

Autism and Other Developmental Disabilities

Enhancing the Monitoring and Tracking of Autism and Other Developmental Disabilities and Advancing Research into the Risk Factors for these Conditions

What is the problem?

- CDC estimates 1 in 88 children has been identified with an autism spectrum disorder (ASD).
- Annual medical expenditures per child with ASD range from \$2,100 to \$11,200. Additionally, we know that intensive behavioral interventions can cost between \$40,000 and \$60,000 per child with autism per year. We also know that nonmedical costs of educating a child with ASD as a qualifying condition for special education is about \$13,000 a year.
- Studies in Asia, Europe, and North America have identified ASD among the population to be 0.6% to over 1%. A recent study in South Korea reported ASD to be 2.6% among the population.
- We do not know all of the causes ASDs.
- There is currently no cure for ASDs.



What do we know?

- Cases of autism are reported to occur in all racial, ethnic, and socioeconomic groups, yet are on average 4 to 5 times more likely to occur in boys than in girls.
- Studies have shown that parents of children with ASDs notice a developmental problem before their child's first birthday. Concerns about vision and hearing were more often reported in the first year, and differences in social, communication, and fine motor skills were evident from 6 months of age.
- Early screening and diagnosis improve access to services during a child's most critical developmental period. However, a diagnosis is not necessary before a parent can get help for their child.
- Most children with autism are not diagnosed until after they reach age 4, when it's too late to get the full benefit of early intervention.

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What can we do?

- We will continue to monitor and track the number of people diagnosed with autism over time to determine if the number is rising, dropping, or staying the same. We can also compare the number of children with autism in different areas of the country and among different groups of people. This information can help us look for causes of autism and can help communities plan for services.
- Through our Study to Explore Early Development (SEED), we will:
 - Examine the physical and behavioral characteristics of children with autism, children with other developmental disabilities, and children without a developmental delay or disability.
 - Compare health conditions among children with and without autism.
 - Investigate factors associated with a child's risk for developing autism.
- In 2011, we began analyzing the initial results of SEED, focusing on describing the children in terms of specific behaviors, developmental progress, medical issues, genetic and pregnancy factors, and demographics (age, race/ethnicity, gender, place of birth/residence). We also initiated the second phase of SEED and completed enrollment of families for the largest study in the U. S. to help identify factors that may put children at risk for autism. This effort will increase the number of families enrolled in SEED, allowing us to get better estimates of risk.
- Most children who have autism are not diagnosed until after they reach age 4, even though many children can be identified before age 2. CDC supports recommendations that all children be screened by age 2, because early screening and diagnosis improve access to services during a child's most critical developmental period.

Did you know?

- Study to Explore Early Development (SEED) enrolled more than 3,700 children and their families in the largest study in the U.S. to help identify what puts children at risk for autism.
- SEED looks at autism risk factors across the population; a unique contribution to the Interagency Autism Coordinating Committee (IACC) Strategic Plan for Autism Research.



“The ‘Learn the Signs. Act Early.’ campaign fits perfectly with the work we do every day with families. The materials give our families a simple, concise overview of key milestones they can watch for in their children. And our staff is glad to have this additional support in talking with families about child development in a consistent, effective way.” Quote from a WIC manager in St. Louis related to the ‘Learn the Signs. Act Early.’ project

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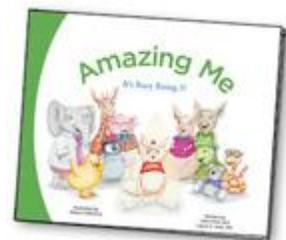
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- NCBDDD's "Learn the Signs. Act Early." program is working to improve awareness of developmental milestones and the importance of tracking them among parents, health care providers and early educators. We are currently funding four state demonstration grants in Utah, Washington, Missouri, and Alaska to help determine effective methods for reaching parents. One grantee in St. Louis, Missouri, has implemented "Learn the Signs. Act Early." messages and materials in 12 Women, Infants and Children (WIC) clinics. Milestone checklists are completed for every child who receives WIC benefits and parents are referred to health care providers as appropriate.
- We continue to track the occurrence of autism in younger children. By tracking autism among 4-year-old children, we can improve efforts at identifying the condition earlier.
- We will continue working with partners and stakeholders to develop ways to close the gap between when parents first have a concern about their child and when they receive a diagnosis. The earlier we can identify that a child has autism and the earlier we can get them into services, the more that child can benefit. However, parents do not need to wait for a diagnosis to get services and support.

