



2020

NCBDDD

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



Table of Contents

Message from the Director.....	2
Saving Babies Through Surveillance, Research, and Prevention of Birth Defects and Infant Disorders.....	4
Helping Children Live to the Fullest by Understanding Developmental Disabilities	8
Protecting People and Preventing Complications of Blood Disorders	12
Improving Health of People with Disabilities.....	16
Fiscal Year 2020 Budget.....	20
Select State-Based Activities and Funding.....	22

Message from the Director

National Center on Birth Defects and Developmental Disabilities (NCBDDD)

MESSAGE FROM THE DIRECTOR



As 2020 comes to a close, I am happy to share with you the 2020 Fiscal Year Annual Report for the National Center on Birth Defects and Developmental Disabilities (NCBDDD). It is my honor to have joined leadership at CDC this year and specifically here at NCBDDD. The Annual Report includes notable programmatic accomplishments, impactful scientific publications, and our vision for the future. Read the Report to celebrate and learn more about the myriad of substantive ways that NCBDDD, along with our partners, has made a difference in the lives of those we serve.

My “north star” and passion has always been children and families—making sure every family has the best opportunity for health and well-being. I have met so many of our partners in these first few months and am humbled by the commitment, passion, and expertise they all bring to our work. Albeit virtual, these meetings have served as an important reminder that we are all in this work together.

This year, many NCBDDD leaders are continuing to work alongside our colleagues as part of the response to the ongoing COVID-19 pandemic. Pivoting from their “day job” to long hours and new responsibilities, I am proud and impressed with the professionalism and depth of service provided. Just as importantly, many NCBDDD staff have picked up new and additional duties to ensure the work of the Center continues and that we continue to move the agenda for babies, children, and people with blood disorders and disabilities forward. Our Center staff have navigated virtual work environments and accompanying stresses and challenges while still keeping our Center’s mission and public service front and center. An example of how this is happening in real-time is the partnership of the Center with the COVID-19 Response Team, following pregnant women and their babies to determine the impact of a COVID-19 infection on long-term outcomes.

I am gratified by the exceptional work that NCBDDD is doing and I look forward to our continued partnership so that together we can meet the Center’s goals of saving babies,

helping children, protecting people with blood disorders, and improving the health of those with disabilities.

To a healthy and fruitful year.

Sincerely,

A handwritten signature in cursive script that reads "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 towards 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 can be the first sign that infectious diseases, environmental hazards, or substances cause serious harm to pregnant women, 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 living with these conditions.

Together, with state, territorial, and local health departments, academic centers, healthcare providers, and other partners, we are working towards 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 other infant disorders by
 - Providing critical data showing that [rates of infant deaths due to birth defects declined by 10% from 2003 to 2017 in the United States](#). However, birth defects are still a leading cause of infant death, and there are differences by race. NCBDDD also found that [1 in every 166 pregnancies ended in stillbirth during 2015–2017 in the United States](#). In addition, [black mothers were more than twice as likely to experience a stillbirth compared to Hispanic and white mothers](#).
 - Making key research contributions toward understanding risk factors for specific birth defects. NCBDDD clarified previous research findings on the [relationship between use of antidepressants during early pregnancy and risk for specific birth defects](#). This study helps healthcare providers and their patients weigh the risks and benefits of using certain medicines during pregnancy.
 - Continuing to monitor the impact of folic acid fortification in the United States to reduce the risk of having a pregnancy with a neural tube defect (NTD). While folic acid fortification of enriched cereal grains has been one of the most successful public health programs, NCBDDD, in collaboration with CDC's National Center for Environmental Health, showed [continued racial and ethnic differences in the risks for NTDs, with about 20% of the U.S. population still at risk for NTDs that can be prevented by folic acid](#).
- Prepared, detected, and responded to emerging threats to pregnant women and their infants by
 - Implementing and expanding [Surveillance for Emerging Threats to Mothers and Babies](#) Network (SET-NET). NCBDDD adapted the mother-baby linked surveillance approach from the Zika virus outbreak to detect and understand the impact of other exposures during pregnancy, such as COVID-19, hepatitis C, and syphilis. NCBDDD also contributed scientific



