

National Center on Birth Defects and Developmental Disabilities (NCBDDD)

Mission: The National Center on Birth Defects and Developmental Disabilities (NCBDDD) strives to advance the health and well-being of our nation's most vulnerable populations.



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Center Organizational Chart

<https://www.cdc.gov/ncbddd/aboutus/organizational.html>

Points of Contact

[Stephanie Dulin, Senior Advisor](#)

[Nikki Walker, Deputy Associate Director for Policy](#)

Priority Areas and Activities

Autism
Birth defects
Blood disorders
Child health and development
Disabilities
Fetal Alcohol Syndrome
Health and Development for People with Disabilities
Neonatal Abstinence Syndrome
Surveillance for Emerging Threats to Mothers and Babies

Center level technical assistance services and programs

- [Birth Defects Research and Tracking](#)
 - o Accurately tracking birth defects and analyzing the collected data is a first step in preventing birth defects. CDC uses tracking and research to identify causes of birth defects, find opportunities to prevent them, and improve the health of people living with birth defects. Understanding the potential causes of birth defects can lead to recommendations, policies, and services to help prevent them.
 - o **Tracking:** Birth defects tracking systems identify babies born with birth defects and collect information to learn more about these conditions. Many states have birth defects tracking systems, which are vital to help us find out where and when birth defects occur and whom they affect.
 - o **Research:** We base our research on what we learn from tracking. By analyzing the collected data, we can identify factors that increase or decrease the risk of birth defects. In addition, research can help us understand the relationship between birth defects and environmental concerns, or other factors such as taking specific medications before and during pregnancy.

For TAC Use Only

- [Fetal Alcohol Spectrum Disorders \(FASD\)](#)
 - o CDC promotes two strategies to reduce the number of alcohol-exposed pregnancies—alcohol screening and brief intervention (SBI) and CHOICES. Broadening CDC’s FASD prevention efforts to include both alcohol SBI and CHOICES provides the opportunity to offer both brief and extended intervention options to women of reproductive age as appropriate, and to address risky alcohol use within the broader context of women’s health.

- [Early Hearing Detection and Intervention](#)
 - o In 2020, CDC awarded multiple states and territories a new four-year award called “Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems.”
 - o This award aims to advance the capacity of jurisdictions to actively track infants to ensure they receive essential diagnostic services and are enrolled in early intervention by–
 - Optimizing jurisdictions’ Early Hearing Detection and Intervention (EHDI) Information Systems
 - Expanding jurisdictions’ ability to report, analyze, and use patient-level data

- [Autism and Developmental Disabilities Monitoring Network](#)
 - o The Autism and Developmental Disabilities Monitoring (ADDM) Network is a group of programs funded by CDC to estimate the number of children with autism spectrum disorder (ASD) and other developmental disabilities living in different areas of the United States. The ADDM Network sites all collect data using the same methods, which are modeled after CDC’s Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP).
 - ADDM Network goals are to–
 - Describe the population of children with ASD
 - Compare how common ASD is in different areas of the country
 - Identify changes in ASD occurrence over time
 - Understand the impact of ASD and related conditions in US communities

- [CDC-Funded State Disability and Health Programs](#)
 - o CDC’s Disability and Health Promotion Branch currently provides funds to 19 State Disability and Health Programs under the cooperative agreement CDC-RFA-DD16-1603: Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs.
 - o These State Disability and Health Programs work to improve the health and quality of life among people with mobility limitations and/or intellectual disabilities (ID) through adaptation and implementation of evidence-based strategies in their communities.
 - o This FOA provides funding to develop and strengthen internal capacity and health-related disability programs to–
 - Improve knowledge and awareness about the usefulness and effectiveness of programmatic, policy, systems, and environmental changes for people with select functional disability types (i.e., mobility limitations and/or ID)
 - Support programs to plan, implement, evaluate, and disseminate nonresearch activities aimed at promoting inclusion and accessibility and reducing health disparities between people with and without disabilities

- [Disability and Health Data System](#)
 - o Disability and Health Data System (DHDS) is an online source of state-level data on adults with disabilities. Users can access information on six functional disability types–
 - Cognitive (serious difficulty concentrating, remembering, or making decisions)
 - Hearing (serious difficulty hearing or deafness)
 - Mobility (serious difficulty walking or climbing stairs)
 - Vision (serious difficulty seeing or blindness)
 - Self-care (difficulty dressing or bathing)
 - Independent living (difficulty doing errands alone)
 - o Data on more than 30 health topics among adults with or without disabilities can be explored in DHDS, including smoking, obesity, heart disease, and diabetes.
 - o Users can customize data maps, charts, and tables, making it easy to see information about their state or region. They can identify health differences between adults with and without disabilities overall, and by age, sex, and race/ethnicity. Data can be used in presentations, reports, and grant applications, or to inform decision makers.

Budget Updates

Total Number of Grants and Cooperative Agreements with Tribes, TECs, or THOs for FY 22.

1

Total Number of Grants and Cooperative Agreements with Tribes, TECs, and THOs for FY 23.

1

For each FY 23 Funding Activity with Tribes, TECs, THOs Complete the Following Information. Please be sure to provide updates for each funding activity including CDC RFA Award Number, Award Title, Award Amount, Funding Period, and Brief Description)

CDC-RFA-DD-23-0004: Enhancing partnerships to address birth defects, infant disorders and related conditions, and the health of pregnant and postpartum people

CDC's Act Early Ambassador Program: CDC onboarded three Tribal Ambassadors from California, New Mexico, and Alaska to join the larger Act Early Ambassador Cohort (63 Ambassadors total) in September 2023. These Tribal Ambassadors have developed workplan goals to expand the reach of the "Learn the Signs. Act Early." program within their Tribal communities and work toward improving early identification of Tribal children with developmental delays and disabilities, including autism. The Tribal Ambassadors' work will be implemented through September 30, 2024.

Health Equity Updates

Does your CIO's Health Equity initiative include activities or metrics that specifically address AI/AN, tribes, TECs, or THOs? (Yes/No) If yes, provide metric and/or describe activities (please be sure to include supporting links).

No

Is your CIO currently collecting, receiving, or producing health equity data that includes AI/AN information? (Yes/No). If yes, describe the data being collected, received, or produced (please be sure to include supporting links).

No

Tribal Updates

Please provide a brief description of any efforts to help tribes/TECs/THOs build or improve data infrastructure. (Please be sure to include supporting links and references).

N/A at this time

Please provide a brief description of any efforts to help tribes/TECs/THOs to collect, acquire, or improve data. (Please be sure to include supporting links and references).

N/A at this time

Please provide a brief description of any efforts to help tribes/TECs/THOs enhance their ability to manage, analyze, interpret, or disseminate data. (Include training or technical assistance tools and resource links.)

N/A at this time