

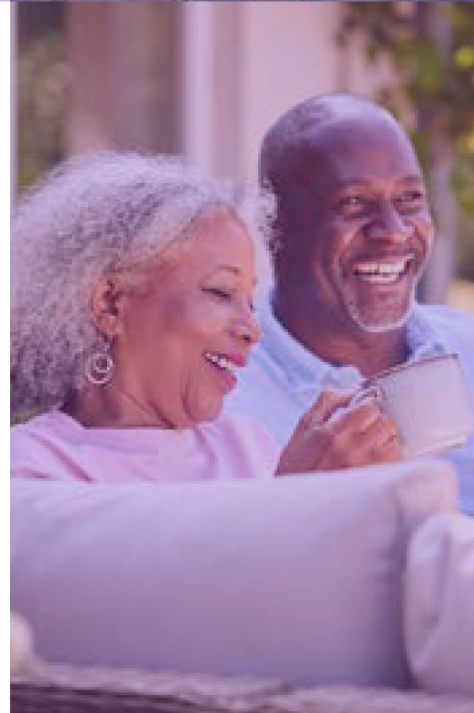


NCBDDD

Fiscal Year 2022

Making a Difference
Across the Lifespan

From Saving Babies
to Protecting People



U.S. Department of
Health and Human Services
Centers for Disease
Control and Prevention



National Center on Birth Defects
and Developmental Disabilities
Centers for Disease Control and Prevention

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Message from the **DIRECTOR**



I am pleased to present the 2022 National Center on Birth Defects and Developmental Disabilities (NCBDDD) Annual Report.

This past year, there was a continued need for our center's expertise in the COVID-19 response and the mpox response. Our staff has truly done this balancing act exceptionally well, as demonstrated by the number of programs, publications and collaborations described in our annual report. Our center's important work has continued to identify potential risk factors for birth defects, collect data on children with intellectual and developmental disabilities, protect the health of people with blood disorders, and improve the health of the 1 in 4 U.S. adults with a disability. Through this work, we provide data to turn into action for our partners, decision makers, state, local, and tribal public health professionals and the American public.

In April, CDC launched its *Moving Forward* initiative, aimed at refining the agency's long-standing practices so we can better respond to pandemics and other public health emergencies. The primary goals of *Moving Forward* are

- Addressing the long-standing inequities that prevent us from achieving optimal health for all,
- Strengthening our nation's long-neglected public health infrastructure, and
- Improving our disease data collection so we can quickly provide guidance to the public, our partners, public health professionals, and healthcare providers to prevent, rather than react to, disease outbreaks.

NCBDDD has fully embraced these goals in our work plans. In this Annual Report you will read about our work to improve accessible and timely communications across responses and the agency. Our staff has worked collaboratively with partners and advocates to have easy to read, infographics, and ASL incorporated into all CDC communications. This work is hard, and we are leaning into it:

- We continue to improve our timely evaluation of data, allowing for quicker opportunities to turn data into action.
- Our work with the Autism and Developmental Disabilities Monitoring (ADDM) Network reduced the time to publication of autism surveillance data by a full year.
- Our sickle cell disease (SCD) data collection network was expanded to include the impact of COVID-19 on people with SCD, allowing states to quickly learn and react to inequities.
- The DBDID teams have quickly pivoted to include the impact of mpox in pregnancy into their work, all while improving the timeliness and ease of data collection.

CDC *Moving Forward* demands that we are actionable, collaborative, and communicative and participate in building a strong public health workforce.

As you read our report, you will see that the professionals of NCBDDD are up to the challenge! I continue to be amazed by our wonderful NCBDDD staff and their forward-leaning, collaborative, and evidence-based approach to reaching our goal of optimal health, equity, and inclusion for all.

Karen Remley

Saving Babies Through Surveillance, Research, and Prevention of Birth Defects and Infant Disorders



CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is working toward a day when all babies are born with the best health possible.

Birth defects are a leading cause of infant death and can cause lifelong health challenges. Birth defects and infant disorders can also be the first sign that infectious diseases, environmental factors, maternal conditions, or substance use can cause serious harm to pregnant people, infants, and children. Our unique surveillance, research, and health promotion programs provide a wealth of information used to

- Identify causes of birth defects and infant disorders;
- Find opportunities to prevent them; and
- Improve the health of those with these conditions.

Together, with state, territorial, and local health departments, academic centers, healthcare providers, and other partners, we are working toward a

day when all babies are born with the best health possible and every child thrives.



Accomplishments

- Modernized systems collecting data on pregnancy and infant outcomes by
 - Conducting targeted technical assistance, using the [Birth Defects Surveillance Readiness Assessment](#), to help birth defects surveillance programs improve their knowledge and understanding of interoperable surveillance. NCBDDD has also developed [a webinar series](#), in collaboration with the Public Health Informatics Institute, on interoperability and data modernization for the birth defects community.
 - Developing an automated way to classify the severity of COVID-19 illness in pregnant people for CDC's Surveillance for Emerging Threats to Mothers and Babies Network (SET-NET). This work, conducted in collaboration with the Georgia Tech Research Institute, can allow for more timely data to improve public health decisions.
- Identified opportunities to prevent birth defects and other infant disorders by

- Studying the role of genetics and gene-environment interactions associated with the risk of birth defects. Using population-based data and DNA samples collected for CDC's National Birth Defects Prevention Study, CDC and the Centers for Birth Defects Research and Prevention have begun studying the DNA of child-parent trios to better understand how variation in genes or the combination of genes and the environment play a role in the risk for birth defects. CDC has recently published findings on exome sequencing for the following birth defects: [colonic atresia](#), [bladder exstrophy](#), [sacral agenesis](#), and [anophthalmia and microphthalmia](#).
- Promoting the U.S. Public Health Service recommendation that all people who could become pregnant get 400 micrograms of folic acid each day to prevent neural tube defects (NTDs), serious birth defects of the brain and spine. This year marked the [30-year anniversary of this historic recommendation](#), which led to folic acid fortification of cereal grain products. Mandatory folic acid fortification in the United States is estimated to prevent more than 1,300 NTDs annually and save an estimated \$600 million each year.
- Prepared for, detected, and responded to emerging threats to pregnant people and their infants by
 - Identifying risk factors for severe illness and adverse birth outcomes in pregnant people with COVID-19. NCBDDD's SET-NET data were critical in CDC's efforts to describe the effects of COVID-19 infection during pregnancy. These data also helped improve public health and clinical recommendations for pregnant people, including the strong recommendation for pregnant people to receive COVID-19 vaccines.
 - Providing data that state, local, and territorial health agencies can use to address emerging issues in their communities. Health departments funded for SET-NET are using the data and the approach to increase surveillance capacity, take public health action, and create new data linkages [within their jurisdictions](#).
- Advanced activities to address the impact of substance use during pregnancy on maternal and infant health by

- Expanding the [MATernal and Infant Network \(MAT-LINK\)](#) to seven clinical sites. MAT-LINK works to improve the understanding of maternal, infant, and child health outcomes associated with medication for opioid use disorder during pregnancy and examine the possible effects of exposure to multiple substances and other risk factors on outcomes.
- Providing data on the use of alcohol during pregnancy. Recent data indicate that during 2018–2020, about [1 in 7 pregnant adults](#) in the United States reported drinking alcohol in the past 30 days, and those with no usual healthcare provider and those reporting frequent mental distress were more likely to drink alcohol. NCBDDD continued work with academic and clinical partners to promote prevention of fetal alcohol spectrum disorders (FASDs) and support use of alcohol screening and brief intervention in medical settings.

Looking to the Future

NCBDDD's innovative mother-baby linked surveillance and long history of birth defects and infant disorders surveillance and research gives our nation the best chance to protect pregnant people and their infants, especially when we are combatting emerging threats. Investments in modernizing and advancing our work, while focusing on health equity, allow CDC to continue strengthening a public health network that can rapidly assess the needs of pregnant people and their infants. We will continue addressing the impact of exposures during pregnancy, such as medicines, substance use, and infectious diseases. Additionally, we will continue identifying opportunities to prevent specific conditions, including congenital heart defects, NTDs, gastroschisis, neonatal abstinence syndrome, and FASDs, and to reduce their impact on health outcomes across the lifespan.

