

# National Center on Birth Defects and Developmental Disabilities Annual Report Fiscal Year 2015

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## HELPING CHILDREN LIVE TO THE FULLEST BY UNDERSTANDING DEVELOPMENTAL DISABILITIES

**CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is at the forefront of improving health and early childhood developmental outcomes for children with developmental disabilities, such as autism and attention-deficit/hyperactivity disorder.**

Developmental disabilities are some of the most significant child health issues facing families and our nation today. About 1 in 6, or roughly 15%, of children aged 3 through 17 years have one or more developmental disabilities, such as attention-deficit/hyperactivity disorder (ADHD), autism, cerebral palsy, hearing loss, vision impairment, learning disability, and intellectual disability.<sup>1</sup> Through tracking, research, and education NCBDDD is paving the way to a better future for individuals, families and communities affected by these conditions.



### Accomplishments

- Launched a new phase of funding for the Autism and Developmental Disabilities Monitoring (ADDM) Network, the only collaborative network to monitor the number and characteristics of children with autism spectrum disorder (ASD) and other developmental disabilities in multiple communities throughout the United States. CDC will invest more than \$20 million over four years to shed light on important issues, such as gaps in early identification of children with ASD and the impact of DSM-5 diagnostic criteria on ASD prevalence.
- Published a new analysis looking at ASD symptoms among young children enrolled in CDC's Study to Explore Early Development (SEED). These results support the idea that ASD symptoms are found in children both with and without ASD. Because the study enrolled children with varying degrees of ASD symptoms, SEED researchers will be able to explore what puts children at risk for ASD and the different ways children may develop ASD.
- Trained and supported 32 Act Early Ambassadors across 29 states to promote developmental monitoring and screening to help young children with developmental delays be identified and connected with appropriate care and support as early as possible. Worked with the Ambassadors and other partners to improve developmental monitoring and early identification of developmental delay. This sparked interest from parents, early care and education providers, health and social service professionals, and partners, resulting in a monthly average of over 140,000 unique visitors to the "Learn the Signs. Act Early." website, as well as 45,000 material downloads and more than 178,000 pieces of printed "Learn the Signs. Act Early." milestones material requested each month.

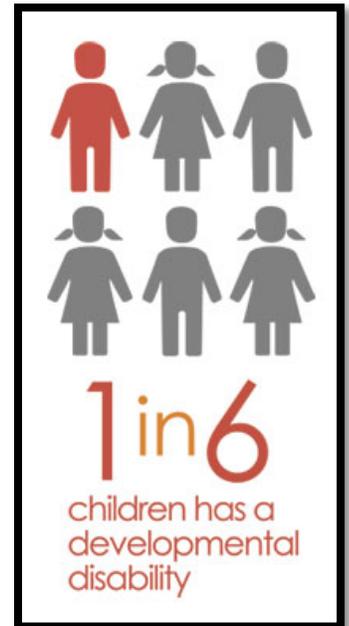
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1. Boyle CA, Boulet S, Schieve L, Cohen RA, Blumberg SJ, Yeargin-Allsopp M, Visser S, Kogan MD. Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics* 2011;27:1034-42.

- Raised awareness of recommended ADHD treatment with families, health professionals and policymakers by establishing benchmark data in relation to the American Academy of Pediatrics clinical practice guidelines for treatment of ADHD in young children.
- Closed the gap in the early identification of deaf and hard of hearing infants by launching EHDI-DASH (Early Hearing Detection & Intervention Data Analysis and Statistical Hub), an interactive dashboard that presents a range of data about the early identification of deaf and hard of hearing infants across the United States. The dashboard allows stakeholders to demonstrate and assess progress in improving referral to services by creating a series of interactive maps that summarize data on the percent of newborns receiving intervention services in states and territories.

## Looking to the Future

For 15 years, NCBDDD and its partners have been at the forefront of tracking, researching and providing information and tools on developmental disabilities such as ASD and ADHD. We know more about developmental disabilities than ever before, and we must continue our research so that children can live to the fullest. For ADHD, that means working to align current practice with best practice for treatment. For ASD, that means getting information to communities to inform action. For both conditions, identifying developmental concerns early offers children the best chance at early intervention and treatment and a path to full potential. To that end, “Learn the Signs. Act Early.” will continue to develop high quality, effective tools to empower parents, health professionals, and communities to closely monitor development and act early on developmental concerns.



## Notable Scientific Publications

Fountain C, et al. Association between assisted reproductive technology conception and autism in California, 1997-2077. *Am J Public Health* 2015;105(5):963-71.

Jo H, et al. Maternal pregnancy body mass index and child psychosocial development at 6 years of age. *Pediatrics* 2015;135(5):e1198-209.

McKeown RE, et al. The impact of case definition on ADHD prevalence estimates in community-based samples of school-aged children. *J Am Acad Child Adolesc Psychiatry* 2015;54(1):53-61.

Van Naarden Braun K, et al. Trends in the prevalence of autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan Atlanta, 1991-2010. *PLoS One* 2015;10(4):0124120.

Visser SN, et al. Treatment of attention-deficit/hyperactivity disorder among children with special health care needs. *J Pediatr* 2015;166(6):1423-30.

Williams TR, et al. Progress in Identifying Infants with Hearing Loss — United States, 2006–2012. *MMWR Morb Mortal Wkly Rep* 2015;64(13):351-356.

Wiggins LD, et al. Using standardized diagnostic instruments to classify children with autism in the Study to Explore Early Development. *J Autism Dev Disord* 2015;45(5):1271-80.



## Spotlight on: The Autism Science Foundation

This Spotlight was contributed by Alison Singer, Co-Founder and President of the Autism Science Foundation.

The Autism Science Foundation, a nonprofit corporation founded in 2009 for charitable and education purposes, helps to advance the most promising and innovative research on autism, one of the most common developmental disabilities addressed by the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities (NCBDDD). The Autism Science Foundation doesn't just fund important studies by the best-known researchers, but we believe it is critical to also support young scientists who are taking smart, new approaches to improving our understanding of autism and developing safe, effective and novel treatments to enhance the quality of life for children and adults with autism. By being nimble and less bureaucratic, we can catalyze innovative research that other funding sources might not be willing or able to support.

Our new Autism Sisters Project initiative exemplifies our mission. This exciting and important effort is engaging families in advancing autism research, specifically the search for a potential "female protective effect" for autism. By asking unaffected sisters of individuals with autism -- and their family members -- to help us build a better national genomic database, we are empowering them to make a difference in the lives of all people with autism. And we are giving scientists powerful data to inform one of the most promising areas of autism research today. As both the sister of an adult brother with autism and the mother of a daughter with autism, I know the Autism Sisters Project's focus on connecting families with scientific pursuit will resonate with many people.

We are also committed to spreading awareness about the importance of early diagnosis and early intervention. Early intervention, using evidence-based methods, can greatly improve the prognosis for a child with autism. We encourage all families to learn the signs and act early by talking to their healthcare provider if they suspect a developmental delay. We are proud to partner with NCBDDD on this important effort.

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