autism including ABA therapy.

The Board found the results of the independent study to be consistent with the Plan's current exclusion of ABA therapy. The study determined that "while there is some evidence to suggest that intensive ABA therapy... shows some potential for improving cognitive function, IQ and language skills in some children, the results are conflicting regarding the efficacy of therapy.<sup>26</sup>" The study conceded that "the available published studies<sup>27</sup> were of poor to good quality, included very small sample sizes, with age ranges of 14 months to 7 years old, and were not conclusive as the standardization of treatment protocol or to the effectiveness of the treatment.<sup>28</sup>" The Board was also concerned that ABA therapists were not (at the time of the study<sup>29</sup>) licensed within the State of Mississippi.

### 2015 - HB 885 – Autism Insurance Coverage Requirement

During the 2015 session of the Mississippi Legislature, House Bill 885<sup>30</sup> was passed and signed into law by the Governor. This bill has since been codified as Miss. Code Ann. §83-9-26. This bill requires most health insurance policies to cover screening, diagnosis, and treatment of ASD up to age eight (8) and also provided the regulatory framework for the licensure and regulation of the practice of Applied Behavior Analysis (ABA), a profession providing empirically based treatment beneficial to people living with ASD.

<sup>&</sup>lt;sup>21</sup> See fn. 2, supra, p.2

<sup>&</sup>lt;sup>22</sup> Available online at: http://billstatus.ls.state.ms.us/documents/2014/pdf/HB/0500-0599/HB0542SG.pdf.

<sup>&</sup>lt;sup>23</sup> Id. p.2.

<sup>&</sup>lt;sup>24</sup> This report is available from the Mississippi Dept. of Finance and Administration upon request.

<sup>&</sup>lt;sup>25</sup> See p. 6 of "Evaluation of Health Insurance Coverage for the Treatment of Autism Spectrum Disorders."

<sup>&</sup>lt;sup>27</sup> Id. p.32, noting that 26 studies with dates ranging from 1987 to 2014 were reviewed.

<sup>&</sup>lt;sup>29</sup> See discussion of 2015 HB 885.

<sup>&</sup>lt;sup>30</sup> Available online at: <a href="http://billstatus.ls.state.ms.us/documents/2015/pdf/HB/0800-0899/HB0885SG.pdf">http://billstatus.ls.state.ms.us/documents/2015/pdf/HB/0800-0899/HB0885SG.pdf</a>.

### Recent Autism-Related Medicaid Reform Efforts

# 2019- Mississippi Division of Medicaid Amendment to State Plan Autism Spectrum Disorder

State Plan Amendment (SPA) 19-0001<sup>31</sup> Targeted Case Management (TCM) for Beneficiaries with Intellectual and/or Developmental Disabilities (IDD) in Community-Based Settings, with a proposed effective date of January 1, 2019, has been approved<sup>32</sup> by the Centers for Medicare and Medicaid Services (CMS). The SPA includes the following changes: a) Adding Autism Spectrum Disorder (ASD) as a covered diagnosis, b) Removing the needs-based criteria, c) Revising the qualifications and training requirements for Targeted Case Managers.

# 2018 - Mississippi Division of Medicaid Home and Community-Based Services Waiver Renewal

In 2018 the Mississippi Division of Medicaid revised their home and community-based waiver program. This program furnishes an array of home and community-based services that assist Medicaid beneficiaries to live in the community including access to in-home supports, community respite, job discovery, transition assistance, day services, shared supported living, supervised living, and supported living.

### 2016 - Mississippi Division of Medicaid Autism Spectrum Services Coverage

In 2016 the Mississippi Division of Medicaid published a proposed<sup>33</sup> state plan amendment 16-0020 "Autism Spectrum Disorder Services." This amendment provides for ASD services, including ABA therapy for Early and Periodic Screening, Diagnosis and Treatment (EPSDT) - eligible beneficiaries when medically necessary, prior authorized, and provided by certain qualified providers operating within their scope of practice.

# **Recent Autism-Related Insurance Efforts**

#### 2018 - Insurance Commission Hotline

In January 2018 Insurance Commissioner Mike Chaney announced an Autism Insurance Hotline based within the Mississippi Insurance Department for families to call if they experienced any problems related to insurance coverage for Autism related treatment or services or had any questions related to Autism insurance coverage.

