

The image features three identical wooden puzzle pieces arranged vertically on a red background. Each piece is light-colored wood with a visible grain and casts a dark shadow to its right. The puzzle pieces are positioned in the left half of the page, with the top piece at approximately the top third, the middle piece at the middle, and the bottom piece at the bottom third of the vertical space.

# Mississippi Autism Advisory Committee Report

**2013  
Recommendations  
for the  
Mississippi  
Legislature**

## CHAIRMAN'S LETTER

Dear Legislators,

I am pleased to submit the report from the Mississippi Autism Advisory Committee 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 – 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 563% percent rise in the number of public school children with autism in the past 11 years. Throughout the state of Mississippi, families and systems of care are struggling to meet the needs of individuals with ASD across their life span.

Autism is a neurodevelopmental disorder that impairs a person's ability to communicate and socialize. It is characterized by restricted and repetitive behaviors. It typically appears within the first three years of life and can range from mild to severe. There is no known cause, and no known cure.

It can cost as much as \$3.2 million to care for an individual with autism across their lifespan. If the state's children currently living with autism do not overcome their challenges by the time they reach adulthood, it could cost Mississippi taxpayers more than 32 billion dollars over the next 50 years. We know early and intensive therapy can improve outcomes but, even though Autism is a biomedical brain disorder, insurance companies routinely exclude coverage for ASD. Thirty-two states have enacted Autism Insurance Reform laws to ensure necessary treatment is provided. Mississippi is NOT one of those states. Coverage will result in significant long-term cost savings to health care and educational systems.

The number of students with ASD in public schools has increased dramatically. Most teachers do not receive training on ASD prior to entering the school system as many teacher preparation programs contain little to no autism related curriculum. There are also no institutions for higher learning in Mississippi offering a specialty program or degree in the area of Autism. One of the few bright spots in the training of professionals to work with the ASD population is through a collaborative effort of The Mississippi Department of Education and the University of Southern Mississippi.

Our report focuses on two key recommendations. This is not an exhaustive list of remedies but will 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

## UNDERSTANDING AUTISM

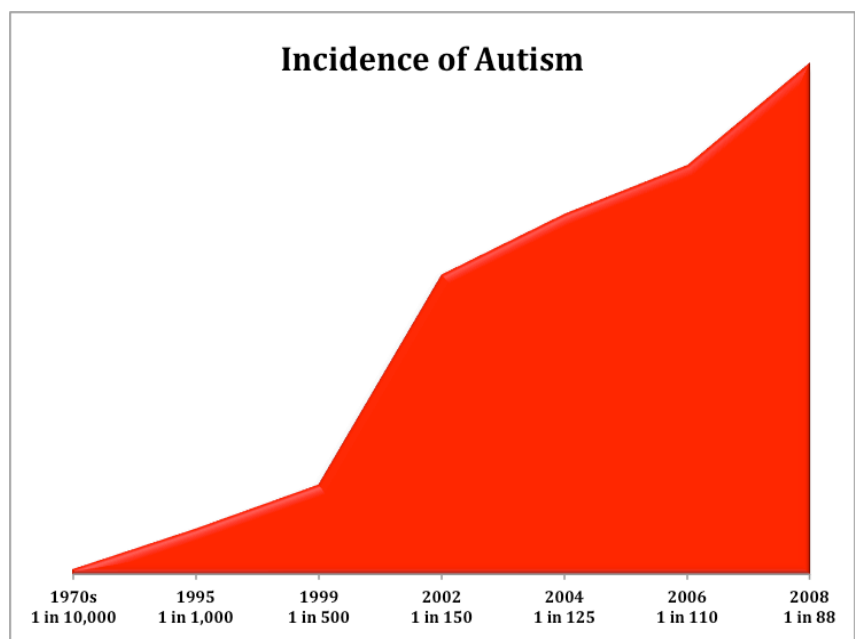
Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. With the publication of the new DSM-5 diagnostic manual, the autism subtypes, which include autism, pervasive developmental disorder, and Asperger syndrome have been merged into one umbrella diagnosis of ASD. There are also certain genetic syndromes which are associated with autism spectrum disorders such as Fragile X, Rett syndrome, and DiGeorge Syndrome to name a few.

