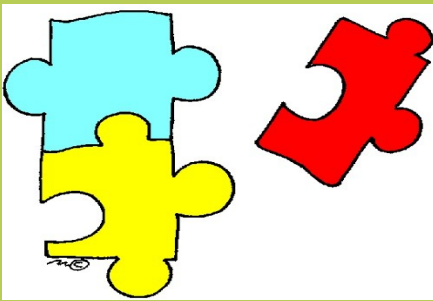


# **Mississippi Autism Advisory Committee**



**Report  
to the  
Legislature**

**July 2012**

## **Background Information & Purpose of Committee**

The Mississippi Autism Advisory Committee was created in 2010 by House Bill 1125 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.

The plan is due July 1 of each year.

Dear Legislators,

I am pleased to submit the report from the Mississippi Autism Advisory Council detailing the findings and recommendations of our committee.

The dramatic growth in the number of children affected by autism spectrum disorders (ASD) now constitutes a public health crisis. An estimated 10,174 Mississippi children have autism<sup>1</sup> – an increase in incidence from 1 in 500 to 1 in 88 within the last decade. Statistics from the Mississippi Department of Education show a 462 percent rise in the number of public school children with autism in the past 10 years.<sup>2</sup> 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 is a pervasive developmental 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's estimated that each person with autism, if not rehabilitated, will cost society \$3.2 million over their lifetime.<sup>3</sup> If none of the state's children currently living with autism overcome their challenges by the time they reach adulthood, it could cost Mississippi taxpayers more than 32 billion dollars over the next 50 years. That's if this population doesn't increase, which it mostly likely will. Early diagnosis and treatment are a child's best chance to overcome the most debilitating effects of autism.<sup>4</sup> They are also Mississippi's best chance at reducing the size and scope of this costly population.

As mentioned above, the number of students with ASD being served in public schools in our state has increased dramatically. Mississippi teachers need more training in order to appropriately serve these students. Most do not receive training on ASD while in college, as many teacher preparation programs in the state contain little to no autism-related curriculum. There are also no institutions for higher learning in Mississippi offering a specialty program or degree in the area of autism spectrum disorder.

Even though autism is a biomedical brain disorder, insurance companies routinely exclude individuals with a diagnosis of ASD. Mississippi is one of only 15 states still allowing insurance companies to exclude coverage for autism. Appropriate coverage will result in long-term cost savings to health care and educational systems in the state - accomplished through improved access to quality medical care, accurate diagnosis, access to treatment, intervention and support services. This benefit will extend far beyond the families who have loved ones with autism reaching all taxpayers.

Increasingly families report that community supports are not available to them during times of crisis. Some families have also reported that even institutional based services are not available to them when faced with a crisis situation. In addition, children with ASD placed into foster care have complex needs and there is insufficient training and support for foster/resource/support families. We must ensure a comprehensive system of wraparound services are in place to support these families.

Our report recommends strategies for implementation in the key areas of infrastructure, early identification and referral, education, healthcare and social services that address key issues identified in our state. These recommendations are by no means an exhaustive list of remedies but they lay the critical foundation needed to address the autism crisis in Mississippi.

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

Sincerely,  
Pam Dollar, Chairperson  
Mississippi Autism Advisory Committee

# Strategies

## Infrastructure

- IR-1:** Reestablish and fund a full-time Mississippi Autism Coordinator position within the state Department of Mental Health to track this population and coordinate statewide efforts to service this community.
- IR-2:** Reestablish and fund a Director of Autism within the state Department of Education.
- IR-3:** Fund an Autism Specific Medicaid Waiver that would provide medical and behavioral treatment options for those with ASD.

## Early Identification and Referral

- EI-1:** Establish minimum standards within each state regulating board for professionals providing both diagnostics and early intervention to children with autism and list those achieving the minimum standards in a state database managed by the Mississippi Autism Coordinator.

## Education

- ED-1:** Require an autism component in four of the 10 clock hours of professional development mandated annually for educators and academic administrators
- ED-2:** Require state institutes of higher learning to include autism training in their curriculum for future teachers.
- ED-3:** Require state institutes of higher learning to add specialty programs/degrees for those who seek extensive training in the education and treatment of those with ASD for the following graduate programs: Special Education, General Education, Speech Language Pathology, Occupational Therapy, Physical Therapy, Social Work and Psychology.

