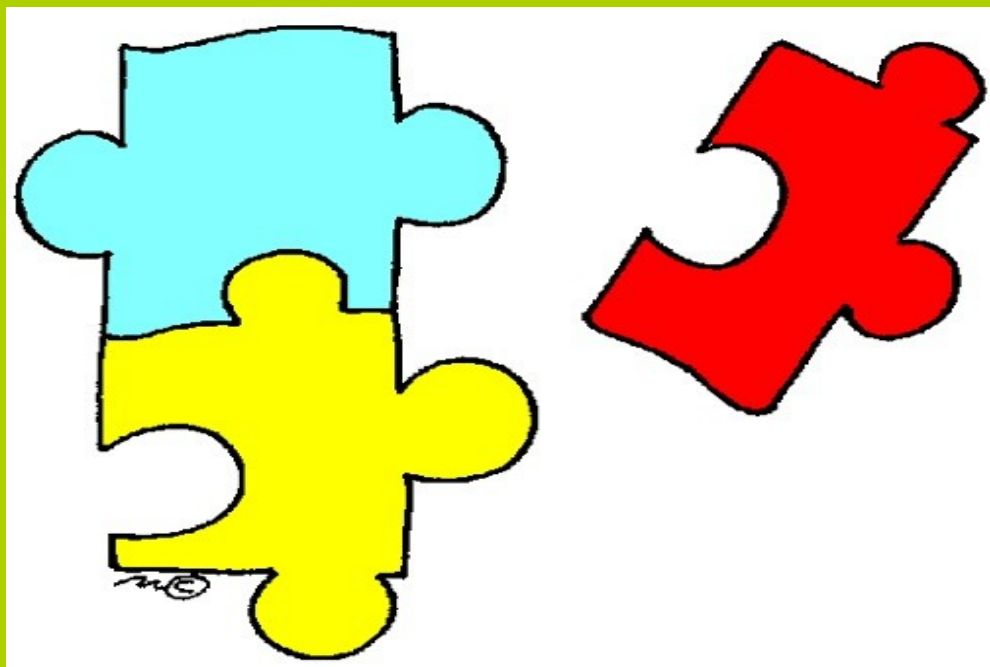


2011

Mississippi Autism Advisory Committee



July 1, 2011

## Background

The Mississippi Autism Advisory Committee was created this year 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 with the workforce ... and to develop an annual plan” outlining this strategies.

That plan is due July 1 of each year.

*Dear Legislators,*

Autism in the state of Mississippi is a ticking time bomb that, if not diffused, will cost taxpayers billions of dollars over the course of the next several decades and beyond.

Autism is a pervasive developmental disorder that impairs a person's ability to communicate and socialize and 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.

An estimated 8,139 Mississippi children have autism – a 368 percent increase in the past decade. <sup>(1)</sup>

Only early, intensive intervention has been shown to help these children improve and, in many cases, overcome the debilitating effects of autism. <sup>(2)</sup> Yet early intervention services, which are plentiful in most states, are sorely lacking in Mississippi. This is partly due to the fact that few families here can afford the cost of these services without insurance reimbursement, and Mississippi currently doesn't require health insurers to cover early intervention. Because few families can afford it, early intervention specialists don't locate in Mississippi.

The result is a burgeoning population of children who enter the school systems at age 4 or 5 with no prior intervention. The challenge of rehabilitating these children therefore falls upon the public and private school teachers, many of whom lack any formal training in the area of autism. The state has no autism training requisite to receive a teaching license nor does it require autism training as part of a teacher's ongoing professional development.

Yet statistics from the Mississippi Department of Education show a 307 percent rise in the number of public school children with autism in the past eight years. <sup>(3)</sup> (No such data exists for the privately schooled or home schooled populations.)

Without the proper intervention – either as preschoolers or within the school system – this population has little chance of gaining independence or becoming contributing members of society. Few resources exist in Mississippi to help these children transition out of school and into adulthood, and as a result, they tend to drain money from state and local coffers instead of contributing to them.

It's estimated that each person with autism, if not rehabilitated, will cost society \$3.2 million over their lifetime. <sup>(4)</sup> Most of that cost comes from adult care and lost wages.