ASD can be associated with difficulties in social interactions, motor coordination and attention and physical health issues such as sleep, gastrointestinal disturbances, and epilepsy. Some persons with ASD excel in visual skills, music, math and art.

Autism appears to have its roots in very early brain development. However, the most obvious signs of autism and symptoms of autism tend to emerge between 2 and 3 years of age. Unfortunately, many of our children with Autism are not diagnosed until much later. Studies have shown that children receiving early intensive intervention can greatly increase their educational and vocational outcomes.

### ***Did you know ...***

- Autism now affects 1 in 88 children and 1 in 54 boys.
- Autism prevalence figures are growing with the CDC announcing that rates could be as high as 1 in 50. Government autism statistics suggest that prevalence rates have increased 10 to 17 percent annually in recent years.
- Autism is the fastest-growing serious developmental disability in the U.S.
- Autism costs a family \$60,000 a year on average
- Boys are nearly five times more likely than girls to have autism
- There is no medical detection or cure for autism
- There is no staff person at any state agency whose primary responsibility is to coordinate services or coordinate training for either professionals working with Autism or individuals with Autism.
- There are no Autism specific training programs or certifications at any of our public university and college institutions
- For insured Mississippians most policies refuse to offer coverage for most Autism treatment services.



## COMMITTEE PURPOSE AND WORK

The Mississippi Autism Advisory Committee was created in 2011 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 report is due July 1 of each year. This is the third report of this committee and there was a 2007 report from a previous task force that was legislatively created and authorized.

This committee has met 6 times this year. In addition, the committee conducted 4 public meetings in Jackson, Starkville, Oxford, and Hattiesburg and worked with organizations to conduct 3 surveys of professional organizations. Plans are being finalized to conduct additional hearings this year and conduct additional surveys from other stakeholder groups.

This committee heard in its public meetings the cry from both parents and providers the need for services from early education to employment support is critical. This committee has chosen to focus this report on our most important and critical recommendations.

## RECOMMENDATIONS

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

#### RATIONAL:

**Issue 1:** There is a need for health insurance coverage in our state that includes medically necessary and appropriate comprehensive services and treatments/interventions for individuals 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.
- Insurance companies providing coverage in our state routinely exclude coverage of some treatments for autism, particularly those that involve communication and behavioral treatments.

- Insurance exclusion for ASD results in financial hardship for some families as they are forced to pay for therapies and treatments excluded solely on the basis of their child's disability. These are families who in many cases already have reduced resources because one parent has been forced to give up their job in order to care for their child.
- 32 states have enacted Autism Insurance Reform laws to ensure that citizens with Autism receive necessary medical and behavioral treatment. Mississippi is NOT one of those states.
- Many people with Autism go without medical and behavioral treatment due to financial reasons.

**Costs: (For Private Insurance) According to a report issued from Autism Speaks in March of 2012. . .**

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

The first year costs of coverage range from \$0.09 per member per month (PMPM) to \$0.30 PMPM. The average first year cost of coverage is \$0.15 PMPM.

- Claims data is available from the second year of implementation in 5 states (i.e., SC, IL, LA, FL and AZ). The second year costs of coverage range from \$0.10 PMPM to \$0.43 PMPM. The average second year cost of coverage is \$0.31 PMPM.
- Minnesota has not enacted autism insurance reform. However as a result of a settlement of litigation against Blue Cross and Blue Shield of Minnesota, they have been required to cover unlimited treatment for ASD since 2001. After 6 years, the premium impact on the commercial market resulting from unlimited coverage for ASD was \$0.83 PMPM.
- Fiscal notes were prepared for the legislatures in 5 of the states where Autism Speaks obtained claims data. These cost projections were prepared for fiscal or calendar years that correspond to available claims data in 3 states. Fiscal projections overestimated the actual cost of autism insurance reform by 293% to 1,261%.