Accomplishments

- NCBDDD and the Health Resources and Services Administration (HRSA) published a study showing that developmental disabilities are common: about 1 in 6 children in the U.S. had a developmental disability in 2006–2008. This tracking data also show that parent-reported developmental disabilities have increased 17.1% from 1997 to 2008. This study underscores the increasing need for health, education and social services, and more specialized health services for people with developmental disabilities.
- NCBDDD developed a mathematical model to estimate how changes in pregnancy and birth factors might have contributed to the subsequent increase in autism. The data showed that each pregnancy factor examined likely accounted for less than 1% of the total increase (pregnancy factors included preterm and very preterm delivery, low and very low birth weight, multiple birth, cesarean delivery, breech presentation, and use of in vitro fertilization or other assisted reproductive technologies).
- To increase awareness of developmental milestones, NCBDDD's "Learn the Signs. Act Early." program has created a new children's book, *Amazing Me: It's Busy Being 3!* The story of an amazing 3-year old kangaroo holds the child's attention and inspires an interest in books and reading while educating the parent-reader about different milestones that are important signs of a child's development. *Amazing Me* also encourages the parent-reader to look for milestones in their own child, provides parents a tool to track their child's development, and encourages parents to talk with their child's doctor about their child's development. Books will be distributed free to low-income parents of 3-year-olds through the Reach Out and Read pediatric network and in partnership with the American Academy of Pediatrics/Bright Futures. [The book is also available on CDC's website.](#)



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- NCBDDD's data on the burden of autism and descriptive characteristics of children with the condition are used to inform the Interagency Autism Coordinating Committee (IACC) Strategic Plan for Autism Research. Working in collaboration with the IACC, our autism activities complement the goals and objectives of the plan.
- NCBDDD conducted a workshop in partnership with Autism Speaks to understand identification issues and risk factors influencing increases in autism. The workshop brought together scientists and stakeholders from the autism community to increase knowledge about autism prevalence, to learn from other conditions, and to share ideas on how to move forward to better understand autism trends. An executive summary and the complete workshop summary are available for download on our website.
- NCBDDD worked with partners from other federal agencies to establish, for the first time, a Healthy People 2020 goal focused on autism screening, diagnosis, and enrollment in services. These measurable goals are important because the Autism and Developmental Disabilities Monitoring (ADDM) data show that caregivers or service providers typically have concerns about a child's development before they are 2, but most children are still being diagnosed much later, after 4.
- NCBDDD, HRSA, and the Association of University Centers on Disability established the Act Early Ambassadors program to strengthen state-level efforts to improve early identification of autism and other developmental disabilities. This program has created a network of champions to expand the reach of the "Learn the Signs. Act Early." program. Ambassadors use and promote "Learn the Signs. Act Early." messages and materials and serve as liaisons to their Act Early state teams. Act Early Ambassadors were funded in ten states during 2011: Hawaii, Illinois, Massachusetts, Montana, North Carolina, New Mexico, Ohio, Rhode Island, Tennessee, and Wisconsin. Additional Act Early Ambassadors were selected in 2012.

Did you know?

- Early intervention (before school age) can have a significant impact on a child's ability to learn new skills as well as reduce the need for costly interventions over time.
- In the United States, about 1 in 110 children has autism and about 1 in 6 children aged 3–17 has a developmental disability.



'Learn the Signs. Act Early'.
Ambassadors, June 23, 2011.

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- The Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee that coordinates all efforts within the Department of Health and Human Services (HHS) related to autism. Through its inclusion of both Federal and public members, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum.
- Each year, the IACC develops a strategic plan for autism research that takes into account all that we've learned about autism in the previous years and keeps the federal response to autism focused and informed.

Looking to the future

- Our ADDM Network will continue to help us learn more about autism, including understanding which children are more likely to have autism diagnosis and at what age that diagnosis is likely to be made.
- NCBDDD will continue collaborations with HRSA to implement and evaluate the "Learn the Signs. Act Early." campaign through four state demonstration grants (Utah, Washington, Missouri, and Alaska). Results on the feasibility and impact of these efforts will be available in early 2013.
- In 2012, through SEED, NCBDDD will investigate maternal medication use, infections, and lifestyle factors and whether they interact with some children's genes to put them at greater risk for autism.
- With the current infrastructure in place, we are well positioned to expand our work in the area of cerebral palsy by:
 - Increasing the tracking sample size to allow better examination of the characteristics of children with cerebral palsy, including socioeconomic factors and specific subtypes.
 - Conducting population-based research to identify additional strategies to prevent cerebral palsy and to detect the relationships between risk factors and cerebral palsy.
- NCBDDD will continue partnerships with National Institutes of Health and Autism Speaks to investigate autism in Somali children compared to other populations located in Minneapolis. Results could provide a framework for future studies on the risk factors and causes of autism and may also provide data that can be used for advocacy and service planning.
- NCBDDD began working through a public/private partnership with Autism Speaks to evaluate the use of direct screening and assessment to enhance the completeness of autism estimates. Through this partnership, Autism Speaks is providing supplemental funding to add complementary screening and assessment to one of the ADDM sites.