## Healthcare

- HR-1:** Enact legislation mandating insurance policies to include coverage for those with Autism Spectrum Disorder (ASD) and require insurance policies provide comprehensive coverage for ASD treatments, including communication and behavioral therapies.

## Social Services

- SS-1:** Require the Mississippi Department of Mental Health and public mental health providers to work together to develop integrated wraparound services for children experiencing significant levels of ASD and their families. Access to these support services must be available before individuals and families reach crisis.
- SS-2:** Increase supportive services and access to training that help empower families/foster/resource/host families and guardians. These services may include information/referral, respite, behavior consultation and assistance, appropriate home modifications, and in-home staff support if necessary.

## Cost

These strategies together will cost the state an estimated total of \$1,220,000 annually.

## Deadline

We recommend each strategy be implemented as soon as possible, and no later than July 1, 2013.

# Infrastructure

**IR-1: Reestablish and fund a full-time Mississippi Autism Coordinator position within the State Department of Mental Health to track this population and coordinate statewide efforts to service this community.**

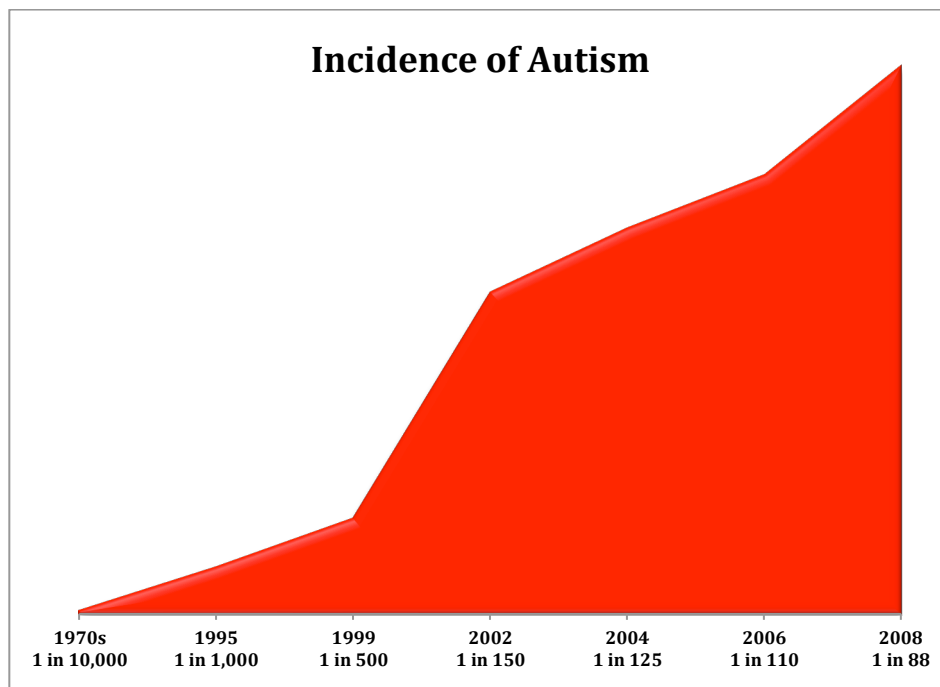
**IR-2: Reestablish and fund a Director of Autism within the State Department of Education.**

**IR-3: Fund an Autism specific Medicaid waiver that would provide medical and behavioral treatment options for those with ASD.**

**Issue:** Mississippi needs a system for reliably identifying, tracking and supporting Mississippians with autism, their families and the professionals who serve them.

## Key findings:

- The Centers for Disease Control and Prevention estimate that 1 in 88 children in the United States have autism, up from the previous estimate of 1 in 500 only a decade ago. Based on the current rate, Mississippi has an estimated 10,174 children (ages 3-21) with autism.<sup>1</sup> (see chart below)



- The Mississippi Department of Education identified 2,356 children (ages 3-21) with the educational ruling of autism in 2010. That's a 462 percent increase from 10 years ago, when the Mississippi Department of Education reported 419 children (ages 3-21) with autism statewide.<sup>2</sup>
- Nearly 150,000 youth statewide are home schooled or in private academies.<sup>5</sup> And many who do attend public schools do not have an educational ruling of autism but are classified by their school districts as developmentally delayed, other health impaired or another educational ruling.
- The true number of Mississippians with autism remains unknown because only one state agency – the Mississippi Department of Education – tracks this population. It does so only for children who have an educational ruling of autism as identified by a public school district.