Notable Scientific Publications

- Crider KS, et al. [Folic Acid and the Prevention of Birth Defects: 30 Years of Opportunity and Controversies](#). *Annu Rev Nutr*. 2022;42:423–452.
- Gosdin LK, et al. [Alcohol Consumption and Binge Drinking During Pregnancy Among Adults Aged 18–49 Years—United States, 2018–2020](#). *MMWR Morb Mortal Wkly Rep*. 2022;71(1):10–13.
- Li J, et al. [Exome Sequencing Identifies Genetic Variants in Anophthalmia and Microphthalmia](#). *Am J Med Genet A*. 2022;188(8):2376–2388.
- Mai CT, et al. [Changes in Spina Bifida Lesion Level After Folic Acid Fortification in the US](#). *J Pediatr*. 2022;249:56–e1.
- Meaney-Delman DM, et al. [A Primer on Monkeypox Virus for Obstetrician–Gynecologists: Diagnosis, Prevention, and Treatment](#). *Obstet Gynecol*. 2022;140(3):391–397.
- Mohan Dass NL, et al. [Associations between Maternal Reports of Periconceptional Fever from Miscellaneous Causes and Structural Birth Defects](#). *Birth Defects Res*. 2022;114(15):885–894.
- Neelam V, et al. [Pregnancy and Infant Outcomes by Trimester of SARS-CoV-2 Infection in Pregnancy—SET-NET, 22 Jurisdictions, January 25, 2020–December 31, 2020](#). *Birth Defects Res*. [online ahead of print].
- Olsen EO, et al. [SARS-CoV-2 Infections Among Neonates Born to Pregnant People with SARS-CoV-2 Infection: Maternal, Pregnancy and Birth Characteristics](#). *Paediatr Perinat Epidemiol*. 2022;36(4):476–484.
- Roth NM, et al. [Zika-Associated Birth Defects Reported in Pregnancies with Laboratory Evidence of Confirmed or Possible Zika Virus Infection—U.S. Zika Pregnancy and Infant Registry, December 1, 2015–March 31, 2018](#). *MMWR Morb Mortal Wkly Rep*. 2022;71(3):73–79.
- Stallings EB, et al. [Co-occurrence of Congenital Anomalies by Maternal Race/Ethnicity Among Infants and Fetuses with Down Syndrome, 2013–2017: A U.S. Population-based Analysis](#). *Birth Defects Res*. 2022;114(2):57–61.

Helping Children Live to the Fullest by Understanding Developmental Disabilities



CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is committed to helping children with developmental disabilities and their families get the support they need to thrive.

Developmental disabilities (DDs) are a group of conditions that can affect a person's physical, learning, language, or behavioral development. DDs may impact day-to-day functioning and usually last throughout a person's life. Approximately [1 in 6 children](#) in the United States have a DD. To best support children and their families, CDC is committed to

- Monitoring the occurrence and characteristics of common DDs in the population.
- Improving early identification of children with DDs.

- Funding partners to help children with DDs and their caregivers.
- Better understanding the health, functioning, and needs of people with DDs as they mature.



Accomplishments

- Reported data from CDC's [Autism and Developmental Disabilities Monitoring \(ADDM\) Network](#) showing that about 1 in 44 8-year-old children were identified with autism spectrum disorder (ASD) across 11 U.S. communities in 2018.
 - For the first time ever, ADDM data showed no overall racial or ethnic difference in 8-year-old children identified with ASD. However, at several of the ADDM sites, the percentage of Hispanic children identified with ASD was lower than that of White or Black children.
 - Early identification continues to increase, as more 4-year-old children are being evaluated and diagnosed with ASD than in the past.

- The ADDM Network also began looking at ASD characteristics among 16-year-old children who had been previously identified by ADDM Network sites at age 8 in 2010.
- Informed public health strategies for young children (ages 3–9 years) with ASD and their families during public health emergencies through feedback from CDC's [Study to Explore Early Development \(SEED\) COVID-19 Impact Assessment](#).
 - Survey topics included the impact of COVID-19 on use of health and education services, child development and resilience, and parental mental health.
- Facilitated timely and complete reporting of hearing loss in children through technical assistance to jurisdictional [Early Hearing Detection and Intervention \(EHDI\)](#) programs. Successfully received complete individual-level datasets on infants born in 2020 from 39 jurisdictions. These data increase understanding of EHDI service provision and delivery to help ensure timely diagnosis and intervention services.
 - The [Outcomes and Developmental Data Assistance Center for Early Hearing Detection and Intervention \(ODDACE\)](#) project is specifically designed to document and assess the relationship between interventions and developmental outcomes. ODDACE has expanded to 18 programs across 15 states, and assessments from more than 2,000 children who are deaf or hard of hearing have been received and scored.
- Continued to support efforts to learn more about certain disabilities, developmental disorders, and related conditions, including persistent tic disorders and attention-deficit/hyperactivity disorder (ADHD).
 - Published an updated report on [mental health among U.S. children](#). CDC worked with other government agencies, including the Substance Abuse and Mental Health Services Administration, the National Institute of Mental Health, and the Health Resources and Services Administration to update this important report in 2022. First published in 2013, this report marked the first-ever multi-government agency report on mental health among U.S. children.
 - [Persistent tic disorders](#), including Tourette syndrome (TS), affect about 1.4 million people in the United States. Between 2016-

2019, [1 out of every 333 U.S. children](#) ages 3-17 years received a TS diagnosis. Most children who are diagnosed with TS (83%) have a co-occurring condition such as ADHD, anxiety disorder, or a learning disability that can further complicate their health and well-being.

- [ADHD diagnosis for children ages 3-17 varies from 6-16% across U.S. states.](#) ADHD treatment and services can also vary across states.
- Funded and supported work to update and expand the reach of “Learn the Signs. Act Early.”
 - Updated CDC’s [Developmental Milestones](#) and parent tips to better support ongoing conversations about children’s development between families and healthcare professionals.
 - Funded and supported [Act Early Response to COVID-19 Teams](#) in 41 states and territories to develop, implement, and evaluate work plans to increase parent-engaged developmental monitoring, bolster early identification of developmental disability, and increase resiliency among families with young children during the pandemic.
 - Used findings from the Act Early Response to COVID-19 Teams to fund and support the [Coordinated and Integrated Data System for Early Identification.](#)
- Funded and supported the American Academy of Pediatrics (AAP) to develop and distribute [educational materials to healthcare professionals and families](#) to encourage early diagnosis of fragile X syndrome (FXS) so that people with FXS can receive appropriate care and services. Additionally, supported AAP to develop [training modules for pediatric healthcare professionals in best practices for FXS diagnosis and treatment.](#)

Looking to the Future

Children with DDs and their families often face personal, social, and financial challenges. NCBDDD and its partners work across many areas to improve early identification of children with DDs; connect these children and their families to medical, developmental, and behavioral services; and provide

tools and resources to help families facing these challenges. NCBDDD is helping to lead efforts to make data more modern and accessible to meet the needs of all populations. These efforts will help to improve our ability to monitor racial/ethnic disparities in identifying ASD and other DDs. NCBDDD's mission also includes understanding development at each stage of life, from promoting school readiness to the health of teens with ASD, and helping families and children get the support they need.

Notable Scientific Publications

- Bitsko RH, et al. [Mental Health Surveillance Among Children—United States, 2013–2019](#). *MMWR Suppl.* 2022;71(2):1–42.
- Cogswell ME, et al. [Health Needs and Use of Services Among Children with Developmental Disabilities—United States, 2014–2018](#). *MMWR Morb Mortal Wkly Rep.* 2022;71(12):453–458.
- Danielson ML, et al. [State-level Estimates of the Prevalence of Parent-reported ADHD Diagnosis and Treatment Among U.S. Children and Adolescents, 2016 to 2019](#). *J Atten Disord.* 2022;26(13):1685–1697.
- Hutchins HJ, et al. [Perceived Racial/Ethnic Discrimination, Physical and Mental Health Conditions in Childhood, and the Relative Role of Other Adverse Experiences](#). *Adv Res Sci.* 2022;3:181–194.
- Maenner MJ, et al. [Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018](#). *MMWR Surveill Summ.* 2021;70(11):1–16.
- Meinzen-Derr J, et al. [Factors Associated with Early Intervention Intensity for Children Who Are Deaf or Hard of Hearing](#). *Children (Basel).* 2022;9(2):224.
- Shaw KA, et al. [Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018](#). *MMWR Surveill Summ.* 2021;70(10):1–14.
- Shaw KA, et al. [Progress and Disparities in Early Identification of Autism Spectrum Disorder: Autism and Developmental Disabilities Monitoring Network, 2002–2016](#). *J Am Acad Child Adolesc Psychiatry.* 2022;61(7):905–914.

