



Inclusion, Accessibility, and Equity for All

Fiscal Year 2021 Annual Report

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Message from the **DIRECTOR**



Over the past year, NCBDDD staff have continued to step forward in unimaginable circumstances—facing the ongoing global threat of COVID-19 by bringing the best public health recommendations to communities daily. I have seen first-hand the late nights, early mornings, and weekends that staff have dedicated to protecting our health and safety—while simultaneously balancing the same challenges of working from home and navigating childcare and virtual schooling. To say the 2021 year was challenging is truly an understatement. COVID-19 has affected—and continues to affect—our community's wellbeing. The populations we serve at NCBDDD are continuing to experience barriers as they navigate their way through the pandemic, as well as the racial intolerance that came to a tipping point over the last year. This report not only summarizes NCBDDD's programmatic and fiscal achievements for 2021, it demonstrates our resolve to promote the health and well-being of babies, children, and adults.

As we continue to face this global health crisis, the inequities in our health systems have become even more evident. During the Fall of 2021, NCBDDD embarked on a strategic visioning and planning process to define our goals promoting and supporting CDC's **CORE** Commitment to Health Equity. This agency-wide strategy aims to integrate health equity into the fabric of all we do:

- **Cultivate** comprehensive health equity science
- **Optimize** interventions
- **Reinforce** and expand robust partnerships
- **Enhance** capacity and workforce engagement

To create change and further advance the health equity movement, NCBDDD is tackling barriers to health equity through its programs in several areas. NCBDDD Health Equity Goals are

- Better understand the use of voluntary corn masa flour fortification to increase folic acid intake among US Hispanic women to reduce the risk of neural tube defect-affected pregnancies.
- Identify health inequities among individuals living with birth defects and related disorders through improved surveillance and propose possible pathways to address the health inequities.

- Identify health inequities in the early identification and intervention of children with developmental disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network and the Early Hearing Detection and Intervention (EHDI) program.
- Establish national reporting of disability status and gender identity for persons with bleeding disorders to inform their health status and service needs, promote early identification of disability, and reduce stigmatization.
- Measure the social vulnerability of people living with sickle cell disease to understand the impact of social determinants of health outcomes.
- Expand CDC surveillance systems to include missing disability status measurements by defining, testing, implementing, and evaluating a new minimum question set to reflect disability status as a demographic in at least one national survey.

NCBDDD aims to create awareness, affect change, and offer solutions within communities to realize a more healthy, equitable, and inclusive society. I am excited and honored to lead NCBDDD activities and endeavors through these historical times, diminish the devastation of COVID-19, and seek to reduce health inequities within our programs. I have always valued how NCBDDD staff rise to meet every challenge and opportunity. I thank them for taking that dedication to new heights this past year as they adapted to the challenges of a global pandemic and delivered uninterrupted service for the populations we served when they needed us the most.

Sincerely,

Karen Remley

Karen Remley, MD, MBA, MPH, FAAP
Director, National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

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 and infant disorders are common, costly, and critical conditions that can cause lifelong health challenges. They may be the first sign that infectious diseases, environmental, occupational, or nutritional factors, maternal conditions, or substance use can cause serious harm to pregnant people, infants, and children. Our unique surveillance, public health research, and world-renowned expertise 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

- Identified and applied targeted strategies to prevent birth defects and infant disorders by
 - Strengthening state-based birth defects surveillance to improve capacity, data quality, and health outcomes of affected populations. NCBDDD now funds [10 state health departments for birth defects surveillance](#).
 - Making key research contributions to understand risk factors for birth defects. NCBDDD and collaborators examined maternal smoking and congenital heart defects (CHDs) among participants in 10 states with data from the [Centers for Birth Defects Research and Prevention](#). We found that multiple CHDs were modestly linked with *any* amount of cigarette smoking around the time of conception. NCBDDD and collaborators also [examined the use of hydroxychloroquine](#) in mothers of babies with and without birth defects in the United States; we found that use of this medicine does not appear to increase the risk for birth defects. NCBDDD continues to study medicine use before and during pregnancy so people and their doctors can make informed decisions about health conditions and treatment.
 - Continuing to monitor health inequities related to the risk of having a pregnancy with a neural tube defect (NTD). NCBDDD showed that [voluntary fortification with folic acid has not yet had an impact on folate status among Hispanic women of reproductive age](#) in the United States. In response, NCBDDD has developed a multiyear targeted strategy to identify and address the folic acid needs of this population.
- Prepared for, detected, and responded to emerging threats to pregnant people and their infants by
 - Expanding the [Surveillance for Emerging Threats to Mothers and Babies](#) Network (SET-NET) to include COVID-19. There are 31 jurisdictions

- currently conducting surveillance through SET-NET to examine COVID-19, hepatitis C, syphilis, and Zika virus.
- Informing public health and clinical recommendations for pregnant people. NCBDDD expertise and SET-NET data have been critical in CDC's efforts to understand the effects of [COVID-19 infection during pregnancy on birth and infant outcomes](#). By establishing that pregnant people with COVID-19 are at an increased risk of severe illness and adverse outcomes, SET-NET demonstrated the need for a strong recommendation for vaccination of pregnant people.
 - Advanced scientific and programmatic activities to address the impact of substance use during pregnancy on maternal and infant health by
 - Expanding surveillance to answer key questions about neonatal abstinence syndrome (NAS). NCBDDD collaborated with the Council on State and Territorial Epidemiologists to support six health departments for [surveillance of NAS](#).
 - Expanding the [MATernal and Infant Network \(MAT-LINK\)](#) to understand outcomes from medicines used to treat opioid use disorder during pregnancy. NCBDDD added three new sites to the MAT-LINK system, bringing the number of sites to seven. In addition to the new locations, all sites will expand data collection of children from 2 years through 6 years of age. This project received support from the U.S. Department of Health and Human Service's Assistant Secretary for Planning and Evaluation's Patient-Centered Outcomes Research Trust Fund.
 - Monitoring trends in alcohol use among pregnant people. NCBDDD found that during pregnancy, [current drinking and binge drinking increased slightly from 2011 to 2018](#). These data are important to help reduce alcohol-exposed pregnancies by identifying groups of women at increased risk of having an alcohol-exposed pregnancy and developing prevention programs aimed at reducing risk behaviors and improving pregnancy outcomes.
 - Helping fill gaps in knowledge about opioid prescriptions for women of reproductive age. Opioid prescriptions among insured women aged 15-44 years have decreased over time but remain common. [About 1 in 5 women with private insurance and about 1 in 4 women enrolled in Medicaid filled at least one opioid prescription](#).