If none of the state's 8,139 children currently living with autism overcome their challenges by the time they reach adulthood, it could cost Mississippi taxpayers more than \$26 billion over the next 50 years. And that's if this population doesn't expand; mostly likely it will. If so, it will strain the Department of Education, the Department of Mental Health, the vocational rehabilitation centers and the families and communities caring for them.

Yet if we begin to address this crisis today, we have the potential to rehabilitate a generation of children and save the state billions of dollars in the end.

The Mississippi Autism Advisory Committee therefore recommends four strategies for implementation that address each of the core deficits in our state's response to the autism crisis. They are by no means an exhaustive list of remedies; rather, they lay the foundation of what's to come. Without their implementation, Mississippi will never achieve its goal to prudently and successfully manage this growing crisis.

Sincerely,

*Emily Le Coz, Chairperson of the Mississippi Autism Advisory Committee*

# **Strategies**

## **Strategy 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.

## **Strategy 2**

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.

## **Strategy 3**

Require an autism component in four of the 10 clock hours of professional development mandated annually for educators and academic administrators, and require state institutes of higher learning to include autism training in their curriculum for future teachers.

## **Strategy 4**

Identify a point person within the Mississippi Department of Education and one within the Mississippi Department of Vocational Rehabilitation to collaborate on ways to strengthen and improve the transition process for children exiting the public schools and entering adulthood.

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## **Cost**

The four strategies together will cost the state an estimated total of \$120,000 annually.

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## **Deadline**

We recommend each strategy be implemented as soon as possible, and no later than July 1, 2012.

# Strategy 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.

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**Why:** Until we can reliably track the number of Mississippians with autism, our state never will understand the scope of this growing problem or what services it needs to address it. Further complicating matters is the fact that, while some services do exist to help this population, they are scattered, disconnected and inconsistent from one part of the state to the next. Finally, we need a better grasp of the taxpayer-funded costs related to this population so we can more wisely manage these funds.

We therefore recommend the state reestablish and fund a full-time Mississippi Autism Coordinator position within the Department of Mental Health to:

- track this population through existing data available from various agencies.
- act as a point person for the scattered public and private entities currently serving this group and link them together into a seamless network of aid across the state.
- identify weakness/gaps within the network of autism-related services and work toward strengthening/filling them.
- create a Mississippi Autism website for parents, educators and health care professionals to find information and resources relating to autism.
- advocate for autism education and awareness statewide.
- work with pediatricians to implement early-sign autism checklists.
- keep tabs on costs and outcomes of all state-funded initiatives related to this population and prepare an annual report compiling and analyzing this data.
- report to the Mississippi Autism Advisory Committee at each committee meeting.

**Cost:** Based on current state employee salaries and benefits, this position will cost Mississippi up to \$100,000 annually. An additional \$20,000 will be needed to develop materials, conduct meetings and develop a website. The Department of Mental Health needs a PIN and the funding for this position.

**Background:** Currently, the Centers for Disease Control and Prevention estimate that one in 110 children in the United States have autism, up from the previous estimate of one in 500 a decade ago. Based on the current rate, Mississippi has an estimated 8,139 children (ages 0-20) with autism.

But the true number of Mississippians with autism remains unknown. That's because only one state agency – the Mississippi Department of Education – tracks this population. And it does so only for children currently enrolled in a public school district who have an educational ruling of autism. But nearly 150,000 youth statewide are home schooled or in private academies <sup>(5)</sup>. And many who do attend public schools are classified by their districts, not as autistic, but as developmentally delayed, emotionally disturbed or otherwise.

According to the MDE, 2,160 children with autism attended public school the most recent academic year. That's a 307 percent jump from eight years ago, when the MDE reported 531 children with autism statewide.

Either way, the rate of autism in Mississippi has drastically risen. Yet we have little available data to understand the scope of this problem or how our state should address it. What we do know is that those on the front lines – parents, pediatricians and educators – have few resources to help these children. A statewide Autism Coordinator is the first step toward clearing the confusion and getting Mississippi down to business.

## Strategy 2

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.