- Tinker SC, et al. [Estimating the Number of People with Tourette Syndrome and Persistent Tic Disorder in the United States](#). *Psychiatry Res.* 2022;314:114684.
- Wanga V, et al. [Stability of Mental Disorder Prevalence Estimates Among School-aged Children and Adolescents: Findings from the Community-based Project to Learn About Youth-Mental Health \(PLAY-MH\) and Replication-PLAY-MH \(Re-PLAY-MH\), 2014–2017](#). *Ann Epidemiol.* 2022;72:82–90.
- Wiggins LD, et al. [Toileting Resistance Among Preschool-Age Children with and Without Autism Spectrum Disorder](#). *J Dev Behav Pediatr.* 2022;43(4):216–223.

- Zubler JM, et al. [Evidence-informed Milestones for Developmental Surveillance Tools](#). 2022;149(3):e2021052138.

Protecting People and Preventing Complications of Blood Disorders



CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is dedicated to reducing the public health burden resulting from blood disorders by contributing to a better understanding of blood disorders and their complications.

Blood disorders affect millions of people each year in the United States, cutting across boundaries of age, race, sex, and socioeconomic status. With proper action, some blood disorders can be prevented. In the case of inherited blood disorders, early intervention can prevent serious complications. At CDC, we are dedicated to helping people with blood disorders by

- Contributing to a better understanding of blood disorders and their complications;
- Working to develop, implement, and evaluate programs to prevent blood disorders and their complications;

- Helping consumers and healthcare providers get the information they need; and
- Encouraging action on behalf of individuals living with or affected by blood disorders.



Accomplishments

- Released a [Morbidity and Mortality Weekly Report](#) and CDC [Vital Signs](#) on the need to prevent life-threatening complications from sickle cell anemia (SCA) in children. These publications highlighted data showing use of screening and treatments to prevent and reduce the severity of SCA complications is far too low. Also, published a supplemental editorial, "[Prioritizing Sickle Cell Disease](#)," in the *Journal of Pediatrics* to reinforce the need to address barriers to care and health inequities faced by underserved racial and ethnic minority populations.
- Highlighted the diversity of people living with sickle cell disease (SCD) through the [Stories of Sickle Cell project](#). Through a [video series](#), [short stories](#), and a [photoblog](#), the Stories of Sickle Cell series provides a

deeper understanding of people living with SCD to help destigmatize the disease and inspire action to support the sickle cell community.

- Provided up-to-date scientific information on inherited bleeding disorders:
 - Published a [review article](#) in the *Journal of Women's Health* that provides an overview of the state of the science of bleeding disorders in women and describes CDC-funded activities, such as [Community Counts](#) and the [Better You Know campaign](#). For a summary of the key points from the review article, [click here](#).
 - Published [findings](#) from a [Community Counts](#) study that estimates the number of people with rare bleeding disorders, other than hemophilia and von Willebrand disease, receiving care at Hemophilia Treatment Centers in the United States.
- Improved CDC's hemophilia treatment product [inhibitor](#) testing and surveillance by studying the stability of blood specimens used in CDC inhibitor assays under various conditions typically encountered during specimen shipping and storage. Knowledge of specimen stability will aid care providers in collection of specimens from patients with limited access to treatment facilities.
- Enhanced awareness of blood clot prevention via ongoing messages displayed every 5 minutes on the Times Square Nasdaq digital screen and billboard during Blood Clot Awareness Month in March. Roughly 360,000 pedestrian visitors daily were exposed to messages from the National Blood Clot Alliance's signature [Stop the Clot, Spread the Word® awareness campaign](#) on [general blood clot awareness](#), and on blood clot risks associated with [pregnancy](#), [cancer](#), and [hospitalization](#). The campaign, developed in collaboration with CDC, has provided lifesaving information to hundreds of millions of people since 2015.
- Studied the impact of COVID-19 on blood disorders:
 - Published [findings](#) from a study of cerebral venous sinus thrombosis (CVST; rare life-threatening blood clots in the brain that had been reported in several people who had received one of the COVID-19 vaccines). This study provided clinicians and the wider public health community access to current and complete data on the epidemiology of CVST in the US population. These data were needed for informed decision-making. Among other

findings, CVST was found to be higher in women vs. men and the risk increased with age. For a summary of the study, [click here](#).

- Published [findings](#) showing an increased rate of SCD-related death during the first year of the COVID-19 pandemic. These findings underscore the need for people with SCD to receive the COVID-19 vaccine. For a summary of the study, [click here](#).
- Developed an [online toolkit](#) for healthcare providers caring for people with thalassemia. Resources include the CDC-funded [virtual thalassemia grand rounds](#), other continuing medical education webinars, scientific articles, information on newborn screening, locations and contact information of specialty thalassemia treatment centers, and more.

Looking to the Future

COVID-19 has directly or indirectly impacted those living with blood disorders. We will continue to monitor and assess the situation, directing possible resources to help reduce the impact on those affected. We will use data to track emerging health trends in hemophilia treatments and treatment-related complications. We will also expand the Sickle Cell Data Collection program and study long-term trends in diagnosis, treatment, and healthcare access for people with sickle cell disease in the United States. Finally, we are continuing to promote awareness of the importance of blood donation to support treatment for both thalassemia and sickle cell disease.

Notable Scientific Publications

- Badawy SM, et al. [Concordance with Comprehensive Iron Assessment, Hepatitis A Vaccination, and Hepatitis B Vaccination Recommendations Among Patients with Sickle Cell Disease and Thalassaemia Receiving Chronic Transfusions: an Analysis from the Centers for Disease Control Haemoglobinopathy Blood Safety Project](#). *Br J Haematol*. 2021;195(5):e160–e164.

- Miller CH. [Monitoring of Von Willebrand Factor Inhibitors in Patients with Type 3 Von Willebrand Disease Using a Quantitative Assay](#). 2021;27(5):823–829.
 - Miller CH, et al. [Women and Girls with Hemophilia Receiving Care at Specialized Hemophilia Treatment Centers in the United States](#). 2021;27(6):1037–1044.
 - Miller CH. [The Clinical Genetics of Hemophilia B \(Factor IX Deficiency\)](#). *Appl Clin Genet*. 2021;14:445–454.
 - Payne AB, et al. [Influenza Vaccination Rates and Hospitalizations Among Medicaid Enrollees with and Without Sickle Cell Disease, 2009–2015](#). *Pediatr Blood Cancer*. 2021;68(12):e29351.
 - Raskob GE, et al. [Cancer-associated Venous Thromboembolism: Incidence and Features in a Racially Diverse Population](#). *J Thromb Haemost*. 2022;20(10):2366–2378.
 - Saber I, et al. [Racial Differences in Venous Thromboembolism: A Surveillance Program in Durham County, North Carolina](#). *Res Pract Thromb Haemost*. 2022;6(5):e12769.
 - Snyder AB, et al. [Surveillance for Sickle Cell Disease — Sickle Cell Data Collection Program, Two States, 2004–2018](#). *MMWR Surveill Summ*. 2022;71(9):1–18.
 - Soucie JM, et al. [Prevalence of Comorbid Conditions Among Older Males with Haemophilia Receiving Care in Haemophilia Treatment Centers in the United States](#). 2022;28(6):986–995.
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- Wendelboe A, et al. [Exploring the Applicability of Using Natural Language Processing to Support Nationwide Venous Thromboembolism Surveillance: Model Evaluation Study](#). *JMIR Bioinform Biotech*. 2022;3(1):e36877.

Improving Health of People with Disabilities



CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) works to ensure that people with disabilities have the same opportunities for good health as people without disabilities.