Looking to the Future

NCBDDD's innovative mother-baby linked surveillance and long history of birth defects and infant disorders surveillance and research give our nation the best chance to protect pregnant people and infants, especially when facing emerging threats. Investments in modernizing and advancing our work enable 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, including COVID-19.

Additionally, we will continue identifying opportunities to prevent specific conditions, including CHDs, NTDs, gastroschisis, NAS, and fetal alcohol spectrum disorders. We also will work to reduce the impact of these conditions on health outcomes across the lifespan.

Notable Scientific Publications

- Bolin EH, Gokun Y, Romitti PA, et al. [Maternal smoking and congenital heart defects. National Birth Defects Prevention Study, 1997-2011.](#) *J Pediatr*. Published online September 8, 2021.
- Denny CH, Acero CS, Terplan M, et al. [Trends in alcohol use among pregnant women in the U.S., 2011–2018.](#) *Am J Prev Med*. 2020;59(5):768-769.
- Galang, RR, Newton SM, Woodworth KR, et al. [Risk factors for illness severity among pregnant women with confirmed SARS-CoV-2 infection – Surveillance for Emerging Threats to Mothers and Babies Network, 22 state, local, and territorial health departments, March 29, 2020 -March 5, 2021.](#) *Clin Infect Dis*. 2021;73:S17–S23.
- Heinke D, Isenburg JL, Stallings EB, et al. [Prevalence of structural birth defects among infants with Down syndrome, 2013-2017: A US population-based study.](#) *Birth Defects Res*. 2021;113(2):189-202.
- Howley MM, Werler MM, Fisher SC, et al. [Maternal exposure to hydroxychloroquine and birth defects.](#) *Birth Defects Res*. 2021;113(17):1245-1256.
- Krause KH, Gruber JF, Ailes EC, et al. [Assessment of neonatal abstinence syndrome surveillance — Pennsylvania, 2019.](#) *MMWR Morb Mortal Wkly Rep* 2021;70:40–45.
- Summers AD, Anderson KN, Ailes EC, et al. [Venlafaxine prescription claims among insured women of reproductive age and pregnant women, 2011–2016.](#) *Birth Defects Res*. 2021;113(4):1052-1056.
- Wang A, Rose CE, Qi YP, et al. [Impact of voluntary folic acid fortification of corn masa flour on RBC folate concentrations in the U.S. \(NHANES 2011–2018\).](#) *Nutrients*. 2021;13(4):1325.
- Woodworth KR, Olsen EO, Neelam V, et al. [Birth and infant outcomes following laboratory-confirmed SARS-CoV-2 infection in pregnancy — SET-NET, 16 jurisdictions, March 29–October 14, 2020.](#) *MMWR Morb Mortal Wkly Rep*. 2020;69:1635–1640.
- Zambrano LD, Ellington S, Strid P, et al. [Update: characteristics of symptomatic women of reproductive age with laboratory-confirmed SARS-CoV-2 infection by pregnancy status—United States, January 22–October 3, 2020.](#) *MMWR Morb Mortal Wkly Rep*. 2020;69:1641–1647.

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, such as autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), hearing loss, cerebral palsy, Tourette syndrome, fragile X syndrome, and vision loss, create delays and/or impairments in daily activities that can affect a child's health and well-being. Approximately 1 in 6 children in the United States have a [developmental disability or other developmental delay](#). To best support children and their families, CDC is committed to

- Improving early identification of developmental disabilities and delays;
- Monitoring the occurrence and characteristics of common developmental disabilities;
- Identifying factors that put children at risk for developmental disabilities and exploring possible causes;
- Improving early identification of developmental disabilities and delays; and
- Providing technical assistance to partners wanting to implement programs to improve the care and quality of life for children with developmental disabilities and their caregivers.



Accomplishments

- Reported data for the first time on the [prevalence of intellectual disability \(ID\) among 8-year-old children](#) in nine communities participating in the Autism and Developmental Disabilities Monitoring (ADDM) Network. CDC estimates that 1.2% (11.8 per 1,000) of children had ID, and 39% of children with ID also had ASD. These findings could be used to help inform strategies to enhance early access to intervention services to improve the quality of life for children with ID.
- Initiated a data visualization project to enhance the use of real-time, patient-level data from the [Early Hearing Detection and Intervention \(EHDl\)](#) program. This will help CDC improve tracking and inform decision making to facilitate enrollment into early intervention services for children who are deaf or hard of hearing. As part of EHDl's work to innovate and drive progress, NCBDDD's [Outcomes and Developmental Data Assistance Center for Early Hearing Detection and Intervention \(ODDACE\)](#) project has successfully onboarded 14 programs across nine states, with continued program recruitment underway. ODDACE is designed to collect and disseminate developmental outcome data among children who are deaf or hard of hearing.
- Funded 43 State and Territorial Act Early COVID-19 Response Teams to support early identification of developmental delays and disabilities and strengthen resiliency among children, families, and communities during the COVID-19 pandemic. Teams identified needs within their communities and developed strategies to address them, which included conducting trainings, developing public service announcements, customizing materials, implementing social media efforts, and establishing new policies.
- Leveraged the Study to Explore Early Development (SEED) infrastructure to collect information on the [impact of COVID-19](#) on services, behaviors, and health of children with ASD, other developmental disabilities or delays, and children from the general population. This study provides data to help inform public health strategies for

children (aged 3–9 years) and their families, particularly during public health emergencies.

