

Testimony of  
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In the late fall of 2005 our family was living in San Antonio, TX while my husband completed his surgical fellowship. My youngest child, Speight at around the age of 22 months developed regressive autism. Almost overnight he digressed from using words and sentences in two languages with fine and gross motor coordination well ahead of developmental milestones to a child who lost nearly all language with impaired neuromuscular control. It was as if a tornado had hit our lives with no end in the foreseeable future to the destruction.

At age 25 months Speight began a rigorous program filled with Behavioral, Speech and Occupational Therapy that has continued after our move to Mississippi. Currently, we can see progress and are cautiously optimistic about the future. He is quite verbal and his gross and fine motor skills have greatly improved. His medical condition is always tenuous as he is believed to suffer from a mitochondrial disorder which is proposed to be a contributing factor for his autism. Simple viruses will turn a high functioning child on the spectrum to a low functioning child within a matter of hours. Today, he will attend his kindergarten open house at Bramlett Elementary in Oxford, Mississippi.

Speight will attend a regular education class and will have some classroom and resource assistance. As the class of 2022 starts kindergarten, schools across this country will look very different. Twenty years ago in this country Speight would have probably been the only child in his kindergarten class or even his school with Autism Spectrum Disorder (ASD). However, his kindergarten class of around 200 students will have 6 children diagnosed with Autism Spectrum Disorder. If you are trying to do the math that is roughly 1 in 34. In Mississippi, a small survey conducted by the state task force indicated that many Mississippi children are often not diagnosed before age five (5) and therefore it is probable this number may go even higher. Although this number of 1 in 34 may be somewhat of an anomaly, it is unfortunately less of an anomaly than we would all like to believe in the kindergarten classes around this country.

The February 2007 Centers for Disease Control and Prevention Autism Prevalence Report was of no surprise to Americans or those of us in Mississippi living with the effects of ASD. The report, which looked at a sample of 8 year olds in 2000 and 2002, concluded that the prevalence of autism had risen to 1 in every 150 American children, and almost 1 in 94 boys. Based on the statistics from the U.S. Department of Education and other governmental agencies, autism is growing at a rate of 10 to 17 percent per year. At this rate in the next decade the prevalence of autism could reach 4 million Americans. Indeed, the class of 2022 will look very different.

Despite the fact the incidence of autism has risen almost 6000% since the 1980's, we have yet to clearly define why there has been such a dramatic increase. The medical establishment, as is often the case, gives credit to itself by stating that better diagnoses is the root cause of the increase. However, this does not completely explain the explosion of Autism in America. Currently, there is no "mainstream" medical treatment for autism. Yet, there are more camps and theories that have lined up in this debate than mosquitoes in Mississippi. And yes, all are lined up in the name of science and of "helping my child."

Everywhere a parent turns there are those telling them the "reason" their child has autism as if they had been whispered a reason by God on high. Parents who believe that vaccines harmed their children have been marginalized by their pediatricians when their have been clear clinical vaccine reactions that propel children into Autistic behavior. Physicians who try to suggest a multiple set of reasons for autism are ignored and rebuffed by their patient's families. An adversarial relationship is thus created, leading to an impasse in determining why my child developed autism and what the underlining medical conditions that

prevent his full recovery. Moreover, we also do not know how we keep your children and grandchildren from suffering the same fate.

As parents we appreciate that Congress has devoted attention to autism, starting with the Children's Health Act of 2000, now almost a decade ago. But, after so many words and so many years, it's absolutely clear that autism is still woefully under funded by the NIH compared to the prevalence and the costs to our society of the condition. The Autism Society of America currently estimates that the lifetime cost of caring for a child with autism ranges from \$3.5 million to \$5 million, and that the United States is facing almost \$90 billion annually in costs for autism.

For parents, the passage of the Combating Autism Act brought great hope that research would begin promptly in identifying children at greater risk for developing the disorder and whether there were sub-populations more predisposed to have ASD children. Yet, to date research has failed to make those clear identifications. Parents and autism professionals are voicing their frustration with the speed or lack thereof with The Interagency Autism Coordinating Steering Committee that is responsible for disbursing the millions of dollars in CAA funds. For parents, this committee looks like the height of Washington Bureaucracy.

The parents of ASD children were thrilled this last year when autism became a major issue for both parties in the presidential campaign. And this year when President Obama became the first President ever to specifically call for a significant increase in autism research in his budget, this Committee did not ratify that policy. I understand Congress's reluctance to mandate NIH dollars for specific research. However, you will understand that parent's confidence is lacking in an entity where their biggest highlight on their "Health Publications about Autism and Related Disorders" web page is about dental and oral care of the special needs population. Parents want more than how to brush and care for our kid's teeth.