- expertise to CDC's COVID-19 response to understand the effects of [COVID-19 infection during pregnancy](#).
- Deepening our understanding of the effects of Zika virus infection during pregnancy. NCBDDD [found that in 2 U.S. territories with widespread Zika virus transmission in 2016-2017, there was a four-fold increase in birth defects potentially related to Zika virus infection](#). NCBDDD and Colombia's Instituto Nacional de Salud [found that birth defects of the brain and eye were more common in Colombia](#) during the Zika virus outbreak in 2015–2016 than before or after it and more common among women with Zika virus infection in the first trimester.
 - Advanced scientific and programmatic activities to address the impact of substance use during pregnancy on maternal and infant health by
 - Providing critical data on use of multiple substances (polysubstance use) during pregnancy showing that the [use of substances, such as tobacco and marijuana, was common among pregnant women who reported alcohol use](#). To highlight this issue, NCBDDD also led a [Public Health Grand Rounds on reducing polysubstance use during pregnancy](#).
 - Strengthening surveillance to answer key questions. NCBDDD collaborated with the Council on State and Territorial Epidemiologists to support six health departments for [surveillance of neonatal abstinence syndrome](#).
 - Implementing and funding four clinical sites for [MATernal and Infant Network \(MAT-LINK\)](#) to understand outcomes from treatment for opioid use disorder during pregnancy. 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.
 - Developing tools and resources for healthcare providers. NCBDDD partnered with the MITRE Corporation to develop [clinical decision support tools](#) on alcohol screening and brief intervention that can be integrated into electronic health records. These tools can help healthcare providers deliver alcohol screening to women of reproductive age and offer evidence-based interventions to those at risk of excessive alcohol use.

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 women and infants, especially when we're combatting emerging threats. Investments in modernizing and advancing our work allow CDC to continue strengthening a public health network that can rapidly assess the needs of pregnant women 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, neural tube defects, gastroschisis, neonatal abstinence syndrome, and fetal alcohol spectrum disorders, and to reduce their impact on health outcomes across the lifespan.

Notable Scientific Publications

- Almli LM, et al. [Infant mortality attributable to birth defects—United States, 2003–2017](#). *MMWR Morb Mortal Wkly Rep*. 2020;69:25–29.
- Anderson KN, et al. [Maternal use of specific antidepressant medications during early pregnancy and the risk of selected birth defects](#). *JAMA Psychiatry*. 2020:e202453.
- Ellington S, et al. [Characteristics of women of reproductive age with laboratory-confirmed SARS-CoV-2 infection by pregnancy status—United States, January 22–June 7, 2020](#). *MMWR Morb Mortal Wkly Rep*. 2020;69:769–775.
- England LJ, et al. [Alcohol use and co-use of other substances among pregnant females aged 12–44 years—United States, 2015–2018](#). *MMWR Morb Mortal Wkly Rep*. 2020;69(31):1009–1014.
- McKnight-Eily LR, et al. [Screening for alcohol use and brief counseling of adults—13 states and the District of Columbia, 2017](#). *MMWR Morb Mortal Wkly Rep*. 2020;69(10):265–270.
- Ospina ML, et al. [Zika virus disease and pregnancy outcomes in Colombia](#). *N Engl J Med*. 2020;383(6):537–545.
- Pruitt SM, et al. [Racial and ethnic disparities in fetal deaths—United States, 2015–2017](#). *MMWR Morb Mortal Wkly Rep*. 2020;69:1277–1282.
- Reefhuis J, et al. [Neural tube defects in pregnancies among women with diagnosed HIV infection—15 jurisdictions, 2013–2017](#). *MMWR Morb Mortal Wkly Rep*. 2020;69:1–5.
- Smoots AN, et al. [Population-based surveillance for birth defects potentially related to Zika virus infection—22 states and territories, January 2016–June 2017](#). *MMWR Morb Mortal Wkly Rep*. 2020;69:67–71.
- Tinker SC, et al. [Use of benzodiazepine medications during pregnancy and potential risk for birth defects, National Birth Defects Prevention Study, 1997–2011](#). *Birth Defects Res*. 2019;111(10): 613–620.

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

- Monitoring common developmental disabilities;
- Identifying factors that put children at risk for developmental disabilities and exploring possible causes;
- Improving 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

- Developed and awarded two cooperative agreements by the [Early Hearing Detection and Intervention \(EHDI\)](#) program to help expand early identification practices, enrollment into early intervention services, and understanding of the factors that impact the developmental outcomes of children who are deaf or hard of hearing. The newly supported—and first of its kind—[NCBDDD Outcomes and Developmental Assistance Center for Early Hearing Detection and Intervention \(ODDACE\)](#) will expand public health capacity to gather, analyze, and use intervention and developmental outcome data of children who are deaf or hard of hearing. In addition, increased collection and [analysis of patient-level data will help establish new ways to improve timeliness of EHDI services](#), such as average age at screening (in days), diagnosis, and enrollment into early intervention services.
- Reported data from the [Autism and Developmental Disabilities Monitoring \(ADDM\) Network 4-year-old and 8-year-old children](#) with ASD in 6 and 11 communities across the United States, respectively. CDC estimates that about 1 in 54 children have been identified with ASD (or 19 per 1,000 8-year-olds). This year's addition of data on 4-year-old children will help NCBDDD identify trends in the early identification of ASD.
- Aimed to learn more about public health prevention and intervention strategies to support children's health and development through NCBDDD's [Project to Learn About Youth-Mental Health \(PLAY-MH\)](#). Through PLAY-MH, NCBDDD analyzed data on ADHD, tic disorders, and other developmental disabilities in school-aged children.
- Worked with multiple Medicaid-funded states and reviewed Medicaid billing data to examine the [quality and consistency of health care among children with](#)



[intellectual disabilities](#), with the goal to increase awareness and identify policy strategies to improve access to health care for priority medical issues in children.

