



Testimony
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Autism Spectrum Disorders:
CDC Research and Prevention Activities

Statement of

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Good afternoon, Senator Harkin and distinguished members of the Subcommittee. Thank you for the opportunity to appear before you on behalf of the Centers for Disease Control and Prevention (CDC), an agency of the Department of Health and Human Services, to discuss our agency's research and prevention activities addressing autism spectrum disorders. Thank you also for your continued support of CDC's goals in support of healthy people throughout all stages of their lives and facets of living. Good health is essential to a good life, and the health and well-being of a nation's people are essential for its continued strength and growth.

Today, our nation and the world are focused on urgent threats such as pandemic influenza, natural disasters, and terrorism. While these threats require and deserve our immediate attention, we cannot lose sight of the pressing realities of public health issues that we face every day, such as autism and other developmental disabilities. Autism spectrum disorders include autistic disorder, pervasive developmental disorder, not otherwise specified (PDD, NOS, including atypical autism), and Asperger's syndrome.

Autism spectrum disorders cause considerable impairments in social interaction and communication that show up early in a child's life . before the family celebrates the child's third birthday . and can dramatically affect a child's ability to participate in activities with loved ones, caregivers, and peers. It is often difficult for a child with an autism spectrum disorder to communicate and interact

with others, and they can retreat from group activities. An affected child may also have unusual ways of learning, paying attention, or reacting to different sensations, and can show unusual behaviors and interests. There is no cure at this time, and the effects of these disorders can last a lifetime. The profound lifelong impact of autism spectrum disorders, tremendous costs to the affected individuals and their families, the lack of known causes or cures, and concerns about the increased rates of diagnosis all make autism spectrum disorders one of our urgent realities, and a top concern for many families, health professionals, educators, and local and national organizations.

CDC's efforts on autism spectrum disorders are led largely by our National Center on Birth Defects and Developmental Disabilities (NCBDDD), which was created following the Children's Health Act of 2000. The Center takes a life-span approach by working to identify and prevent birth defects and developmental disabilities . including autism spectrum disorders . and by promoting the health of children and adults with disabling or potentially disabling conditions. The Center's top priorities are improving health and wellness for people with disabilities, preventing birth defects, and addressing autism and related conditions.

As reauthorized by the Combating Autism Act of 2006 (Public Law 109-416), NCBDDD's work in autism spectrum disorders focuses on three broad areas - understanding rates and trends, advancing public health research in the search for causes or a possible cure, and improving early detection and diagnosis so

that affected children can begin receiving intervention as soon as possible. Early intervention that provides structure, direction, and organization can often help a child with an autism spectrum disorder. Today, I will provide an update on the prevalence of autism spectrum disorders, discuss the launch of CDC's epidemiologic study of potential causes and correlates, and share with you some of our successes in promoting early identification of autism spectrum disorders and other developmental disabilities.

CDC's work in Autism Spectrum Disorders Prevalence

Parents, policy makers, and the public want to better understand how many people are affected by autism spectrum disorders . and whether the higher rates are due to better identification or a true increase in the occurrence. In order to address these questions about rates and trends, we have focused our efforts on developing prevalence estimates of autism spectrum disorders in multiple communities over time. %Prevalence+is the number of existing disease cases in a defined group of people during a specific time period, and it should be differentiated from %Incidence,+which is the number of new cases for a given period of time.

Previous efforts to understand the prevalence of these conditions have varied widely in their methods and findings- making it difficult to accurately answer critical questions about trends. For example, studies published before 1985 indicated that the prevalence of autism and related conditions was 0.4 - 0.5 per 1,000 children. However, later studies using updated diagnostic criteria and

differing methods from multiple countries have identified rates ranging from 2.0 to 12.0 per 1,000 children with ~~best estimate~~ rates ranging from 2.0 to 6.0 per 1,000 children. Two previous CDC studies specific to U.S. communities from the mid-1990s found rates of 3.4 and 6.7 per 1,000 children 3-10 years of age and have identified the urgent need for population-based autism spectrum disorder prevalence monitoring in the United States.

CDC has been monitoring the prevalence of developmental disabilities since the 1980s and autism spectrum disorders specifically since 1996. Since 1999, CDC and its partners in 14 states have been building the Autism and Developmental Disabilities Monitoring (ADDM) Network to better understand the size and characteristics of the population of children with autism spectrum disorders, and to provide consistent and reliable estimates over time. This network, the only one of its kind, provides multiple-site, multiple-source, population-based prevalence data on the number of children with an autism spectrum disorder. CDC began with six sites (Arizona, Georgia, Maryland, New Jersey, South Carolina, and West Virginia) in 2000 and in 2002 expanded to include eight additional sites (Alabama, Arkansas, Colorado, Missouri, North Carolina, Pennsylvania, Utah, and Wisconsin). Today, we are continuing our surveillance efforts in ten of these sites. While this method does not provide a nationally representative sample, the network represents the largest effort to monitor prevalence to date, capturing up to 10 percent of the U.S. population of 8-year-old children. The network aims to provide accurate information and a strong basis for bringing autism and

developmental disabilities surveillance to scale, similar to our national efforts in monitoring other urgent realities.