\*

**Why:** As with any disorder whose origin and treatment modern medicine hasn't conclusively determined, autism has attracted a host of professionals claiming the ability to diagnose, treat and even cure it. These professionals come from a variety of backgrounds and disciplines, and while many truly have something to offer, some may not. Parents, educators and pediatricians therefore struggle to find appropriate – or even legitimate – professionals to accurately identify these children and effectively help them. Until it sets minimum standards for diagnostics and treatment, Mississippi will continue to foster a wild-west atmosphere of “anything goes” when it comes to this population.

We therefore recommend the state require the regulating bodies of each area of expertise to create and adopt a set of minimum standards for diagnostics and treatment of autism. The state Autism Coordinator will work with these groups and collect information from them to make available. Professionals meeting the minimum guidelines will be listed on the state website as a resource to parents, educators, pediatricians and others.

**Cost:** None anticipated; included within the cost of Strategy No. 1.

**Background:** Together, early diagnosis and early intervention are a child's best chance to overcome the most debilitating effects of autism. They're also Mississippi's best shot 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 normal 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 somewhat to society. The rest will receive little benefit and require a lifetime of aid. (2)

If we had a seamless and reliable network of professionals to diagnose and treat autism at an early age now, we could possibly prevent 4,070 children from becoming lifelong dependents on state services. That's a significant reduction of costly, state-funded special education services, family support services, and adult care services.

Again, each child with autism is estimated to cost society \$3.2 million over the course of their lifetime unless they're able to be totally or partially rehabilitated.

But Mississippi doesn't have a seamless or reliable network of professionals who diagnose and treat autism at any age – much less the crucial first years. 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.

We must, however, begin somewhere. And we feel an important first step involves the identification and regulation of the autism professionals our state currently does have.

## Strategy 3

Require an autism component in four of the 10 clock hours of professional development mandated annually for educators and academic administrators, and require state institutes of higher learning to include autism training in their curriculum for future teachers.

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**Why:** Along with parents, public school teachers now stand at the front lines of the autism epidemic. They are responsible for educating these children 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 that they can successfully educate them. Special education teachers especially need training, but so too do regular classroom teachers and assistants who often teach high-functioning children. Finally, school administrators must learn the basics of autism to better manage how their districts handle the growing number of children with this disorder.

Public educators in Mississippi already are required to take 10 clock hours of professional development per year. We recommend four of those hours focus on autism and and/or developmental disorders which, as a whole, have increased at an alarming rate in Mississippi – as they have elsewhere in the nation. This would be an annual requirement.

We also recommend that autism training be required for any person seeking to obtain a Mississippi teaching certificate. And finally, we recommend the Mississippi Institutes of Higher Learning and the Mississippi State Board of Community and Junior Colleges mandate autism-related curriculum within their respective teacher programs.

**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.

**Background:** The Mississippi Department of Education's own statistics show a 307 percent rise in the number of public school children with autism, up from just eight years ago. <sup>(3)</sup> This trend isn't expected to decline. In fact, it's likely to rise.

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. Currently, Mississippi public schools graduate less than 30 percent of students who have Individualized Education Plans (IEPs), which includes most children with autism. <sup>(6)</sup> We can do better than that, especially after we create a seamless transition of early childhood intervention into the public schools.

Furthermore, teachers who specialize in autism not only can educate children with autism, but can help integrate many of them into regular classroom settings. A study by the Center for Special Education Finance recently showed it costs nearly twice as much to educate the average student with disabilities as it does the typical student with no special needs.

In its 2012 Budget Presentation, the MDE listed its base, per-student cost as \$4,901.77. We therefore can assume it costs nearly \$10,000 per child with autism requiring special services. It's the goal of the Mississippi Autism Advisory Committee to reduce the number of children requiring special services and thereby slash state education expenditures. Many of these children can be rehabilitated. But we need early intervention (Strategy No. 2) and we need trained public school teachers (Strategy No. 3).

## Strategy 4

Identify a point person within the Mississippi Department of Education and one within the Mississippi Department of Rehabilitation Services to collaborate on ways to strengthen and improve the transition process for children exiting the public schools and entering adulthood.

