Caring for Mississippi Children and Families with Autism

Task Force Report
December 2007

The Honorable Haley Barbour, Governor of Mississippi

The Honorable Amy Tuck, Lieutenant Governor of Mississippi

The Honorable William McCoy, Speaker of the House of Representatives

Dear Governor and Members of the Legislature:

We are please to submit the Report from the Caring for Mississippi Individuals with Autism Task Force. The report details the findings and recommendations of the Autism Task Force, pursuant to House Bill 1267.

This report is the result of an eight month process that involved a wide range of stakeholders throughout the state. In addition to three public hearings, convened in the north, central, and southern parts of the state, individual members and staff of the Task Force participated in seven, day long task force meetings and numerous conference calls and individual interviews. The task force is very appreciative of the time of all of all the hundreds of individuals that contributed to this process and finally these recommendations.

The investigations and recommendations underscore the importance of ASD as a public health crisis and the need for immediate action by the legislature and state agencies. ASD is a complex disorder that affects all facets of life and this report reflects the complex nature of this disorder. Successful outcomes for individuals with ASD will be achieved with early and intense educational, behavioral, and medical interventions. Interventions that must be performed by a well trained and educated workforce on ASD. Although this report is ASD specific, it is our belief that if these recommendations are executed they will be beneficial to many Mississippians with additional developmental disorders and educational delays.

On behalf of the individuals with ASD. their families, and the professionals who work with those with ASD, the Task Force stands ready to assist the Governor and Legislature in the implementation of these recommendations.

Sincerely,

Susan Buttross, MD
Task Force Chair

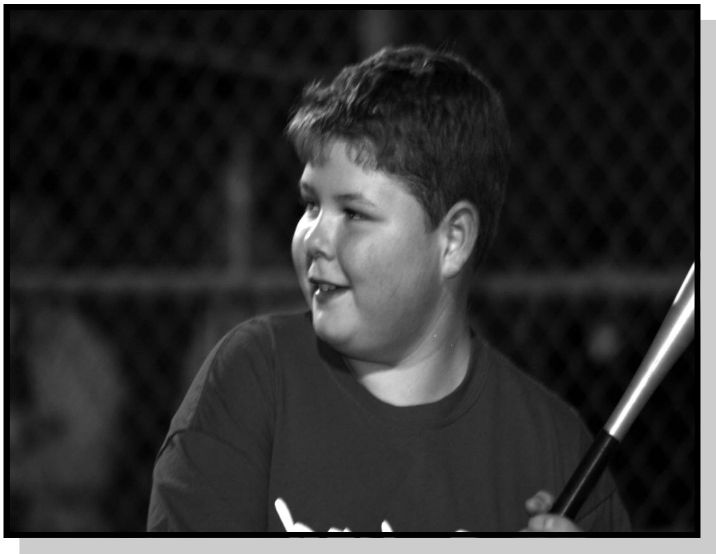
Nicole Boyd, JD
Task Force Vice Chair

Table of Contents

Recommendations

Appendices

Every twenty minutes in America a child is diagnosed with Autism.



Mandates of House Bill 1267

The Caring for individuals with Autism Task Force was charged in House Bill 1267 as signed by Governor Barbour with the following responsibilities:

The task force shall:

(a) Review the best practices of other states with regard to educational, medical and early intervention services provided to individuals diagnosed with autism or ASD and identify the best practices of other states;

(b) Review the standard of services provided by local Mississippi school districts and early intervention programs to individuals diagnosed with autism or ASD, identify any additional potential funding sources for school districts, and identify guidelines for measurable educational and instructional goals that can be used by members of the education community for serving children with autism or ASD;

(c) Assess the medical availability of services currently provided for early screening, diagnosis and treatment of autism and ASD and provide recommendations for enhancing medical services;

(d) Identify the role of higher education in developing a workforce in Mississippi possessing the skills necessary to assist individuals with autism or ASD in medical, educational, and vocational efforts or in providing additional services associated with autism or ASD;

(e) Evaluate and identify any and all additional relevant information and make legislative recommendations regarding the development and implementation of a continuum of educational and medical services for individuals with autism or ASD; and

The CDC has called autism a national public health crisis.

(f) File a report with those standing committees of the Mississippi State Legislature and with those state agencies having jurisdiction over specific recommendations of the task force, not later than December 1, 2007.

What is Autism?

Autism is a complex neurobiological disorder that persists throughout a person's lifetime. Autism impairs a person's ability to communicate and socially relate to others. It is also associated with rigid routines and repetitive behaviors, such as obsessively arranging objects or following very specific routines. Symptoms can range from very mild to quite severe. It is part of a group of disorders known as autism spectrum disorders (ASD). The group of disorders include:

Autism
Pervasive Developmental Disorder - Not Otherwise Specified
Asperger Syndrome
Rhett Disorder
Childhood Disintegrative Disorder

Today, 1 in 150 individuals is diagnosed with ASD, making it more common than pediatric cancer, diabetes, and AIDS combined. The increase in incidents of Autism connotes a jump in the last 10 years of over 300 %. Males are affected 4 times more often than females. Females seem to be affected by the disorder much more severely. Although there are no racial, social or cultural differences found in the rate and severity of autism, there are known disparities in early diagnosis and appropriate intervention. African American children are seen by physicians, on average, 3 times more than Caucasian children before an appropriate diagnosis is given.

Today, 1 in 150 individuals is diagnosed with ASD, making it more common than pediatric cancer, diabetes, and AIDS combined.

Studies including twins and entire families have supported a suspicion of a genetic predisposition. It has been shown that once a child with ASD is born to a family, that family is at a 4 to 8% greater risk of having a second child with ASD. Multiple genes have been linked to ASD and research is ongoing to further identify the genetic causes.

Although there is no single identifiable cause for ASD, both genetic and environmental factors appear to play a role. A small percentage of ASD cases are due to known genetic disorders such as Fragile X syndrome, Tuberous Sclerosis, Neurofibromatosis, and untreated Phenylketonuria (PKU).

To further complicate the findings, there is mounting suspicion that environmental factors play a role in many cases. A genetic predisposition may cause certain individuals to be more sensitive to environmental toxins. Specific environmental toxins have not yet been identified, however, lead, mercury, and other chemical toxins have been implicated. There has been concern that certain dietary components may be a causative factor in some cases. Viral infections including rubella, measles, and CMV (cytomegalic virus) have also been linked to ASD. Illicit drugs and alcohol used by the mother during pregnancy are also known to increase the risk of a child developing ASD.

There is a great deal of ongoing research in this area. Mississippi has a unique opportunity to participate in this research due to the cultural and racial diversity that our state possesses. There is much left to be learned about the many possible reasons for ASD. Support for this research is imperative.

Executive Summary

The dramatic growth in the number of children affected by autism spectrum disorders (ASD) now constitutes a public health crisis in our nation. This crisis has not spared our state. Throughout the state of Mississippi, families, school systems, medical professionals, and others are struggling to meet the needs of individuals with ASD.

The Task Force established a statewide forum and process using extensive surveys, public hearings, individual interviews, and other approaches to obtain input from families and other ASD stakeholders. Additionally, the task force consulted with state, regional, and national experts to identify the best practices and the significant gaps in services, programs and funding.

In order for the state to appropriately care for the individuals with ASD, each and all of these recommendations should be strongly considered for actions. Significant barriers continue to prevent best practices and models from effectively being used and these recommendations are offered as solutions to removing many of these obstacles. These recommendations are offered with the Task Force's understanding that a "phase in" approach must be taken to act on this report in its entirety. The Task Force is committed to assisting in the implementation of this report.

Executive Summary

The Task Force Recommends that:

Workforce Training

WTR-1: The Mississippi Institutions of Higher Learning (IHL) review the best practices of other states that have successful programs in preparing graduates from community colleges, universities and the University of Mississippi Medical Center to work with the ASD population.

WTR-2: That IHL mandate all general education and special education programs require courses with courses and a practicum in behavioral interventions and other methods used in best practices for children with ASD.

WTR-3: A practicum experience for those in training in both education, medical, psychology and allied health services at model programs already available, such as UMC's Mississippi Child Development Institute, be supported with stable funding and be duplicated in the northern and southern areas of the state.

WTR-4: IHL add a special certification program for those extensively trained in the education and treatment for those with ASD for the following graduate programs: Special Education, General Education, Speech Language Pathology, and Psychology.

WTR-5: Mississippi's community colleges include classes in ASD and behavioral strategies used in teaching individuals with ASD for teachers, paraprofessionals and parents.

Medical Interventions and Treatment

MITR-1: Continuing education programs and training be conducted across the state for all health care professionals to increase the general knowledge of ASD and to develop an understanding of appropriate screening, diagnosis and treatment.

MITR-2: All Mississippi children be screened for ASD through a standardized screening protocol, as recommended by the American Academy of Pediatrics by their primary care provider at regular intervals.

MITR-3: Funding be made available to increase the number of trained physicians, psychologists, nurses and allied health professionals who are available to diagnose and provide ongoing treatment for those with ASD.

MITR-4: Incentives be developed to attract more qualified health care professional and therapists to work with those individuals with ASD.

MITR-5: A resource manual that is both in hard copy and available on line be developed by the State Department of Mental Health for parents, service providers and others that lists available services and providers for individuals with ASD.

MITR-6: A Medicaid waiver program and mandates to private insurance companies be considered in order for comprehensive health services to be insured for those with ASD.

> *"Doctors, psychologists, nurses, teachers, police officers, parents, peers, therapists...we all need more training because if you haven't met or been involved with an individual with ASD yet... tomorrow you will."*
>
> *~ASD Professional Comment*

> *"There is not a magic pill for this disorder, it's multi-factorial to say the least.*
>
> *~Parent/Physician Comment, Public Hearing*

Executive Summary (continued)

“Early diagnosis is good, early do something is better.”

~Parent Comment, Public Hearing

Early Intervention

EI-1: Early Intervention Services for ASD children under the age of 3 should include a minimum of 25 hours per week for 12 months of the year.

EI-2: To ensure consistency of educational/treatment options and opportunities, The Mississippi Department of Health and the Mississippi Department of Mental Health develop cohesive, statewide rules for administering a menu of appropriate services based on best practices.

EI-3: Funding be increased to Early Intervention Program providers to enhance continuity and to accommodate the increase in service provision focused on language/ communication development, behavioral support, and social development.

EI-4: The Department of Education, the Department of Health, the Department of Mental Health, and the University of Mississippi Medical Center Division of Child Development and Behavioral Pediatrics collectively to promulgate regulations to determine which evaluation instruments should be used by all EIP providers and school districts and that regulations be implemented by July 1, 2008 that will eliminate transition problems between early intervention providers and school districts.

EI-5: EIP programs increase the number of trained professionals in best practices for the education of children with ASD and the training of their families.

Educational Recommendations

E-1: To ensure consistency in educational options and opportunities, The Mississippi Department of Education develop cohesive, statewide rules for administering a menu of appropriate services based on best practices in the treatment of those with ASD.

E-2: All students with ASD have access to appropriate services for a minimum of 30 hours per week unless otherwise justified on the Individual Education Plan of the child.

E-3: All school district personnel instructing children with ASD be trained in behavioral supports, including applied behavioral science and techniques.

E-4: School districts provide children with ASD access to appropriate diagnostic assessments in a timely manner in accordance with the Mississippi State Department of Education policies and procedures. Additional assessments that conform to MDE criteria and best practices must also be considered when available.

E-5: School districts with less than 30 children in the ASD spectrum be mandated by the Department of Education to form consortiums with joining school districts so that a collective sharing of resources on ASD and other behavioral and medical disorders can be shared.

E-6: A priority in education be to increase the number of trained professionals educating children with ASD. These activities should include 1) in-service training for current regular and special educators, 2) establishing an expert within each school district for 2009-2010 the next year on autism and behavioral intervention treatment, and 3) establishing within the next 2 years an expert within each school site.

E-7: School districts at a minimum employ or obtain through contractual services professionals to appropriately treat children with ASD **including** *occupational therapists, Speech/ language therapists, behavioral analysts or similar professional, and behavioral techs.*

“We have been told many times by the school system (We see there is something going on, but because he is not failing, our hands are tied).”

~Parent Comment, Public Hearing

Executive Summary (continued)

E-8: School administrators participate in ASD training at least every two years.

E-9: Opportunities be made available for school districts to receive technical assistance in autism education, including methods for inclusion and appropriate transitions from one level of education to the next.

E-10: Resource centers specializing in both ASD and other medical and behavioral disorders be established to provide school districts with training and hands-on technical assistance.

E-11: The Department of Education designate one expert in Autism as a staff member of the ASD statewide support and training program. This individual will provide technical assistance to parents and school districts and act as a liaison between school district personnel and parents.

E-12: School districts and parents jointly coordinate and participate and train on ASD.

E-13: A joint task force comprised of the Department of Education, Rehabilitation Services, Department of Mental Health, the University of Mississippi Medical Center and other needed state agencies continue to meet to make recommendations on transition services and vocational training and report to the legislature by August 1, 2008.

