Developmental disabilities, such as autism spectrum disorder (ASD), attention-deficit/hyperactivity disorders (ADHD), cerebral palsy, and hearing or vision loss, create delays and/or functional limitations that can impact a child’s health and well-being. Approximately 1 in 6 children in the United States have developmental disabilities or other developmental delays. To best support children and their families, CDC is committed to

- Monitoring common developmental disabilities,
- Identifying factors that can put children at risk for disabling conditions,
- Exploring possible causes of developmental disabilities, and
- Improving identification of developmental delays.

Accomplishments

• Published updated ASD characteristics and prevalence among 8-year-old children in 11 communities in the United States from data collected by the Autism and Developmental Disabilities Monitoring Network. This study identified about 1 in 59 children with ASD in 2014 compared to about 1 in 69 children in 2012. These data have been used to
  - Promote early identification of children with ASD;
  - Plan for service needs of children with ASD and their families; and
  - Guide research and inform policy.

• Supported deaf/hard-of-hearing children to have a healthy launch into school. Ensuring that children have received hearing screening, diagnosis, and intervention services early is critically important for their learning and development. CDC’s Early Hearing Detection and Intervention (EHDI) Program tracks the 1-3-6 milestones (on page 9) to confirm timely receipt of these critical services. However, some children are lost to the system. CDC partnered with the EHDI Program in Texas to understand how to prevent loss-to-follow-up and loss-to-documentation of receiving services among infants who do not pass a newborn hearing screening. The team identified
  - Potential reasons children do not receive services;
  - Barriers to documenting the diagnosis and intervention status of infants who did not pass their hearing screening; and
  - Recommendations to reduce these challenges. Findings will help states increase the number of deaf/hard of hearing children who receive the appropriate hearing services at the appropriate time so they are ready to learn in school.
• Published more than 10 peer-reviewed articles using data from the Study to Explore Early Development (SEED), the largest study in the United States that focuses on identifying factors that may put children at risk for ASD and examining common characteristics among children with ASD. SEED researchers found
  - A possible link between shorter and longer time periods between births and having a child with ASD;
  - Self-injurious behaviors were more common among children with ASD than in children with developmental disabilities without ASD symptoms; and
  - A link between immune conditions in mothers and ASD and other developmental disabilities in their children.

CDC also began enrolling participants in SEED Teen, a follow-up study to help broaden our understanding of the health and development of individuals with ASD as they reach adolescence and adulthood.

• Conducted the Zika Outcomes and Development in Infants and Children (ZODIAC) investigation through CDC’s partnership with Brazil’s Ministry of Health, via support from the U.S. Agency for International Development. This follow-up assessment of children aged 12-24 months who were conceived during the 2015-2016 Zika virus outbreak in Brazil provided a first-ever description of the longer-term health and developmental effects of congenital Zika virus infection in children with microcephaly. ZODIAC findings are being used to
  - Understand the full range of potential healthcare problems;
  - Educate parents and healthcare providers;
  - Prepare communities for long-term medical and social service needs; and
  - Assist children in developing to their full potential.

• Launched the Learn the Signs. Act Early. Milestone Tracker App in Spanish and English to help parents monitor their child’s development and get tips for taking action when there is a concern. Since its launch, the Milestone Tracker App was downloaded more than 140,000 times in 2018. Additionally, to promote developmental monitoring and screening for young children, CDC increased the number of state and territorial Act Early Ambassadors (55 total), who help identify and connect young children with developmental delays with the appropriate services and support as early as possible.
Looking to the Future

Children with developmental disabilities and their families often face personal, social, and financial challenges. CDC and its partners work across systems to improve identification of developmental delays, increase the connection of these children and their families to medical, developmental, and behavioral intervention services, and provide tools and resources to help families facing these challenges. NCBDDD’s mission extends to understanding optimal development at each stage of life, from promoting school readiness to the health of teens with ASD, as well as helping families and children get the support they need.

Notable Scientific Publications


SPOTLIGHT ON:

Association of Maternal and Child Health Programs

The Association of Maternal & Child Health Programs (AMCHP) is a national resource, partner, and advocate for state public health leaders and others working to improve the health of women, children, and families, including children and youth with special healthcare needs (CYSHCN). Recognizing the value of building high-quality systems of care for CYSHCN, AMCHP partnered with CDC, the Health Resources and Services Administration, and the Association of University Centers on Disabilities to support the Learn the Signs. Act Early (LTSAE) State Systems project and implement the State Public Health Autism Resource Center (SPHARC).

Helping State Grantees Improve Early Identification
AMCHP supports state and jurisdiction LTSAE grantees to strengthen systems for the early identification and improved coordination of services for children at risk for autism spectrum disorder and other developmental disabilities (ASD/DD). With AMCHP grants and technical assistance, state teams promote the use of CDC’s materials to help increase parental engagement of developmental monitoring. Successes include the production of culturally relevant cable access TV shows promoting LTSAE and the development and implementation of LTSAE trainings and materials for physicians, public libraries, hospitals, parents, and early childhood care providers (WIC, Head Start, etc.). To learn more, visit the LTSAE State Systems Grantees web page.

Peer-to-Peer Exchange (P2P) to Improve Systems of Care
AMCHP’s SPHARC convenes an annual P2P Exchange, which enables cross-state learning and capacity building for state programs implementing systems of care for children and youth with ASD/DD. The 2018 Exchange highlighted the importance of parents- and self-advocates, and featured the sharing of best practices and resources. The newsletter article relays the impactful stories told by a parent and self-advocate. Additionally, SPHARC released an interactive story wall featuring family navigators’ stories on their experiences supporting families as they access comprehensive systems of care for CYSHCN. To learn more, visit the SPHARC web page.

NCBDDD’s Developmental Disabilities and Child Development Topics

- Attention-Deficit/Hyperactivity Disorder
- Autism Spectrum Disorder
- Caring for Children in a Disaster
- Cerebral Palsy
- Child Development
- Children’s Mental Health
- Fetal Alcohol Spectrum Disorders
- Hearing Loss
- Intellectual Disability
- Learn the Signs. Act Early. Program
- Tourette Syndrome

Visit www.cdc.gov/ncbddd to learn more.