On behalf of parents, I am asking this committee in the future to be very explicit to the NIH in how research dollars are spent for autism. We want the questions answered that identify children more likely to develop autism by looking at the current parents of ASD children. Also, we want the true research questions answered on vaccines and autism that have been pointed out by Dr. Bernadine Healy the former director of the NIH.

For the population of children already with ASD we know certain behavioral therapies can greatly diminish a child's autism. Let's look back at my son's kindergarten class and these "Bramlett 6." For the "Bramlett 6" there are signs of optimism. Five of the six children with ASD have been fortunate enough to receive private behavioral therapy. 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. In addition, when implemented intensively and early in life (beginning prior to the age of 5 years), ABA may produce large gains in development, reduce in the need for special services and forego costly intensive special education in the future.

Although these "Bramlett 6" are still not finished with this therapy, you can already see positive signs from the intensive behavioral intervention. One child went from hiding under a table in a

complete meltdown due to over stimulation at another child's birthday party to being the center of attention at her own birthday party just six months after intensive therapy was initiated. For the "Bramlett 6" needed classroom supports are already decreasing from their Pre-Kindergarten years. It is easy even at this very early age to understand why the investment in intensive therapy is critical.

A February 2009 report from Autism Speaks on *Arguments in Support of Private Insurance Coverage of Autism Related Services* notes:

A 1998 study by John W. Jacobson and others titled, *Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism – General Model and Single State Case*, examined the cost/benefit relationship of early intensive behavioral intervention treatment at varying levels of treatment success. The study used estimates of costs for early intensive behavioral interventions (EIBI) from childhood (age three) through adulthood (age 55) based on prices in the Commonwealth of Pennsylvania and compared these costs with the expected amount of income the child would earn later in life to arrive at an estimated cost savings. With a success rate of 47 percent for early intensive behavioral intervention therapy (as determined by Lovaas), Jacobson's study found that cost savings per child served are estimated to be from \$2,439,710 to \$2,816,535 to age 55.

The study also accounts for the initial investment in early intervention by concluding that, with an initial annual cost of \$32,820, the total cost-benefit savings of EIBI services per child with autism or PDD for ages 3-55 years averages from \$1,686,061 to \$2,816,535 with inflation.

Additionally the report found:

According to a 2005 Government Accounting Office (GAO) report, "the average per pupil expenditure for educating a child with autism was more than \$18,000 in the 1999-2000 school year. This amount was almost three times the average per pupil expenditure of educating a child who does not receive any special education services.

Investments into this intensive therapy will, in the long run pay benefits, both economic and social, to the greater population. However in Mississippi this intensive therapy is not an option for all concerned parents. These "Bramlett 6" are a rare story in Mississippi. The Mississippi autism task force noted:

*At present, funding for comprehensive treatment must be provided privately in most instances by families as there is limited governmental or insurance support. The average cost for a privately-contracted comprehensive treatment plan is well over \$50,000.00 a year. When the average Mississippi family only makes \$34,343.00 annually 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.*

One autism mother (who had private health insurance) noted to Mississippi 's task force: "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." For the parents of these "Bramlett 6", paying for this therapy has been financially stressful. For one child's parents, they both took 2<sup>nd</sup> jobs. Sadly, both parents had private health care insurance which would not pay for the needed therapy. For the other parents of the "Bramlett 6", cushioned bank accounts, big vacation trips, and college savings accounts are non-existent.

The question we have to ask ourselves as a nation is not whether we can afford to provide these therapies but whether we can afford not to. It is imperative that we look at both the private and public sectors for this support as the costs of autism is borne by everyone. On behalf of the parents, I implore you to end the insurance discrimination for our children, fund intensive intervention through early intervention programs, and look at mandating coverage for those on Medicaid systems. Additionally, I would give a cautionary word of warning when looking at a national single payer health care system. For parents who are utilizing Medicaid services, the services can be described at best as "limited." For example, in Mississippi, speech therapy services for special needs children were essentially eliminated as of July 1, of this year. Furthermore, provider numbers willing to see these children is limited due to low reimbursement rates.

Additionally, I ask you as Senators to support legislation such as Senate Bill 493 that would create tax-exempt savings accounts to care for individuals with disabilities and other measures that would ease the burden of our families.

When the Mississippi Autism Task Force held public hearings financial issues were not the only stressors. The lack of 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 were listed as major stressors for families.

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

Another, sometimes unnoticed, turmoil created by autism is the affect 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 sister's behaviors are so erratic. Typical assistance offered by family and friends are less available as a result of the difficulty in managing behaviors.

For the above reasons, depression is often high among our parents. This year in our region of Mississippi we lost two parents from the stress and depression produced due to the difficulties from parenting an ASD child.

However, we see our families improve as their children's prognosis improves. Senators with the growth of the disorder and its impact on families we must move quickly to provide the necessary treatment and intervention for these ASD children and their families.