__Infrastructure__

IR-1: The Mississippi Legislature enact legislation that prohibits Insurance policies from excluding those with ASD from coverage and requires that insurance policies provide coverage for ASD treatments, including behavioral therapies.

IR-2: The Mississippi Legislature fund an Autism Specific Medicaid Waiver that would provide medical and behavioral treatment options for those with ASD.

IR-3: The Mississippi Legislature appoint one agency to serve as a coordinator for those with ASD and as a coordinator for federal, and state funding.

IR-4: The Mississippi Legislature create an ASD State Support and Training Program that would assist in coordinating services throughout the state and regionally; and that the program form interagency agreements with Universities, and other entities providing services and training to those individuals with ASD and those who work with individuals with ASD.

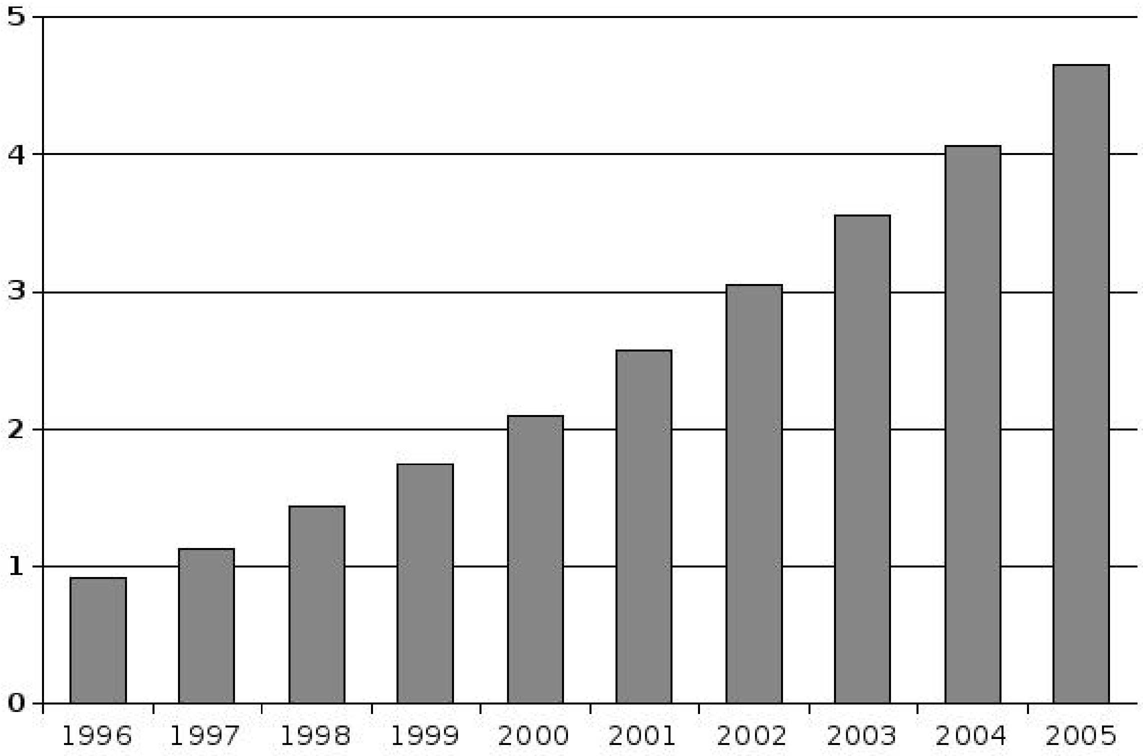
IR-5: The Mississippi Legislature create an Independent ASD Advisory Board comprised of members similar in composition of the present task force to advise, review, and make recommendations to the Legislature and agencies overseeing autism programs.

Intensive Early Intervention works and the overall savings are estimated to range from $1 million to $2 million per ASD individual across the life span.

Prevalence and Incidence

Mississippi has difficulty in clearly delineating the prevalence of cases of ASD (the number of current cases) and the incidence of ASD (the number of new cases diagnosed during a specified period). Some of the many issues that act as barriers to clarifying the number of cases in our state include inaccurate diagnosis, limited resources that parents can access for diagnosis and inaccurate reporting (such as children in the 3 to 5 year category being called "developmentally delayed" instead of a specific diagnosis being given). The 2005 census stated that there were 809,580 children from 3-21 years residing in Mississippi. By present prevalence data, our state should have approximately 4,847 children in that age range with ASD. However, at the time of this report the number of children identified in that age range that have been educationally ruled with ASD is only 965. Due to the barriers mentioned above, there is clearly an under-identification of cases of ASD in our state.

> *"Our state needs to provide these children with the proper therapy. If they provide them the right therapy these children can get better. So, Mississippi can either pay now and get them therapy or they can pay a lot more later for long term care. The latter just does not make sense."*
>
> *~Parent comment, Public Hearing.*



Information |Description=Bar chart of the number (per 1,000 U.S. resident children aged 6–11) of children aged 6–11 who were served under the Individuals with Disabilities Education Act (IDEA) with a diagnosis of autism, from 1996 through 2005.

Is there treatment?

As noted earlier, medical research is ongoing for ASD treatment but to date there is no known medical cure. Medical treatment at present is limited to that of treating symptoms that may cause significant problems with day-to-day functioning in the lives of individuals with ASD. Self injurious behaviors and medication treatment of other disorders that may co-exist with ASD such as seizure disorders, mood disorders or other attention problems need to be accomplished by well-trained medical providers. Other successful treatments have included behavioral, speech/language and occupational therapies. Studies have shown that as many as 47% of the ASD children that undergo early intensive behavioral therapies achieve higher education placement and increased intellectual levels in programs that use the science of Applied Behavior Analysis (ABA). The 2001 U.S. Surgeon General's Report on Mental Health states, "Among the many methods available for treatment and education of people with autism, ABA has become widely accepted as an effective treatment. Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior." A significant portion of children who receive ABA are placed into mainstream/regular educational settings. These results have been shown to last well beyond the end of treatment. The effectiveness of early and intensive ABA therapy has allowed many children to forego costly intensive special education in the future. In addition, many studies demonstrate that ABA is effective in reducing problem behavior and a number of studies also indicate that, when implemented intensively and early in life (beginning prior to the age of 5 years), ABA may produce large gains in development and reductions in the need for special services.

The most famous study of the effectiveness of behavioral modification treatments was conducted in 1987 by psychologist O. Ivar Lovaas. There have been many subsequent studies in the last twenty years that have confirmed his findings. A significant portion of children who receive ABA are placed into mainstream/regular educational settings. These results have been shown to last well beyond the end of treatment. The effectiveness of early, (prior to the age of 5 years), and intensive ABA therapy has allowed many children to forego costly intensive special education in the future.

The effectiveness of ABA and other structured behavioral programs, as provided by the proposed benefit, would be experienced in the short-term as well as the long-term. Therapy as noted in some of these studies consisted of 40 hour a week therapy that was conducted for 2 years. As noted throughout this report, most children within Mississippi do not receive this type of intensive behavioral intervention. Neither insurance nor Medicaid cover this type of intensive therapy in Mississippi and thus only children of parents who are able to provide the $50,000.00 plus a year to provide this therapy are able to benefit. While many states are currently providing this type of therapy to those with ASD, Mississippi does not, missing a huge opportunity to help this group of children to become productive members of society. Other treatments that should also be provided are aggressive speech/language services that address deficits in language pragmatics, social communication skills and non-verbal communication strategies.

Studies have shown that as many as 47 percent of the ASD children that undergo early intensive behavioral therapies achieve higher education placement and increased intellectual levels in programs that use the science of Applied Behavior Analysis (ABA).

Is there treatment? (continued)

Individuals with autism spectrum disorders also need sensory integration therapy by Occupational Therapists certified in this area, to assist them in learning sensory self-regulating skills. Many individuals have severe sensory integration deficits that cause sound, light, smell, taste and other environmental stimuli to be overwhelming. Proper sensory integration strategies will help buffer the effects of these stimuli thus allowing the individual to participate in many more activities in most envi-

The Impact on Families

Autism Spectrum Disorders (ASD) not only affects individuals with the diagnosis, but the entire family. Raising any family can be difficult, but it becomes even more complex when a family member is diagnosed with ASD. After the diagnosis, families are filled with questions, confusion, anger, grief, and despair. Physical stressors, compounded by psychological stressors further complicate the issues for parents. Because of the unusual behaviors and a lack of social skills that are common in those with ASD, families face isolation from friends, family and their community.

> *The part of this disease that makes me the saddest is the fact that I know the therapy my child needs to become better and I do not have the money to give my child the therapy.*
>
> ***~Parent Comment***

When the *Caring for Mississippi Individuals with Autism Task Force* held public hearings in Jackson, Oxford and Hattiesburg, comments were heard from family members expressing the need for training and family support. 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. Nationally divorce rates of parents with ASD children are about 80%.

Another, sometimes unnoticed, turmoil created by autism is the effect on the siblings. An excessive amount of parents' time has to be focused on the child with ASD. Siblings commonly experience diminished attention and support from parents while parents devote substantial energy and resources getting a diagnosis and treatment for the child with ASD. Often, siblings find themselves socially isolated from friends, family, and community because the brother or sisters behaviors are so erratic. Typical assistance offered by family and friends are less available as a result of the difficult to manage behaviors.

Financial concerns are never ending for most families. At present, funding for comprehensive treatment must be provided privately in most instances by families as there is limited governmental or insurance support. This is not acceptable. The average cost for a privately-contracted comprehensive treatment plan is over $50,000.00 a year. When the average Mississippi family only makes $34,343, according to the 2006 U.S. census bureau, the amount of financial stress is overwhelming for parents trying to provide private therapy for their child with ASD.

The Impact on Families (continued)

Additional frustrations on families include childcare, adversarial relations with the educational system to obtain appropriate services, finding employment, to pay for the services and the potential need for long-term care for their child with ASD. Families need and deserve adequate support to help them navigate this difficult road.

ASD family support programs allow families the ability to gain knowledge, strength and social connections to help them deal with the daily activities of living and educating someone with ASD. Resource programs are greatly needed to support both families and professionals.

Nationally divorce rates of parents with ASD children are about 80%.

I had no idea that so much of my energy would be spent having to fight people for services my child is legally entitled to receive . . .The school for educational services, Medicaid for basic treatment, the insurance company to pay for even his earaches, and the list goes on and on. . . My child needs me to spend my energy working with him and instead I have to waste energy on things that should be automatic.

~Parent Comment
Public Hearing

“I think it is extremely important that families be given the freedom to direct their child’s care, as they are typically the one constant person in that child’s life.”

~Parent Comment,
Public Hearing

Workforce Training Recommendations

The task force, through surveys and public hearing, has found that there is a need in our state for training in the field of Autism Spectrum Disorders. The training needs range from basic training on autism and related issues to very specific topics when dealing with intervention and treatment strategies.

Training for Screening, Assessment and Diagnosis

Primary healthcare providers who see children need to understand and use the excellent ASD screening tools that are available. Regular use of these tools will lead to earlier identification and intervention which will ultimately lead to a better outcome for those with ASD. There is also an ongoing need to increase the number of professionals who are training to complete formal assessments of those suspected of having ASD. Optimally, Mississippi should have three assessment centers in our state that would cover the northern, central and southern regions. UMMC's Child Development Center is already is in operation and serves as an excellent diagnostic center for Mississippi. At present UMMC is the only diagnostic center that serves the entire state. The distance and limited number of professionals funded at UMMC leads a lengthy wait for the diagnostic evaluation for many.

In order that all individuals are appropriately diagnosed in a timely fashion, there should be an increased number of healthcare professionals who are well trained in the screening diagnosis and treatment of ASD. Training needs to be conducted on recommended screening instruments for initial identifications purposes. Additionally, Mississippi needs an increase in the numbers of professionals at UMMC and other diagnostic centers that are able to complete intense assessments and treatments for those with ASD.

Training for Parents

Once a child is diagnosed with autism, parents need an avenue to become better educated about their child's diagnosis, treatment and education needs. It is important that parents proceed with an informed plan that will help their child progress to become a productive citizen. Parent training is a form of support that begins to remove much of the unknown of this disability and give the parents a plan to insure their child's success.

Training for Educators and School Personnel

The strongest comments shared by the individuals participating in both the surveys and public hearings were those concerning the need for increased training of teachers and other school personnel. Next to the parents, school personnel are the most dominant presence of a child's everyday life. However, the Task Force heard many comments from parents of children with ASD who are not being adequately served in schools due to the lack of program or service availability. Often, the inadequate services are due to the lack of sufficiently trained personnel. In the absence of such trained educational staff, many children are given minimal services. Intense and continued training support is the key to correcting this issue.

WTR-1: The Mississippi Institutions of Higher Learning review the best practices of other states that have successful programs in preparing graduates from community colleges, universities and the University of Mississippi Medical Center to work with the ASD population.