**Costs: (For Public Insurance)**

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

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

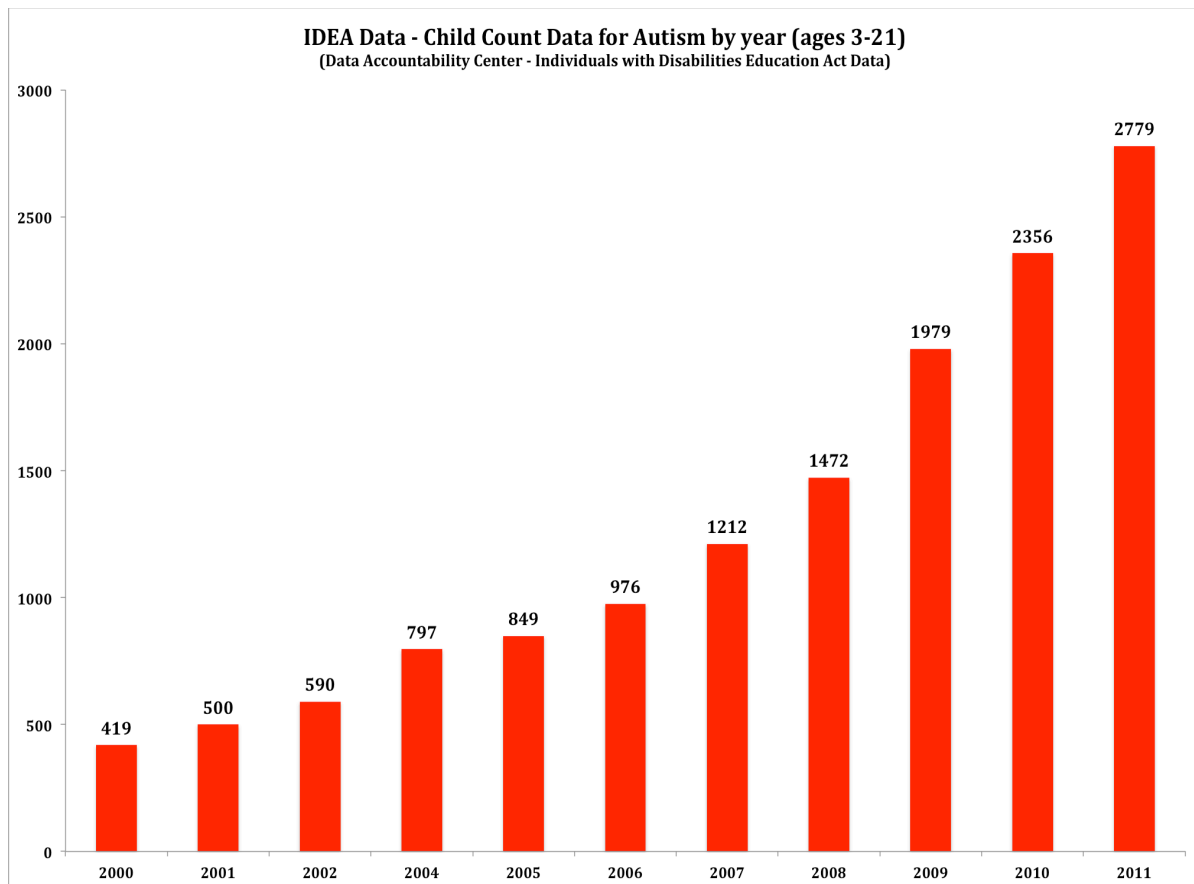
RATIONAL

**ISSUE 2.1: APPROPRIATE EDUCATIONAL INSTRUCTION FOR CHILDREN WITH AUTISM AND TRAINING FOR PROFESSIONALS WORKING WITH THOSE WITH AUTISM**

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

**Key Findings:**

- The Mississippi Department of Education identified 2779 children (ages 3-21) with the educational ruling of autism in 2011. The numbers reflect a 563% increase from 11 years ago, a 185% increase from 5 years ago and a 40% increase from 3 years ago.



- This explosion in the number of children diagnosed with Autism has created a huge demand for trained professionals to work with the Autism population
- No Mississippi college or university offers Autism specific certifications or degrees requiring most all training to come from the Mississippi Department of Education.
- The lack of a trained work force to assist those with Autism was one of the biggest issues reported at the public meetings by both parents and teachers.
- Some services currently exist to support this population but they are scattered, disconnected and inconsistent from one part of the state to the next.
- The State Department of Education has supported the development of a training program in conjunction with the Department of Curriculum and Instruction at the University of Southern Mississippi. Their work is highlighted at the end of this report.