<sup>&</sup>lt;sup>31</sup> Available online at: <a href="https://medicaid.ms.gov/spa-19-0001-targeted-case-management-tcm-for-beneficiaries-with-intellectual-and-or-developmental-disabilities-idd-in-community-based-settings/">https://medicaid.ms.gov/spa-19-0001-targeted-case-management-tcm-for-beneficiaries-with-intellectual-and-or-developmental-disabilities-idd-in-community-based-settings/</a>

<sup>&</sup>lt;sup>32</sup> Available online at: <a href="https://medicaid.ms.gov/intellectual-disabilities-developmental-disabilities-id-dd-waiver-approved">https://medicaid.ms.gov/intellectual-disabilities-developmental-disabilities-id-dd-waiver-approved</a>.

<sup>&</sup>lt;sup>33</sup> The amendment can be viewed online at: <a href="https://medicaid.ms.gov/wp-content/uploads/2016/12/SPA-16-0020-Pages-Proposed.pdf">https://medicaid.ms.gov/wp-content/uploads/2016/12/SPA-16-0020-Pages-Proposed.pdf</a>.

# 2018 - Insurance Raises Age of Coverage

In January 2018 Secretary of State Delbert Hosemann and Insurance Commissioner Mike Chaney announced that three Mississippi insurance companies had voluntarily agreed to lift the age limit on coverage of ABA therapy for people with Autism Spectrum Disorder.

# Appendix A

### Comparison of Mississippi 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 people 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 Service consists of a director, coordinator, project specialist, and administrative support assistant. Besides overseeing home and community waivers, The Missouri Office of Autism Services has created state guidelines that now help to coordinate the five (5) Missouri Autism Projects, manage the ASD 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 people with ASD and other related-disabilities. The majority of these websites have been developed and maintained through state funding. For families that do not 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	Mandated	Coordinated	Parents Receiving	Statewide
	Committee	Autism	Autism Services	Information about	Autism
	with	Insurance	Within Depts. of	Autism Services	Research
	Stakeholders	Reform That	Mental Health,	From Central State	Collaborative
	From	Includes ABA	Education, and	Agency or	
	Different	Therapy	Vocational Rehab.	Nonprofit.	
	State				
	Agencies				
Mississippi	Yes	Yes	No	Partial	No
Alabama	Yes	Yes	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 people with ASD and their families:

#### MISSISSIPPI DEPARTMENT OF EDUCATION

- The Mississippi Department of Education (MDE) identified 5,527 children, ages 3-21, with the educational disability ruling of Autism (AU) as of November 1, 2019.
- 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.

Mississippi IDEA Data-Child Count Data for Autism by **Year (ages 3-21)** (Data Accountability Center -**Individuals with Disabilities Education Act Data**) of students with ASD receiving special 4500 4000 4360 3500 education services 3000 3279 2989 2500 2000 2356 1979 1500 1472 1000 1212 500 0 2005 2006 2007 2008 2009 2010 2011 2012 2013 2014 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

• The true number of people with ASD in Mississippi 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 only the primary educational disability ruling of Autism (AU).

- In Fiscal Year 2017, the Mississippi public community mental health system served 34,795 children and adolescents with serious emotional disturbance<sup>34</sup>. (Note: Totals might include some duplication across community mental health centers and other nonprofit programs. And most likely include persons with ASD).
- The Autism Training Initiative began in 2012 and is designed to build capacity in Mississippi to provide evidence-based, lifespan services and supports based on the premise that people with autism are included in all settings. Since February 2014, 63 Autism Foundations trainings have been offered throughout the entire state with over 2700 attendees through August 2019. Plans are to continue to offer this training approximately four times per year, with each training being offered in a different region of the state.
- Department of Mental Health in partnership with the Mississippi Coalition for Citizens with Disabilities and with the Mississippi Statewide Autism Training Initiative held on August 29, 2019, the fifth Annual Autism Conference: Creating Your Own Path: Successful Transitions for Persons with Autism. The Conference featured Dr Temple Grandin as the keynote speaker with over 400 participants and 90 parents were awarded stipends to attend this year's conference. The 2019 conference also included a half day pre-conference. CE's were provided for teachers, social workers, nursing home administrators, SEMI, and DMH credentials. The 2020 Annual Autism Conference was held September 10, 2020 as a free virtual conference due to COVID-19 precautions and a total of 242 participants enrolled. CE's were provided for teachers, social workers, nursing home administrators and DMH credentials.