WTR-2: That IHL mandate all general education and special education programs require courses with courses and a practicum in behavioral interventions and other methods used in best practices for children with ASD.

WTR-3: A practicum experience for those in training in both education, medical, psychology and allied health services at model programs already available, such as UMC's Mississippi Child Development Institute, be supported with stable funding and be duplicated in the northern and southern areas of the state.

Training for Law Enforcement and other Emergency Professionals

Due to the major concerns surrounding the misinterpretation of many of the classic behaviors exhibited by an individual with an autism spectrum disorder, a better understanding of these behaviors is imperative for Law Enforcement, Emergency Medical Service Professionals, Hospitals and Firefighters. This training would provide for a safer interaction for individuals with an autism spectrum disorder as well as a more effective intervention for the professional. It is recommended that this training be conducted for all Highway Patrol Officers and other Law Enforcement officers as well as Firefighters, First Responders, and Emergency Medical Professionals both in the field and at Hospitals.

WTR-4: IHL add a special certification program for those extensively trained in the education and treatment for those with ASD for the following graduate programs: Special Education, General Education, Speech Language Pathology, and Psychology.

Development and Changes in the Instructional Curriculum at Institutions of Higher Learning

All of the mentioned recommendations are paramount to moving Mississippi forward to overcoming much of the existing training shortcomings that are faced daily by families and professionals in the field. The key to changing the future while ensuring the development of a more positive Mississippi on the topic of autism spectrum disorders is the need for Mississippi's Institutions of Higher Learning to examine their curriculum offerings. This examination should result in changes that would begin to offer significant training opportunities for young professionals in specific fields. These fields should include but not be limited to; medicine/psychiatry, nursing, education, special education, psychology, computer sciences, allied health professionals, speech/language pathology, occupational and physical therapy. Existing curriculums presently neglect the topic of autism spectrum disorders due in part to the erroneous belief that autism spectrum disorders continue to be a low incident disability. Currently it is the second most common developmental disability. Intellectual Disabilities (Mental Retardation) is the most common. Due to the significant change in this data (CDC 2007) it is strongly recommended that these changes are address with a great sense of urgency.

Training on specific issues in the field of autism spectrum disorders

As more basic training is offered the next training step will be to provide more detailed and specific training opportunities. The field of autism spectrum disorders is very dynamic and will require constant updating to all training efforts and curriculum development efforts. More detailed and specific training will certainly be needed in the areas of specific treatment and intervention approaches. A constant stream of information will be necessary between service providers and resources in order to be both effective and efficient in moving Mississippi forward.

WTR-5: Mississippi's community colleges include classes in ASD and behavioral strategies used in teaching individuals with ASD for teachers, paraprofessionals and parents.

All of the training needs addressed in this section of this report could be performed through a well planned and developed Mississippi Autism Resource Center Network. This network would be made available for all of the mentioned areas and professionals and support could be provided in an expeditious and competent manner. The Mississippi Autism Resource Center Network would serve at a proactive component to driving the development of training materials, the dissemination of needed awareness and training materials, technical training support, family support and of course futures planning for individuals and services.

Medical Treatment and Intervention Recommendations

Screening, Diagnosis and Treatment

Early diagnosis and appropriate intervention of children with ASD leads to a better outcome. Infants and toddlers are routinely seen by their primary healthcare providers. These providers are in position to screen children early for possible ASD. Unfortunately, most children in Mississippi are not routinely screened for ASD. Therefore, many children with ASD are being diagnosed later than is optimal and precious time for treatment is lost. Excellent screening tools are now available for healthcare providers to use in their offices that will allow early discovery of those with symptoms of ASD. There are 3 free and easy to use screening tools that are readily available that could be used in any office: Modified Checklist for Autism in Toddlers (M-CHAT), Autism Alarm, and First Signs. The task force recommends that screening tools such as these be made widely available and that training be provided to primary healthcare providers in their use. An understanding of the use of the tools will lead to earlier referral and diagnosis of those children suspected of having ASD.

MITR-1: Continuing education programs and training be conducted across the state for all health care professionals to increase the general knowledge of ASD and to develop an understanding of appropriate screening, diagnosis and treatment.

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. That team should be comprised of a physician, psychologist, speech/language pathologist and occupational therapist. A certified ABA therapist, autism specialist, and physical therapist should also be available to the team. Parents reported at public hearings that referrals to specialists were often delayed. One likely cause for this is that Mississippi presently has too few trained specialists available.

"Treatment for individuals on the Autism Spectrum is a team effort."

~Parent Comment, Public Hearing

ASDs are not generally "curable", but are treatable. In this vein, chronic management is required. Outcomes in individuals with ASD are variable and behavioral symptoms change over time. Most children with ASD continue to have symptoms as adults and thus need continued support and treatment throughout their lifespan. The primary goals of the treatment of ASD should be to increase communication and socialization skills, to reduce behaviors that are maladaptive and to enhance achievement skills. Excellent medical care will have a positive impact on the progress of the individual with ASD. As noted earlier, although medications are not part of the primary treatment, they may be necessary for other underlying conditions that occur more frequently in those with ASD such as seizure disorders, sleep problems, self-injurious behaviors, or psychiatric illnesses.

MITR-2: All Mississippi children be screened for ASD through a standardized screening protocol, as recommended by the American Academy of Pediatrics by their primary care provider at regular intervals.

The National Research Council's statement on "Educating Children with Autism" states that children need appropriate interventions 25 to 30 hours per week, 12 months per year. Behavior therapy, speech/language therapy and occupational therapies are essential components in the treatment of individuals with ASD. As children grow and progress in their skill levels, often the deficits that they have are largely in the area of social skills. Therefore, those with higher functioning ASD often benefit significantly from social skills instruction.

To assess the availability of services currently provided for early screening, diagnosis and treatment of autism, we on the Autism Task Force chose to survey the availability of medical, speech-language, occupational and psychological services throughout the state.

Parent Survey

Parents of children with autism spectrum disorder responded to an online survey regarding early screening, diagnosis and treatment that revealed the following:

- *Even though early diagnosis is very important, more than 60% of children were not diagnosed until after age 3 year while 75% of those same children had symptoms noted prior to age 2 years.*
- *Psychologists and developmental pediatricians most frequently made the diagnosis of ASD.*
- *Once the diagnosis was made the services that were most commonly recommended included speech-language therapy, occupational therapy, educational services, behavioral therapy and early intervention services, but often services were not readily available. Over 25% of parents stated that they were not able to obtain behavioral therapy.*
- *Twenty-seven percent of the respondents had to travel more than 50 miles to obtain these services.*
- *Even though Medicaid and private insurances provide some coverage for services, 75% of parents reported that all of the needed services were not covered. Overall 82% of parents believed that their children did not receive the necessary amount of therapy to achieve their maximum capabilities.*
- *The average income of respondents was $50,000-75,000.*

> *"Family doctors, pediatricians, and educators should be able to direct parents to available resources."*
>
> *~Parent Comment, Public Hearing*

Physician Survey

A survey on ASD was sent to all pediatricians across the state. Results from the survey indicated that there are few physicians who do standardized screening for autism. Although there are some physicians in the state who do use available screening tools, most physicians tend to refer to sub-specialists such as developmental pediatricians, child psychiatrists, and child neurologists for a definitive diagnosis. The number of sub-specialists who are well versed in diagnosing autism is very limited which often delays the diagnosis.

Once the diagnosis is made, many patients continue to need follow-up with the sub-specialist to help with developmental tracking and need for further intervention which may include prescribing needed speech-language, occupational therapy, and behavioral therapy.

Some individuals in north Mississippi are seen for evaluation in Memphis due to the distance to Jackson. Those in south Mississippi, again due to distance, have sought services in Alabama or Louisiana. There is a need for more providers to develop diagnostic services across the state.

Mental Health Services Survey:

A survey was conducted of the 15 community mental health centers across the state. Results of this survey showed that the average number of masters level staff is 40 per region. Of those masters level staff only 14 work with individuals with ASD, and only 4 per region have any specialized training.

MITR-3: Funding be made available to increase the number of trained physicians, psychologists, nurses and allied health professionals who are available to diagnose and provide ongoing treatment for those with ASD.

MITR-4: Incentives be developed to attract more qualified health care professional and therapists to work with those individuals with ASD.

There are private services by psychologists in Mississippi, however due to the cost and lack of insurance coverage for much of the services, only the wealthy in the state are able to receive ongoing services from these sources

Speech-Language Services:

A survey of speech-language pathologists (SLPs) who are members of the Mississippi Speech-Language-Hearing Association was conducted. The respondents came from throughout the state. Their service delivery settings were as follows: public school 57%, private practice 16%, university based clinic/program 20%, and hospital/clinic 7%. Ages served by respondents were: 0-3years 21%, 4-5 years 33%, 6-12 years 31%, and 13-adult 15%.

Providers reported that over 80% of speech-language services received by children with ASD are provided in public settings some of which are only partially publicly funded.

The top four concerns expressed by the SLPs who see children with ASD were: (1) training and continuing education; (2) accurate diagnoses and rulings; (3) appropriate and quality services and (4) the need for more parental information, education and counseling.

Occupational Therapy Services:

A survey was completed by occupational therapists throughout the state. The work settings included: Child care facilities, early intervention services, hospitals, mental health regional centers, outpatient clinics and school systems. Significant concerns by those completing the survey included:

- *Services are being provided by inexperienced and under-trained professionals.*
- *Lack of training in educational programs and not enough readily available training in the state.*
- *Early identification and treatment are often not implemented.*
- *Those with ASD are often not gaining skills necessary to integrate into society, have a career, manage their money, perform self-care, and establish relationships.*
- *Health Systems of Mississippi and the Department of Medicaid are considering autism and autism spectrum disorders to be an "educational" diagnosis and are cutting services.*
- *General pediatricians and family doctors need more education on how to identify a child with possible ASD and who to refer the family to that is professionally trained to diagnose and provide treatment with education for the family.*
- *Support and training for parents is needed so that they will be able to access trustworthy, proven treatment strategies, payment plans, social opportunities, medical professionals.*
- *Insurance reimbursements/caps limit services for children under the age of 3 years who need outpatient services.*
- *Need for more knowledgeable support services at the high school to adult transition level toward life skills options, to keep these adults in the least restrictive living situations for the long term.*

Present services for comprehensive diagnosis and training

The University of Mississippi Medical Center's (UMMC) Department of Pediatrics and Division of Child Development and Behavioral Pediatrics has a multidisciplinary clinic that is well versed in the diagnosis of autism. Patients from around the state are seen in the Child Development Clinic (CDC) where a multidisciplinary evaluation is conducted which includes formal psychological testing and medical evaluation. This division trains medical students and physicians through a rotation in the CDC in the diagnosis and management of ASD. Additionally, the CDC runs a model autism school (Mississippi Child Development Institute-MCDI) which was set up to allow physicians, psychologists, nurses, teachers and therapists to observe the appropriate management of ASD. In recent years the additional demands being placed on this program by families with children on the autism spectrum has grown exponentially. Unfortunately, the numbers served are limited due to the lack of adequate funding which in-turn limits the ability to hire additional staff to meet this growing need.

Several universities and colleges across the state have different training programs in psychology, education and allied health professionals. The amount of training in ASD varies greatly and in general the time spent on specific training in this area is lacking.

There are private services across the state that evaluate and treat children with ASD, but the resources are limited and not available to all.

Parental Information of Providers and Treatment

Once a child has received a diagnosis of autism, parents begin the often desperate search for Mississippi providers and information about the disorder. A resource book manual or website highlighting service providers and support group information should be developed and maintained by designated lead agency.

Summary of Medical Services and Interventions

A timely and accurate diagnosis targeting each child's individual needs is a must. The services needed include some or all of the following: intensive speech-language therapy, behavioral therapy, medication therapy, appropriate education services, occupational therapy, social skills and vocational training, respite care, and crisis management. However, Mississippi lacks the number of well trained professionals needed to make the diagnosis and care for the long term needs of those with ASD. This lack of well trained individuals makes it impossible for the increasing numbers of those diagnosed with ASD to receive adequate diagnostic and interventional services in a timely manner. Therefore our state must increase the numbers of healthcare providers, allied health professionals, psychologists and behavioral therapists who are well-versed in the diagnosis and treatment of ASD. To ensure that comprehensive and continuous health services are given to those with ASD, the legislature must also ensure that these providers can be compensated through private insurance and Medicaid assistance programs. To accomplish the needed increase of professionals, there should be increased funding made available to training programs such as the one at UMMC . A model program that is available in the northern and southern ends of Mississippi would allow improved access to all individuals in our state.

MITR-5: A resource manual that is both in hard copy and available on line be developed by the State Department of Mental Health for parents, service providers and others that lists available services and providers for individuals with ASD.

A mother's sensitivity is greater than any test"

~Dr. Raun Melmed, Director of the Melmed Center Scottsdale, AZ

MITR-6: A Medicaid waiver program and mandates to private insurance companies be considered in order for comprehensive health services to be insured for those with ASD.