- Supported the National Resource Center (NRC) at Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD) and Tourette Association of America (TAA) to provide evidence-based ADHD and Tourette syndrome education, health promotion and support for families, educators, healthcare providers, and the public. As examples from this year, CHADD/NRC produced three web-based toolkits, [“Diagnosis and Treatment of Children and Teens,”](#) [“Your Emerging Adult,”](#) and [“ADHD & COVID-19 Resources.”](#) TAA created an [“Emotional Overload” toolkit](#). Both partners hosted multiple, virtual trainings for providers, reaching more than 1,000 providers.
- Developed and disseminated web-based interactive tools, [Promoting Emotional Wellbeing and Resilience](#), supported by the National Academies of Sciences, Engineering, and Medicine. These tools provide engaging learning strategies for children and adolescents to reduce stress and anxiety during the COVID-19 pandemic.

Looking to the Future

NCBDDD and its partners work across systems to improve early identification of children with developmental disabilities and delays, connect these children and their families to medical, developmental, and behavioral intervention services, and provide tools and resources to help families facing these challenges. NCBDDD’s mission also includes understanding optimal development at each stage of life, including promoting school readiness, enhancing comprehensive care for teens with ASD, and helping families and children get the support they need.

Notable Scientific Publications

- Abercrombie J, Pann J, Shin F, et al. [Evaluation of the feasibility and perceived value of integrating *Learn the Signs. Act Early.* developmental monitoring resources in Early Head Start.](#) *Early Childhood Educ J.* Published online August 16, 2021.
- Barry CM, Robinson L, Kaminski J, et al. [Behavioral and socioemotional outcomes of the Legacy for Children™ randomized controlled trial to promote healthy development of children living in poverty, 2 to 6 years postintervention.](#) *J Dev Behav Pediatr.* Published online May 3, 2021.
- Charania SN, Danielson M, Claussen A, et al. [Bullying victimization and perpetration among US children with and without Tourette syndrome.](#) *J Dev Behav Pediatr.* Published online May 26, 2021.
- Claussen AH, Robinson L, Kaminski J, et al. [Factors associated with self-regulation in a nationally representative sample of children ages 3-5 years: United States, 2016.](#) *Matern Child Health J.* 2021;25(1):27-37.
- Maenner MJ, Graves SJ, Peacock G, et al. [Comparison of 2 case definitions for ascertaining the prevalence of autism spectrum disorder among 8-year-old children.](#) *Am J Epidemiol.* 2021;190(10):2198-2207.
- Meinzen-Derr J, Wiley S, Grove W, et al. [Kindergarten readiness in children who are deaf or hard of hearing who received early intervention.](#) *Pediatrics.* 2020;146(4):e20200557.

- Powell PS, Pazol K, Wiggins L, et al. [Health status and health care use among adolescents identified with and without autism in early childhood – four U.S. Sites, 2018-2020](#). *MMWR Morb Mortal Wkly Rep*. 2021;70:605-611.
- Wiggins LD, Nadler C, Rosenberg S, et al. [Many young children with autism who use psychotropic medication do not receive behavior therapy: a multisite case-control study](#). *J Pediatr*. 2021;232:264-271.
- Yoshinaga-Itano C, Mason CA, Wiggin W, et al. [Reading proficiency trends following newborn hearing screening implementation](#). *Pediatrics*. 2021;148(4):e2020048702.
- Zuvekas SH, Grosse SD, Lavelle TA, et al. [Healthcare costs of pediatric autism spectrum disorder in the United States, 2003-2015](#). *J Autism Dev Disord*. 2021;51(8):2950-2958.

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 regardless of age, race, sex, and socioeconomic status. With proper action, some blood disorders can be prevented, and with 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

- Partnered with the [National Blood Clot Alliance](#) to launch a public service announcement campaign that aired more than 22,000 times and garnered 134 million media impressions.
 - Trained over 1,800 U.S. professionals with the curriculum, “Stop the Clot, What Every Provider Should Know,” in order to continue to improve awareness of [venous thromboembolism](#).
- Garnered more than 9,500 healthcare provider registrants for CDC’s [Public Health Webinar Series on Blood Disorders](#). The webinars addressed and highlighted clinical best practices in the diagnosis, treatment, and prevention of blood disorders. Topics included COVID-19 and coagulopathy (a condition that affects the blood’s ability to form clots), [thalassemia](#) management, new guidelines on [von Willebrand disease](#), [hemophilia](#), and [hereditary hemorrhagic telangiectasia](#).
- Analyzed data and published three scientific articles to better characterize bleeding disorder occurrence rates, treatment, and complications using CDC’s surveillance data specific to von Willebrand disease.
 - Higher rates of bleeding and use of treatment products found among young boys compared to girls with von Willebrand disease. Read [the full study](#) in the *American Journal of Hematology* or the [key findings](#) for a summary of the study.
 - Occurrence rates of von Willebrand disease among people receiving care in specialized treatment centers in the United States. Read [the full study](#) in *Haemophilia* or the [key findings](#) for a summary of the study.
 - Characteristics, complications, and sites of bleeding among infants and toddlers less than 2 years of age with von Willebrand disease. Read [the full study](#) in *Blood Advances* or the [key findings](#) for a summary of the study.