## **ISSUE 2.2: APPROPRIATE MENTAL HEALTH SERVICES AND COORDINATION OF SERVICES FOR PEOPLE WITH AUTISM IS NEEDED**

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

### **Key Findings:**

- In FY 2012, the Department of Mental Health's certified community mental health agencies served approximately 220,000 individuals with serious mental illness, serious emotional disturbance and intellectual/developmental disabilities.
- The true number of individuals with ASD served remains unknown because only one state agency – the MS Department of Education – tracks this population only for children who have an educational ruling of autism.
- To determine the prevalence rate of ASD in adults, a research project was conducted in England. In general, they found that an estimated prevalence of ASD in adults approximates the current estimates of ASD in prevalence in children at 1.1% (Brugha, 2011).
- Boys are four times more likely than girls to have Autism and there is a higher prevalence of ASD among men (Brugha, 2011).
- Key findings show that Autism is the 5<sup>th</sup> most prevalent diagnosis in children aged 3-17 years:
  - Attention Deficit Hyperactivity Disorder (6.8%)
  - Behavioral or conduct problems (3.5%)
  - Anxiety (3%)

- Depression (2.1%)
- Autism Spectrum Disorders (1.1%)
- 83% of children with Autism also exhibit emotional, conduct and hyperactivity problems.

Some services currently exist to support individuals with ASD and their families, but they are scattered and inconsistent from one part of the state to the next. The rate of ASD in Mississippi has risen and yet we have little available data to understand the scope of this problem. Therefore, a full-time position and funding for an ASD Coordinator is needed at the Department of Mental Health to track this population through available data systems, to identify gaps of autism-related services and to facilitate the development of a state-wide strategic plan to improve and expand effective services/resources for individuals with ASD.

### **ISSUE 2.3: VOCATIONAL EMPLOYMENT FOR PEOPLE WITH AUTISM**

Many people with Autism have the potential to hold full time employment. However, the committee through their experiences and through the public meetings realize that as the population of Autism explodes vocational training for this population must expand if we are to get and keep this population in the workforce. Expertise must be developed within our vocational rehabilitation programs. Persons holding this position would also work with the Mississippi Autism Advisory Committee at each committee meeting.

**Key Findings:** In reviewing the employment of those with Autism in the community:

- For youth with an ASD, 34.7% had attended college (Shattuck, 2012)
- 55.1% had held paid employment during the first 6 years after high school (Shattuck, 2012)
- More than 50% of youth who had left high school in the past 2 years had no participation in employment or education (Shattuck, 2012)
- Youth with an ASD had the lowest rates of participation in employment and the highest rates of no participation compared with youth in other disability categories (Shattuck, 2012)
- Higher income and higher functional ability were associated with higher adjusted odds of participation in postsecondary employment and education (Shattuck, 2012)
- State vocational rehabilitation agencies are one of the most important sources of employment services for individuals with autism spectrum disorders and other disabilities, and the number of people with autism spectrum disorders seeking VR services has risen steadily. The number who exited VR services more than tripled between 2003 and 2008, and in 2008 5,344 individuals with autism spectrum disorders completed VR services.
- In 2009, 59% of people with autism spectrum disorders gained employment after receiving VR services. It is interesting that this figure was higher compared to the corresponding figure for people with any types of disabilities (56%).



## 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 extreme challenge is the number of youth with ASD who are reaching adulthood. State agencies and other concerned parties will need to work now and in the future to develop new programs that provide the flexibility, training, and level of support to persons with ASD so they can 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 creating the infrastructure 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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## COMMITTEE MEMBERSHIP

We would like to thank the following Mississippi Autism Advisory Committee Members for their time and commitment in creating this report:

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<b>Nicole Boyd</b> , MS Department of Rehabilitation Services, Oxford, MS	Lieutenant Governor
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With invaluable assistance provided by the MS Department of Mental Health staff:

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## **PROMISING PRACTICE ON TEACHER TRAINING WITH THE COLLABORATION BETWEEN THE UNIVERSITY OF SOUTHERN MISSISSIPPI AND THE DEPARTMENT OF EDUCATION**

To: Pam Dollar, Chairperson, Mississippi Autism Advisory Committee

From: Dr. Tim Morse, Director of Training/Positive Behavior Support Specialist;  
The University of Southern Mississippi-Gulf Coast Autism Project

Subj: The University of Southern Mississippi-Gulf Coast Autism Project  
(November 1, 2009 – June 21, 2013)

### Overview of The University of Southern Mississippi-Gulf Coast (USMGC) Autism Project

The USMGC Autism Project was created on November 1, 2009 through funding provided by the Mississippi Department of Education-Office of Special Education (MDE). On December 1, 2012 the MDE established the project as a university-based program as authorized in Sections 37-23-31 through 37-23-35 of the Mississippi Code. This university-based resource has been designed to enable Mississippi to develop its internal capacity for addressing the needs of students with autism, rather than to have to continually contract with personnel or agencies outside of the state to do the same. Hence, the project is intended to have a statewide outreach as the project's staff strive to accomplish their mission, which is to demonstrate for school personnel and parents how to design and implement appropriate school-based programs for students with autism.

As has been the case throughout the operation of the Autism Project, Autism Project staff have accomplished their mission by performing two primary tasks: conducting various training activities and operating an Autism Demonstration School. Training activities that have been developed and implemented include large-group regional trainings throughout the state, distance education activities that have been broadcast throughout the state, and on-site trainings at the project's base of operations (i.e., Long Beach Middle School) that have included various school personnel, USM students, parents, interested citizens (e.g., Court Appointed Special Advocates), and professionals who work on behalf of students with autism in various capacities (e.g., Department of Defense employees who are involved in the Department's Exceptional Family Member program and Mississippi Department of Health employees who work in the state's Early Intervention Program). Additionally, the MDE used a five-year statewide autism training plan (2012-2016) that I proposed to begin securing the services of national and international experts in the field of autism for the purpose of coming to Mississippi each July to conduct statewide training (e.g., Emily Rubin).

Regarding the project's Autism Demonstration School, it is located at Long Beach Middle School, and functions as a university-based program for students with autism. This past school year (2012-2013), the Demonstration School was comprised of three classrooms for students with autism, Preschool-Grade 2. Additionally, an Outdoor Play Area, Training Facility, Parent Resource Library, Professional Library, and Teacher Workroom/Make-and-Take Room have been constructed within the space at Long Beach Middle School that is used for the Autism Project. During the 2012-2013 school year, 21 students with autism received services at the school. Since the school opened in August 2010, 26 students have received services at the school.

The project currently employs 17 personnel in full-time or part-time positions, or as consultants. These include professionals from various disciplines who provide the educational services that result in the provision of an appropriate school-based program for a student with autism: Special Education Teachers, Speech Language Pathologists, Instructional Assistants, Board Licensed Psychologists, Occupational Therapists, and a Physical Therapist. Additionally, a young adult with autism who recently graduated from Long Beach High school is a volunteer worker at the school. Autism Project staff also have established a collaborative relationship with the USM Libraries. Specifically, both the Collection Management and Information Resources librarians from the USMGC Library have performed work on behalf of the project that have enabled it to populate and manage the Parent Resource Library and Professional Library.

A summary of the work that has been performed by USMGC Autism Project staff is presented below.

- Creation of an Autism Demonstration School: During the 2013-2014 school year, this school will consist of 3 classrooms for students with autism, Preschool - 2<sup>nd</sup> Grade, and a Preschool language group. By the end of the school year, 32 students will have received services at the school since it opened.
- 110 Onsite presentations/Small group offsite presentations
- 8 Workshops
- 1,886 Training participants
- 4 SPE 401L USM practicum students
- 1 CIE 301L USM Math Lab Student
- 1 CIR 309 USM practicum student
- 12 SPE 431L and 451L USM practicum students
- 1 International conference presentation
- 3 National conference presentations
- 7 state conference presentations

#### Planned Activities for the 2013-2014 School Year

The information presented above pertains to work that has been performed by USM Autism Project staff from the project's inception on November 1, 2009 until the present day. Autism Project staff plan to perform the work documented below during the upcoming 2013-2014 school year.