Early Intervention Programs

The advantages of early intervention should be made available to all Mississippi children with ASD. The National Research Council recommendations for early intervention emphasize that services should begin as soon as ASD is suspected. Services for those under 3 should include a minimum of 25 hours per week, 12 months per year of appropriate interventions. Depending upon the age and needs of the child and the family, a methodically designed, developmentally suitable educational plan should be developed and implemented that works towards identified objectives.

Essential components of early intervention programs include:

1. *Comprehensive curriculum, addressing core domains of imitation, language, toy play, and social interaction;*
2. *Sensitivity to normal developmental sequences,*
3. *Highly supportive teaching strategies based on applied behavioral procedures,*
4. *Behavioral strategies for reducing interfering behaviors,*
5. *Involvement and training of parents,*
6. *Gradual, careful transition from a highly supportive environment (usually one on one) to a less structured environment (small group),*
7. *A staff trained in autism spectrum disorders,*
8. *Supervisory and review mechanisms,*
9. *Intensive intervention, i.e., at least 25 hours per week of structured intervention for at least two years (per National Research Council recommendations),*
10. *Parental and caregiver training; and*
11. *Intervention by two years of age whenever possible.*

Presently, in Mississippi the State Department of Health is the designated lead agency for Early Intervention in the state for all developmental delays. As the lead agency, the Department of Health is responsible for identifying children with or at risk for developmental delays. The Referrals can be made through various sources, including but not limited to Health Department personnel, physicians, family members, and care givers. Evaluations are conducted and service providers are contracted. Evaluations are conducted and children are assigned to a provider. The Department of Mental Health is the largest contractor of Early Intervention Services within the state of Mississippi.

Early Intervention Services are limited often times due to access of qualified evaluators and services providers. There is a dearth of evaluators and services providers and this lack of access leads to a myriad of problems. The most significant of these problems is that children do not get enough early intervention services needed to progress appropriately. The less early intervention services children with ASD receive, the more money and services will be required as they get older. Funding must be increased so that services can be expanded to increase language/ communication development, behavioral support programs, and social development for ASD children .

EI-1: Early Intervention Services for ASD children under the age of 3 should include a minimum of 25 hours per week for 12 months of the year.

EI-2: To ensure consistency of educational/treatment options and opportunities, The Mississippi Department of Health and the Mississippi Department of Mental Health develop cohesive, statewide rules for administering a menu of appropriate services based on best practices.

EI-3: Funding be increased to Early Intervention Program providers to enhance continuity and to accommodate the increase in service provision focused on language/ communication development, behavioral support, and social development.

Training and Retaining Providers

Among Early Intervention service coordinators there is a high turnover rate of service coordinators. This turnover impacts continuity and coordination of services. The turnover rate appears to be significantly impacted by the salary paid thus the state needs to review the practices and management of the service coordinators to diminish turnover rates. Additionally, service coordinators and providers need to be trained in how to implement the intensive therapies needed for ASD children.

EI-4: The Department of Education, the Department of Health, the Department of Mental Health, and the University of Mississippi Medical Center Division of Child Development and Behavioral Pediatrics collectively to promulgate regulations to determine which evaluation instruments should be used by all EIP providers and school districts and that regulations be implemented by July 1, 2008 that will eliminate transition problems between early intervention providers and school districts.

Transition from Early Intervention Programs into the School District

Currently children who require Early Intervention Program (EIP) support (including those children with ASD) are supposed to transition to receiving special education support through their local school district at the age of three. Conceptually, it is proposed through Part C of Individuals with Disabilities Education Act (IDEA) that when a child receiving EIP services turns 2 years, 6 months to 2 years 9 months of age that the Service Coordinator (working through the Mississippi Department of Health) begin to look at where the next service for the child will take place. In the three to six months prior to the child's third birthday, the Service Coordinator sets a meeting with the school district personnel responsible for preschool services (e.g., special education director, preschool coordinator). During the meeting, previous testing is to be reviewed to determine if the child is eligible for special education services. If the child is eligible based on previous assessment data, then an Individual Education Plan (IEP) is developed. If testing not current, the school district conducts the assessment, establishes eligibility, and then develops an IEP.

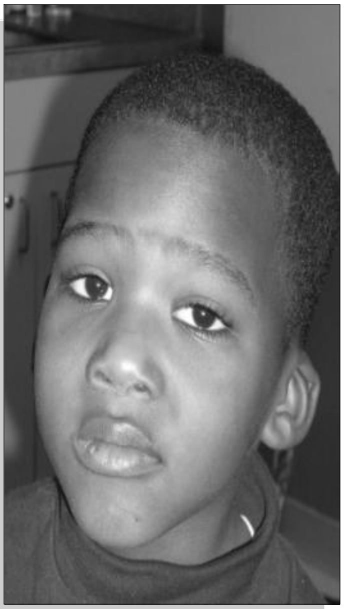
Parents, EIP programs, and school districts reported significant problems in the transition process throughout the state. Children at this critical age should not have a gap in services. The Task Force found that these gaps are more common than not. The Department of Education, Department of Health, the Department of Mental Health, and the University of Mississippi Medical Center Child Development Center need to collectively promulgate regulations to eliminate the transition problems between early intervention providers and school districts. Additionally, regulations need to specify which evaluation instruments should be used by all EIP providers and school districts to ease transitions problems and the need for lengthy re-testing which delays service interventions for these children.

EI-5: EIP programs increase the number of trained professionals in best practices for the education of children with ASD and the training of their families.

CHILD FIND Program

As noted earlier, the number of children identified with ASD is low compared with national statistics. School districts report numerous children being registered for Kindergarten who have ASD and yet have never been identified with developmental issues and have had no early intervention. Sadly, some of the most valuable time for this child to have meaningful intensive intervention has passed. Child Find programs that locate children with developmental disabilities such as Autism must be increased and intensified by early intervention programs and school districts. The Department of Education, Department of Health, and the Department of Mental Health should develop/document a model program for local entities to replicate.

Educational Recommendations for 3-21



ASD is a ruling that falls under special education and qualifies individuals for special education services. Mississippi schools should serve more individuals under the age of 21 with ASD than any other agency in the state. Parents' surveyed and public comments obtained at the recent task force hearings, revealed that our education system for children with ASD is broken and greatly in need of an overhaul.

There are a few quality educational programs for those with ASD in some school districts, but they are limited in number. According to parents, many school districts have struggled to develop and monitor coherent and meaningful policies and services for those with ASD. Because early intervention services are vital in the treatment of children with ASD, the role of the education system is critical. Although school districts are required to provide a free and appropriate education for children ages 3 through 21, reports throughout the state revealed that many school districts provide only limited access to school for these children.

All school age children with ASD must have access to appropriate services in the public school setting, for a minimum of 30 hours per week based on their individual needs.

Standardization of Services across the State

School districts in Mississippi have considerable autonomy in defining autism-related services, resulting in great variation from one district to another. There is also inconsistency regarding initial assessment, diagnostic protocols and the availability of treatment options.

School districts self reported significant variations in the tools used to develop the goals of each student's Individual Education Plan. Instruments and regulations used in other states with excellent programs ensure that inclusion (placement in a regular classroom) be the first option considered; that social skills and pragmatic language deficits always be addressed; that there be a consistent policy regarding services beyond the regular school day and year; and that vocational training be given high priority. Developing this type of protocol would ensure that a system is in place that is effectively providing appropriate education to children with ASD. Appropriate education programming could reduce the enormous expense of long term care for adults with ASD who did not receive proper services early .

District Collaboration

The large number of historically small school districts within this state causes a unique problem that most other states do not have. There is a strong need for districts to collaborate and share resources.

E-1: To ensure consistency in educational options and opportunities, The Mississippi Department of Education develop cohesive, statewide rules for administering a menu of appropriate services based on best practices in the treatment of those with ASD.

E-2: All students with ASD have access to appropriate services for a minimum of 30 hours per week unless otherwise justified on the Individual Education Plan of the child.

E-3: All school district personnel instructing children with ASD be trained in behavioral supports, including applied behavioral science and techniques.

E-4: School districts provide children with ASD access to appropriate diagnostic assessments in a timely manner in accordance with the Mississippi State Department of Education policies and procedures. Additional assessments that conform to MDE criteria and best practices must also be considered when available.

School districts with less than 30 children in the ASD spectrum should be mandated by the Department of Education to form consortiums with larger school districts to collectively share resources for those with ASD and other behavioral and medical disorders.

E-5: School districts with less than 30 children in the ASD spectrum be mandated by the Department of Education to form consortiums with joining school districts so that a collective sharing of resources on ASD and other behavioral and medical disorders can be shared.

Programming

Programming methods vary across the state. Only half of the school districts surveyed reported using any form of Applied Behavior Analysis (ABA) one of the most effective therapies for individuals with ASD. Again, programming methods were varied and only half the districts reported using any form of Applied Behavior Analysis (ABA) programming techniques. Not only will the behavioral techniques learned through training in ABA benefit children with ASD, but those techniques can be used for children with other disorders including ADHD, Emotional Disturbance, Mental Retardation, and has even proven effective in neuro-typical children. For children with ASD, ABA methods and/or programming should be utilized in all educational settings with an emphasis placed on moving away from a clinical setting to an inclusive setting while maintaining independence, social development, and learning. Parents have also reported that many school districts do not have available services from speech pathologists and occupational therapists for their children with ASD. All children with ASD need services from both. School districts report a shortage of therapists who are well trained in the treatment of ASD which further compounds the difficulty of obtaining appropriate services.

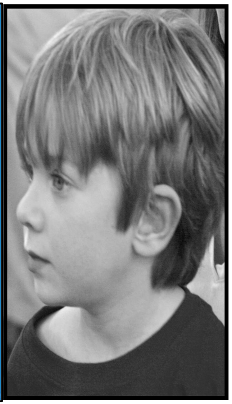
Teacher Support in Schools

Teachers in this state, including those in the special education, state that they rarely have any autism-specific training. School Districts responded in the survey that their greatest area of concern was providing adequate training to staff. Training provided in the many school districts is often not related to the type of programming actually provided by the district.

E-6: A priority in education be to increase the number of trained professionals educating children with ASD. These activities should include 1) in-service training for current regular and special educators, 2) establishing an expert within each school district for 2009-2010 the next year on autism and behavioral intervention treatment, and 3) establishing within the next 2 years an expert within each school site.

Although when given adequate support, many children with ASD could be in a regular classroom setting, however, this often does not occur. In addition to the lack of training for teachers, there are too few professionals and paraprofessionals available for the needed evaluation and treatment support.

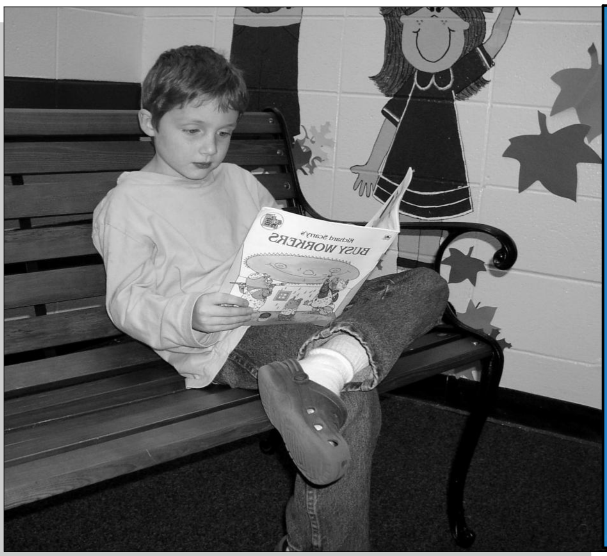
School districts at a minimum should employ or contract the following professionals to meet the educational requirements of these children: a behavioral specialist in ASD treatment, a speech/language pathologist, an occupational therapist and a school psychologist.



Quality of Educational Services

Despite the mandate provided in the Federal IDEA legislation that children be educated in the least restrictive environment, some school districts do not have inclusion as their policy or practice for initial placement for children with ASD. Nearly one third of parents reported that their child was in regular education for less than 20% of the day. Parents report schools rarely provide services that extend beyond the school day and year. Most children do not receive social skills and pragmatic language training, which are required to address the core deficits of autism.

The problems that families face in our educational system are far ranging. Parents through the surveys and public comments received report that not only do they struggle with the daily challenges of raising a child with ASD but in many instances they are also challenged with helping to educate the school district staff about ASD. Only 36% of parents surveyed stated that they have good confidence in their child's educational programming. Almost 80% of parents indicate that they do not believe their child is receiving enough therapy to meet their educational goals and 70% of parents believe that their school district staff is not properly trained to meet their child's needs.



E-7: School districts at a minimum should employ/obtain contractual services with the following professionals to appropriately treat ASD children OT, Speech, PT, Behavioral Analysts or similar professional, Behavioral Techs or other professional who will implement ABA and social skills programming that is data driven and periodically monitored for each individual student.