- Some services currently exist to support this population but they are scattered, disconnected and inconsistent from one part of the state to the next.
- We need a better grasp of the taxpayer-funded costs related to this population so we can more wisely manage these funds.
- The rate of autism in Mississippi has drastically risen and yet we have little available data to understand the scope of this problem or how it should be addressed. What we do know is that those on the front lines – parents, pediatricians and educators – have few resources to help these children.

**Recommendations:**

IR-1 - Reestablish and fund a full-time Mississippi Autism Coordinator position within the state Department of Mental Health to track this population and coordinate statewide efforts to service this community.

IR-2 - Reestablish and fund a Director of Autism within the state Department of Education.

A major goal of these two positions will be identifying, developing and coordinating services regionally throughout the state; and to form interagency agreements with universities, other entities providing services and training to individuals with ASD, and those who work with individuals with ASD. Persons holding these two positions would also report to the Mississippi Autism Advisory Committee at each committee meeting.

IR-3 - Fund an Autism Specific Medicaid Waiver that would provide medical and behavioral treatment options for those with ASD.

**Cost:** Based on current state employee salaries and benefits, these positions will cost Mississippi up to \$200,000 annually. An additional \$20,000 will be needed to develop materials, conduct meetings and develop a website. The Department of Mental Health and the Mississippi Department of Education both need a Position Identification Number (PIN) and the funding for these positions.

Cost estimate to implement an autism specific Medicaid waiver is \$1,000,000. This would provide approximately 200 waiver slots at an estimated \$20,000/person with Mississippi providing \$1,000,000 in funding with approximately \$3,000,000 of matching federal dollars providing a total funding base of approximately \$4,000,000.

# Early Identification and Referral

***EI-1: Establish minimum standards within each state regulating board for professionals providing both diagnostics and treatment to children with autism and list those achieving the minimum standards in a state database managed by the Mississippi Autism Coordinator.***

**Issue:** Mississippi needs a system for reliably identifying, tracking and supporting Mississippians with autism, their families and the professionals who serve them.

## **Key findings:**

- Parents, educators and pediatricians struggle to find appropriate – or even legitimate – professionals to accurately identify children with ASD and effectively treat them.
- Families have no way to ensure the professionals diagnosing and treating their children have an appropriate level of knowledge regarding ASD.
- Early diagnosis and treatment are a child's best chance to overcome the most debilitating effects of autism. They are also Mississippi's best chance at reducing the size and scope of this costly population. Studies show that of children who receive early and intensive therapy, about half will successfully integrate into a typical school setting and become productive adults. About 30-40 percent will achieve moderate gains, thereby weaning themselves from some social services and allowing them to contribute to society. The rest will receive little benefit and require a lifetime of aid.<sup>4</sup>
- In a study reported in 2007, analyses were performed comparing the cost impact of 18 years of Special Education to 3 years of early intensive behavioral intervention (EIBI); finding that EIBI minimized the need for Special Education, saving \$208,500 per child over 18 years.<sup>6</sup>
- It is estimated to cost society \$3.2 million dollars to care for a person with autism over the course of their lifetime unless they are able to be totally or partially rehabilitated.<sup>3</sup>

## **Recommendations:**

EI-1 - Establish minimum standards within each state regulating board for professionals providing both diagnostics and treatment to children with autism and list those achieving the minimum standards in a state database managed by the Mississippi Autism Coordinator.

A reliable network of professionals to diagnose and treat autism at an early age could prevent a significant number of people with ASD from becoming lifelong dependents on state services. This would result in a substantial reduction of costly, state-funded special education services, family support services, and adult care services. The Mississippi Autism Advisory Committee recognizes it will take time for the state to establish a respectable network of resources in this field. Many reasons for this exist, and we will address them purposefully and methodically during the course of our tenure.