Disabilities may include difficulty with movement, attention, social interaction, hearing, seeing, concentrating, remembering, emotions, or making decisions. Many people will experience a disability during their lifetimes, but having a disability does not mean that a person is unhealthy or cannot be healthy. People with disabilities need healthcare services and programs that provide information for optimal health for the same reasons everyone else does—to stay well, active, and participate fully in their communities. CDC works to ensure that people of all abilities can live their lives to the fullest.



Accomplishments

- Supported the [inclusion of people with disabilities](#) in state, territorial, and local health department preparedness and response efforts. Disability specialists served as subject matter experts embedded in public health emergency preparedness planning and response programs. This was accomplished in partnership with the Association of State and Territorial Health Officials and the National Association of City and County Health Officials (NACCHO). Also, in collaboration with NACCHO, supported 2 additional graduate students, 19 total since the program began, to be a voice for people with disabilities in local health departments through a Health and Disability Fellowship program.
- Led efforts to increase inclusion of people with disabilities in public health data to learn more about health disparities, focus disease prevention and health promotion activities, and evaluate outcomes. Efforts focus on increasing the use of standard disability questions in

data collection systems. Collaborations also help enhance the use of administrative and survey data in identifying people with disabilities.

- Developed new [Easy to Read information](#) on COVID-19 booster shots and COVID-19 Community Levels. These materials provide critical information in an accessible format for all people, including people with intellectual and developmental disabilities.
- Accelerated surveillance and research to improve the lives of people living with congenital heart defects, muscular dystrophy, and spina bifida. Studying health issues and needs throughout life can provide data to plan for services and ensure that people with these conditions receive the care they need. In 2022, NCBDDD
 - Provided data [showing that hospitalized patients with heart defects are up to twice as likely to have severe outcomes of COVID-19 illness as hospitalized COVID-19 patients without heart defects](#). NCBDDD also found that 40% of adults with heart defects have a disability. Adults with heart defects are diagnosed more frequently with [post-traumatic stress disorder, anxiety, and depression](#), as well as [early-onset dementia](#).
 - Developed and launched the [Congenital Heart Defects Toolkit for Physicians](#) to promote lifelong congenital cardiac care for people with heart defects.
 - Identified needs and care opportunities for people living with muscular dystrophies. Data from Muscular Dystrophy Surveillance, Tracking, and Research Network showed that specific [use of glucocorticoids \(steroids used to help maintain muscle strength\), use of assistive devices for coughing, and scoliosis \(spinal curvature\) surgery all improved survival](#). Data also showed that there has not been improvement in the time to diagnosis for individuals with Duchenne muscular dystrophy (DMD). Families without a history of DMD wait an average of 2.2 years to receive a diagnosis.
 - Analyzed data from the more than 11,000 National Spina Bifida Patient Registry participants to better understand the relationships between medical procedures and health outcomes. Research from 2021 explored treatment for [tethered spinal cord release](#) by age; the relationship between [motor level and](#)

[baseline transfer ability](#); and outcomes of fetal surgery compared to surgery after birth for [Chiari II malformation](#).

Looking to the Future

NCBDDD is dedicated to promoting inclusive communities, programs, and policies that provide opportunities for people with disabilities and their families to live full, healthy lives. NCBDDD plans to continue to provide guidance to partners to help public health programs become fully accessible and inclusive by offering effective tools and resources to improve the accessibility of program materials focused in particular on healthy living (such as physical activity and nutrition) and [COVID-19 guidance](#). NCBDDD is also committed to ensuring people with heart defects, spina bifida, and muscular dystrophy are aware of the specialized care they need to live healthy lives. Continuing to strengthen NCBDDD's surveillance systems will help address gaps in knowledge through each stage of life, such as the often-difficult transition of health care for adolescents with disabilities into adulthood. NCBDDD will continue to promote the healthy development and inclusion of people with disabilities across their lifespans.

Notable Scientific Publications

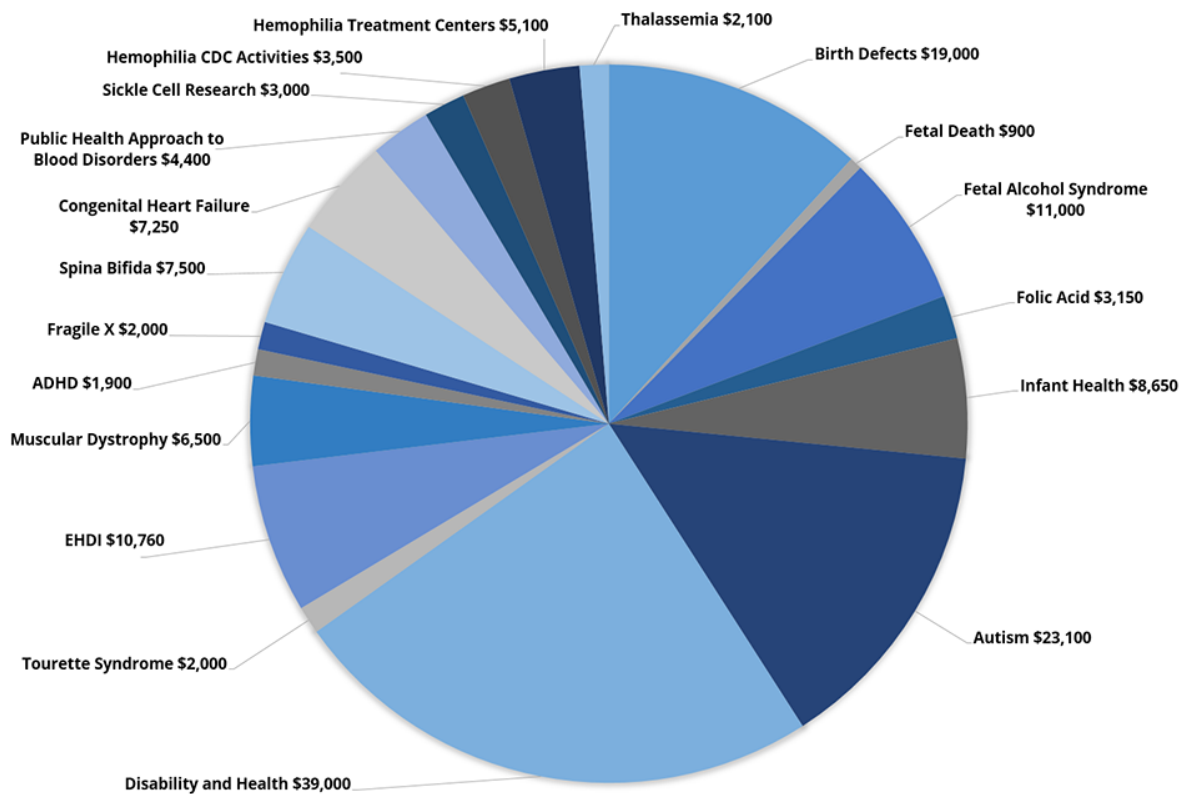
- Downing KF, et al. [Preventive Dental Care and Oral Health of Children and Adolescents with and Without Heart Conditions — United States, 2016–2019](#). *MMWR Morb Mortal Wkly Rep*. 2022;71:189–195.
- Farr SL, et al. [Prevention and Awareness of Birth Defects Across the Lifespan Using Examples from Congenital Heart Defects and Spina Bifida](#). *Birth Defects Res*. 2022;114(2):35–44.
- Horner-Johnson W, et al. [Time Trends in Emergency Department Use Among Adults with Intellectual and Developmental Disabilities](#). *Disabil Health J*. 2022;15(2):101225.
- Koyama AK, et al. [Severe Outcomes, Readmission, and Length of Stay Among COVID-19 Patients with Intellectual and Developmental Disabilities](#). *Int J Infect Dis*. 2022;116:328–330.