E-8: School administrators and board members will participate in ASD training at least every two years.

E-9: Opportunities be made available for school districts to receive technical assistance in autism education, including methods for inclusion and appropriate transitions from educational setting to the next and from one level of education to the next.

Legal Rights Being Violated

Numerous parents at the public hearings reported that there were many school districts not in legal compliance with the federal IDEA. They reported extreme frustration in trying to resolve their disputes. They also reported a lack of knowledge on the part of the school district staff on how to appropriately resolve these disputes. Additionally, over half of all parents reported that they did not understand their child's educational rights. Due to the continued problems and lack of understanding of many parents and schools, legal trainings for parents and school district staff on federal IDEA as it applies to children with ASD should be conducted by the Department of Education with significant publicity and at times appropriate for working parents.

Vocational Training and Transition programs

The lack of services for teens with ASD is even more deficient than those for young children. A prerequisite for productivity as a young adult is appropriate vocational training, yet there are few opportunities for adolescents with ASD to receive vocational training. Public comment revealed that transition services for children as they enter their teens are often severely lacking or non-existent. This group of teens, if left un-served, could further burden our state by having a growing number of individuals who cannot contribute to our work force. This group represents the next significant population that will require institutionalization if something is not done hastily.

There is much work to be accomplished in this area. The Task Force recommends that a joint advisory board comprised of the Department of Education, Rehabilitation Services, Department of Mental Health, and other needed personnel advise the legislature by August 1, 2008 of recommendations on transition programs and vocational training issues.

My child is going to be 18 in 2 years... then what?

~Parent Comment, Public Hearing

E-10: Resource centers specializing in both ASD and other medical and behavioral disorders should be established to provide school districts with training and hands-on technical assistance.

E-11: The Department of Education should designate one expert in Autism as a staff member of the statewide resource center. This individual will provide technical assistance to parents and school districts and act as a liaison between school district personnel and parents.

E-12: School districts and parents should jointly coordinate therapies and services, participate in education of children and receive training on ASD.

E-13: A joint task force comprised of the Department of Education, Rehabilitation Services, Department of Mental Health, and other needed state agencies and personnel should continue meeting to make recommendations on transition services and vocational training, and report to the legislature by August 1, 2008.

Needed Infrastructure Changes

Parents of children with autism face enormous barriers in accessing early intensive behavioral treatments and other therapies. According to the Institute of Medicine , the term “access” is defined as “the timely use of personal health services to achieve the best possible health outcomes.” For a child with autism, lack of access to services can be the cause of inconsistent and uncoordinated care. Children with autism often experience barriers to access with even greater frequency than children with other special health care needs. A study of the Tennessee Medicaid system, Tenn Care, found that for children with autism, “the rate of service use was only *one-tenth* what should be expected based on prevalence rates.” Anecdotal comments from parents during the Autism Task Force hearings would indicate similar percentages in Mississippi . Private insurance reform to cover autism and the funding and passage of Autism Specific, Home and Community Based Waiver Services through Medicaid are two important changes needed in Mississippi to diminish this problem.

> ***“We keep coming across people that seem to act like, if they just ignore us we will eventually go away…we don’t have anywhere left to go away to.”***
>
> ***~Parent Comment***

Private Insurance Reform

Nationally, there are very few private insurance companies or other employee benefit plans that cover behavioral and other needed therapies. Most insurance companies designate autism as a diagnostic exclusion, “meaning that any services rendered explicitly for the treatment of autism are not covered by the plan, even if those services would be covered if used to treat a different condition.” A 2002 study by Pamela B. Peele and others of 128 behavioral health plans administered by one of two large managed behavioral health organizations found that all the plans had some type of limit on benefits for behavioral therapies – over half of the plans had limits on the number of annual outpatient sessions and 65 percent of the plans imposed limits on the number of inpatient days covered per year. As noted through out this report, parents report that most Mississippi ’s children with ASD are denied coverage outright or their treatment for any specific autism condition is automatically excluded. Parents can often spend upwards of $50,000 per year on autism-related therapies, often being forced to venture their own futures and the futures of their non-autistic children to pay for vital autism-related therapies. Children whose parents cannot afford to pay for behavioral and other therapies simply go without these interventions. Sadly, the progress these children will make is usually quite limited.

IR-1: The Mississippi Legislature enact legislation that prohibits Insurance policies from excluding those with ASD from coverage and requires that insurance policies provide coverage for ASD treatments, including behavioral therapies.

The Mississippi Legislature should enact, and the Governor of Mississippi should sign into law, legislation modeled after South Carolina's ***Ryan's Law.*** South Carolina ’s legislation, was passed by both the South Carolina House of Representatives and Senate on May 31, 2007. The bill was then vetoed by Governor Mark Sanford on June 6. On June 7, the bill was brought back to the House and Senate floors, and unanimous votes in both chambers overrode the Governor's veto. This law goes into effect in July 2008. The legislation provides:

-Treatments, including behavioral therapies, which are prescribed by the individual’s treating medical doctor in accordance with a treatment plan;
-An individual must be diagnosed with autistic spectrum disorder at age eight or younger. The coverage must be provided to any eligible person less than sixteen years of age; and
-Coverage for behavioral therapy is subject to a $50,000 maximum benefit per year.

Autism Specific, Home and Community Based Waiver Services through Medicaid
Children with ASD who have a Medicaid card may still have problems accessing needed and effective services. Providers noted to the Autism Task Force that they have difficulties in obtaining reimbursement for services because the Medicaid program may consider the therapy as educationally relevant rather than medically necessary. Speech therapy and occupational therapies are often severely limited or denied.

The cornerstone need for developing direct services is the funding of an Autism Specific Home and Community Based Waiver. This money, through the Division of Medicaid, will create the potential for services to be rendered to families by a number of service providers. Currently, there are five states participating in this type of waiver. However, many states are presently looking at creating this waiver through the Department of Health and Human Services. Five states— Massachusetts , Colorado , Indiana , Maryland , and Wisconsin —are operating Medicaid waivers covering home- and community-based services specifically for people with autism. All are limited to children. Forty-four (44) states and the District of Columbia have received waivers to provide home- and community-based services to people with developmental disabilities (DD). Depending on each state's DD definition, these waivers may cover services to people with autism. There is huge variation of services in the 44 states. Most other states include autism in their definition of DD and give the agency or unit that has programmatic responsibility for this population responsibility for services to those with autism, as well. Services among these states greatly vary and in many states behavioral services are covered among their waivers. According to a recent Government Accountability Office (GAO) report on federal autism activities, states' autism waiver programs generally offer the same services as their developmental disability waivers; the primary difference is that the autism waiver may offer early intervention behavioral therapies targeted to young children.

IR-2: The Mississippi Legislature fund an Autism Specific Medicaid Waiver that would provide medical and behavioral treatment options for those with ASD.

Mississippi should fund and apply for an Autism Specific, Home and Community Based Waiver Services through Medicaid that would include behavioral as well as medical support services to children. Providing an avenue for children to receive this therapy would be massively beneficial to the many Mississippi families who do not have the financial resources to treat their children with the needed extensive behavioral therapies. Although initially costly for the state, the alternative of providing extensive long term care that the state will eventually have to provide if effective treatment is not utilized is dramatic.

Don't put me on another waiting list!

~Parent Comment, Public Hearing

Currently the Mississippi share of the Medicaid match is 23.71% of each dollar. If waiver money is appropriated in the 2008 regular *session, the* money will be available for service on July 1, 2008. Currently the Department of Mental Health has a request of $500,000.00 for this waiver; the *Autism Task Force* would recommend that the amount be increased to $2,000,000.00. This yields a service expenditure potential of approximately 8,000,000.00.

Infrastructure Recommendations (Continued)

IR-3: The Mississippi Legislature appoint one agency to serve as a coordinator for those with ASD and as a coordinator for federal, and state funding.

Appointment of an Agency as a Coordinator of Services for ASD

Many individuals with ASD are of school age, live at home with parents, and receive various services through the public school system. As these individuals age out of the public school system, and as their caregivers become physically, fiscally and/or psychologically incapable of caring for them, enormous burdens will be sited upon public agencies to provide services to fulfill the requirements of the ASD population. There is no single agency in Mississippi that has been created to address the varied needs of individuals with ASD. Instead, depending on eligibility guidelines, competency of service providers and public funding, individuals with ASD are currently receiving program services from multiple agencies of varying degrees of adequacy and inadequacy. These programs include:

First Steps (Mississippi Early Intervention System)

Mississippi Department of Mental Health

Home and Community Based Waiver/Comprehensive Choices Plan

Vocational Rehabilitation

The lack of a single public agency or program devoted to serving individuals of all ages diagnosed with ASD has resulted in service gaps throughout Mississippi and throughout the age span for individuals with ASD. Additionally, there is not an existing system in Mississippi to coordinate state, federal, private or other funding sources for individuals with ASD, their families and caregivers. Yet, financial resources are warranted to assure that services and supports are available. Thus the designation of a single agency to coordinate services is recommended.

IR-4: The Mississippi Legislature create an ASD State Support and Training Program that would assist in coordinating services throughout the state and regionally; and that the program form interagency agreements with Universities, and other entities providing services and training to those individuals with ASD and those who work with individuals with ASD.

Creation of Individuals with ASD Regional/State Support and Training Programs

The Mississippi Legislature should create legislation that develops the "Individuals with ASD Support Program" (the Program) within the lead state agency designated to coordinate autism services throughout the state. The Program would be responsible for implementing monitoring services, training programs, resource centers and other supports for individuals with ASD, their families and caregivers, their providers, and educators. The Program would be staffed with qualified personnel assigned exclusively to the Program. The Program should form interagency agreements, agreements with the Universities and other entities providing services and training to those with ASD and those training to work with those with ASD. The administrative costs of staffing and operating the Program should be financed with a combination of state general fund revenues as well as Medicaid funds. The Program would serve as a coordinating body to keep an active inventory of services and resources available to individuals with ASD, their families, caregivers and service providers. The Program should establish clear guidelines and criteria for service providers to participate in the Program, and the Program would contract with these service providers throughout Mississippi to deliver approved services to individuals with ASD covered under the Program. The Program should encompass, to the fullest extent allowed through the Medicaid program, stipulations permitting self-determination and creating consumer directed options, whereby individuals with ASD, their families and caregivers would have broad discretion in evaluating the services to meet the individual needs of those with ASD.

Creation of an Independent ASD Advisory Board

The legislation creating the above mentioned Program should include the creation of an advisory board consisting of family members of individuals with ASD, service providers, adults with ASD and other interested citizens that would consult regularly with the executive management personnel of the Program regarding the functions, duties and mission of the Program. The advisory board should be appointed and provide guidance in the creation of the Program to help ensure stakeholder participation from the outset in implementing and maintaining the Program. The advisory board would serve as a conduit between the public and the Program in order to provide structured input to the Program regarding the quality and quantity of the services being provided through the Program as well as all other aspects of the Program. The advisory board should approve a long term strategic plan that is presented by the Program. Additionally, the board should be charged with evaluating the services of the Program and should make a report to the legislature by August 1, of each year.

IR-5: The Mississippi Legislature create an Independent ASD Advisory Board comprised of members similar in composition of the present task force to advise, review, and make recommendations to the Legislature and agencies overseeing autism programs.

Glossary of Terms, Acronyms, and other helpful information

ABA "Applied Behavior Analysis"

Acronym in common use by adherents of some behavioral techniques to refer to a kind of careful analysis and tracking of behavior including its cues and consequences.

ADA "Americans with Disabilities Act"

US law that ensures rights of persons with disabilities with regard to employment and other issues.

ADHD

Attention-Deficit/Hyperactivity Disorder (ADHD) is a neurological condition related, in part, to the brain's chemistry and anatomy. ADHD manifests itself as a persistent pattern of inattention and/or hyperactivity/impulsivity that occurs more frequently and more severely than is typically observed in people at comparable levels of development. These symptoms must occur for at least six months and have been present since before age 7.

Allied health professional

Clinical healthcare professionals distinct from the medical and nursing professionals. As the name implies, they are allies in a healthcare team, working together to make the healthcare system function.

Apraxia

A neurologically-based disorder which occurs in adults, often (but not exclusively) as a consequence of stroke. The person has difficult sequencing movements in the service of a goal. e.g., he may have the ability to raise his arm and to wave his hand, but not when he consciously intends to do so. Apraxia may be specific to speech (e.g., "apraxia of speech") or to the movement of other body parts (e.g., "limb apraxia").

ARI "Autism Research Institute"

ARI is a non-profit autism research based organization founded by Dr. Bernard Rimland.

AS "Asperger Syndrome"

A developmental disorder on the autism spectrum defined by impairments in communication and social development and by repetitive interests and behaviors. Unlike typical autism, individuals with Asperger Syndrome have no significant delay in language and cognitive development.

Autism A.L.A.R.M.