- Increased understanding of hemoglobinopathies (red blood cell disorders) by
 - Expanding CDC’s [Sickle Cell Disease Data Collection program](#) from 2 to 11 states,
 - Developing the first fact sheet of the educational series “[Steps to Better Health for People with Sickle Cell Disease](#),”
 - Launching a CDC accredited [Virtual Thalassemia Grand Rounds](#) seminar, and
 - Issuing recommendations on transfusion management of beta-thalassemia to address concerns for people with [sickle cell disease and thalassemia](#).
- Improved hemophilia treatment product [inhibitor](#) testing at CDC by studying how well the chromogenic Bethesda assay (a test to detect the presence of inhibitors) works in patients receiving a special treatment with Emicizumab (a medicine used in the management and treatment of hemophilia).

Looking to the Future

COVID-19 continues to directly or indirectly impact people with blood disorders, including venous thromboembolism. We will continue to assess the effects of COVID-19, directing resources to better understand and reduce the impact to those affected with blood disorders. We will use data to track emerging trends in hemophilia treatments and treatment-related complications. We will also study long-term trends in diagnosis, treatment, and healthcare access for people with sickle cell disease in the United States. In addition, we are continuing to promote awareness of thalassemia and the importance of blood donations for both sickle cell disease and thalassemia.

Notable Scientific Publications

- Badawy S, Payne A, Hulihan M, 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.
- Boylan B, Niemeyer G, Werner B, et al. [Evaluation of anti-factor VIII antibody levels in patients with haemophilia A receiving immune tolerance induction therapy or bypassing agents.](#) *Haemophilia.* 2021;27(1):e40–e50.
- Dupervil B, Abe K, O’Brien S, et al. [Characteristics, complications, and sites of bleeding among infants and toddlers less than 2 years of age with VWD.](#) *Blood Adv.* 2021;5(8):2079-2086.
- Miller C. [Monitoring of von Willebrand factor inhibitors in patients with type 3 von Willebrand disease using a quantitative assay.](#) *Haemophilia.* 2021;27(5):823–829.
- Miller C and Boylan B. [The chromogenic Bethesda assay and the Nijmegen-Bethesda assay for factor VIII inhibitors in hemophilia A patients: Are they equivalent?](#) *J Thromb Haemost.* 2021;19(7):1835-1837.
- Miller C, Boylan B, Payne A, et al. [Validation of the chromogenic Bethesda assay for factor VIII inhibitors in hemophilia A patients receiving Emicizumab.](#) *Int J Lab Hematol.* 2021;43(2):e84–e86.

- Panepinto J, Brandow A, Mucalo L, et al. [Coronavirus disease among persons with sickle cell disease, United States, March 20-May 21, 2020](#). *Emerg Infect Dis*. 2020;26(10):2473-2476.
- Payne A, Adamkiewicz T, Grosse S, 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.
- Soucie J, Miller C, Byams V, et al. [Occurrence rates of von Willebrand disease among people receiving care in specialized treatment centers in the United States](#). *Haemophilia*. 2021;27(3):445-453.
- Wendelboe A, Campbell J, Ding K, et al. [Incidence of venous thromboembolism in a racially diverse population of Oklahoma County, Oklahoma](#). *Thromb Haemost*. 2021;121(6):816-825.

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 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

- Launched three new 5-year funding cycles to support [national](#) and [state](#) programs to reduce health inequities and improve health outcomes for people with disabilities throughout their lives.
- Supported projects to address the [greater impact of COVID-19 on people with disabilities](#):
 - Included disability champions within 14 state, 1 territorial, and 10 city and county health departments within public health emergency preparedness and response programs. These programs helped to ensure that (1) issues impacting people with disabilities are considered in planning and emergency response efforts, and (2) local emergency response plans are updated to better serve the needs of people with disabilities during outbreaks, pandemics, and other national emergencies.
 - Developed and launched an [online central repository](#) of COVID-19 resources. This repository provides technical assistance and training for health departments and organizations that serve people with disabilities. The online repository also offers informational resources for audiences who may need connections and referrals to local emergency services and support.
 - Developed a suite of COVID-19 resources, in both English and Spanish, for people with intellectual and developmental disabilities who also have literacy challenges, their direct care service providers, and healthcare professionals. These resources included posters, interactive activities, stories, videos, and tip sheets. They are housed on a [dedicated web platform](#) for easy access.

- Expanded surveillance and research to improve the lives of people with congenital heart defects (CHDs), spina bifida, and muscular dystrophies. Examining health issues and needs across each phase of life can provide data to plan for services and ensure that people with these conditions receive the care they need. In 2021, NCBDDD
 - Highlighted the healthcare needs and characterized health outcomes among the growing population of people with CHDs. NCBDDD studies showed that [adults with CHDs may be more likely than the general population to report additional cardiovascular issues](#), such as heart failure and stroke. Additionally, [women with CHDs may have a higher risk of some pregnancy-related health complications](#) than women without CHDs. NCBDDD also funded eight state health departments to examine how and when critical CHDs are diagnosed and any differences in time of diagnosis between different populations.
 - Informed standards of care and treatment for patients with spina bifida. NCBDDD and investigators from the [National Spina Bifida Patient Registry compared surgery during pregnancy versus after delivery for children with myelomeningocele](#), the most serious type of spina bifida. This research helps inform conversations between healthcare providers and parents about potential risks of surgery during pregnancy for expecting mothers and their infants with spina bifida. Through a quality improvement project among pediatric and adult clinics, NCBDDD also continued to address the care needs of people living with spina bifida as they transition from childhood to adult care.
 - Better described the characteristics of people living with muscular dystrophies. Data from NCBDDD's [Muscular Dystrophy Surveillance, Tracking, and Research Network \(MD STARnet\)](#) showed that, compared to [non-Hispanic white males, Duchenne and Becker muscular dystrophies were more common in Hispanic males, but less common in non-Hispanic Black males](#). Another NCBDDD study from MD STARnet described the [sociodemographic, clinical, and mortality characteristics of individuals with seven types of muscular dystrophies](#).

