



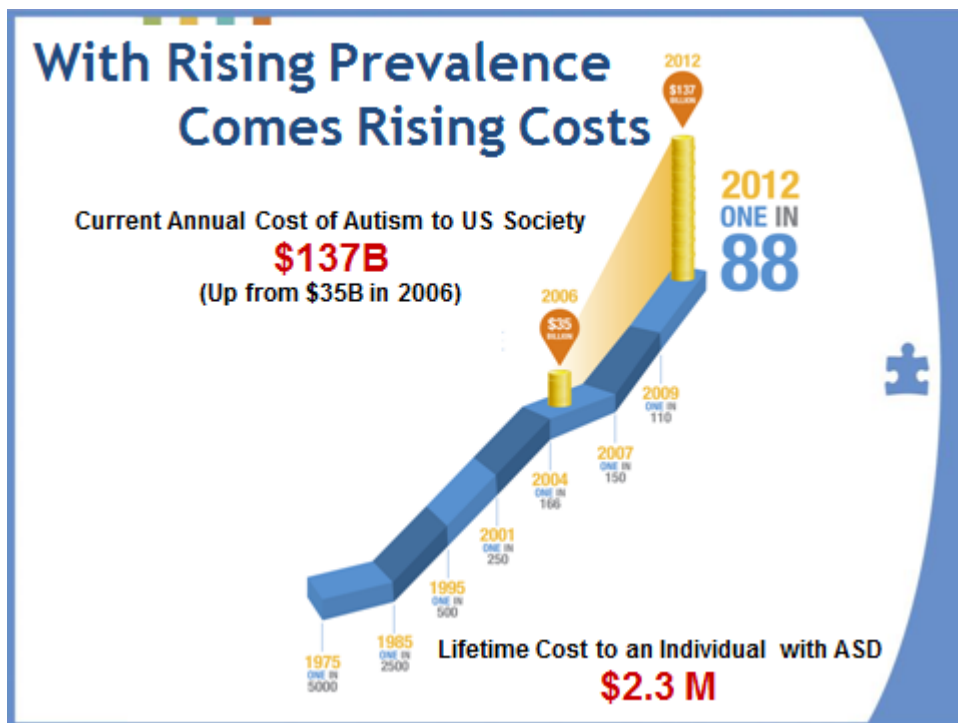
**TESTIMONY PRESENTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE  
ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED  
AGENCIES BY JAMITHA FIELDS, VICE PRESIDENT FOR COMMUNITY AFFAIRS  
AT AUTISM SPEAKS**

Chairman Kingston, Ranking Member DeLauro, and members of the subcommittee, thank you for the opportunity to offer testimony on the importance of continued funding for autism. The Combatting Autism Act authorizes \$22 million for autism activities within the Centers for Disease Control and Prevention's (CDC); \$48 million for autism research, treatment and training activities at the Health Research and Services Administration's (HRSA); and \$161 million for research and coordination at the National Institutes of Health (NIH).

I am Jamitha Fields Vice President for Community Affairs at Autism Speaks. Autism Speaks is the world's leading autism science and advocacy organization. Our goal is to change the future for all who struggle with autism spectrum disorders. We are dedicated to funding research into the causes, prevention, treatments and a possible cure for autism. We strive to raise public awareness about autism and its effects on individuals, families, and society and we advocate for the needs of individuals with autism and their families. We have invested over \$400 million in this effort and we are committed to continuing our work.

Autism and autism spectrum disorder (ASD) are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. There are some with autism who need very little intervention but there are others who cannot speak or care for themselves and will need lifelong assistance.

Autism is the fastest growing developmental disability in the United States. The number of children on the spectrum has risen so sharply that American families are now ten times more likely to have a child with autism than just a decade ago. The estimated annual cost to society is \$137 billion a year. For many families, the out-of-pocket costs for autism treatment and therapy, which can rise to \$60,000 a year, are out of reach. But autism is not just a healthcare issue. The economic burden associated with ASD can be measured across multiple sectors of our society, particularly education.



Since the enactment of the Combating Autism Act (CAA) in 2006 and its reauthorization in 2011, federal agencies, in partnership with Autism Speaks and others in the private sector, have made strides in addressing one of our nation's top health priorities. The law has increased the number, scope, pace and coordination of autism research, surveillance, public education and professional training. As a result, the proportion of infants and toddlers being screened for ASD is rising; the proportion of children diagnosed by age three is growing; and there are continuing improvements in decreasing the time between diagnosis and intervention.

That is good news but more needs to be done.

While more children are being diagnosed earlier, most children are not. Studies demonstrate that signs of autism emerge as early as 6 to 12 months. Thanks to research, we have effective tools for screening children for autism risk as early as one year. Yet according to CDC, the average age of diagnosis is 4-5 years. The situation in some ethnic and low income communities is even more troubling. Multiple studies have shown that black and Latino children are under identified, diagnosed significantly later, and once diagnosed, they receive poorer quality of care.

That's why Autism Speaks is focusing on the Early Access to Care initiative which seeks to reduce the age of diagnosis and increase access to high-quality early intervention for *all* children on the autism spectrum. We have partnered with CDC, the American Academy of Pediatrics and others to educate communities about the disparities and carry out evidence based strategies to bring about effective change. Improving this unacceptable situation will take the combined efforts of public and private partners including families, healthcare professionals,

educators, autism advocates in every community and leaders like all of you who can help focus public attention on issues like this.

The earlier children are identified, the earlier they are able to receive early intervention services. Evidence-based early intervention services have been shown to reduce the core symptoms of autism; improve IQ and daily functioning; and reduce the cost of lifelong care by two-thirds. Considering the cost of autism over the lifespan is estimated at \$2.3 million, those are significant savings.

This is just one example of a pressing need related to autism. In fact, the funding that has been provided through this subcommittee is just one piece of the puzzle. Autism Speaks and the three million plus members of our community here in the United States are of course grateful for this funding. It is making a difference. But while we know more than we did a decade ago, there is still so much more to discover. Why are boys four to five times more likely to have autism than girls? What accounts for the differences between those who are eventually able to live independently versus those who will require lifelong assistance?

As I hear from the families struggling to find and to pay for the appropriate services and treatments for their children; struggling to address the hazards of wandering; and struggling to find housing and jobs for the fast growing population of adults with autism; I know there is so much more to do as well.

We need leadership now more than ever. We need to start looking not just at the cost of what we are doing, but also the cost of not doing more. Thank you for the work you have done so far and I hope we can count on you to make a difference.