**Cost:** None anticipated; included within the cost of Infrastructure Strategies.

## Education Services

**ED-1:** *Require an autism component in 4 of the 10 clock hours of professional development mandated annually for educators and academic administrators.*

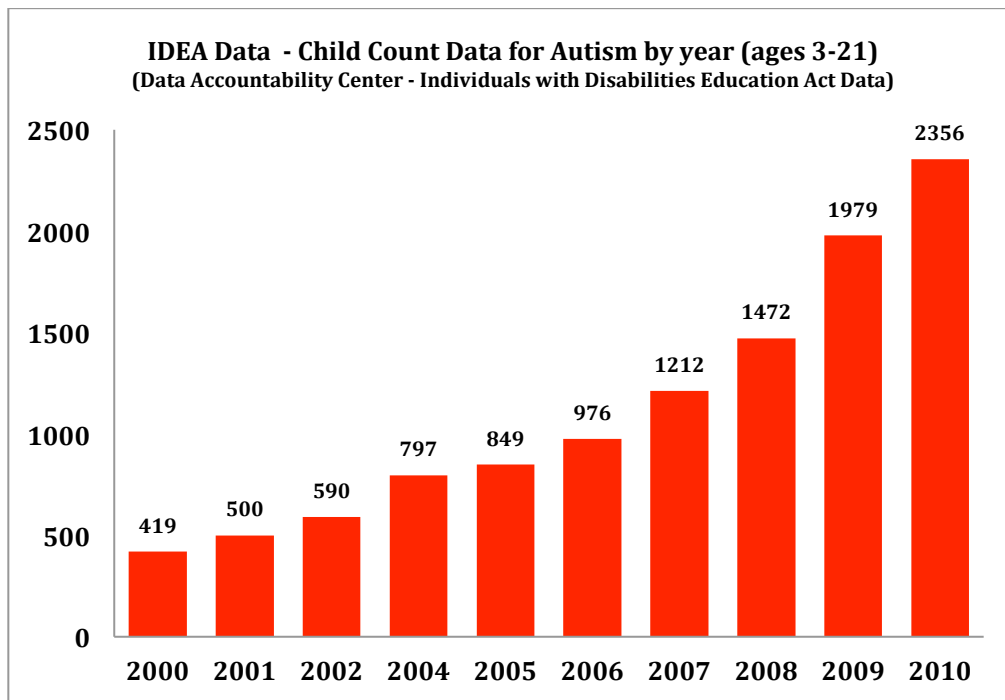
**ED-2:** *Require Mississippi Institutes of Higher Learning and the Mississippi State Board of Community and Junior Colleges to include autism-related curriculum within their respective teacher programs.*

**ED-3:** *Require the Mississippi Institutes for Higher Learning to add specialty programs/degrees for those who seek extensive training in the education and treatment of those with ASD for the following graduate programs: Special Education, General Education, Speech Language Pathology, Occupational Therapy, Physical Therapy, Social Work and Psychology.*

**Issue:** The existing education systems in Mississippi are often inadequate to meet the increasingly complex needs of individuals identified with ASD.

### Key findings:

- Mississippi Department of Education statistics show a 462 percent rise in the number of public school children with autism within the past ten years.<sup>2</sup> (see chart below) This trend is not expected to decline. In fact, it is likely to rise.



- In the 2009-2010 school year, Mississippi public schools graduated 33 percent of students with autism who have Individualized Education Plans (IEPs).<sup>7</sup> We can do better, especially after we increase the number of students entering public school having received intensive early childhood services, create a seamless transition into public schools and ensure we have teachers, secondary transition coordinators and other school personnel who have the appropriate knowledge to serve the unique needs of students with ASD.



- Teachers are responsible for educating students with autism from preschool through high school graduation. More than ever, teachers need the tools to help them understand autism and how it affects their students so they can successfully educate them using research-based teaching methods proven to be successful for students with ASD.
- Special education teachers need training, as do general education classroom teachers and assistants who often teach students on the spectrum. Based on the sharp rise in the incidence of autism over the past decade, general education teachers will be more likely to have one or more children with autism in their classroom each year.
- Many teacher preparation programs in the state contain little to no autism-related curriculum.
- Currently there are no institutions for higher learning in Mississippi offering a specialty program or degree in the area of autism spectrum disorder. Students are forced to travel out of state to participate in a program offering emphasis in ASD.

**Recommendations:**

ED-1 - Require an autism component in 4 of the 10 clock hours of professional development mandated annually for educators and academic administrators.

ED-2 - Require Mississippi Institutes of Higher Learning and the Mississippi State Board of Community and Junior Colleges to include autism-related curriculum within their respective teacher programs.

ED-3 - Require the Mississippi Institutes for Higher Learning to add specialty programs/degree for those who seek extensive training in the education and treatment of those with ASD for the following graduate programs: Special Education, General Education, Speech Language Pathology, Occupational Therapy, Physical Therapy, Social Work and Psychology.