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 will continue to provide guidance to stakeholders to help public health programs become fully accessible and inclusive by offering effective tools and resources to improve the accessibility of program materials focused on healthy living (such as physical activity and nutrition) and [COVID-19 guidance](#).

By turning existing disability data and information into action, NCBDDD can help ensure that everyone has the same opportunities to participate in every aspect of life to the best of

their abilities. Additionally, CDC is committed to the ongoing efforts to expand surveillance systems by including disability status measurements in national surveys. 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.

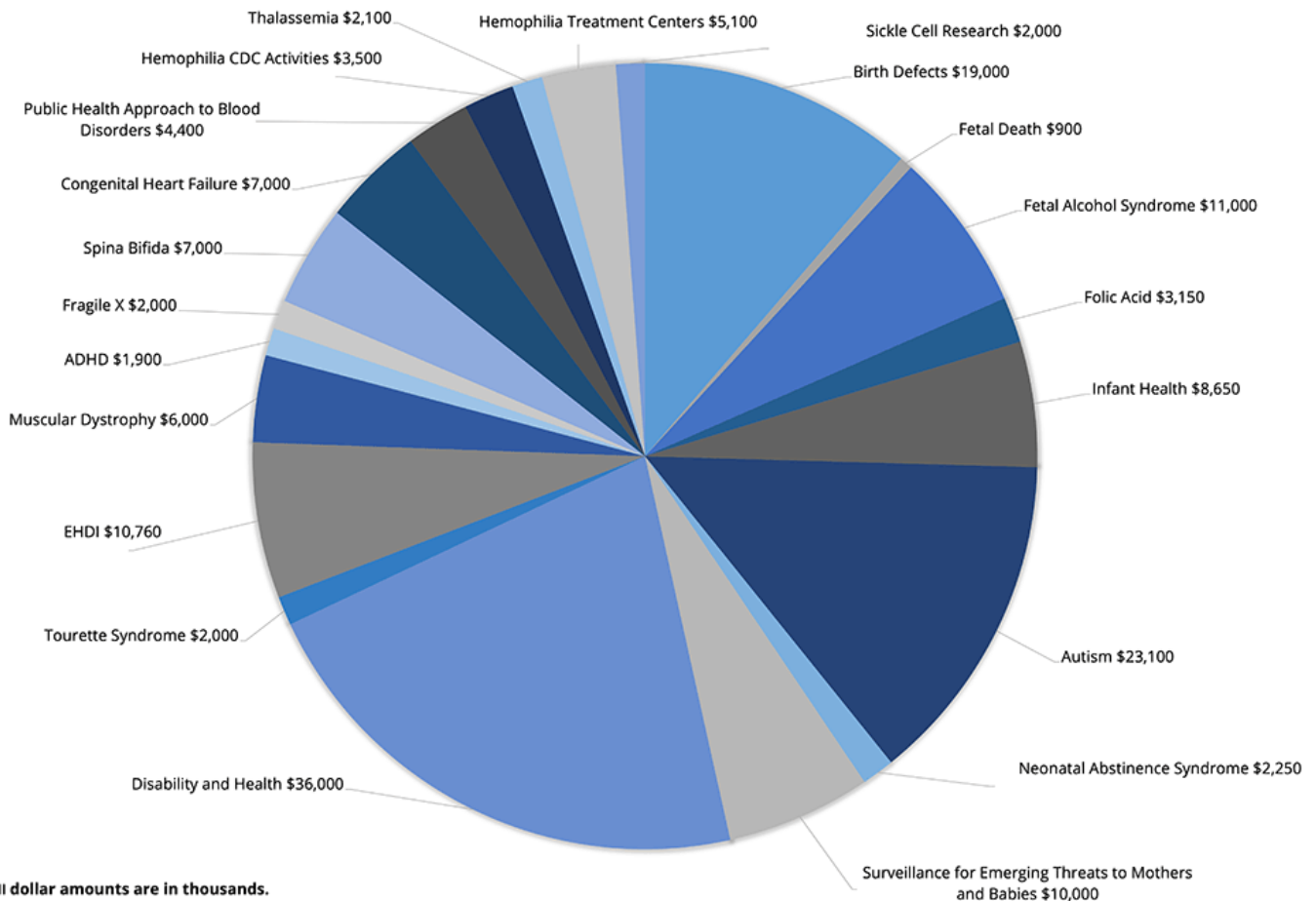
Notable Scientific Publications

- Glidewell MJ, Farr SL, Book WM, et al. [Individuals aged 1–64 years with documented congenital heart defects at healthcare encounters, five U.S. surveillance sites, 2011–2013](#). *Am Heart J*. 2021;238:100-108.
- Khavjou OA, Anderson WL, Honeycutt AA, et al. [State-level health care expenditures associated with disability](#). *Public Health Rep*. 2021;136(4):441-450.
- Okoro CA, Strine TW, McKnight-Eily L, et al. [Indicators of poor mental health and stressors during the COVID-19 pandemic, by disability status: a cross sectional analysis](#). *Disabil Health J*. 2021;14(4):101110.
- Oster ME, Riser AP, Andrews JG, et al. [Comorbidities among young adults with congenital heart defects: Results from the Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG — Arizona, Arkansas, and Metropolitan Atlanta, 2016–2019](#). *MMWR Morb Mortal Wkly Rep*. 2021;70(6):197–201.
- Rogers-Brown JS, Wanga V, Okoro C, et al. [Outcomes among patients referred to outpatient rehabilitation clinics after COVID-19 diagnosis — United States, January 2020–March 2021](#). *MMWR Morb Mortal Wkly Rep*. 2021;70(27):967–971.
- Ryerson AB, Rice CE, Hung M, et al. [Disparities in COVID-19 vaccination status, intent, and perceived access for noninstitutionalized adults, by disability status — National Immunization Survey Adult COVID Module, United States, May 30–June 26, 2021](#). *MMWR Morb Mortal Wkly Rep*. 2021;70(39):1365–1371.
- Tanaka ST, Yerkes EB, Routh JC, et al. [Urodynamic characteristics of neurogenic bladder in newborns with myelomeningocele and refinement of the definition of bladder hostility: Findings from the UMPIRE multi-center study](#). *J Pediatr Urol*. 2021;17(5):726-732.
- Verlenden JV, Zablotsky B, Yeargin-Allsopp M, et al. [Healthcare access and utilization for young adults with disability: U.S., 2014-2018](#). *J Adolesc Health*. Published online October 15, 2021.
- Worley G, Greenberg RG, Rocque BG, et al. [Neurosurgical procedures for children with myelomeningocele after fetal or postnatal surgery: a comparative effectiveness study](#). *Dev Med Child Neurol*. 2021;63(11):1293-1301.
- Zhang Y, Mann JR, James KA, et al. [Duchenne and Becker muscular dystrophies' prevalence in MD STARnet surveillance sites: An examination of racial and ethnic differences](#). *Neuroepidemiology*. 2021;55(1):47-55.

Fiscal Year 2021 Budget

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) fiscal year (FY) 2021 appropriation includes **\$167,810,000** 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.



NCBDDD FY 2021 Appropriations
(in thousands)

Birth Defects	\$19,000
Fetal Death	\$900
Fetal Alcohol Syndrome	\$11,000
Folic Acid	\$3,150
Infant Health	\$8,650
Autism	\$23,100
Neonatal Abstinence Syndrome	\$2,250
Surveillance for Emerging Threats to Moms and Babies	\$10,000
Disability and Health	\$36,000
Tourette Syndrome	\$2,000
Early Hearing Detection and Intervention (EHDI)	\$10,760
Muscular Dystrophy	\$6,000
Attention Deficit Hyperactivity Disorder (ADHD)	\$1,900
Fragile X	\$2,000
Spina Bifida	\$7,000
Congenital Heart Failure	\$7,000
Public Health Approach to Blood Disorders	\$4,400
Hemophilia CDC Activities	\$3,500
Thalassemia	\$2,100
Hemophilia Treatment Centers	\$5,100
Sickle Cell Research	\$2,000
NCBDDD Total	\$167,810
COVID-19 Response*	\$1,074

Note: NCBDDD spent \$4,831 of its annual appropriations on COVID related activities for people with the conditions we serve.