- Paramsothy P, et al. [Selected Clinical and Demographic Factors and All-cause Mortality Among Individuals with Duchenne Muscular Dystrophy in the Muscular Dystrophy Surveillance, Tracking, and Research Network](#). *Neuromuscul Disord*. 2022;32(6):468–476.
- Simeone RM, et al. [Post-traumatic Stress Disorder, Anxiety, and Depression Among Adults with Congenital Heart Defects](#). *Birth Defects Res*. 2022;114(3-4):124–135.
- Theis KA, et al. [Prevalence of Arthritis and Arthritis-attributable Activity Limitation—United States, 2016–2018](#). *MMWR Morb Mortal Wkly Rep*. 2021;70(40):1401–1407.
- Thomas S, et al. [Time to Diagnosis of Duchenne Muscular Dystrophy Remains Unchanged: Findings from the Muscular Dystrophy Surveillance, Tracking, and Research Network, 2000–2015](#). *Muscle Nerve*. 2022;66(2):193–197.
- Yuan Y, et al. [COVID-19 Cases and Hospitalizations Among Medicare Beneficiaries with and Without Disabilities—United States, January 1, 2020–November 20, 2021](#). *MMWR Morb Mortal Wkly Rep*. 2022;71(24):791–796.
- Zhang QC, et al. [State-specific Prevalence of Current E-cigarette Use by Disability Status and Disability Type—United States, BRFSS 2016–2018](#). *Disabil Health J*. 2022;15(1):101182.

Fiscal Year 2022 Budget

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) fiscal year (FY) 2022 appropriation includes **\$177,060,000** for Child Health and Development, Health and Development with Disabilities, and Public Health Approach to Blood Disorders.

Funds are currently supporting surveillance, research, and prevention activities that address issues with the greatest public health burden and implementing strategies to improve health outcomes.



*All dollar amounts are in thousands.

**NCBDDD FY 2022 Appropriations
(in thousands)**

Birth Defects	\$19,000
Fetal Death	\$900
Fetal Alcohol Syndrome	\$11,000
Folic Acid	\$3,150
Infant Health	\$8,650
Autism Spectrum Disorders (ASD)	\$23,100
Disability and Health	\$39,000
Tourette Syndrome	\$2,000
Early Hearing Detection and Intervention (EHDI)	\$10,760
Muscular Dystrophy	\$6,500
Attention Deficit / Hyperactivity Disorder (ADHD)	\$1,900
Fragile X Syndrome	\$2,000
Spina Bifida	\$7,500
Congenital Heart Failure	\$7,250
Public Health Approach to Blood Disorders	\$4,400
Sickle Cell Research	\$3,000
Hemophilia CDC Activities	\$3,500
Hemophilia Treatment Centers	\$5,100
Thalassemia	\$2,100
Neonatal Abstinence Syndrome	\$3,250
Surveillance for Emerging Threats to Mothers and Babies	\$13,000
NCBDDD Total	\$177,060

Select State-Based Activities and Funding

Alabama

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems

Alabama Department of Public Health (DD20-2006, 000084)

\$160,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs

Alabama Department of Public Health (DD16-1603, 000017)

Project ended 12/31/21

National Centers on Health Promotion for People with Disabilities

University of Alabama at Birmingham (DD16-1602, 001157)

Project ended 9/30/22

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

University of Alabama at Birmingham (DD19-001, 001237- Comp B)

\$80,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

University of Alabama at Birmingham (DD19-001, 001236- Comp C)

\$25,000

Sickle Cell Data Collection Program

University of Alabama at Birmingham (DD20-2003, 000018)

\$250,000

Improving Health of Americans with Mobility Limitatons through Evidence-Based Health Promotion Programs

University of Alabama at Birmingham (DD21-2104, 00022)

\$6,042,429

Alaska

Implementing Alcohol Screening and Brief Intervention in Healthcare Systems Providing Women's Health Services

University of Alaska Anchorage (DD18-1802, 000005)

No cost extension until 9/29/23

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Alaska Department of Health and Social Services (DD20-2006, 000075)

\$160,000

Reaching Healthcare Professionals in the Prevention of Fetal Alcohol Spectrum Disorders through National Professional Organizations

University of Alaska Anchorage (DD18-1803, 000006)

No cost extension until 2/28/23

National Partnerships to Address Prenatal Alcohol and Other Substance Use and Fetal Alcohol Spectrum Disorders

University of Alaska Anchorage (DD22-2201, 000017)

\$280,000

Arizona

Enhancing Public Health Surveillance of Autism Spectrum Disorder through the ADDM Network

Arizona Board of Regents, University of Arizona (DD19-1901, 000003)

\$387,806

Surveillance of Congenital Heart Defects Among Children, Adolescents, and Adults

University of Arizona (DD19-1902, 000055)

\$480,000

Surveillance for Emerging Threats to Mothers and Babies

Arizona Department of Health (CK19-1904, 000511)

\$309,458

Advancing Population-Based Surveillance of Birth Defects

Arizona Department of Health (DD21-2101, 000108)

\$360,000

Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health

Association of State and Territorial Public Health Nutrition Directors (ASTPHND) (OT18-1802, 000279)

\$110,000

Arkansas

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems

Arkansas Department of Health (DD20-2006, 000065)

\$160,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs

University of Arkansas (DD16-1603, 000016)

Project ended 12/31/21

Birth Defects Study To Evaluate Pregnancy exposures (BD-STEPS) II

Arkansas Children's Research Institute (DD18-001, 001285)

\$890,000

Enhancing Public Health Surveillance of Autism Spectrum Disorder through the ADDM Network

University of Arkansas for Medical System (DD19-1901, 000006)

\$543,657

California

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) II

Stanford University (DD18-001, 001226)

\$600,000

Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health

ChangeLab Solutions (OT18-1802, 000307)

\$400,000

Enhancing Public Health Surveillance of Autism Spectrum Disorder through the ADDM Network

University of California San Diego (DD19-1901, 000011)

\$392,274

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

The Children's Hospital of Los Angeles (DD19-001, 001274- Comp B)

\$80,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

The Children's Hospital of Los Angeles (DD19-001, 001273- Comp C)

\$25,000

Characterizing the Complications Associated with Therapeutic Blood Transfusions for Hemoglobinopathies

The Regents of the University of California, San Francisco (DD19-1903, 000002)

\$250,000

Sickle Cell Data Collection Program

Public Health Institute (DD20-2003, 000016)

\$497,426

Surveillance for Emerging Threats to Mothers and Babies

Los Angeles County Department of Public Health (CK19-1904, 00498)

\$622,646

Colorado

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3

University of Colorado Denver (DD16-001, 001210)

Project ended 6/30/22

NCBDDD Outcomes and Developmental Data Assistance Center for EHDl (ODDACE) Programs

The Regents of the University of Colorado (DD20-2005, 000099)

\$800,000

Study to Explore Early Development (SEED) Follow up Studies

University of Colorado Denver (DD21-001, 001290)

\$730,002

Sickle Cell Data Collection Program

Communication Institute International, Inc. (DD20-2003, 000022)

\$250,000

Connecticut

Implementing Alcohol Screening and Brief Intervention in Healthcare Systems Providing Women's Health Services

University of Connecticut Health Center (DD18-1802, 000004)

No cost extension until 9/29/23

Florida

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems

Florida Department of Health (DD20-2006, 000059)

\$160,000

The Muscular Dystrophy Surveillance, Tracking and Research Network

University of Florida (DD19-002, 001243- Comp B)

\$395,000

Advancing Population-Based Surveillance of Birth Defects

University of Florida (DD21-2101, 00107)

\$300,000

Georgia

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems

Georgia Department of Public Health (DD20-2006, 000061)

\$160,000

Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health
Council of State and Territorial Epidemiologists (OT18-1802, 000297)
\$1,950,000

Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health
Task Force for Global Health (OT18-1802, 000316)
\$2,775,996

Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health: Analysis and Dissemination of State-Wide Population-Based Sickle Cell Disease Data
National Foundation for CDC (OT18-1802, 000288)
\$155,800

Surveillance of Congenital Heart Defects Among Children, Adolescents, and Adults
Emory University (DD19-1902, 000057 – Comp A)
\$495,000

Surveillance of Congenital Heart Defects Among Children, Adolescents, and Adults
Emory University – (DD19-1902, 0000098- Comp B)
\$300,000

Characterizing the Complications Associated with Therapeutic Blood Transfusions for Hemoglobinopathies
Georgia State University, University Foundation, Inc. (DD19-1903, 000003)
\$252,520

Sickle Cell Data Collection Program
Georgia State University, University Foundation, Inc. (DD20-2003, 000021)
\$500,000

Surveillance for Emerging Threats to Mothers and Babies
Georgia Department of Public Health (CK19-1904,000529)