# 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 2020:

FY	Number Served	Funds spent
2014	226	\$ 328,828
2015	249	\$ 481,040
2016	240	\$ 525,843
2017	253	\$ 526,779
2018	254	\$ 517,675
2019	400 (as of 4/30/19)	\$1,000,317
2020	604 (as of 6/29/20)	\$1,634,156

<sup>&</sup>lt;sup>34</sup> Report available online: <a href="https://msdh.ms.gov/msdhsite/\_static/resources/7758.pdf">https://msdh.ms.gov/msdhsite/\_static/resources/7758.pdf</a>.

- Mississippi Department of Rehabilitation Services (MDRS), Office of Vocational Rehabilitation has a program specialist assigned to Autism whose duties include:
  - o Providing field staff updated information regarding ASD.
  - o Coordinating training for field staff on matters related to ASD.
  - Coordinating services provided for individuals with autism through private organizations.
  - Working with Vocational Rehabilitation Counselors who are requesting other services for client with ASD.
  - Working closely with the Supported Employment Program Specialist regarding individuals with ASD by participating in Personal Care Planning (PCP) meetings along with the VR 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.
  - O Project SEARCH Program: The Project SEARCH program is a unique, business led, one-year employment preparation program that prepares young people with developmental disabilities for competitive, integrated, employment through total workplace immersion. The program provides real-life work experience combined with training in employability and independent-living skills to assist young people with developmental disabilities make a successful transition into adult life. MDRS partners with a school district and a host business to facilitate this program. There are currently 11 Project SEARCH sites throughout the state. The current plan is to continue adding five to seven sites per year.

### INSTITUTIONS OF HIGHER LEARNING

- The University of Southern Mississippi and Mississippi State University now offer courses that have been approved by the Behavior Analyst Certification Board (BACB) as meeting the requirements for behavior analyst certification.
- The University of Mississippi offers courses approved by the BACB as meeting the requirements for associate behavior analyst certification.
- Holmes Community College now offers courses that have been approved as meeting the
  education requirements for Registered Behavior Technician certification as designated by
  the BACB.

# **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
Robbie Sellers, Transition Specialist, Petal Schools	Superintendent, State
	Department of Education
Craig Kittrell, Director, Bureau of Intellectual and	Executive Director, MS
Developmental Disabilities, MS Department of Mental	Department of Mental Health
Health, Jackson, MS	
Melody Madaris, Parent of a Child with Autism	Governor
Dr. Margaret Ellmer, Interim State Special Education	Superintendent, State
Director, Jackson, MS	Department of Education
Christan Toney, T.K. Martin Center, Starkville, MS	Director, T.K. Martin Center
Shelly Crunk, Mississippi licensed school psychologist,	President, Mississippi
Madison, MS	Association of Psychologists in
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James W. Moore, Ph.D. BCBA-DLBA, Director of	Executive Director, MS
Autism Solutions, Canopy Children's Solutions, Jackson,	Department of Mental Health
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Pam Dollar, Executive Director, MS Parent Training and	Executive Director, MS Parent
Information Center, Jackson, MS	Training and Information Center
Ellen Ellis, Special Education Teacher, Pearl Public	Superintendent, State
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Jennifer Jackson, Autism Coordinator, MS Department	Executive Director, MS
of Rehabilitation Services, Jackson, MS	Department of Rehabilitation
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Amanda Felder, Parent of a Child with Autism, Clinton,	Lieutenant Governor
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Ms. Debra Sturgis-Stamps, Member of the Copiah	Superintendent, State
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Leah Gregory-Johnson, Licensed Speech Pathologist	President, MS Speech Language
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Pascagoula Gautier School District, Ocean Springs, MS	Psychologists in the Schools
Lee Harbison, Parent of a Child with Autism	Speaker of the House
<b>April Rice</b> , Director of Special Education, Biloxi Public	Superintendent, State
School District, Biloxi, MS	Department of Education

Phillips Strickland, JD, MS Insurance Department,	Commissioner of Insurance
Jackson, MS	
<b>Dr. Courtney Walker.,</b> Department of Pediatrics,	Vice Chancellor, University of
University of MS Medical Center, Jackson, MS	MS Medical Center
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Panel, Jackson, MS	Advisory Committee
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Gail Smith, Special Projects Officer, Department of	Executive Director of the
Human Services	Department of Human Services

With invaluable assistance provided by the MS Department of Mental Health staff: Deborah Etzold, Director, Community Support Program, Bureau of Intellectual and Developmental Disabilities.