*NCBDDD received an additional \$1,074 beyond NCBDDD appropriations to support additional COVID related activities.

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 Health of Americans with Mobility Limitations through Evidence-Based Health Promotion Programs

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

No cost extension until 12/31/21

National Centers on Health Promotion for People with Disabilities

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

No cost extension until 9/30/21

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

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

\$70,000

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

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

\$25,000

Sickle Cell Data Collection Program

The 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, Birmingham (DD21-2104,000022)

\$5,092,429

Alaska

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

University of Alaska, Anchorage (DD18-1802, 000005)

\$400,000

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI 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)

\$250,000

Arizona

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

Arizona Department of Health Services (DD16-1601, 004950)

Project ended 1/31/21

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)

\$316,458

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)

No cost extension until 12/31/21

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

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

\$1,150,000

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

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

\$543,657

California

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

Stanford University (DD18-001, 001226)

\$900,000

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

ChangeLab Solutions (OT18-1802, 000307)

\$406,766

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

Regents of the 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)

\$249,438

Sickle Cell Data Collection Program

Public Health Institute (DD20-2003, 000016)

\$415,340

Surveillance for Emerging Threats to Mothers and Babies

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

\$413,439

Surveillance for Emerging Threats to Mothers and Babies

Public Health Foundation Enterprises, Inc (CK19-1904, 00539)

\$675,000

Behavioral Risk Factor Surveillance System (BRFSS):

California Department of Health (DP20-2007, 006864)

\$75,000

Colorado

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

Colorado Department of Public Health and Environment (DD16-1601, 004940)

Project ended 1/31/21

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

University of Colorado, Denver (DD16-001, 001210)

12 month no-cost extension until 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)

\$570,172

Behavioral Risk Factor Surveillance System (BRFSS):

Colorado Department of Health (DP20-2007, 006855)

\$25,000

Sickle Cell Data Collection Program

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

\$360,119

Connecticut

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

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

\$397,744

Behavioral Risk Factor Surveillance System (BRFSS):

Connecticut Department of Public Health (CK19-1904, 006866)

\$30,000

Florida

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

Florida Department of Health (DD16-1601, 004946)

Project ended 1/31/21

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

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

Florida Department of Health (DD16-1603, 000012)

No Cost Extension until 10/31/21

The Muscular Dystrophy Surveillance, Tracking and Research Network

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

\$350,000

Surveillance for Emerging Threats to Mothers and Babies

Florida Department of Health (CK19-1904, 000554)

\$425,000

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, 000279)

\$1,315,000

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)

\$3,670,000

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)

\$275,800

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)

\$252,518

Sickle Cell Data Collection Program

Georgia State University, University Foundation, Inc (DD20-2003, 000021)

