

# LOOKING BACK




## CDC's Impact on Families in 2024



### Dear Partners and Colleagues,

We are grateful for you! CDC's National Center on Birth Defects and Developmental Disabilities has many impactful successes from 2024 thanks to you. You help us do things better and reach our goals. And this year has been particularly successful in that we exceeded all our goals. It has been a year

filled with collaboration and doing more with less. We have so many important partnerships that have lasted through the years helping families. We have highlighted a few major accomplishments to share in our review of 2024. Please join us in our celebration.



**2.3M+**  
APP DOWNLOADS

Exceeded the goal of 2.3 million downloads of the *Milestone Tracker* app ahead of schedule

**MMWR**

Published the first national estimates in more than a decade of the number of adults with ADHD



Published award-winning rapid estimates of mpox vaccine effectiveness using nationwide electronic health record data

**20X** GREATER REACH

Reached a record number of hispanic women with media Mother's Love: Roots of Life with Folic Acid

**SCDC**  
SICKLE CELL DATA COLLECTION

The SCDC program expanded to 16 states, covering 50% of the U.S. population with SCD



Co-hosted inaugural CDC Disability Summit attended by more than 1,900 participants

## **CDC's Developmental *Milestone Tracker* App Exceeded Milestone Goal—Over 2.3 Million Downloads**

Research shows the dramatic impact of COVID-19 on early evaluation and identification of developmental delays in young children. Moved to action by this data, CDC launched an initiative to support families and identify children who may benefit from early intervention services. CDC partnered with federal agencies and organizations promoting children's health such as the American Academy of Pediatrics, Head Start, and Sesame Street to address the impact of developmental delays in young children. This partnership supercharged a strong intentional focus on early childhood development and evaluation of any issues early, resulting in earlier access to services and intervention across the United States. Successes of the initiative include:

- Exceeded the goal of 2.3 million downloads of the *Milestone Tracker* app ahead of schedule.
- The families of 70% of children the app identified as missing a milestone shared a concern with their child's healthcare provider.
- At least 45% of them report their child received services.
- Act Early Ambassadors engaged Federally Qualified Health Centers from 29 states (including 1 tribal entity) and 3 territories over the past year.
- Announced newest Act Early Ambassador cohort. 63 Ambassadors (including 18 NEW); representing 49 states, Washington, DC; 2 territories; 2 tribal entities; and 1 freely associated state.

## **CDC Published First National Estimates in More Than a Decade of the Number of Adults with ADHD**

CDC's publication Attention-Deficit/Hyperactivity Disorder Diagnosis, Treatment, and Telehealth Use in Adults was covered in major news outlets with 225 stories that reached 244 million people. These are the first national estimates in more than a

decade of the number of adults with ADHD, and the first to describe how old they were when diagnosed. The research found:

- Almost 15.5 million adults in the U.S. have diagnosed ADHD, and more than half were diagnosed in adulthood (aged older than 18 years).
- Nearly 1 in 3 adults with ADHD take stimulant medication, and the majority (71.5%) of them had difficulty filling their prescription because it was not available.
- Almost half of adults with ADHD have ever used telehealth for ADHD services.

## **Big Data, New Answers to Help Young Families Thrive**

In 2024 NCBDDD participated in a new private-public partnership with EPIC-COSMOS to use big data to answer important questions for US families living with disabilities and rare disorders. Increasingly, children are living through adulthood and families want to know what to expect for their child's future. As new curative and life-changing therapies are rapidly emerging, our colleagues at NIH, CMS, HRSA, and AAP and the patient community require more information to make decisions of prioritization and funding for therapies and outcomes. NCBDDD worked with Epic to use their COSMOS database which includes over 226 million patients to answer access, outcomes, and lifespan questions. Two examples of these data being used to look at the lifespan of people living with rare disorders includes those living with cystic fibrosis and sickle cell disease. Since 2008 both patient groups' lifespan increased in 2022 from 26 years of age to 66; and from 50 years of age to 60, respectively. This publicly available interactive database will continue to provide lifespan and other information for rare diseases—from birth defects, inborn errors of metabolism, blood disorders and those impacting behavior—such as autism. CDC anticipates new findings in 2025. Also working with EPIC Systems, CDC award-winning publication provided the first nationwide estimates of JYNNEOS vaccine effectiveness against mpox disease. The study's design and the successful partnership between CDC and Epic Systems allowed for rapid

and timely estimation of mpox vaccine effectiveness using nationwide electronic health record data. Results from the study informed CDC's Advisory Committee on Immunization Practices, clinical guidelines for high-risk individuals, and contributed to the unanimous approval to use the 2-dose JYNNEOS series during an mpox outbreak.