Autism A.L.A.R.M. is a project funded through a cooperative agreement between the American Academy of Pediatrics and CDC's National Center on Birth Defects and Developmental Disabilities. It is a tool being used by organized medicine to teach primary caregivers and medical personnel how to spot autism in young children.

Autism

Autism is a complex neurobiological disorder that typically lasts throughout a person's lifetime. It is part of a group of disorders known as autism spectrum disorders (ASD). Today, 1 in 150 individuals is diagnosed with autism, making it more common than pediatric cancer, diabetes, and AIDS combined. It occurs in all racial, ethnic, and social groups and is four times more likely to strike boys than girls. Autism impairs a person's ability to communicate and relate to others. It is also associated with rigid routines and repetitive behaviors, such as obsessively arranging objects or following very specific routines. Symptoms can range from very mild to quite severe

ASD "Autism Spectrum Disorders"

Term that encompasses autism and similiar disorders. More specifically, the following five disorders listed in DSM-IV: *Autistic Disorder, Asperger Disorder, PDD-NOS, Childhood Disintegrative Disorder,* and *Rett Disorder*.

Behavior analysts

Professionals trained in the scientific study of principles of learning and behavior. It has two main branches: experimental analysis of behavior (EAB) and applied behavior analysis (ABA).

CARS "Childhood Autism Rating Scale"

A test developed to diagnose autism. The child is rated in 15 areas on a scale up to 4 yielding a total up to 60, than ranges are considered to be non-autistic, autistic, and severely autistic.

Glossary of Terms, Acronyms, and other helpful information continued...

CDC "Center for Disease Control"

US Government agency.

Childhood Disintegrative Disorder

Childhood disintegrative disorder is a condition in which young children develop normally until age 3 or 4, but then demonstrate a severe loss of social, communication and other skills. Doctors sometimes confuse this rare disorder with late-onset autism because both conditions involve normal development followed by significant loss of language, social, play and motor skills. However, autism typically occurs at an earlier age. There's also a more dramatic loss of skills in children with childhood disintegrative disorder and a greater likelihood of mental retardation. In addition, childhood disintegrative disorder is far less common than autism.

Cytomegalovirus

Cytomegalovirus (CMV) is a virus found around the world. It is related to the viruses that cause chickenpox and infectious mononucleosis (mono). Between 50 percent and 80 percent of adults in the United States have had a CMV infection by age 40. Once CMV is in a person's body, it stays there for life.

MCHAT "Modified Checklist for Autism in Toddlers"

A checklist to be used by General Practitioners at 18 months to see if a child has Autism.

DD "Developmental Disabilities"

Developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person's lifetime

DSM-IV TR "Diagnostic and Statistical Manual"

The Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association, is the standard classification of mental disorders used by mental health professionals in the United States.

Emotional Disturbance

Emotional and behavioral disturbances represent significant behavioral excesses or deficits. Many labels are used to denote deviant behavior; these labels include: emotionally handicapped or disturbed, behaviorally disordered, socially maladjusted, delinquent, mentally ill, psychotic, and schizophrenic. Each of these terms refers to patterns of behavior that depart significantly from the expectations of others.

Fragile X syndrome (FXS)

The most common cause of *inherited* mental impairment. This impairment can range from learning disabilities to more severe cognitive or intellectual disabilities. Symptoms also can include characteristic physical and behavioral features and delays in speech and language development.

IDEA "Individuals with Disabilities Act"

A US Law mandating the "Free and Public Education" (FAPE) for all persons with disabilities between the ages of 3 and 21.

IEP "Individualized Educational Plan"

In the US, the IDEA requires public schools to develop an IEP for every student with a disability who is found to meet the federal and state requirements for special education. The IEP must be designed to provide the child with a Free Appropriate Public Education (FAPE).

LRE "Least Restrictive Environment"

The least restrictive environment is identified as one of the six principles that govern the education of students with disabilities. By law, schools are required to provide a Free and Appropriate Education (FAPE) in the least restrictive environment for students who have disabilities. "Least restrictive environment" means that a student who has a disability should have the opportunity to be educated with non-disabled peers, to the greatest extent possible. They should have access to the general education curriculum, extracurricular activities, or any other program that non-disabled peers would be able to access.

Glossary of Terms, Acronyms, and other helpful information continued…

Mainstreaming (Inclusion)

Placement of a disabled child with non-disabled peers in a regular classroom.

Measles

Measles is an infectious disease caused by a virus. It spreads easily from person to person. The main symptom of measles is an itchy skin rash. The rash often starts on the head and moves down the body. Other symptoms include fever, cough, runny nose, and conjunctivitis (pink eye).

Mental Retardation

Intellectual disability is characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities. Intellectual disability is sometimes referred to as a cognitive disability or mental retardation.

National Research Council

The mission of the NRC is to improve government decision making and public policy, increase public education and understanding, and promote the acquisition and dissemination of knowledge in matters involving science, engineering, technology, and health.

Neurofibromatosis

The neurofibromatoses are genetic disorders of the nervous system that primarily affect the development and growth of neural (nerve) cell tissues. These disorders cause tumors to grow on nerves and produce other abnormalities such as skin changes and bone deformities

Neuro-typical (NT)

Neuro-typical is a neologism used to describe people whose neurological development and state are consistent with what most people would perceive as normal in their ability to process linguistic information and social cues. While originally coined among the autistic community as a label for non-autistic persons, the concept was later adopted by both the neurodiversity movement and the scientific community

NIH "National Institutes of Health"

U.S. government agency.

NIMH "National Institutes for Mental Health"

U.S. government agency.

OT "Occupational Therapy" or "Occupational Therapist"

Like Physical Therapy only deals with fine motor skills, e.g. picking up small objects like coins. Occupational therapists would be the people who provide Sensory Integration Therapy

Paraprofessionals

A job title given to people in various occupational fields, such as education, healthcare, and law, that have obtained a certificate by passing an exam, enabling them to perform a task requiring significant knowledge, but without having the occupational license to perform at the professional level in the field.

PDD-NOS or PDD/NOS "Pervasive Development Disorder--Not Otherwise Specified"

Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) is a 'sub threshold' condition in which some - but not all - features of autism or another explicitly identified Pervasive Developmental Disorder are identified.

Phenylketonuria (PKU).

Phenylketonuria (PKU) is a genetic disorder in which the body can't process part of a protein called phenylalanine (Phe). Phe is in almost all foods. If the Phe level gets too high, it can damage the brain and cause severe mental retardation. All babies born in U.S. hospitals must now have a screening test for PKU. This makes it easier to diagnose and treat the problem early

Glossary of Terms, Acronyms, and other helpful information continued…

Public Law 94-142

Also known as The Education for All Handicapped Children Act of 1975 (EAHCA). USA Federal law providing funds to states that maintain certain standards in their education of handicapped children, i.e. providing a free and appropriate education in a least restrictive environment. I believe IDEA is the more recent version of this law.

Rhett Disorder (RTT)

A debilitating neurological disorder diagnosed almost exclusively in females. Children with RTT appear to develop normally until 6 to 18 months of age when they enter a period of regression, losing speech and motor skills. Most develop repetitive hand movements, irregular breathing patterns, seizures and extreme motor control problems. RTT leaves its victims profoundly disabled, requiring maximum assistance with every aspect of daily living.

Rubella

Rubella is an illness with flu-like symptoms followed by a rash. Common symptoms include low-grade fever, headache, runny nose, red eyes, and muscle or joint pain. Rubella is usually mild, so mild a person may get it and not even know it.

Ryan’s Law

During the 2006 session of the South Carolina General Assembly, parent advocates organized an initiative seeking new legislation that would require insurance companies to provide coverage for the treatment of a Pervasive Developmental Disorder (PDD).

School psychologist

School psychologists work to find the best solution for each student and situation; they use different strategies to address student needs and to improve school and district-wide support systems. School psychologists work with students individually and in groups. They also develop programs to train teachers and parents about effective teaching and learning strategies, techniques to manage behavior at home and in the classroom, working with students with disabilities or with special talents, addressing abuse of drugs and other substances, and preventing and managing crises.

Sensorimotor

Pertaining to brain activity other than automatic functions (respiration, circulation, sleep) or cognition. Sensorimotor activity includes voluntary movement and senses like sight touch and hearing.

SI "Sensory Integration” or SIT “Sensory integration Therapy”

The main form of sensory integration therapy is a type of occupational therapy that places a child in a room specifically designed to stimulate and challenge all of the senses. During the session, the therapist works closely with the child to provide a level of sensory stimulation that the child can cope with, and encourage movement within the room. It also deals with fine and gross motor skills.

SLP "Speech-Language Pathologist"

Speech-language pathologists, sometimes called *speech therapists*, assess, diagnose, treat, and help to prevent speech, language, cognitive-communication, voice, swallowing, fluency, and other related disorders.

Transition Programs

A transition program is the series of strategies or activities that a cluster of schools agree to implement to assist students making the transition from primary school to secondary school.

Tuberous Sclerosis

Tuberous sclerosis complex (TSC) is a genetic disorder that causes tumors to form in many different organs, primarily in the brain, eyes, heart, kidney, skin and lungs. You will see it referred to both as tuberous sclerosis (TS) and tuberous sclerosis complex (TSC).

Vocational Training Programs

Vocational training programs prepare learners for careers that are based in manual or practical activities, traditionally non-academic and totally related to a specific trade, occupation or *vocation*, hence the term, in which the learner participates. It is sometimes referred to as *technical education*, as the learner directly develops expertise in a particular group of techniques or technology.

Referenced Information and Useful Websites

The Advocate: http://www.autism-society.org

The American Association on Intellectual and Developmental Disabilities: http://www.aamr.org

The American Academy of Pediatrics: http://www.aap.org

Autism-Asperger's Digest Magazine: http://www.autismdigest.com

The Autism Asperger Syndrome Source: http://www.asperger.org

Autism Connect: http://www.autismconnect.org

The Autism Link Page: http://www.transmil.nl/alp

Autism-PDD Resources Network: http://www.autism-pdd.net

Autism Society of American (ASA): www.autism-society.org

Autism Speaks: http://www.autismspeaks.org

Bill of Rights for Individuals with Autism Spectrum Disorders: http://www.autismbillofrights.com

The U.S. Census Bureau: http://www.census.gov

Centers for Disease Control (CDC): http://www.cdc.gov

The Center for the Study of Autism: http://www.autismwebsite.com

Cure Autism Now (CAN) official website: http://www.cureautismnow.org

Exceptional Children: http://www.cec.sped.org

Families for Early Autism Treatment: http://www.feat.org

Floor Time: www.floortime.org

Future Horizons, Inc: www.FHautism.com

National Institute of Mental Health: http://www.nimh.nih.gov

The Office of the Surgeon General: http://www.surgeongeneral.gov

Online Asperger Syndrome Information and Support (OASIS): http://www.udel.edu/bkirby/asperger

Picture Exchange Communication System (PECS) www.pecs.com

Relationship Development Intervention (RDI): www.rdiconnect.com

SCERTS: www.scerts.com

Social Stories: http://www.TheGrayCenter.org

Southwest Autism Research and Resource Center (SARRC): www.autismcenter.org

Together Enhancing Autism Awareness in Mississippi (TEAAM): www.TEAAM.org

Treatment and Education of Autism and Communication (TEACCH): www.teacch.com

Journal of Autism and Development Disorders: 233 Spring Street New York, NY 10013

The Caring for Mississippi Individuals with Autism Task Force Members

Chair

Susan Buttross, M.D.	*University of Mississippi Medical Center Representative*

Vice Chair

Nicole Boyd, J.D.	*Speaker of the House Parent Appointee*

Committee Members

Elle Sullivan, R.Ph.	*Governor Parent Appointee*
Shana Hale, M.A.	*Lt. Governor Parent Appointee*
Trese Evans, M.S.	*State Department of Education Representative*
Sheila Williamson, Ph.D.	*State Superintendent of Public Education Appointee*
Shirley Miller, MPPA	*State Department of Mental Health Representative*
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Maureen Martin, Ph.D.	*President of MS Speech, Language, and Hearing Assoc. Appointee*

Department of Mental Health Staff

Mark Yeager, Ph.D.	*Division of Autism Spectrum Disorders, Director*
Joe Maury, B.S.	*Division of Autism Spectrum Disorders, Project Officer*

Bibliography

Community Mental Health Services Survey
Caring for Mississippi Individuals with Autism Task Force (HB1267)

Please remember that this information is for summary purposes only. Please provide accurate information so that we know what services are available and where they are available throughout the state so appropriate information can be given to the legislature and we hopefully can better serve this population. If you have information that would be helpful for this task force, I encourage you to get it to me. This is an important assignment and I want to make sure we make the most of it. Thank you so much for you time completing this form.

