



**Testimony before the  
Committee on Oversight and Government  
Reform  
United States House of Representatives**

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**Autism Spectrum Disorder**

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Good afternoon Chairman Issa, Ranking Member Cummings, and distinguished members of the Committee. Thank you for the opportunity to be here today. I am Dr. Coleen Boyle, Director of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC). CDC continually works to keep America safe from health threats of all kinds. The Budget includes \$21.265 million in FY 2012 for CDC's autism work. Today, I will focus my remarks on how CDC uses those funds in our autism portfolio and on CDC's role on the Interagency Autism Coordinating Committee (IACC).

### **Introduction**

Autism Spectrum Disorder (ASD) continues to be an important public health concern in the United States and around the world. ASD is a group of developmental disorders characterized by unusual patterns in a person's communication, behavior, and interactions with others. Symptoms of ASD are usually present after a child's first birthday, but before three years of age, and can be identified by observing a child's behavior and development. While there is currently no known medication or treatment to cure ASD, intensive research efforts are yielding progress on the development of innovative screening tools that can be used to detect ASD in early childhood and behavioral therapies that can improve cognitive function and social development in children and adults with ASD.

Data from CDC indicate that more children are being identified with ASD than in previous years, though many of these children are not being identified as early as they could be. The emotional toll on families and communities is staggering, and the economic burden can be significant. Because of the long-term effects of ASD, the lack of a known cause or cure, costs, and concerns about the increasing identified prevalence, ASD have profound implications for affected children, families, educators, healthcare professionals, local and national organizations, and the Federal Government.

CDC is supporting communities by tracking ASD, helping families through early identification efforts, and addressing unanswered questions through research into the risk and protective factors associated with autism.

### **Supporting communities by tracking ASD**

To better understand the prevalence of ASD in the United States, and to gain insights into potential causes, CDC expanded surveillance of autism and developmental disabilities in additional geographic areas of the United States. CDC now supports surveillance programs in 12 States: Utah, Colorado, Arizona, Missouri, Wisconsin, North Carolina, New Jersey, Maryland, South Carolina, Arkansas, Alabama, and Georgia. This collaborative body, known as the Autism Developmental Disabilities Monitoring (ADDM) Network, seeks to develop or improve programs that track the number of children with ASD in their States. The goal of the ADDM Network is to provide comparable, population-based estimates of the prevalence rates of autism and related disorders in different sites over time.

In March 2012, CDC released updated estimates of prevalence from the ADDM Network (the third report in a continuing series of reports) indicating that 1 in 88 children had been identified with an ASD. This number compares with an identified prevalence of 1 in 110 in 2009, estimated using data from surveillance year 2006. In 2007, we reported a rate of 1 in 150 children, based on data from 2002.

While there is no simple explanation for the increase, we know that it is due in part to improved methods for identification and diagnosis, and to increased public awareness partly resulting from the expansion of behavioral health services in local communities. However, we do not know exactly how much of the increase is due to these factors. To better understand the causes of the increase, we need to continue tracking ASD and continue working with our colleagues at NIH and in the broader scientific community to improve identification of risks and protective factors associated with autism.

Based on the methods we use for tracking autism, we know more than just how many children have ASD. For example, we know that ASD remains nearly five times more common among boys than girls. We also know that the largest increases in identified prevalence over time were among Hispanic, African-American children, and children without intellectual disability. Some of the most recent increases can be attributed to greater awareness of ASD and improved identification of children with ASD within communities. However, this explanation can only account for part of the increase over time, since more children were identified with ASD among all racial and ethnic groups and at all levels of intellectual ability.

In the 2008 reporting cycle, we also saw more variation in prevalence estimates across sites than in previous years, fluctuating anywhere from 1 in 210 to 1 in 47. We know that some of this variation is due to differences in the way children are identified and served in their communities. Our data also show that more children are being diagnosed at earlier ages, which is a positive trend because of the value of early intervention. Still, most are not diagnosed until after four years of age, when it may be too late to receive the full benefit of early intervention services. The one thing these data tell us with certainty is that more children and families need help.

Through CDC's work in tracking ASD over the past 15 years, we know more about which children are more likely to have ASD, at what age they are likely to be diagnosed, and we know whether progress has been made in early diagnosis of children with ASD. Communities need this type of information to plan for services and to understand where improvements can be made to help children and their families.