\$454,078

Surveillance for Emerging Threats to Mothers and Babies

Georgia Department of Public Health (CK19-1904,000529)

\$308,875

Improving the Health of People with Mobility Limitations

Georgia State University, University Foundation, Inc (DD21-2103, 000024)

\$575,176

Hawaii

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 Hawaii System – bona fide agent for American Samoa (DD17-1701, 000071)

No cost extension until 1/31/21

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

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

\$160,000

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 Hawaii System – Bona fide agent for Marshall Islands (DD17-1701, 000072)

No cost extension until 1/31/21

Idaho

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

Idaho Department of Health (DD20-2006, 000068)

\$160,000

Illinois

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

Illinois Department of Public Health (DD16-1601, 004947)

Project ended 1/31/21

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI 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)

\$2,105,814

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)

\$79,999

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 EHDI Surveillance Practices and Information Systems

Indiana State 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 EHDI 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)

No cost extension until 12/31/21

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

University of Iowa (DD18-001, 001223)

\$900,000

The Muscular Dystrophy Surveillance, Tracking and Research Network

University of Iowa (DD19-002, 001248- Comp A)

\$375,000

The Muscular Dystrophy Surveillance, Tracking and Research Network

University of Iowa (DD19-002, 001247- Comp C)

\$80,000

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)

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

Kansas Department of Health (DD20-2006, 000066)

\$126,177

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

American Academy of Family Physicians (DD18-1803, 000010)

\$247,704

Behavioral Risk Factor Surveillance System (BRFSS):

Kansas Department of Health, (DP20-2007, 006876)

\$20,000

Kentucky

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

Kentucky Cabinet for Health and Family Services (DD16-1601, 004938)

Project ended 7/31/21

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)

No cost extension until 12/31/21

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI 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 of Health (CK19-1904, 000505)

\$119,367

Louisiana

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

Louisiana Department of Public 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 EHDI 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)

\$75,000

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)

No cost extension 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)

12 month no cost extension until 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)

\$1,780,000

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

John 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)

\$50,000

Study to Explore Early Development (SEED) Follow up Studies

John Hopkins University (DD21-001, 001297)

\$1,198,320

Behavioral Risk Factor Surveillance System (BRFSS):
Maryland Department of Health (DP20-2007, 006857)
\$35,000

Massachusetts

Implementing Alcohol Screening and Brief Intervention in Healthcare Systems Providing Women's Health Services
Boston Medical Center Corporation (DD18-1802, 000002)
\$397,046

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)
No cost extension until 6/30/22

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) II
Massachusetts Department of Public Health (DD18-001, 001224)
\$1,150,000

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

\$287,530

Improving the Health of People with Mobility Limitations

Massachusetts Department of Public Health (DD21-2103, 000030)

\$ 585,000

Michigan

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

Michigan Department of Health and Human Services (DD16-1601, 004944)

Project ended 4/30/21

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)

No cost extension until 12/31/21

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

Henry Ford Health System (DD18-1802, 000001)

\$395,177

Sickle Cell Data Collection Program

Regents of the University of Michigan (DD20-2003, 000014)

\$472,775

Advancing Population-Based Surveillance of Birth Defects

Michigan Department of Health and Human Services (DD21-2101, 000105)

\$674,051

Improving the Health of People with Mobility Limitations

Michigan Department of Health and Human Services (DD21-2103, 000026)

\$585,000

Behavioral Risk Factor Surveillance System (BRFSS):

Michigan Department of Health and Human Services (DP20-2007, 006880)

\$37,500

Minnesota

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

Minnesota Department of Health (DD16-1601, 004939)

Project ended 1/31/21

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)

\$242,852

Advancing Population-Based Surveillance of Birth Defects

Minnesota Department of Health (DD21-2101,00104)

\$375,000

Behavioral Risk Factor Surveillance System (BRFSS):

Minnesota Department of Health (DP20-2007, 006881)

\$35,000

Mississippi

Behavioral Risk Factor Surveillance System (BRFSS):

Mississippi State Department of Health (DP20-2007, 006882)

\$10,000

Missouri

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

Missouri Department of Health and Senior Services (DD16-1603, 000013)

Project ended 6/30/21

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

Missouri Department of Health (DD20-2006, 000082)

\$160,000

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

The Washington University (DD19-1901, 000005)

\$418,911

Study to Explore Early Development (SEED) Follow up Studies

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

\$308,443

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 and Intellectual Disabilities through State-based Public Health Programs

Montana Department of Public Health and Human Services (DD16-1603, 000018)

Project ended 6/30/21

Improving the Health of People with Mobility Limitations

Montana Department of Public Health and Human Services (DD21-2103.000027)

\$572,500

Nebraska

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

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

\$160,000

Behavioral Risk Factor Surveillance System (BRFSS):

Nebraska Department of Health & Human Services (DP20-2007,000684)

\$17,500

Nevada

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI 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 Organization

Nevada System of Higher Education (DD18-1803, 000008)

\$250,000

Behavioral Risk Factor Surveillance System (BRFSS)

Nevada Health Systems of Higher Education DP20-2007, 006885)

\$15,000

New Hampshire

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI 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)

No cost extension until 6/30/22

Improving the Health of People with Mobility Limitations

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

\$572,500

New Jersey

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

New Jersey Department of Health (DD16-1601, 004941)

Project ended 1/31/21

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI 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 Public Health (DD21-2101, 00106)

\$300,000

Behavioral Risk Factor Surveillance System (BRFSS):

New Jersey Department of Public Health (DP20-2007, 006905)

\$37,500

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

Behavioral Risk Factor Surveillance System (BRFSS):

New Mexico Department of Health (DP20-2007, 006887)

\$25,000

New York

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

Health

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)