Region Number _________ Main office located in ________________________ County

Name of person completing information _______________________________________

Contact information: _______________________________ (Email) _____________(Phone)

Total number of Master's level staff providing direct services to individuals? __________

How many Master's level staff members work with people with autism or ASD?_______

Do any of these people have specialized training to work with autism or ASD? ________

If so, what training do they have? ____

____

What services are available to individuals with autism or ASD? ____________________

____

Approximately how many individuals with autism or ASD do you think your region serves in

a 12 month period? _______________

Of these, approximately how many are adults vs children? ______adults vs ______ children

Do you have staff that gives a tentative diagnosis of autism or ASD at first visit? _________

Do people with autism or ASD also see the psychiatrist for medication? ________________

Do people with autism or ASD get any type of medical workup (blood work, EEG or MRI)?

If so, what and by whom (psychiatrist, family practitioner, specialist)? ___________________

____

Any other information regarding early screening, diagnosis and treatment of people with

autism or ASD? ____

Bibliography

Higher Education Services Survey
Caring for Mississippi Individuals with Autism Task Force (HB1267)

1. Your location:
- **(a) Name of your University ________________________________**
- **(b) Name of your Academic Department______________________**
- **(c) Name of your State_____________________________________**

2. Check any that are applicable to your program.
- **(a) Undergraduate_______,**
- **(b) UG/Graduate______,**
- **(c) UG/Grad/Doctoral ____________,**
- **(d) Research Institution _____**

3. Do you include training about autism in your curriculum? Yes____No____

4. If you answer No to this question, would you please state the reason?

____

If you answer Yes to question #3, please go on to question #5. If you answer No, go no further with the questionnaire. Please return it in the envelope provided.

5. If #3 is yes, in what undergraduate courses is training included? ___________

6. If #3 is yes, in what graduate, doctoral or research courses is training included?

____

7. Do you include <u>nonstandard interventions</u> (dietary treatments, neurophysiological retraining, sensory integration training, chiropractic, facilitated communication, secretin injections, anti-motion sickness) in your training? Yes___ No___. If you do, which ones?________________________

8. Which of the following <u>current intervention approaches</u> to Autism Spectrum Disorder do you include in your curriculum?
- **(a) Relationship-based interventions such as Floor Time __________.**
- **(b) Skill-based interventions such as Picture Exchange Communication Systems (PECS) ___________.**
- **(c) Physiologically oriented interventions such as sensory integration or psychopharmacologic and dietary treatments___________.**
- **(d) Programs that combine intervention approaches such as Project TEACH, SCERTS (Social Communication, Emotional Regulation, Transactional Supports), or Applied Behavioral Analysis (ABA) ____________.**

9. Do you include teaching about <u>best practice considerations</u> with individuals with ASD? (Best practices as defined by the National Research Council in 2001 and the American Academy of Child & Adolescent Psychiatry (1999) Yes _____ No_____

Bibliography

Higher Education Services Survey (continued)...

10. Which of the following do you include in the training? Please check all that apply: understanding and assessing play ___, understanding and assessing social-emotional development _____, sensory and motor considerations ______, the use of augmentative communication systems/devices with individuals with ASD _______, understanding and assessing communication _______.

11. Which diagnostic tools do you include in your teaching?
(a) Checklist for Autism in Toddlers (CHAT) ____
(b) Australian Scale for Asperger's Syndrome ____
(c) Modified CHAT (M-CHAT) ____
(d) Other ___________________________________(please explain)

12. Do you have any way of assessing student knowledge in the area of ASD, following completion of the course (clinical practicums, follow up with school systems, students' own feedback)? Yes _________ No __________. If your answer is Yes, please explain ____.

13. Do you include any of the following in the academic training?
(a) planning and coordination of routine comprehensive health care for individuals with ASD Yes____No____
(b) use of a preventive medical checklist specific to the individual's condition Yes____No____
(c) diet and nutritional approaches Yes____No____
(d) growth monitoring Yes ____ No ___
(e) seizure monitoring Yes ____No____
(f) mental health monitoring Yes____ No____
(g) psychoparmacology Yes ____No____
(h) orthopedic care and physical therapy Yes____ No____
(i) self-care, activities of daily living, and occupational therapy Yes____No____
(j) pain or acute illness Yes ____No____
(k) safety and sexuality Yes ____No____
(l) sleep problems Yes ___No_____

14. Who typically diagnoses autism in your local area/state? __________________

If you know of others in your department/program/university who could complete this survey, please reproduce, ask them to do so, and return it with yours in the enclosed stamped envelope.

If you would be interested in continuing this dialogue through an electronic listserv following the completion of this survey, please complete the name and address information below.

Name ______________________________________Mailing Address _________________________

Email address ___________________I wish to know the outcomes of this survey Yes ___ No _____.

Bibliography

Medical Services Survey
Caring for Mississippi Individuals with Autism Task Force (HB1267)

County in which you practice ________________

Name of person completing survey (optional) ______________________________

Contact information (optional) ____
____

Do you personally make the diagnosis of autism in children? ___________________

Approximately how many patients with the tentative diagnosis of autism do you see per year?
____

What screening tools, if any, do you use to make the diagnosis of autism?___________
____

What local referral sources are available to you to help make the diagnosis?_________
____

Once the diagnosis is suspected, you
☐ complete the evaluation <u>or</u> ☐ refer to someone else to complete the evaluation.

If a referral is made to further the evaluation, to whom do you send your patient?
☐ Psychologist ☐ Psychiatrist ☐ Developmental pediatrician ☐ Neurologist
☐ Other (please specify) ____

If you complete the medical evaluation, what tests do you routinely order?
☐ EEG ☐ MRI ☐ CT ☐ Chromosomes
☐ Other blood work (Please specify)_____________________________________

Once the diagnosis is made to what services do you routinely refer?
☐ Early Intervention Services ☐ Local school district ☐ Private therapists
☐ Speech pathologists ☐ Occupational therapists ☐ Psychologists
☐ Behavioral therapists, ☐ Other (please specify) ____________________

Once the diagnosis of Autism is made, what areas of service do you have difficulty accessing?
____

Is your local early intervention program seemingly adequately staffed and knowledgeable about autism? ____ If not, what seem to be the areas of deficiency?_______________
____

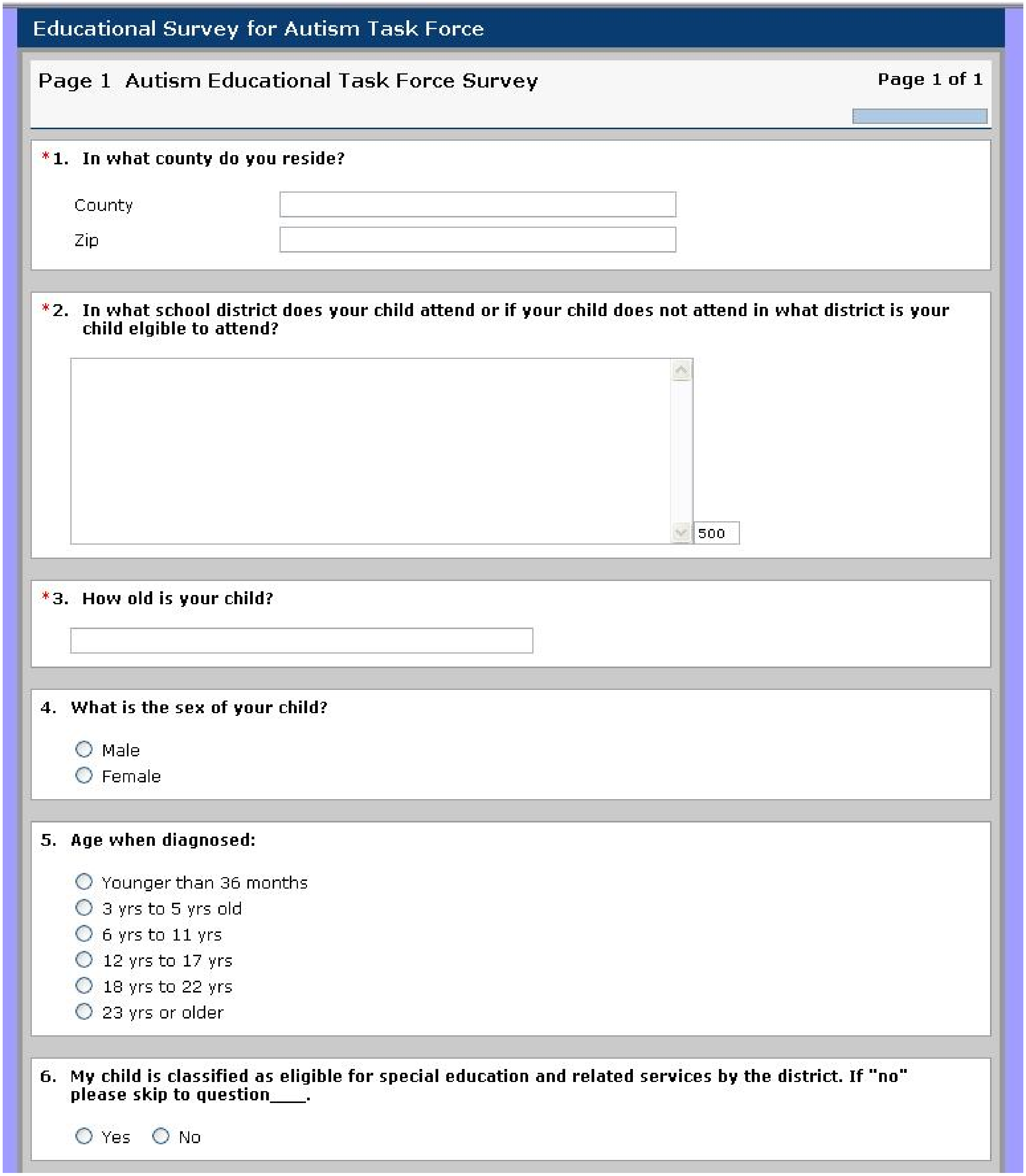
What is your perception of ease of transition from early intervention services into the public school system? ____

Does your local school district appear to adequately serve your patients with autism?____

Bibliography

Education Services Survey
Caring for Mississippi Individuals with Autism Task Force (HB1267)

This survey was conducted online and is reprinted here in its original form



Educational Survey for Autism Task Force

Page 1 Autism Educational Task Force Survey

Page 1 of 1

*1. In what county do you reside?

County

Zip

*2. In what school district does your child attend or if your child does not attend in what district is your child elgible to attend?

500

*3. How old is your child?

4. What is the sex of your child?

○ Male
○ Female

5. Age when diagnosed:

○ Younger than 36 months
○ 3 yrs to 5 yrs old
○ 6 yrs to 11 yrs
○ 12 yrs to 17 yrs
○ 18 yrs to 22 yrs
○ 23 yrs or older

6. My child is classified as eligible for special education and related services by the district. If "no" please skip to question____.

○ Yes ○ No

Bibliography

Education Services Survey (continued)…
Caring for Mississippi Individuals with Autism Task Force (HB1267)

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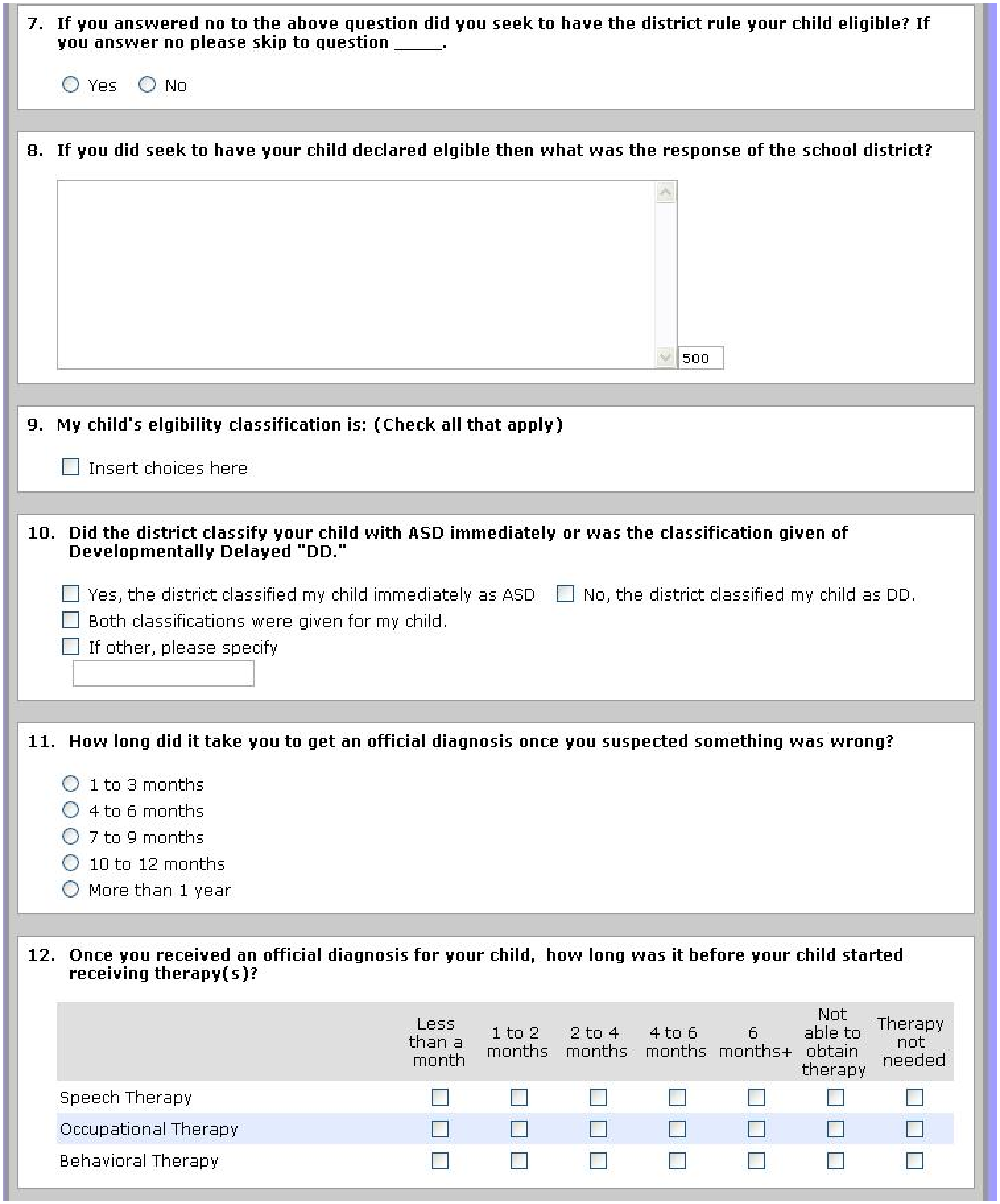

7. If you answered no to the above question did you seek to have the district rule your child eligible? If you answer no please skip to question _____.