## **Helping families through early intervention**

While we know that many individuals with ASD will need support throughout their lives, a growing body of research tells us that the earlier a child is identified with an ASD and connected to services, the greater the benefit of intervention will be to that child. And unfortunately, the data tell us that there are many children with ASD who are not being diagnosed as early as they could be. CDC is working hard to change that, offering free tools through our “Learn the Signs. Act Early.” program, which aims to improve the early identification of children with ASD. We are putting these tools in the hands of healthcare professionals, childcare providers, and parents, with a special focus on minority and economically disadvantaged populations. CDC is also working with States and local communities to improve early identification. Notably, we have worked with partners from other Federal agencies to develop national goals in early screening, diagnosis, and enrollment in services for children with ASD giving communities, for the first time, a benchmark to measure progress.

## **Answering unanswered questions through research**

CDC knows that people want answers about autism, and so do we. To identify the causes of ASD, the scientific community first needs to better understand the risk factors for ASD. CDC’s surveillance data serve as a guide for our autism research and for the research of other scientists across the country. At CDC, we are conducting the Study to Explore Early Development (SEED), which is helping to identify factors that put children at risk for ASD. SEED is looking at many potential risk factors including genetic, environmental, maternal health, and behavioral factors. One key strength of SEED is that it offers an in-depth look not only into the characteristics of ASD, but also the interaction with environmental and genetic factors. We completed the first phase of this study in 2012 and recently began the second,

which we hope will ultimately help us to better understand what makes one child more or less likely to have an ASD.

CDC also conducts epidemiologic studies using national survey data on children's health. These studies include indepth assessments of differences in ASD prevalence in various demographic subgroups, family impact of having a child with an ASD, and assessment of co-occurring health conditions and health care needs in children with autism and other developmental disabilities. We have also used ADDM surveillance data and survey data to assess factors that might be contributing to the observed increases in autism prevalence.

ASD is one of a few conditions that have a Federal committee tasked with coordinating research efforts. The IACC has played a pivotal role in helping Federal agencies, non-profit organizations, and members of the public work together to identify priorities and strategies to address key issues of importance to the autism community. CDC is an active member of the IACC, providing an epidemiologic and public health perspective on ASD. As a member of the IACC, CDC seeks to engage other Federal agencies and public stakeholder groups and individuals in a complementary and cooperative fashion that is consistent with and responsive to Congressional direction and intent. CDC's work informed the development of the IACC Strategic Plan for Autism Research and CDC's autism activities are key components of this comprehensive plan to address ASD.

It has become clear that there are likely several complex causes influencing what makes one child more likely to have an ASD than another. This is a challenging and complex disorder to unravel. While we search, it is important that we not lose sight of the many individuals, families, and communities struggling with ASD today.

## **Conclusion**

ASD is an important and immediate public health concern. More children than ever before are being identified with ASD. Families and communities are struggling with financial burdens, complex healthcare decisions, and need for services. We are bringing our collective resources to bear to understand what is putting our children at risk for autism. We at CDC will continue providing communities with essential data on the prevalence of ASD so that they can adequately plan for services to meet the needs of these children. We will continue developing resources that help identify children with ASD as early as possible so they can benefit from the early intervention services that can help them reach their full potential. And, we will continue the important research to better understand why some children are more likely to develop autism than other children.

Thank you for the opportunity to present this testimony to you today. I would be happy to answer any questions.

Coleen A. Boyle, PhD, MS hyg



## **Director, National Center on Birth Defects and Developmental Disabilities**

Dr. Boyle received her M.S.(hyg.) in biostatistics and Ph.D. in epidemiology from the University of Pittsburgh School of Public Health and completed postdoctoral training in epidemiologic methods at Yale University. Before joining CDC, Dr. Boyle served as a faculty member in epidemiology at the University of Massachusetts, Program in Public Health.

Dr. Boyle began her career at CDC in 1984, working on a large multi-faceted project to examine the impact of Agent Orange exposure on U.S. military personnel who served in Vietnam. She joined the Division of Birth Defects and Developmental Disabilities in 1988, and has been with the National Center on Birth Defects and Developmental Disabilities (NCBDDD) since its creation in 2001, serving as associate director for science before becoming Director of NCBDDD in 2010. Dr. Boyle received the CDC Charles C. Shepard Award for scientific excellence in 1997.