\$469,411

Improving the Health of People with Mobility Limitations
Georgia State University, University Foundation, Inc. (DD21-2103, 000024)

\$575,176

I-FASD: Understanding Clinical Data and Pathways to Inform Surveillance of
Children with Fetal Alcohol Spectrum Disorders

Emory University (DD22-2202, 000020)

\$403,992

Hawaii

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and
Intervention Data through Optimization of EHDl Surveillance Practices and
Information Systems

Hawaii State Department of Health (DD20-2006, 000062)

\$160,000

Idaho

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and
Intervention Data through Optimization of EHDl Surveillance Practices and
Information System

Idaho Department of Health (DD20-2006, 000068)

\$160,000

Illinois

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Illinois Department of Public Health (DD20-2006, 000079)

\$160,000

Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health
American Academy of Pediatrics (OT18-1802, 000282)

\$2,755,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

Ann & Robert H. Lurie Children's Hospital of Chicago (DD19-001, 001272-Comp B)

\$80,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

Ann & Robert H. Lurie Children's Hospital of Chicago (DD19-001, 001271-Comp C)

\$25,000

Characterizing the Natural History of Fragile X Syndrome

Rush University (DD21-002,001298)

\$800,000

Indiana

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Indiana Department of Health (DD20-2006, 000088)

\$160,000

Capacity Building for Sickle Cell Disease Surveillance

Indiana Hemophilia and Thrombosis Center (DD20-2003, 000020)

\$250,000

Iowa

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Iowa Department of Public Health (DD20-2006, 000087)

\$160,000

Surveillance of Congenital Heart Defects Among Children, Adolescents, and Adults

University of Iowa (DD19-1902, 000097)

\$400,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs

Iowa Department of Public Health (DD16-1603, 000019)

Project ended 12/31/21

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) II

University of Iowa (DD18-001, 001223)

\$850,000

The Muscular Dystrophy Surveillance, Tracking and Research Network
University of Iowa (DD19-002, 001248- Comp A)

\$415,000

The Muscular Dystrophy Surveillance, Tracking and Research Network
University of Iowa (DD19-002, 001247- Comp C)

\$80,000

Surveillance for Emerging Threats to Mothers and Babies
Iowa Department of Health (CK19-1904,) 000504

\$41,709

Kansas

Improving the Health of People with Mobility Limitations and Intellectual
Disabilities through State-based Public Health Programs

University of Kansas Center for Research, Inc. (DD16-1603, 000006)

Project ended 6/30/22

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and
Intervention Data through Optimization of EHDI Surveillance Practices and
Information Systems

Kansas Department of Health and Environment (DD20-2006, 000066)

\$95,000

National Partnerships to Address Prenatal Alcohol and Other Substance Use
and Fetal Alcohol Spectrum Disorders

American Academy of Family Physicians (DD22-2201, 000014)

\$280,000

Kentucky

Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs
Kentucky Cabinet for Health and Family Services (DD16-1603, 000010)

Project ended 12/31/21

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Kentucky Cabinet for Health and Family Services (DD20-2006, 000067)

\$160,000

Surveillance for Emerging Threats to Mothers and Babies

Kentucky Department for Public Health (CK19-1904, 000505)

\$210,740

Small Business Research Innovation (SBIR)

PGXL Technologies, LLC (PA21-259 , 001299)

\$309,250

Louisiana

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Louisiana Department of Health (DD20-2006, 000064)

\$159,998

Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health

National Network of Public Health Institute (OT18-1802, 00303)

\$166,925

Maine

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Maine Department of Health and Human Services (DD20-2006, 000071)

\$160,000

Tribal Public Health Capacity Building and Quality Improvement

Wabanaki Health And Wellness, NPC (OT18-1803, 000257)

\$40,000

Maryland

Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs

Maryland Department of Health (DD16-1603, 000005)

Project ended until 12/31/21

Implementing Evidence-Based Health Promotion Programs for Children with Attention-Deficit/Hyperactivity Disorder (ADHD) or Tourette Syndrome (TS)

CHADD, Inc. (Children and Adults with Attention-Deficit/Hyperactivity Disorder) (DD19-1904, 000002)

\$850,000

Centers for Autism and Developmental Disabilities Research and

Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3

Johns Hopkins University (DD16-001, 001214)

Project ended 6/30/22

Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health

Association of University Centers on Disabilities (OT18-1802, 000280)

\$2,408,396

Enhancing Public Health Surveillance of Autism Spectrum Disorder through the ADDM Network

Johns Hopkins University (DD19-1901, 000004)

\$556,538

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems

Maryland Department of Health (DD20-2006, 000072)

\$160,000

Strengthening Public Health Laboratories Newborn Screening and Genetics - Hemoglobinopathies Project

Association of Public Health Laboratories (OE20-2001, 000104)

\$48,582

Study to Explore Early Development (SEED) Follow up Studies

Johns Hopkins University (DD21-001, 001297)

\$1,302,102

Massachusetts

Implementing Alcohol Screening and Brief Intervention in Healthcare Systems Providing Women's Health Services

Boston Medical Center Corporation (DD18-1802, 000002)

No cost extension until 8/29/23

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems

Massachusetts Department of Public Health (DD20-2006, 000070)

\$160,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs
Massachusetts Department of Public Health (DD16-1603, 000002)
Project ended 6/30/22

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) II
Massachusetts Department of Public Health (DD18-001, 001224)
\$990,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
The Children's Hospital Corporation (DD19-001, 001266- Comp B)
\$80,000

Surveillance for Emerging Threats to Mothers and Babies
Massachusetts Department of Public Health (CK19-1904, 000518)
\$277,367

Improving the Health of People with Mobility Limitations
Massachusetts Department of Public Health (DD21-2103, 000030)
\$585,000

Population-based surveillance of outcomes, needs and
Trustees of Boston University (DD22-2203, 000111)
\$387,003

Michigan

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems
Michigan Department of Health and Human Services (DD20-2006, 000095)
\$160,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs
Michigan Department of Health and Human Services (DD16-1603, 000001)
Project ended 12/31/21

Implementing Alcohol Screening and Brief Intervention in Healthcare Systems Providing Women's Health Services
Henry Ford Health System (DD18-1802, 000001)
No cost extension until 9/29/23

Sickle Cell Data Collection Program
Regents of the University of Michigan (DD20-2003, 000014)
\$392,888

Advancing Population-Based Surveillance of Birth Defects
Michigan Department of Health and Human Services (DD21-2101, 000105)
\$673,982

Improving the Health of People with Mobility Limitations
Michigan Department of Health and Human Services (DD21-2103 ,000026)
\$585,000

Surveillance for Emerging Threats to Mothers and Babies
Michigan Department of Health and Human Services (CK19-1904, 000510)
\$164,253

Minnesota

Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs
Minnesota Department of Health (DD16-1603, 000009)
No cost extension until 6/30/22

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems

Minnesota Department of Health (DD20-2006, 000096)

\$160,000

Enhancing Public Health Surveillance of Autism Spectrum Disorder through the ADDM Network

Regents of the University of Minnesota (DD19-1901, 000007)

\$394,784

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

Gillette Children's Specialty Healthcare (DD19-001, 001268 - Comp B)

\$80,000

Sickle Cell Disease Collection Program

Minnesota Department of Health (DD20-2003, 000017)

\$250,000

Advancing Population-Based Surveillance of Birth Defects

Minnesota Department of Health (DD21-2101, 00104)

\$375,000

I-FASD: Understanding Clinical Data and Pathways to Inform Surveillance of Children with Fetal Alcohol Spectrum Disorders

Minnesota Department of Health (DD22-2202, 000019)

\$450,000

Population-based surveillance of outcomes, needs and

Minnesota Department of Health (DD22-2203, 000110) 000110

\$400,000

Surveillance for Emerging Threats to Mothers and Babies

Minnesota Department of Health (CK19-1904, 000508)

\$37,997

Missouri

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems

Missouri Department of Health and Senior Services (DD20-2006, 000082)

\$160,000

Enhancing Public Health Surveillance of Autism Spectrum Disorder through the ADDM Network

Washington University in St. Louis (DD19-1901, 000005)

\$418,911

Study to Explore Early Development (SEED) Follow up Studies

Washington University in St. Louis (DD21-001, 001289)