○ Yes ○ No

8. If you did seek to have your child declared elgible then what was the response of the school district?

500

9. My child's elgibility classification is: (Check all that apply)

☐ Insert choices here

10. Did the district classify your child with ASD immediately or was the classification given of Developmentally Delayed "DD."

☐ Yes, the district classified my child immediately as ASD
☐ No, the district classified my child as DD.
☐ Both classifications were given for my child.
☐ If other, please specify

11. How long did it take you to get an official diagnosis once you suspected something was wrong?

○ 1 to 3 months
○ 4 to 6 months
○ 7 to 9 months
○ 10 to 12 months
○ More than 1 year

12. Once you received an official diagnosis for your child, how long was it before your child started receiving therapy(s)?

	Less than a month	1 to 2 months	2 to 4 months	4 to 6 months	6 months+	Not able to obtain therapy	Therapy not needed
Speech Therapy	☐	☐	☐	☐	☐	☐	☐
Occupational Therapy	☐	☐	☐	☐	☐	☐	☐
Behavioral Therapy	☐	☐	☐	☐	☐	☐	☐

Bibliography

Education Services Survey (continued)…
Caring for Mississippi Individuals with Autism Task Force (HB1267)

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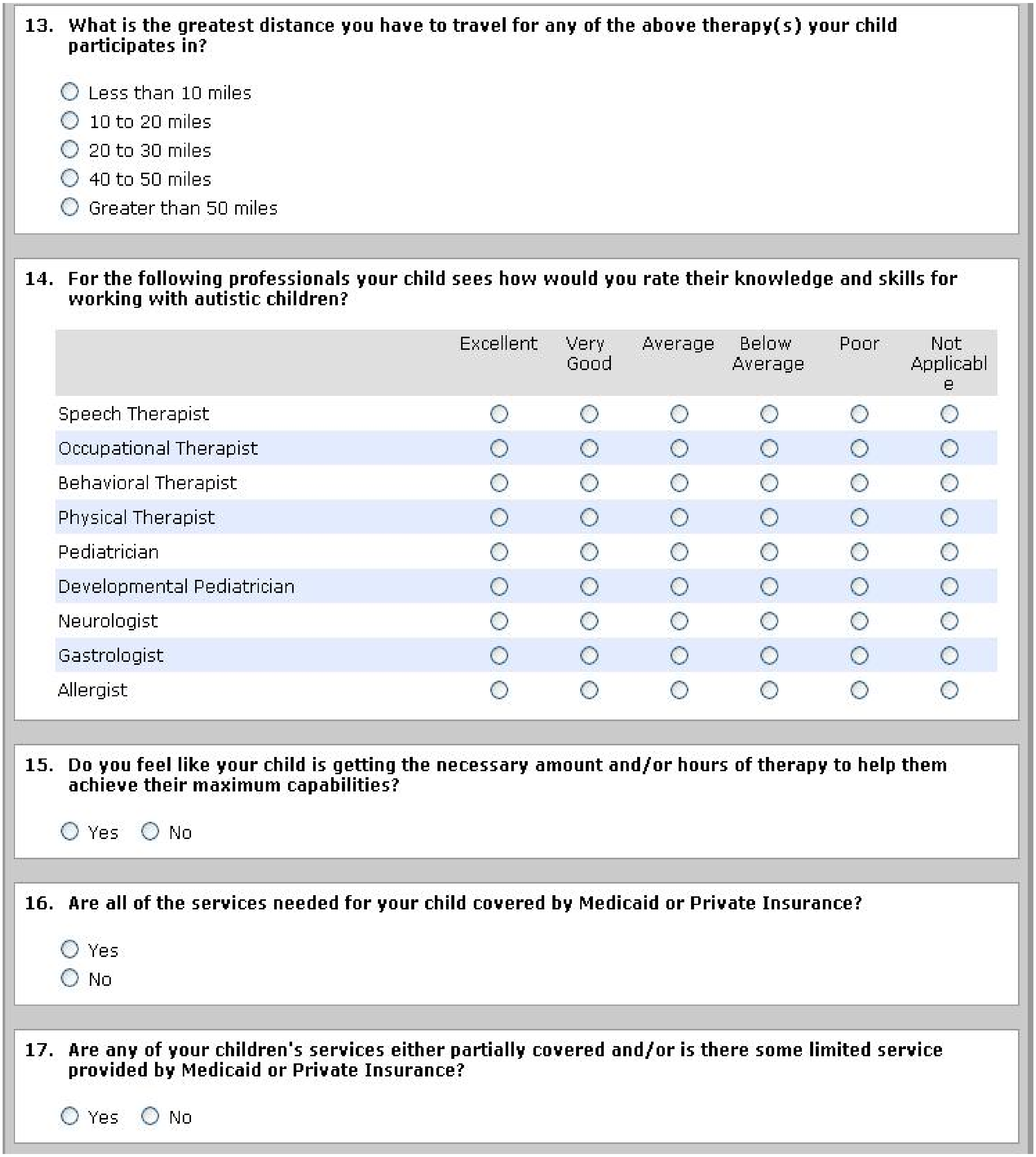

13. What is the greatest distance you have to travel for any of the above therapy(s) your child participates in?

○ Less than 10 miles
○ 10 to 20 miles
○ 20 to 30 miles
○ 40 to 50 miles
○ Greater than 50 miles

14. For the following professionals your child sees how would you rate their knowledge and skills for working with autistic children?

	Excellent	Very Good	Average	Below Average	Poor	Not Applicable
Speech Therapist	○	○	○	○	○	○
Occupational Therapist	○	○	○	○	○	○
Behavioral Therapist	○	○	○	○	○	○
Physical Therapist	○	○	○	○	○	○
Pediatrician	○	○	○	○	○	○
Developmental Pediatrician	○	○	○	○	○	○
Neurologist	○	○	○	○	○	○
Gastrologist	○	○	○	○	○	○
Allergist	○	○	○	○	○	○

15. Do you feel like your child is getting the necessary amount and/or hours of therapy to help them achieve their maximum capabilities?

○ Yes ○ No

16. Are all of the services needed for your child covered by Medicaid or Private Insurance?

○ Yes
○ No

17. Are any of your children's services either partially covered and/or is there some limited service provided by Medicaid or Private Insurance?

○ Yes ○ No

Bibliography

Education Services Survey (continued)...
Caring for Mississippi Individuals with Autism Task Force (HB1267)

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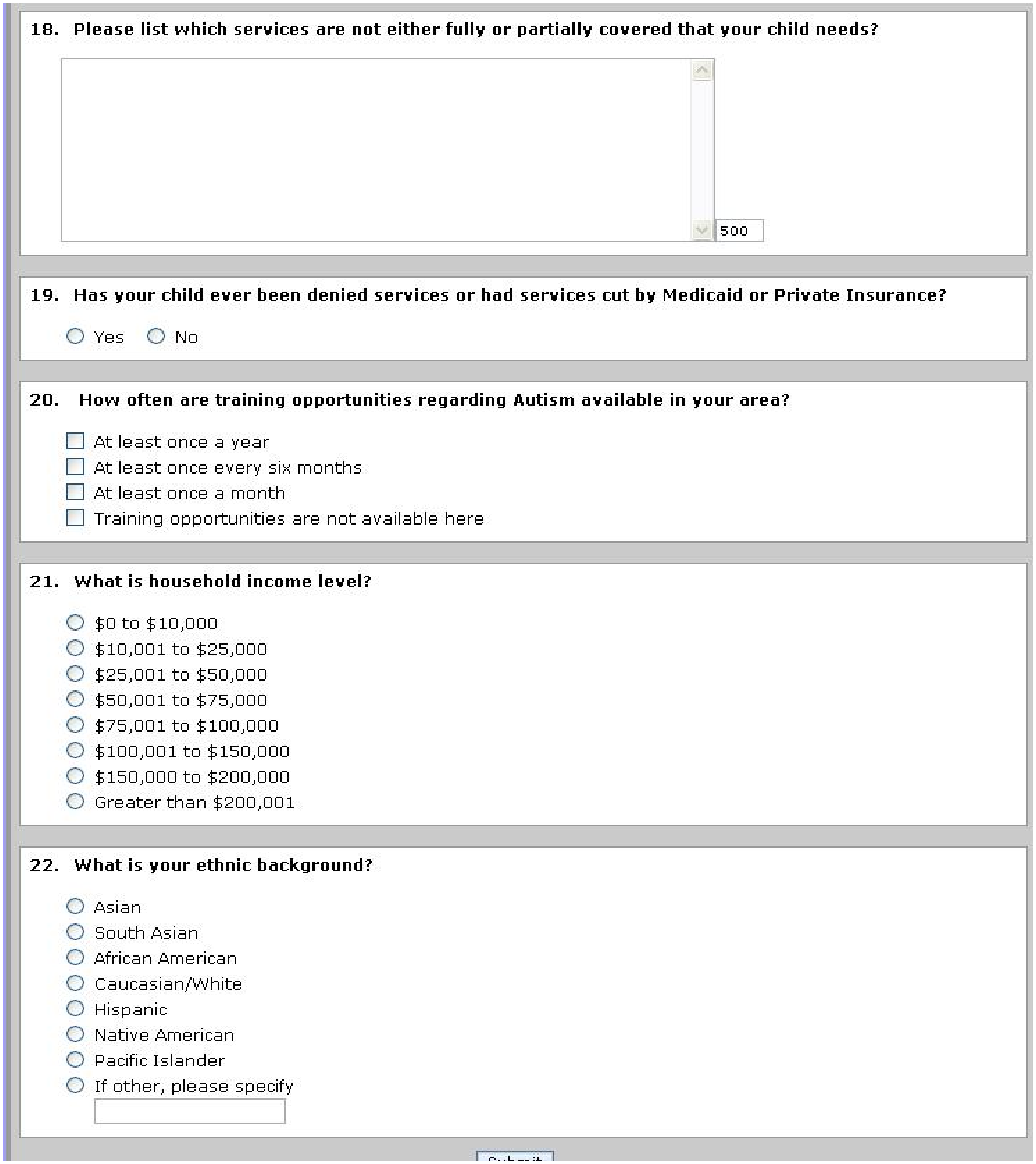

18. Please list which services are not either fully or partially covered that your child needs?

19. Has your child ever been denied services or had services cut by Medicaid or Private Insurance?

○ Yes ○ No

20. How often are training opportunities regarding Autism available in your area?

☐ At least once a year
☐ At least once every six months
☐ At least once a month
☐ Training opportunities are not available here

21. What is household income level?

○ $0 to $10,000
○ $10,001 to $25,000
○ $25,001 to $50,000
○ $50,001 to $75,000
○ $75,001 to $100,000
○ $100,001 to $150,000
○ $150,000 to $200,000
○ Greater than $200,001

22. What is your ethnic background?

○ Asian
○ South Asian
○ African American
○ Caucasian/White
○ Hispanic
○ Native American
○ Pacific Islander
○ If other, please specify

"I work with the children who, if we can teach them to communicate and interact with others, they have the potential to find the cure for cancer, take astronauts to Mars, and solve many of societies problems. These children have a unique capacity to see the world and problems in a completely different way. We can not afford to throw these children away as they can be huge gifts to society."

Dr. Sheila Williamson
(On her work with Autism students in the Desoto County Schools)