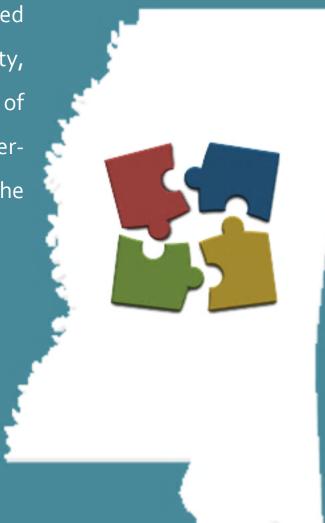
# **MISSION**

Identify common goals related to enhancing the accessibility, number, and quality of Autism Spectrum Disorderrelated services available in the state of Mississippi.



### STRATEGIC GOAL 1

Establish an Office of Autism Services to coordinate ASD efforts among primary agencies that serve Mississippi's population of children and adults with ASD and their families.

### STRATEGIC GOAL 2

Increase Mississippi's capacity for diagnosis, treatment, services, and supports for people with ASD across their lifespan.

### STRATEGIC GOAL 3

Expand the number and quality of professionals providing services to people with ASD.

### STRATEGIC GOAL 4

Promote a well-informed, empowered and supportive Mississippi population around the issue of ASD.

### STRATEGIC GOAL 5

Maximize public and private funding sources to support the full scope of services needed for all Mississippians with ASD.



# AUTISM SPECTRUM DISORDER STRATEGIC PLAN FOR MISSISSIPPI

### MISSISSIPPI AUTISM ADVISORY COMMITTEE

#### A WORD FROM THE COMMITTEE

he Mississippi Autism Advisory Committee (MAAC) is pleased to present the Autism Spectrum Disorders Strategic Plan for Mississippi to the members of the Mississippi Legislature. This strategic plan is a roadmap for building Mississippi's autism-related services infrastructure. In this document you will find an assessment of Mississippi's challenges and learn how key investments can improve the lives of people living with autism spectrum disorder.

Autism spectrum disorder constitutes a public health crisis in Mississippi. Data from the Centers for Disease Control shows a steady increase in the prevalence of ASD with 1 in 68 children being affected.

Although this plan does not capture all the ideas discussed at our Committee meetings, it sets forth five strategic goals: (1) establish an Office of Autism Services to coordinate ASD efforts among primary agencies that serve Mississippi's population of children and adults with ASD and their families; (2) increase Mississippi's capacity for diagnosis, treatment, services, and supports for people with ASD across their lifespan; (3) expand the number and quality of professionals providing services to people with ASD; (4) promote a wellinformed, empowered and supportive Mississippi population around the issue of ASD; and (5) maximize public and private funding sources to support the full scope of services needed for all Mississippians with ASD. These goals will help our state meet its present challenges and secure a better future for all Mississippians.

On behalf of people living 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 these improvements.

Sincerely,

Members of the MAAC







29 Committee members including parents of children diagnosed with ASD, mental health professionals, and employees of various state agencies.



15 different stakeholders have appointment authority including the Governor, Lt. Governor, the Speaker of the House, and the Commissioner of Insurance.



The MAAC has issued 6 annual reports since its creation. The Committee also meets at least 6 times per year.



# STRATEGIC GOAL 1 - ESTABLISH AN OFFICE OF AUTISM SERVICES TO COORDINATE ASD EFFORTS AMONG PRIMARY AGENCIES THAT SERVE MISSISSIPPI'S POPULATION OF CHILDREN AND ADULTS WITH ASD AND THEIR FAMILIES.

#### GOAL OVERVIEW

n Office of Autism Services ("OAS") is needed to identify gaps in autismrelated services and to facilitate the development of a state-wide strategic plan to improve and expand effective services and resources for people with ASD and their families. Every year since its inception, the MAAC has made the recommendation to the legislature, in one form or another, to establish an entity dedicated to coordinating ASD services in the state.

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. 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." 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.

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 MAAC envisions an Office of Autism Services that operates as follows:

- Implement an Autism Spectrum Disorders Strategic Plan for Mississippi
- Provide an integrated support system for families of children with ASD by facilitating communication with state agencies providing ASD-related services.
- 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 ASD Handbook that contains information about how to navigate the medical, educational, and community services in Mississippi.
- Coordinate with state agencies providing ASD-related services to track, identify, and assist people diagnosed with ASD.



# STRATEGIC GOAL 2 - INCREASE MISSISSIPPI'S CAPACITY FOR DIAGNOSIS, TREATMENT, SERVICES, AND SUPPORTS FOR PEOPLE WITH ASD ACROSS THEIR LIFESPAN.

#### GOAL OVERVIEW

utism spectrum disorder is 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. Early diagnosis and appropriate intervention for children with ASD leads to better outcomes.

There is no single agency in Mississippi that has been created to address the varied needs of individuals with ASD. Instead, individuals with ASD are currently receiving program services from multiple agencies of varying degrees of adequacy and inadequacy.

Objective 2.1 - Establish information sharing and service coordination agreements between ASD service providing state agencies. As noted in the 2017 MAAC annual report to the legislature, the 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. 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 Office of Autism Services, once established, must work to develop information sharing and service coordination agreements between these state agencies. Objective 2.2 - Encourage adoption of transition services standards and policies which ensure effective education, supports, and transition implementation for school aged children.