\$311,079

Improving the Health of People with Mobility Limitations

University of Missouri System (DD21-2103, 000029)

\$585,000

Montana

Improving the Health of People with Mobility Limitations

Montana Department of Public Health and Human Services (DD21-2103, 000027)

\$572,500

National Partnerships to Address Prenatal Alcohol and Other Substance Use and Fetal Alcohol Spectrum Disorders

Montana State University (DD22-2201, 000016)

\$280,000

Nebraska

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Nebraska Department of Health and Human Services (DD20-2006, 000094)

\$160,000

Nevada

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Nevada Division of Public and Behavioral Health (DD20-2006, 000090)

\$160,000

Reaching Healthcare Professionals in the Prevention of Fetal Alcohol Spectrum Disorders through National Professional Organizations

University of Nevada, Reno - Board of Regents (DD18-1803, 000008)

No cost extension until 9/29/23

National Partnerships to Address Prenatal Alcohol and Other Substance Use and Fetal Alcohol Spectrum Disorders

University of Nevada, Reno - Board of Regents (DD22-2201, 000011)

\$280,000

New Hampshire

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

New Hampshire Department of Health and Human Services (DD20-2006, 000091)

\$160,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs

University of New Hampshire (DD16-1603, 000007)

Project ended 6/30/22

Improving the Health of People with Mobility Limitations

University System of New Hampshire (DD21-2103, 000025)

\$572,500

New Jersey

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

New Jersey Department of Health (DD20-2006, 000093)

\$160,000

Enhancing Public Health Surveillance of Autism Spectrum Disorder through the ADDM Network

Rutgers, The State University of New Jersey (DD19-1901, 000008)

\$400,729

Advancing Population-Based Surveillance of Birth Defects

New Jersey Department of Health (DD21-2101, 00106)

\$300,000

Surveillance for Emerging Threats to Mothers and Babies
New Jersey Department of Health (CK19-1904, 000525)
\$681,717

New Mexico

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems
New Mexico Department of Health (DD20-2006, 000085)
\$160,000

New York

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems
Health Research, Inc. (DD20-2006, 000060)
\$160,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs
Health Research, Inc. (DD16-1603, 000004)

Project ended until 12/31/21

Public Health Surveillance for the Prevention of Complications of Bleeding Disorders
American Thrombosis and Hemostasis Network (DD20-2004, 000020)
\$4,300,000

Implementing Evidence-Based Health Promotion Programs for Children with Attention-Deficit/Hyperactivity Disorder (ADHD) or Tourette Syndrome (TS)
Tourette Syndrome Association, Inc. (DD19-1904, 000001)
\$900,000

Evaluation of Health Promotion and Preventive Program for Blood Disorders
Cooley's Anemia Foundation, Inc. (DD20-2002, 000005)

\$150,000

Evaluation of Health Promotion and Preventive Program for Blood Disorders
National Hemophilia Foundation (DD20-2002, 000006)

\$500,000

Birth Defects Study To Evaluate Pregnancy exposures (BD-STEPS) II
Health Research, Inc./New York Department of Health (DD18-001, 001227)

\$800,000

Surveillance of Congenital Heart Defects Among Children, Adolescents and
Adults

New York State Department of Health (DD19-1902, 000056)

\$480,000

Characterizing the Complications Associated with Therapeutic Blood
Transfusions for Hemoglobinopathies

Joan & Sanford I. Weill Medical College of Cornell University (DD19-1903,
000001)

\$250,000

The Muscular Dystrophy Surveillance, Tracking and Research Network
Health Research, Inc./New York Department of Health (DD19-002, 001252-
Comp A)

\$415,000

The Muscular Dystrophy Surveillance, Tracking and Research Network
Health Research, Inc./New York Department of Health (DD19-002, 001250-
Comp C)

\$80,000

The Muscular Dystrophy Surveillance, Tracking and Research Network
Health Research, Inc./New York Department of Health (DD19-002, 001251-
Comp E)

Project ended 8/31/22

Surveillance for Emerging Threats to Mothers and Babies
Health Research, Inc. (CK19-1904, 000516)

\$417,493

Surveillance for Emerging Threats to Mothers and Babies
New York City Department of Health and Mental Hygiene (CK19-1904,
000517)

\$192,516

Improving the Health of People with Mobility Limitations
Health Research, Inc. (DD21-2103, 000028)

\$585,000

Health Promotion and Disease Prevention Research Centers-
University of Rochester (DP22-003, 006394)

\$262,923

Health Promotion and Disease Prevention Research Centers
New York University (DP22-003, 006396)

\$239,991

North Carolina

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and
Intervention Data through Optimization of EHDI Surveillance Practices and
Information Systems

North Carolina Department of Health and Human Services (DD20-2006,
000081)

\$150,000

Centers for Autism and Developmental Disabilities Research and
Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3
University of North Carolina, Chapel Hill (DD16-001, 001205)

Project ended 6/30/22

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) II
University of North Carolina, Chapel Hill (DD18-001, 001231)

\$800,000

Research Approaches to Improve the Care and Outcomes of People Living
with Spina Bifida

Duke University (DD19-001, 001278- Comp B)

\$80,000

Research Approaches to Improve the Care and Outcomes of People Living
with Spina Bifida

Duke University (DD19-001, 001276- Comp C)

\$25,000

Surveillance of Congenital Heart Defects Among Children, Adolescents, and
Adults

Duke University (DD19-1902, 000054)

\$400,000

The Muscular Dystrophy Surveillance, Tracking and Research Network
Research Triangle Institute (DD19-002, 001255 – Comp A)

\$415,000

The Muscular Dystrophy Surveillance, Tracking and Research Network
Research Triangle Institute (DD19-002, 001253 – Comp C)

\$79,987

The Muscular Dystrophy Surveillance, Tracking and Research Network
Research Triangle Institute (DD19-002, 001254 – Comp D)

\$275,000

Small Business Innovation Research Grant
Health Outcomes, Inc. (SBIR19-272, 001232)

No cost extension until 9/29/23

Sickle Cell Data Collection Program

North Carolina Department of Health and Human Services (DD20-2003, 000015)

\$333,558

Study to Explore Early Development (SEED) Follow up Studies

University of North Carolina at Chapel Hill, (DD21-001, 001293)

\$588,918

Advancing Population-Based Surveillance of Birth Defects

North Carolina Department of Health and Human Services (DD21-2101, 000100)

\$331,000

North Dakota

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems

Minot State University (DD20-2006, 000092)

\$160,000

Ohio

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

Cincinnati Children's Hospital Medical Center (DD19-001, 001279- Comp B)

\$80,000

Improving the Health of People with Mobility Limitations

The Ohio State University (DD21-2103, 000032)

\$572,500

Oklahoma

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Oklahoma State Department of Health (DD20-2006, 000086)

\$160,000

Tribal Public Health Capacity Building and Quality Improvement

Southern Plains Tribal Health Board Foundation (OT18-1803, 000265)

\$40,000

Oregon

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Oregon Health Authority, Public Health Division (DD20-2006, 000073)

\$160,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

Oregon Health and Science University (DD19-001, 001275- Comp B)

\$80,000

Improving the Health of People with Mobility Limitations

Oregon Health and Science University (DD21-2103 ,000023)

\$585,000

Pennsylvania

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

University of Pittsburgh (DD19-001, 001280- Comp B)

\$80,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

Pennsylvania State University (DD19-001, 001270- Comp B)

\$80,000

Surveillance for Emerging Threats to Mothers and Babies

Pennsylvania Department of Health (CK19-1904, 000527)

\$125,547

Evaluation of Health Promotion and Prevention for Blood Disorders

National Blood Clot Alliance (DD20-2002, 000007)

\$350,000

Rhode Island

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Rhode Island Department of Health (DD20-2006, 000078)

\$160,000

South Carolina

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems

South Carolina Department of Health and Environmental Control (DD20-2006, 000089)

\$160,000

Coordinating Center for Research and Training to Promote the Health of People with Developmental and Other Disabilities

University of South Carolina (DD17-001, 001218)

No cost extension until 9/29/23

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs

University of South Carolina (DD16-1603, 000011)

Project ended 6/30/22

Surveillance of Congenital Heart Defects Among Children, Adolescents, and Adults

South Carolina Department of Health and Environmental Control (DD19-1902, 000052)