With the proper training, teachers can – and must – educate these students to ensure they receive an appropriate public education designed to meet their unique needs and prepare them for further education, employment or independent living. Armed with a quality education, people with autism are much more likely to be employed thereby resulting in less dependence on state and federally funded programs which will result in astronomical savings for our state and a higher quality of life for people with autism.

**Cost:** None anticipated; Colleges and universities can recoup costs of autism programs through student tuition; school districts already obtain the same amount of training annually.

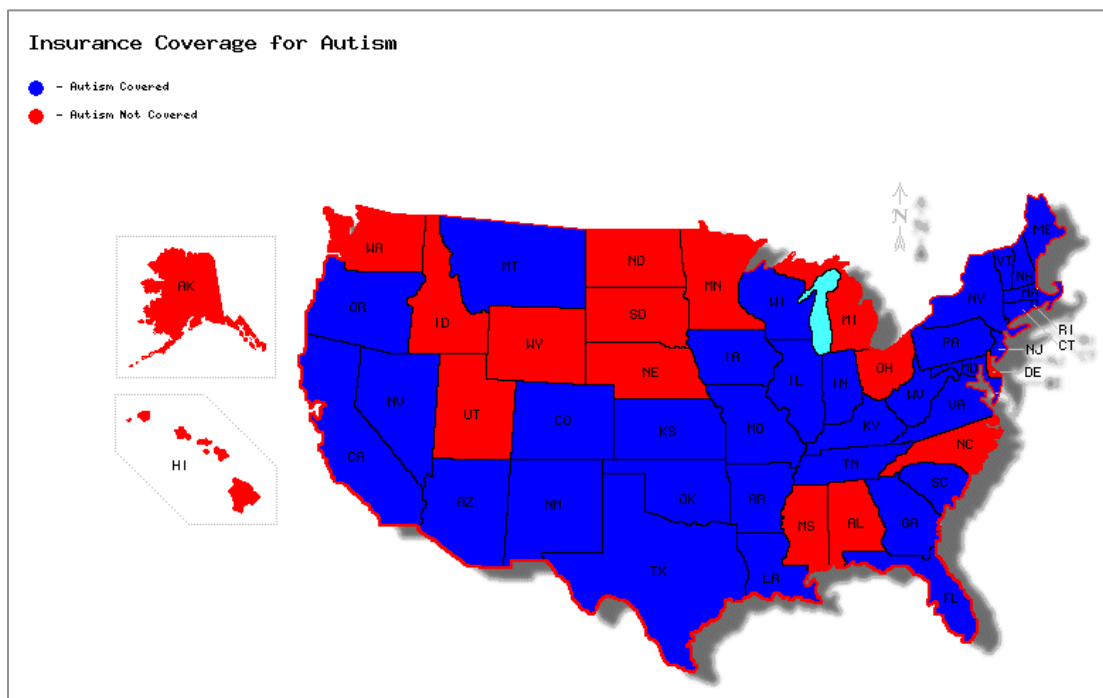
# Health Care

**HC-1: Enact legislation that mandates insurance policies to include coverage for those with ASD and requires insurance policies provide comprehensive coverage for ASD treatments, including communication and behavioral therapies.**

**Issue:** There is a need for health insurance coverage in our state that includes medically necessary and appropriate comprehensive services and treatments/interventions for individuals on the autism spectrum.

## Key findings:

- Autism is a biomedical brain disorder. As is true of many other biomedical disorders, there is currently no cure for autism. Rather, autism care is focused on controlling or diminishing symptoms and associated impairments. In this way it does not differ from numerous other chronic medical disorders whose treatment is covered routinely by health insurance, including hypertension, diabetes, renal failure, and asthma.
- 35 states now require/mandate insurance coverage for autism.<sup>8</sup> (see map below) Mississippi is one of only 15 states still allowing insurance companies to exclude coverage for individuals with ASD.



- Insurance companies providing coverage in our state routinely exclude coverage of some treatments for autism, particularly those that involve communication and behavioral treatments.
- Some families in the state report that even well child and routine pediatric care is not covered because a child has autism.
- 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 in order to care for their child.

**Recommendations:**

HC-1 - Enact legislation that mandates insurance policies to include coverage for those with ASD and requires insurance policies provide comprehensive coverage for ASD treatments, including communication and behavioral therapies.