School-aged children diagnosed with ASD must be adequately prepared to transition from a primary school-based setting to the workforce or other school setting as appropriate. All of the agencies listed in Objective 2.1 play a role in preparing students to transition to life beyond the high school experience. Information related to transition resources should be fully documented, readily available, and regularly distributed to ASD families. The OAS must compile a list of fundamental ASD transition services for children ages 7-21 for each agency providing those services. In order to streamline the availability of transition services, the OAS must also identify key areas of service crossover between agencies and develop best practices for transition service coordination.



# STRATEGIC GOAL 3 - EXPAND THE NUMBER AND QUALITY OF PROFESSIONALS PROVIDING SERVICES TO PEOPLE WITH ASD.

#### GOAL OVERVIEW

amilies and parents of children diagnosed with ASD have reported a shortage of medical professionals in Mississippi that provide ASD-specific services. Infants and toddlers are routinely seen by their primary healthcare providers who provide screening for signs of ASD. Children who are identified as having symptoms of ASD should quickly be referred to a multidisciplinary team of professionals who are well-versed in the diagnosis and treatment of ASD.

Depending on the need of the patient, this team could be comprised of any of the following medical professionals: physician, psychologist, speech/language pathologist, occupational therapist, a board certified behavior analyst ("BCBA"), board certified assistant behavior analyst "(BCaBA"), registered behavior technician ("RBT"), autism education specialist, and physical therapist. During the 2015 session of the Mississippi Legislature passed House Bill 885, part of which establishes the regulatory framework for the licensure and regulation of the practice of applied behavior analysis, a form of therapy beneficial to people living with ASD. This legislation allows for Mississippi mental health professionals to be licensed as a BCBA, BCaBA, RBT, or board certified behavior analyst-doctoral ("BCBA-D"). Mississippi currently has only thirty-three (33) licensed BCBAs. BCBAs have reported difficulty retaining RBTs due to better opportunities in neighboring states. Some committee members have reported that their family members receive care out of state. In spite of recent progress there is still a need to expand the number and quality of professionals providing services to people with ASD.

Objective 3.1 - Develop a recruitment and retention plan for a skilled and sufficient ASD workforce throughout the state. Our state must make an effort to identify gaps in Mississippi's workforce development infrastructure. The Mississippi Dept. of Education reports that they lost twenty percent (20%) of their special education directors last year alone. Mississippi's student to school psychologist ratio is the worst in the country. The University of Mississippi Medical Center has only two full-time developmental pediatricians on staff. MAAC members also expressed the need for more speech language pathology professors in Mississippi's colleges and universities.

As has been done in other states, a detailed training, recruitment, and retention plan must be developed and implemented if Mississippi is to have a sufficient ASD workforce. This effort should include consideration of the education programs offered at our in-state universities as well as Mississippi's easily accessible community college system.



# STRATEGIC GOAL 4 - PROMOTE A WELL-INFORMED, EMPOWERED AND SUPPORTIVE MISSISSIPPI POPULATION AROUND THE ISSUE OF ASD.

#### GOAL OVERVIEW

broader understanding of ASD is needed in our state. Information on ASD-related services should be readily available from a variety of sources and should provide consistent information. The Office of Autism Services must develop and maintain various mediums for distributing information and resources related to ASD such as a website, tollfree phone number, and contact information for key assisters at various state agencies. As stated herein, Mississippi does not have a designated entity tasked with providing guidance to the public regarding ASD-related services. It is difficult for Mississippi citizens to make well-informed decisions without access to reliable information.

The OAS should also 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. It is also important to organize and coordinate a comprehensive program of outreach, involving the dissemination of information on Mississippi ASD resources to families, service providers, and local communities.

Certain professions such as teachers, physicians, physician assistants. nurse practitioners, and pediatricians could benefit from enhanced ASD-education. The OAS coordinate should with professional associations, governing boards, and state agencies to facilitate a reevaluation of their educational requirements related to Autism.

It is difficult for Mississippi citizens to make well-informed decisions without access to reliable information.



# STRATEGIC GOAL 5 - MAXIMIZE PUBLIC AND PRIVATE FUNDING SOURCES TO SUPPORT THE FULL SCOPE OF SERVICES NEEDED FOR ALL MISSISSIPPIANS WITH ASD.

#### GOAL OVERVIEW

ississippi's insurance coverage age limit for Applied Behavioral Analysis ("ABA") therapy should be updated to bring it more in ABA Therapy Age Limitations in the Southeast Region line with surrounding states. The average ABA therapy age limitation for 18 southeast region states 18 is sixteen (16) 21 years of age. The most common age limitation is eighteen (18)years old. ASD affects an entire family,

not just the person diagnosed. In 2007 the Caring for Mississippi Individuals with Autism Task Force held public hearings in Jackson, Oxford and Hattiesburg. The Task Force noted that families are overwhelmed by financial issues, the need for medical care, insurance coverage, inadequate educational supports, finding additional therapy services and time away from job and home to obtain the needed

services for their family member with ASD.

The Task Force went on to say that the average cost for a privatelycontracted comprehensive treatment plan is over \$50,000 a year. When the average Mississippi family only makes \$39,655, according to 2015 data from the U.S. Census Bureau, the

amount of financial stress is overwhelming for parents trying to provide private therapy for their child with ASD.

Mississippi now has a law that requires most health insurance policies to cover screening, diagnosis, and treatment of autism spectrum disorder. Under the law, treatment for ASD includes ABA therapy. However this law only requires coverage of ABA therapy up to age eight (8).

## MAAC

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