Recent Prevalence Estimates

Together with our partners in the ADDM network, CDC is beginning to answer one of the critical concerns that I discussed earlier— are rates of autism spectrum disorders truly increasing? In February of this year, the CDC released the largest summary of prevalence data from multiple U.S. communities ever reported. The results showed an average of 6.7 children out of 1,000 with an autism spectrum disorder in the six communities assessed in 2000, and an average of 6.6 children out of 1,000 with an autism spectrum disorder in the 14 communities included in the 2002 study. The average finding of 6.6 and 6.7 per 1,000 eight-year-olds translates to approximately 1 in 150 children in these communities. This estimate is consistent with the upper end of prevalence estimates from previously published studies, with some of the communities having an estimate higher than those previously reported in U.S. studies. Reported rates ranged from about 1 in 100 to 1 in 300 children in the 2002 study year.

Six of the participating sites (Arizona, Georgia, Maryland, New Jersey, South Carolina, and West Virginia) reported data in both 2000 and 2002. Autism spectrum disorder prevalence was similar across the two years in four of the six sites. New Jersey's prevalence estimates are higher than all other sites in both years, but did not increase significantly between 2000 and 2002. In West Virginia, the prevalence estimate is significantly higher in 2002 than in 2000; the

prevalence in Georgia appears to have increased, but not significantly. While the stability of autism spectrum disorders in four of the six sites is fairly consistent, the increase in two sites is a concern.

As anticipated, the findings from both study years confirmed a higher prevalence for boys than girls; this finding is consistent with past studies. Also, the data show some differences in rates among children by race or ethnicity. Similar to past reports, prevalence rates in most sites were similar for white and black children; however, five of the 14 sites found a higher prevalence among white children compared to estimates for black children.

In addition to measuring prevalence and demographic differences, the studies looked at when parents and others first noted signs of developmental concerns in their children. We know that autism and related conditions can be diagnosed as early as 18 months. However, these studies showed that up to 88 percent of children with an autism spectrum disorder had documented developmental concerns before the age of three, but half of these were diagnosed between four-and-a-half and five-and-a-half years. It is of critical importance to diagnose the child as early as possible, as early intervention services hold the most promise to improve the quality of life for these children and their families.

The 2000 and 2002 data points do not constitute a trend, but they do provide important baseline information on the prevalence of autism spectrum disorders in

multiple areas of the United States. As I mentioned earlier, we are continuing to work with our network partners on prevalence estimates for 10 of these same sites for 2004 and 2006. Since the system has now been established, I expect information for these new data points will come more quickly, hopefully by the end of 2008.

I want to stress that CDC and many of our public and private partners see these numbers as an important step in understanding autism spectrum disorders, but more importantly, we recognize that 1 in 150 children represents the lives of the hundreds of thousands of children and parents touched by autism and related conditions. Because of this, we are committed to the search for answers. We are also working to ensure that parents, health care and child care professionals, and everyone who cares for children, are able to recognize the early signs of autism spectrum disorders. In the absence of a cure, early identification and action hold the most promise for affected children and families.

Epidemiologic Research

We all want to know the causes of autism and related conditions. In addition to building a public health surveillance network for developmental disabilities, CDC has also been researching potential causes. Following the passage of the Children's Health Act of 2000, CDC has been working closely with partners in five sites to develop the Centers for Autism and Developmental Disabilities Research and Epidemiology, or CADDRE. This multi-state collaborative study

will help to identify factors that may put children at risk for autism spectrum disorders and other developmental disabilities.

CADDRE is a collaborative effort from which we expect to build a large pooled data set that will be used to examine priority research questions. As the largest epidemiologic study of its kind, it holds the potential to be an important complement to the array of other work occurring at the National Institutes of Health and in academia. It is important to note that what CDC brings to autism spectrum disorder research is a unique perspective of studying health issues in large populations . not just among individuals or families who self-refer for intervention or study. To date, CADDRE sites have studied conditions that often occur with autism spectrum disorders, screening and management, and associations with immune system and genetic and environmental factors.

Later this spring, CADDRE will begin data collection to study a number of factors for their potential association with autism spectrum disorders. Known as the Study to Explore Early Development (SEED), the factors include: infections or abnormal responses to infections in the child, mother, or father; genetic factors in the child, mother and father; mother's reproductive history; abnormal hormone function in the child, mother or father; gastrointestinal problems in the child; family history of medical and developmental problems; select environmental exposures; behaviors during pregnancy; and parents' occupations and other socio-demographic factors. The information will be obtained by conducting

interviews and exams, reviewing medical records, and by collecting cheek swabs and blood and hair samples.