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**Why:** Although children receive the most focus when talking about autism, the disorder does not end at age 18, especially for those with a more severe form of the disability. Even with the best treatments available, an estimated half of all individuals with autism will continue to need some services throughout their lifetime. The period beginning in high school and continuing into adulthood for this particular population is called “transition,” and it lays out plans that include vocational rehabilitation, community college and/or adult care.

Unfortunately, this process often begins too late and omits too many key components to produce effective results for either the student, the family or the community. As a consequence, adults with autism who might otherwise have jobs and become taxpaying members of society instead become dependent on society.

We therefore recommend the Department of Education and the Department of Rehabilitation Services appoint one person each from within their agencies to collaborate on ways to strengthen and improve the transition process for children with autism. If neither agency has an appropriate staff member to serve, they can appoint someone outside their agencies to serve on their behalf. The point persons will:

- Serve in an auxiliary capacity to their regular duties, if currently employed within the agencies. If appointed from outside the agencies, they will serve as unpaid volunteers.
- Meet as needed over the course of a year to study current transition practices and offer improvements.
- Receive support and assistance from the Mississippi Autism Coordinator.
- Draft a report of recommendations for the Legislature and the Autism Advisory Committee.

**Cost:** None anticipated

**Background:** It has been known for decades that individuals with autism, including those with significant impairment or who have behaviors that others find challenging, can attain higher education and/or work when they are given appropriate supports. It also is clear these individuals can benefit from these post-secondary experiences. However, many traditional vocational rehabilitation practices are not only ineffective for people with autism, but actually distressing to them. This frequently leads to clients withdrawing from the process. One agency recently documented a 90 percent drop-out rate for clients with autism, most of whom never got past the vocational evaluation. (7)

Traditionally, the biggest barrier for people with autism in college or the workplace is their challenge with social skills – not their intelligence or ability. Even people with very high-functioning autism face dropout or job loss due to social difficulties. People who have significant challenges or more severe autism need supported or customized employment. Mississippi is just this year providing training to a small group of people at Vocational-Rehabilitation (VR) to begin a customized employment program. But at the present time, the task of figuring out “what comes next” when a child exits high school rests on the shoulders of families. Even persons with milder forms of autism who choose to attend college have little support, so once again, the burden of “figuring it all out” or developing and implementing a plan is left to families, who in our state often have limited knowledge and resources.



# Conclusion

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By implementing relatively simple yet innovative strategies, the state can lay the foundation for a comprehensive approach to its growing autism crisis.

These strategies will not require large financial investments or sweeping changes in state policies. They require simply the recognition that a problem exists and that Mississippi already has talented citizens able to address it. Those citizens just need to be identified and to be given the tools and support to do it.

Because autism is a lifelong disorder, the Mississippi Autism Advisory Committee targeted key challenges in each stage of life: early childhood, the school years and adulthood. For each of these areas, we recommended a practical and affordable solution. In addition, we recommended a statewide autism coordinator to provide policy research, support and oversight.

Once these strategies are in place, the state can evaluate the results and build upon the foundation we have laid. But without this start, Mississippi will not move forward. And we would once again face last place in a nation where other states already have taken the lead.

Let's put Mississippi's best talent to work and address the autism crisis before it's too late.

## FOOTNOTES

- (1) The Centers for Disease Control and Prevention estimate that one in 110 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 8,139 children (ages 0-20) with autism.
- (2) Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism – General Model and Single State Case
- (3) The 2010-2011 Mississippi Department of Education District Data Profile Report listed 2,160 children with autism attended public school the most recent academic year. That's up from the 2002-2003 District Data Profile Report, which listed 531 children with autism statewide.
- (4) Harvard University School of Public Health, 2006
- (5) The 2010 Census lists 638,539 school-aged children (ages 5-19) in Mississippi. The Mississippi Department of Education lists 490,702 students attending public schools in the most recent academic year. That leaves 147,837 school-aged children not accounted for by the MSDE. It's assumed these children attend private school or receive home-school educations.
- (6) Mississippi Report Card 2009-2010
- (7) "Adult Autism & Employment," Disability Policy and Studies School of Health Professions, University of Missouri Health System

# 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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