\$400,000

The Muscular Dystrophy Surveillance, Tracking and Research Network

South Carolina Department of Health and Environmental Control (DD19-002, 001244- Comp C)

\$80,000

The Muscular Dystrophy Surveillance, Tracking and Research Network

South Carolina Department of Health and Environmental Control (DD19-002, 001245- Comp A)

\$495,000

Advancing Population-Based Surveillance of Birth Defects
South Carolina Department of Health and Environmental Control (DD21-
2101, 000101)
\$300,000

Tennessee

Enhancing Public Health Surveillance of Autism Spectrum Disorder through
the ADDM Network
Vanderbilt University Medical Center (DD19-1901, 000010)
\$416,369

Research Approaches to Improve the Care and Outcomes of People Living
with Spina Bifida
Vanderbilt University Medical Center (DD19-001, 001234- Comp C)
\$25,000

Research Approaches to Improve the Care and Outcomes of People Living
with Spina Bifida
Vanderbilt University Medical Center (DD19-001, 001235- Comp B)
\$80,000

Sickle Cell Data Collection Program
The University Of Memphis (DD20-2003, 000019)
\$333,558

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and
Intervention Data through Optimization of EHDI Surveillance Practices and
Information Systems
Tennessee Department of Health (DD20-2006, 000063)
\$160,000

Surveillance for Emerging Threats to Mothers and Babies
Tennessee Department of Health (CK19-1904, 000528)

\$268,041

Advancing Population- Based Surveillance of Birth Defects
Tennessee Department of Health (DD21-2101, 000103)

\$349,214

National Partnerships to Address Prenatal Alcohol and Other Substance Use
and Fetal Alcohol Spectrum Disorders

Oak Ridge Associated Universities (DD22-2201, 000013)

\$338,004

Texas

Population-Based Surveillance of Birth Defects and Data Utilization for Public
Health Action

Texas Department of State Health Services (DD16-1601, 004942)

Project ended 1/31/22

Reaching Healthcare Professionals in the Prevention of Fetal Alcohol
Spectrum Disorders through National Professional Organizations

University of Texas at Austin (DD18-1803, 000009)

No cost extension until 9/29/23

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and
Intervention Data through Optimization of EHDI Surveillance Practices and
Information Systems

Texas Department of State Health Services (DD20-2006, 000080)

\$160,000

Research Approaches to Improve the Care and Outcomes of People Living
with Spina Bifida

Baylor College of Medicine (DD19-001, 001265- Comp B)

\$80,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

Baylor College of Medicine (DD19-001, 001263- Comp C)

\$25,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

University of Texas Southwestern Medical Center (DD19-001, 001262- Comp B)

\$80,682

Advancing Population-Based Surveillance of Birth Defects

Texas Department of State Health Services (DD21-2101, 000102)

\$300,000

National Partnerships to Address Prenatal Alcohol and Other Substance Use and Fetal Alcohol Spectrum Disorders

University of Texas at Austin (DD22-2201, 000012)

\$280,000

Utah

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information System

Utah Department of Health (DD20-2006, 00083)

\$160,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs

Utah Department of Health (DD16-1603, 000003)

Project ended 10/31/21

Enhancing Public Health Surveillance of Autism Spectrum Disorder through the ADDM Network

University of Utah (DD19-1901, 000009)

\$570,129

Surveillance of Congenital Heart Defects Among Children, Adolescents, and Adults

University of Utah (DD19-1902, 000053)

\$475,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

University of Utah (DD19-001, 001282- Comp C)

\$25,000

The Muscular Dystrophy Surveillance, Tracking and Research Network

University of Utah (DD19-002, 001249 – Comp A)

\$415,000

The Muscular Dystrophy Surveillance, Tracking and Research Network

University of Utah (DD19-002, 001246- Comp C)

\$80,000

Advancing Population-Based Surveillance of Birth Defects

Utah Department of Health (DD21-2101, 000109)

\$363,000

Improving the Health of People with Mobility Limitations

Utah Department of Health (DD21-2103, 000031)

\$585,000

Vermont

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Vermont Department of Health (DD20-2006, 000076)

\$160,000

Virginia

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Virginia Department of Health (DD20-2006, 000074)

\$160,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

Spina Bifida Association (DD19-001, 001257- Comp A)

\$665,000

The Muscular Dystrophy Surveillance, Tracking and Research Network

Virginia Commonwealth University (DD19-002, 001242- Comp B)

\$395,000

Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health

Association of State and Territorial Health Officials (OT18-1802, 000290)

\$150,000

Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health

March of Dimes (OT18-1802, 000284)

\$701,473

Sickle Cell Data Collection Program
Virginia Department of Health (DD20-2003, 000023)
\$246,777

Washington

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems

Washington State Department of Health (DD20-2006, 000058)
\$160,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

Seattle Children's Hospital (DD19-001, 001284- Comp C)
\$24,999

Surveillance for Emerging Threats to Mothers and Babies
Washington State Department of Health (CK19-1904, 000515)
\$308,501

Wisconsin

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3
University of Wisconsin—Madison (DD16-001, 001215)

Project ended 6/30/22

Enhancing Public Health Surveillance of Autism Spectrum Disorder through the ADDM Network

Board of Regents of the University of Wisconsin System (DD19-1901, 000002)
\$418,803

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

Children's Hospital of Wisconsin (DD19-001, 001240- Comp B)

\$80,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida

Children's Hospital of Wisconsin (DD19-001, 001239- Comp C)

\$25,000

Sickle Cell Data Collection Program

Medical College of Wisconsin (DD20-2003, 000013)

\$250,000

Study to Explore Early Development (SEED) Follow up Studies

University of Wisconsin System (DD21-001, 001291)

\$337,586

Wyoming

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDl Surveillance Practices and Information Systems

Wyoming Department of Health (DD20-2006, 000070)

\$160,000

District of Columbia

National Public Health Practice and Resource Centers on Health Promotion for People with Disabilities

Special Olympics (DD16-1602, 001156)

Project ended 7/31/22

Reaching Healthcare Professionals in the Prevention of Fetal Alcohol Spectrum Disorders through National Professional Organizations
American College of Obstetricians and Gynecologists (DD18-1803, 000007)

No cost extension until 3/29/23

Promoting Resources for Fetal Alcohol Spectrum Disorders Awareness and Prevention

National Organization on Fetal Alcohol Syndrome (DD18-1801, 000003)

Project ended 9/29/22

Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health

American Public Health Association (APHA) (OT18-1802, 000294)

\$13,712

Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health

National Association of County and City Health Officials (NACCHO) (OT18-1802, 000306)

\$1,653,115

Strengthening Public Health Systems and Services through National Partnerships to Improve and Protect the Nation's Health

Association of Maternal & Child Health Programs, Inc. (AMCHP) (OT18-1802,000296)

\$799,508

Evaluation of Health Promotion & Prevention Program for Blood Disorders
Hemophilia Federation of America (DD20-2002, 000008)

\$320,000

Improving Health of Americans with Intellectual and Developmental Disabilities Through Evidence-Based Health Promotion Programs

Special Olympics (DD21-2102, 00021)

\$15,482,425

National Partnerships to Address Prenatal Alcohol and Other Substance Use and Fetal Alcohol Spectrum Disorders
American College of Obstetricians and Gynecologists (DD22-2201, 000015)
\$280,000

National Partnerships to Address Prenatal Alcohol and Other Substance Use and Fetal Alcohol Spectrum Disorders
National Organization on Fetal Alcohol Syndrome (DD22-2201, 000018)
\$338,004

Guam

Documentation and Use of Follow up Diagnostic and Intervention Services Data through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)
University of Guam (DD17-1701, 00093)
Project ended 10/31/21

Puerto Rico

Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action
Puerto Rico Department of Health (DD16-1601, 004945)
Project ended 11/30/21

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems
Puerto Rico Department of Health (DD20-2006, 000069)
\$160,000

Switzerland

Global Noncommunicable Disease Prevention and Health Promotion

World Health Organization (GH21-2180, 000087)

\$125,995



View online at:

<https://www.cdc.gov/ncbddd/aboutus/report>



**Centers for Disease Control
and Prevention**
National Center on Birth Defects and
Developmental Disabilities