Several steps in the development of SEED have already been completed. The protocol has been written, and Institutional Review Board approval has been obtained. In addition, site-specific advisory boards have been established to review the study materials and the study design. Focus groups with parents of children . with and without developmental disabilities . were conducted to obtain additional feedback on the study design and feasibility of the study. The implementation and quality control protocols for all aspects of SEED field work have been developed and train-the-trainer sessions for field implementation procedures have been completed. Data sharing protocols and general analysis plans have been developed, and the CADDRE Information System (web-based subject tracking and data collection application) has been established. We expect data collection to take three to four years, and preliminary results would be available shortly thereafter.

Study participants will include approximately 3,000 children ages 2-5 years and their parents. All study children will be drawn from the cohort of children born and currently residing in the study areas of each CADDRE site in select birth years. Three groups of children will be selected: children identified with autism spectrum disorders, children identified with other developmental problems, and a random sample of all children in each area born in the selected birth years (most

of them typically developing).

Learn the Signs. Act Early.

Recent studies have shown that developmental disabilities such as autism spectrum disorders can be diagnosed as early as 18 months; however, we know that about half of all children are not diagnosed until much later. Early intervention is a child's best hope for learning to communicate and connect with his or her parents and friends and to be able to learn in a classroom with his or her peers.

CDC, in collaboration with a number of national partners . the American Academy of Pediatrics (AAP), Autism Speaks (Cure Autism Now and the National Alliance for Autism Research, which have both recently merged with Autism Speaks), the Autism Society of America (ASA), First Signs, the Interagency Autism Coordinating Committee (IACC), and the Organization for Autism Research (OAR) . launched a national public awareness campaign in 2004 called *Learn the Signs. Act Early.* The campaign aims to educate parents, health care professionals, and child care providers about child development, including the early signs of autism spectrum disorders and other developmental disabilities, and to encourage developmental screening and intervention. *Learn the Signs. Act Early.* builds on familiar experiences of parents, such as monitoring their children's physical growth, and expands to social and emotional milestones such as how children speak, learn, act, and play. Just as taking a first step is a developmental milestone, so are smiling, pointing, and waving

goodbye.

We know that when developmental delays are not recognized early, children cannot get the help they need. By increasing the awareness of autism spectrum disorders and other developmental disabilities and their signs and symptoms, we can increase early developmental screening, diagnosis and intervention. This means affected children can receive the help they need to enhance their development and improve the quality of life for them and their families.

To date, the campaign has reached more than 11 million health care professionals, parents, partners, campaign champions, and it is achieving its first goal- to encourage target audiences to ~~learn~~ *Learn the Signs* of autism spectrum disorders and other developmental disabilities. Outcome data show significant improvements in the percentage of parents who are aware of early warning signs of developmental delays, as well as increases in the number of pediatricians who agree that a child with an autism spectrum disorder can be diagnosed as early as the age of 18 months. Since the launch of the campaign, more pediatricians report that they regularly screen pediatric patients for developmental delays.

In November 2006, *Learn the Signs. Act Early* launched the childcare provider segment, targeting the more than 407,000 childcare facilities in the United States. This new phase will provide free materials to help childcare providers

and preschool teachers educate parents about child development and autism spectrum disorders.

Future Opportunities

CDC recognizes that parents want answers. If a child has an autism spectrum disorder, his or her parents want to know what caused it, the most effective intervention, and how they can lower their risks if they plan to have other children. We share their frustration at not having more answers about the causes and possible cure for the debilitating symptoms of autism and related conditions. That is why CDC continues to track the rates of autism spectrum disorders, research possible causes, and provide accurate information about identifying developmental concerns and seeking help during a child's early years of development.

CDC is positioned to bring surveillance, research, awareness and intervention activities to scale. Building on the encouraging success in these areas, CDC can continue answering important questions about prevalence and trends and can bring to bear population-based research tools in the effort to find answers about potential causes of autism spectrum disorders. The CDC can encourage the best known timely interventions for children and their families. Enhancing our programs would allow us to maintain surveillance in key sites and evaluate prevalence for different age groups, research potential causes more aggressively, and answer prevalence and trend questions faster. We can

build on successes in educating the public about early intervention and education in our *Learn the Signs* campaign by continuing to develop and implement strategies to support parents, healthcare professionals and childcare providers in their efforts to *Act Early* when concerns are raised about autism spectrum disorders and other developmental disabilities.

Thank you for the opportunity to appear here today to discuss this important public health issue. Thank you also for your continued interest in, and support of, our activities on autism spectrum disorders. Together we hope to find answers for this very complex disorder.

I appreciate your longstanding support for our vision of healthy people throughout all stages of their lives and all facets of living. I will be happy to answer any questions you may have.