There is evidence that a number of diverse treatments can lead to significantly improved functioning in autism even though they do not lead to a cure. Like many other medical conditions these treatments include non-pharmacologic approaches. For instance, exercise, general diet and avoidance of environmental factors such as salt and concentrated sugars are considered to be key elements of the management of hypertension and diabetes. Very often these treatments lead to markedly improved function, even though the core disorder remains. Insurance coverage would provide critical early intervention services and therapies proven to improve functioning in ASD thereby reducing costs to the state for long-term care of individuals with autism.

**Cost:** None anticipated; insurance companies would recoup any related costs in premium payment increases, which have proven to be very minimal in the states already mandating coverage.

# Social Services

**SS-1:** *Require DMH and public mental health providers to work together to develop integrated wraparound services for individuals experiencing significant levels of ASD and their families. Access to support services must be available before they reach crisis.*

**SS-2:** *Increase supportive services and access to trainings that help empower families/foster/resource/host families and guardians. These services may include information/referral, respite, behavior consultation and assistance, appropriate home modifications, and in-home staff support if necessary.*

**Issue:** Individuals with ASD need a system of support in place which offers a variety of services to them and their families to ensure they receive the needed care in times of crisis and are not unnecessarily forced into institutional placement.

## Key findings:

- Autism is a multifaceted disorder with varying degrees of severity, which can sometimes cause extremely challenging behavior.
- Increasingly families are reporting that community supports are not available to them during times of crisis and some have had no other option than to seek institutional placement to obtain needed support services.
- Some families have also reported that even institutional based services are not available in times of crisis with at least 2 reports of individuals with autism being forced to remain in the emergency room – one for as long as 3 days – because needed crisis intervention services were not available.
- Children with ASD placed into foster care have complex needs and there is insufficient training and support for foster/resource/support families.
- Empowered families are an important key to long-term success for a child with ASD. However, family support services and trainings available to families caring for children and adults experiencing ASD are limited.

## Recommendations:

SS-1 - Require DMH and public mental health providers to work together to develop integrated wraparound services for individuals experiencing significant levels of ASD and their families. Access to support services must be available before they reach crisis.

SS-2 - Increase supportive services and access to training that help empower families/foster/resource/host families and guardians. These services may include information/referral, respite, behavior consultation and assistance, appropriate home modifications, and in-home staff support if necessary.

Mississippi already has a program in place for children with serious emotional disturbance (SED) called MYPAC which is funded through a Medicaid waiver. It is suggested this program be used as a model in the development of the needed wraparound support services for individuals with ASD and their families.

**Cost:** None anticipated; included within the cost of Infrastructure Strategies.

## Conclusion

The number of Mississippians with autism is growing exponentially and yet service systems in our 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 our state. 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 autism.

The need for change is clear. The work outlined in this report illustrates that we have many gaps in our system of care. One severe 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 assist 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 autism spectrum disorders and their families must play a critical role in all aspects of the process.

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

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### FOOTNOTES

<sup>1</sup> Centers for Disease Control and Prevention estimate that one in 88 children in the United States have autism, and the 2010 Census shows Mississippi has 895,293 residents under 21. Based on those figures, Mississippi has an estimated 10,174 children (ages 0-20) with autism.

<sup>2</sup> Data Accountability Center, Individuals with Disabilities Education Act (IDEA) Data, State-Level Data Profiles, Part B Child Count 2000-2010.

<sup>3</sup> Harvard University School of Public Health, 2006

<sup>4</sup> Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism – General Model and Single State Case.

<sup>5</sup> 2010 Census lists 638,539 school-aged children (ages 5-19) in Mississippi. The Mississippi Department of Education lists 491,078 students attending public schools in the 2011-2012 academic year. That leaves 147,461 school-aged children not accounted for by the MSDE. It's assumed these children attend private school or receive home-school educations.

<sup>6</sup> Cost comparison of early intensive behavioral intervention and special education for children with autism. Journal of Child and Family Studies 2007.

<sup>7</sup> Data Accountability Center, Individuals with Disabilities Education Act (IDEA) Data, Part B Exiting, Table 4-1.

<sup>8</sup> National Conference of State Legislatures, January 2012.

# Mississippi Autism Advisory Committee Members

*We would like to thank the following members for their time and commitment in creating this report:*

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*Continued on the next page ...*

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*With invaluable assistance provided by the Mississippi Department of Mental Health staff:*

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