1. Support student teaching placements for USM undergraduate students. During the fall 2013 semester, five undergraduate USM students are scheduled to complete all or a part of their student teaching assignment at the Autism Demonstration School. At the moment, one undergraduate USM student is scheduled to complete part of her student teaching assignment at the Autism Demonstration School during the spring 2014 semester.
2. Support the completion of externships by USM graduate students who are studying to be speech-language pathologists. During the fall 2013 semester, two USM graduate students who are studying to be speech language pathologists will complete one part of their externship at the Autism Demonstration School.
3. Support practicum placements for USM undergraduate students. During the fall 2013 semester, an undetermined number of USM undergraduate students will complete one or more practicum experiences at the Autism Demonstration School.

4. Add a part-time class to the Autism Demonstration School. In addition to continuing the operation of three classrooms at the Autism Demonstration School, Autism Project staff will provide services three days per week to a group of preschool students with autism. The purposes for beginning this group are to (a) increase the number of students with autism who will receive services at the Autism Demonstration School and (b) enable Autism Project staff to begin planning for how they will fill the spots that will be opened when a number of the students in the three classrooms transition back to their local education agency for the 2014-2015 school year - and beyond. In all, 27 students are scheduled to receive services at the Autism Demonstration School during the 2013-2014 school year.
5. Conduct individual and small group trainings, on an as requested basis, at the Autism Project's facility.
6. Conduct two types of large group trainings: a five-part Webinar series and a two-day conference. The focus of these trainings will be the design and implementation of appropriate, comprehensive school-based programs for students with autism.
7. Develop a case study/portfolio reporting format that can be used to provide the receiving local education agency (LEA) with detailed information about one of their students who is transitioning back to the LEA after having attended the Autism Demonstration School.
8. In November 2013, Dr. Morse will make a presentation at a national conference that pertains to the safety skills curriculum Autism Project staff have developed within the Autism Project.
9. Autism Project staff are awaiting word on whether a grant proposal they submitted to Autism Speaks will be funded. The proposal pertains to creating a protocol school personnel can use to develop a comprehensive intervention program that addresses the development of the social communication skills of students with autism who are receiving services in school-based programs.

#### Summary of the key features of the USMGC Autism Project

In summary, key features of the Autism Project are as follows.

1. The project is a collaborative endeavor between state agencies that functions as a cost-effective, state-based training and service delivery resource working on behalf of individuals with autism. Participating state agencies and organizations include USM-GC, the Long Beach School District, Mississippi Department of Education, Mississippi Council on Developmental Disabilities, Mississippi Department of Health, and the school districts that have placed students at the Autism Demonstration School or will do so in the upcoming school year (i.e., Bay-Waveland, Hancock County, Gulfport, Biloxi, Jackson County, George County, Harrison County). Furthermore, project staff are collaborating with professionals from other universities (e.g., Louisiana State University) and a national organization (i.e., United States Society for Augmentative and Alternative Communication). Although other state and national organizations have declined opportunities to collaborate with the project, project staff remain open to the idea of including other organizations in future work.
2. Via the Autism Demonstration School, the project provides a means through which undergraduate and graduate students from various disciplines can receive training during student teaching placements, practicum assignments, and externships. Hopefully, these individuals will subsequently take what they learn from their training to other organizations in Mississippi that employ them and help these organizations

build their internal capacity for serving individuals with autism. At the very least, these individuals can become advocates for individuals with autism as a result of their experiences at the school. Hence, the Autism Project aligns with the university's historical teacher training mission.

3. The project's staff provides instruction to four diverse groups of students: preschool and elementary students with autism, pre-service teachers, practicing teachers, and parents of students with autism.
4. The project has served as a source for contributions of scholarly activities to the field of autism. For instance, the project provides a means for conducting applied research, grant writing, and publication of various papers that can contribute to the literature that pertains to individuals with autism. To date, two project-related papers have been published in a peer-reviewed journal and project staff have made presentations at one international conference, three national conferences, and seven state conferences.