No cost extension until 12/31/21

Public Health Surveillance for the Prevention of Complications of Bleeding Disorders

American Thrombosis and Hemostasis Network (DD15-1507, 000001)

No cost extension until 9/29/21

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)

\$900,000

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)
\$375,000

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)
\$80,000

Surveillance for Emerging Threats to Mothers and Babies
Health Research Inc. (CK19-1904, 000516)
\$425,000

Surveillance for Emerging Threats to Mothers and Babies
New York City Department of Health & Mental Hygiene (CK19-1904, 000517)
\$333,142

Behavioral Risk Factor Surveillance System (BRFSS)
Health Research Inc. (DP20-2007, 006888)
\$25,000

Improving the Health of People with Mobility Limitations
Health Research, Inc. (DD21-2103, 000028)
\$585,000

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)

12 month no-cost extension until 6/30/22

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

University of North Carolina, Chapel Hill (DD18-001, 001231)

\$900,000

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)

\$399,459

The Muscular Dystrophy Surveillance, Tracking and Research Network

Research Triangle Institute (DD19-002, 001255 – Comp A)

\$374,928

The Muscular Dystrophy Surveillance, Tracking and Research Network

Research Triangle Institute (DD19-002, 001253 – Comp C)

\$79,951

The Muscular Dystrophy Surveillance, Tracking and Research Network

Research Triangle Institute (DD19-002, 001254 – Comp D)

\$249,686

Small Business Innovation Research Grant

TeleSage Inc (SBIR19-272, 001232)

No cost extension until 9/29/22

Sickle Cell Data Collection Program

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

\$317,698

Study to Explore Early Development (SEED) Follow up Studies

University of North Carolina, (DD21-001, 001293)

\$581,307

Advancing Population-Based Surveillance of Birth Defects

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

\$330,852

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

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

Oklahoma State Department of Health (DD16-1601, 004949)

Project ended 2/2/21

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

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

\$160,000

Behavioral Risk Factor Surveillance System (BRFSS):

Oklahoma State Department of Health (**DP20-2007,0006891**)

\$22,800

Tribal Public Health Capacity Building and Quality Improvement

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

\$75,000

Oregon

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

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

\$160,000

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

Oregon Health and Science University (DD16-1603, 000014)

Project ended 6/30/21

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

Oregon Health Authority (DD16-1601, 004951)

Project ended 1/31/21

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)

\$370,968

Evaluation of Health Promotion and Prevention for Blood Disorders

National Blood Clot Alliance (DD20-2002, 000007)

\$350,000

Rhode Island

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

Rhode Island Department of Health (DD16-1601, 004943)

Project ended 8/31/21

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

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

\$160,000

Behavioral Risk Factor Surveillance System (BRFSS):

Rhode Island Department of Health (DP20-2007,006893)

\$20,000

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)

\$1,230,900

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

University of South Carolina (DD16-1603, 000011)

No Cost extension to 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)

\$375,000

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)

\$457,682

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)

\$253,371

Advancing Population- Based Surveillance of Birth Defects

Tennessee Department of Health (DD21-2101, 000103)

\$349,214

Texas

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

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

No cost extension until 1/31/22

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

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

\$250,000

Documentation and Use of Follow up Diagnostic and Intervention Services Data through the

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

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

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

Utah Department of Health (DD16-1601, 004948)

Project ended 1/31/21

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 ends 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)

\$375,000

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)

\$362,164

Improving the Health of People with Mobility Limitations

Utah Department of Health (DD21,2103, 000031)

\$585,000

Behavioral Risk Factor Surveillance System (BRFSS):

Utah Department of Health (DP20-2007, 006896)

\$25,000

Vermont

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

Vermont Department of Health (DD20-2006, 000076)

\$160,000

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

Vermont Department of Health (DD16-1603, 000008)

Project ended 6/30/21

Virginia

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI 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)

\$342,314

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

Assoc of State/Territorial Health Officials (OT18-1802, 000290)

\$800,000

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

March of Dimes, Inc (OT18-1802, 000284)

\$516,736

Behavioral Risk Factor Surveillance System (BRFSS):

Virginia Department of Health (DP20-2007, 0006898)

\$241,740

Sickle Cell Data Collection Program

Virginia Department of Health (DD20-2003, 000023)

\$358,645

Washington

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

Washington 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 Department of Health (CK19-1904, 000515)
\$33,246

West Virginia

Behavioral Risk Factor Surveillance System (BRFSS)
West Virginia Department of Health and Human Resources (DP20-2007, 006899)
\$17,500

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)
\$100,796

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)

\$249,793

Study to Explore Early Development (SEED) Follow up Studies

University of Wisconsin (DD21-001, 001291)

\$389,087

Wyoming

Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI 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)

No cost extension until 3/31/22

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

American College of Obstetricians and Gynecologists (DD18-1803, 0000007)

\$250,000

Promoting Resources for Fetal Alcohol Spectrum Disorders Awareness and Prevention

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

\$400,000

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)

\$429,366

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)

\$650,000

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)

\$13,682,425

Improving Clinical and Public Health Outcomes

The American College of Obstetricians and Gynecologists (CK20-2003, 000589)

\$70,000

Puerto Rico

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

Puerto Rico Department of Health (DD16-1601, 004945)

Project ends 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

Peru

Building Capacity for National Public Health Institutes Region

Instituto Nacional de Salud Ins (GH20-2132,000064)

\$350,000

Switzerland

Global Noncommunicable Disease Prevention and Health Promotion

World Health Organization (GH21-2180, 000087)

425,000

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)

No cost extension until 10/31/21

Commonwealth of the Northern Mariana Islands

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)

Commonwealth Healthcare Corporation (DD17-1701, 00059)

Project ended 6/30/21



View online at:

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



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