## Reaching Hispanic Women with Important Pregnancy Health Messages

CDC launched a unique campaign, A Mother's Love: Raising Folic Acid Awareness to Prevent Neural Tube Defects (NTDs). 2024 analysis revealed voluntary fortification of corn masa flour is insufficient in raising folate levels in Hispanic mothers. Our efforts in 2024, focused to address the continued folate deficiencies in Hispanic mothers. The 2024 theme emphasized the importance of a mother's love and family, particularly focusing on the role of mothers, grandmothers, and spouses, in promoting folic acid intake. Materials were created to encourage multigenerational dialogues and share messages on how they can easily incorporate folic acid into their daily routines. And videos were also developed to focus on a few key things such as incorporating folic acid into traditional dishes (by looking for fortified products, like corn masa flour), leveraging family relationships, incorporating culturally relevant elements like food, and multi-generational family talking and passing tradition/knowledge. The uptake of this novel approach allowed CDC to reach 10 million through multiple media outlets such as Hulu and Spotify. Compared to the reach from last year of almost 1 million. CDC continues to measure the impact of this innovative outreach in 2025.

## Innovations with our State Teams Provide New Hope for Young Families

In 2023, sickle cell research funding doubled to 6 million dollars, allowing expansion of CDC's Sickle Cell Data Collection (SCDC) program to 16 states. SCDC now represents approximately 50% of people living with sickle cell disease (SCD) in the United States. The SCDC data are immediately used

by states. California used SCDC data to support legislative action to direct resources to establish SCD clinics in geographic areas with the greatest burden. Michigan found that there were five times more people eligible for the expanded healthcare services program than were originally known to the state. North Carolina was able to identify 20 emergency departments with the highest volume of SCD care to participate in a patient pre/post survey in partnership with Medicaid positively impacting provider education. Alabama identified more than 3,000 people with SCD living in the state. They collaborated with community-based organizations (CBOs) to provide these data to inform fundraising events and awareness campaigns to improve support and services for the AL SCD community. These efforts revealed the need for enhanced transportation options to facilitate access to SCD specialists. This information will inform AL SCDC program plans to focus their upcoming activities on analyzing and presenting their data in ways that will inform local- and state-level policies that improve access to SCD health care through improved transportation options.

## Bringing Data to Action for People with Disabilities

Held CDC's inaugural Disability Summit titled, Achieving Health Equity for All on September 26, 2024, the 51st anniversary of the Rehabilitation Act. This virtual half-day event was attended by more than 1,900 participants from CDC and other HHS agencies. 94% of participants were satisfied with the content and information shared at the Disability Summit. The summit's discussions underscored the significance of the following:

- Working **with** the disability community, rather than **for** them
- Fully integrating disability inclusion across HHS efforts
- Crafting culturally appropriate and accessible messaging
- Providing accurate information swiftly

Additionally, CDC has invested in improving data on people with disabilities during emergencies through developing disability definitions for the CDC National Syndromic Surveillance Program or NSSP. NSSP is a core CDC surveillance system

used to detect outbreaks and monitor public health emergencies through surveillance of emergency department (ED) visits. However, prior to this project, there has been no way to identify people with disabilities within this system. CDC engaged a scientific panel including people with disabilities and syndromic surveillance experts to develop definitions to identify emergency department visits from people with disabilities. These diagnostic-code based definitions can be used to disaggregate monitored health outcomes (such as heat-related illness) by disability status and type (for example hearing, vision, or mobility-related disabilities) and will ultimately help improve emergency and ongoing surveillance efforts.

## **Faster Science to Promote Healthy Pregnancies in 2024**

CDC has the only surveillance data network in the world to respond to new and emerging threats to pregnancies. While some infectious diseases are known to cause birth defects, developmental disabilities, and stillbirths, we do not know enough about how infectious diseases and toxic exposures impact mothers and their babies. Surveillance for Emerging Threats to Mothers and Babies Network (SET-NET) is a preparedness and response surveillance network that identifies an exposure during pregnancy and captures data to understand the effects and ways to save the lives and of mothers and babies. Using this network, CDC provided timely recommendations on how to prevent impacts of congenital syphilis, hepatitis, and congenital CMV (cCMV) on pregnancies and answered important questions of emerging threats to pregnant women and babies.

Through assessment of infections impacting pregnancies and infants, SET-NET can rapidly pivot into response mode yielding important clinical and public health data to inform interventions and treatment guidance for the best outcomes for mothers, babies, and young families. In 2024, fully integrated SET-NET as the first ever preparedness and response surveillance network that identifies an exposure during pregnancy and captures data to understand the effects and ways to save the lives and of mothers and babies. This allows CDC to rapidly deploy SET-NET to answer important questions about the impact of emerging threats on pregnant women and babies during emergencies. SET-NET addressed new emerging threats in 2024 including dengue in Puerto Rico and Oropouche.

## **Preparing for 2025, to Report Update on Prevalence and Early identification of Autism Spectrum Disorder**

CDC tracks and monitors the prevalence and early identification of autism spectrum disorder (ASD) among children 4 and 8 years old across 16 Autism and Developmental Disabilities Monitoring (ADDM) Network sites. And most recently monitored co-occurring conditions and educational transition planning among adolescents with ASD aged 16 years at nine ADDM Network sites. CDC's findings were used by HRSA and DOE to improve services and guideline funding; AAP and other professional organizations in guideline development; and state Medicaid, education, and public health leaders to inform policy and programs and funding. CDC's new data will be published March 2025.