Notable 2011 NCBDDD Scientific Publications

- Schieve LA, Rice C, Devine O, Maenner MJ, Lee LC, Fitzgerald R, Wingate MS, Schendel D, Pettygrove S, van Naarden Braun K, Durkin M. (2011). **Have secular changes in perinatal risk factors contributed to the recent autism prevalence increase? Development and application of a mathematical assessment model.** Ann Epidemiol, 21(12):930-45. Epub 2011 Oct 13.
- Boyle CA, Boulet S, Schieve L, Cohen RA, Blumberg SJ, Yeargin-Allsopp M, Visser S, Kogan MD. (2011). **Trends in the prevalence of developmental disabilities in US children, 1997-2008.** Pediatrics, 127(6):1034-42.

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- Avchen, R., Wiggins, L.D., Devine, O., Van Naarden-Braun, K., Rice, C., Hobson, N.C., Schendel, D., & Yeargin-Allsopp, M. (2011). **Evaluation of a records-review surveillance system used to determine the prevalence of autisms.** J Autism Dev Disord, 41(2):227-36.
- Kirby RS, Wingate MS, Van Naarden Braun K, Doernberg NS, Arneson CL, Benedict RE, Mulvihill B, Durkin MS, Fitzgerald RT, Maenner MJ, Patz JA, Yeargin-Allsopp M. (2011). **Prevalence and functioning of children with cerebral palsy in four areas the United States in 2006: A report from the Autism and Developmental Disabilities Monitoring Network.** Res Dev Disabil, 32(2):462-9.
- Jarquin VG, Wiggins LD, Schieve LA, Van Naarden-Braun K. (2011). **Racial disparities in community identification of autisms over time; Metropolitan Atlanta, Georgia, 2000-2006.** J Dev Behav Pediatr, 32(3):179-87.
- Schieve LA, Boulet SL, Kogan MD, Yeargin-Allsopp M, Boyle CA, Visser SN, Blumberg SJ, Rice C. (2011). **Parenting aggravation and autisms: 2007 National Survey of Children's Health.** Disabil Health J, 4(3):143-52.
- Benedict RE, Patz J, Maenner MJ, Arneson CL, Yeargin-Allsopp M, Doernberg NS, Van Naarden Braun K, Kirby RS, Durkin MS. (2011). **Feasibility and reliability of classifying gross motor function among children with cerebral palsy using population-based record surveillance.** Paediatr Perinat Epidemiol, 25(1):88-96.
- Schelonka RL, Maheshwari A, Carlo WA, Taylor S, Hansen NI, Schendel DE, Thorsen P, Skogstrand K, Hougaard DM, Higgins RD for the Neonatal Research Network. **T cell cytokines and the risk of blood stream infection in extremely low birth weight infants.** Cytokine, 53(2):249-255.
- Obi O, Van Naarden Braun K, Baio J, Drews-Botsch C, Devine O, Yeargin-Allsopp M. (2011). **Effect of incorporating adaptive functioning scores on the prevalence of intellectual disability.** Am J Intellect Dev Disabil, 116(5):360-70.
- Amendah, D., Grosse, S.D., Peacock, G., & Mandell, D.S. (2011). **The economic costs of autism: A review.** In D. Amaral, D. Geschwind, & G. Dawson (Eds.), *Autisms* (pp. 1347-1360). Oxford: Oxford University Press.

Featured Videos

[Baby Steps: "Learn the Signs. Act Early."](#)

[Learn the Signs. Act Early. Three Mothers - Television PSA](#)

[The Autism Developmental Disabilities and Monitoring Network](#)

[What is Autism?](#)

[Importance of the ADDM Network](#)

[What is SEED?](#)

[Importance of SEED](#)

[Who is participating in SEED?](#)



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[What is surveillance?](#)

[What is Epidemiology?](#)

[National Birth Defects Prevention Study](#)

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