- Expanded the reach of its [Learn the Signs. Act Early. \(LTSAE\) program](#) by increasing the number of [Act Early Ambassadors](#) to 60 representatives. With this added support, NCBDDD has increased capacity for early identification of children with ASD and other developmental disabilities, supported COVID-19 response efforts, and strengthened resilience, skills, behaviors, and resources for children, families, and communities.
- Awarded funding to the Research Triangle Institute to provide support to the Fragile X Clinical and Research Consortium for analysis of longitudinal data on individuals with full-mutation fragile X syndrome via the [Fragile X Online Registry with Accessible Research Database](#).

Looking to the Future

Children with developmental disabilities and their families often face personal, social, and financial challenges. 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, 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. [Indicators of social competence and social participation among US children with Tourette syndrome](#). *J Child Neurol*. 2020;35(9):612–620.
- Danielson ML, et al. [Community-based prevalence of externalizing and internalizing disorders among school-aged children and adolescents in four geographically dispersed school districts in the United States](#). *Child Psychiatry Hum Dev*. 2020 Jul 30.
- Dietz PM, et al. [National and state estimates of adults with autism spectrum disorder](#). *J Autism Dev Disord*. 2020;50(12):4258–4266.
- Do TQN, et al. [Fragile X syndrome-associated emergency department visits in the United States, 2006](#) *Am J Intellect Dev Disabil*. 2020;125(2):103–108.
- Lindgren S, et al. [Disability, hospital care, and cost: utilization of emergency and inpatient care by a cohort of children with intellectual and developmental disabilities](#). *J Pediatr*. 2020 Sep 2.

- Maenner MJ, et al. [Prevalence of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2016](#). *MMWR Surveill Summ*. 2020;69(No. SS-4):1–12.
 - Robinson LR, et al. [Trends over time and jurisdiction variability in Supplemental Security Income and State Supplementary Payment programs for children with disabilities](#). *J Public Health Manag Pract*. 2020;26(Suppl 2):S45–S53.
 - Shaw KA, et al. [Early identification of autism spectrum disorder among children aged 4 years—Early Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2016](#). *MMWR Surveill Summ*. 2020;69(No. SS-3):1–11.
 - Wiggins LD, et al. [Disparities in documented diagnoses of autism spectrum disorder based on demographic, individual, and service factors](#). *Autism Res*. 2020;13(3):464–473.
-
- Wiggins LD, et al. [Wandering among preschool children with and without autism spectrum disorder](#). *J Dev Behav Pediatr*. 2020;41(4):251–257.

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

- Partnered with the [National Blood Clot Alliance](#) to launch a new arm of the [Stop the Clot, Spread the Word® campaign](#) to continue to improve awareness of [venous thromboembolism \(VTE\)](#) in the United States. The new campaign materials garnered more than 500 million media impressions. These resources helped to educate patients and providers about blood clots, specifically [cancer-associated VTE](#).
- Addressed and highlighted clinical best practices in the diagnosis, treatment, and prevention of VTE through CDC's [Public Health Webinar Series on Blood Disorders](#), which included [Selection of a Risk Assessment Model for VTE Prevention in Hospitalized Medical Patients](#) and [Update on COVID-19 and Thrombosis Risk](#). Each presentation had more than 500 registrants.
- Developed and launched two new components of the [Community Counts Data Visualization Tool](#), an interactive platform that describes characteristics of more than 65,000 individuals with bleeding disorders.
 - The "Treatments" tab allows users to explore information about treatment plans, types of treatment products used, age at first treatment, age when regular infusions of clotting factor concentrates were begun in order to prevent bleeding (called continuous prophylaxis), and use of treatment products that are made from plasma.
 - The "Bleeding Disorders Burden" tab displays information about an individual's experience living with a bleeding disorder, including location of care, emergency department and hospital visits, school and work absenteeism, long-term pain and its relationship to opioid use, and other medical conditions.
- Improved laboratory monitoring of [inhibitors](#), a complication related to certain treatments for bleeding disorders, by evaluating the current CDC inhibitor testing



and reporting procedures to determine the most accurate and efficient methods for testing given the changing treatment product landscape.

- Increased understanding of hemoglobinopathies (red blood cell disorders) through expanded health monitoring and characterization of these conditions, including the impact that COVID-19 is having on the health of people with [sickle cell disease and thalassemia](#).

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 to those affected. We will use data to track emerging trends in hemophilia treatments and treatment-related complications. We will also expand the and study long-term trends in diagnosis, treatment, and healthcare access for people with sickle cell disease in the United States. Finally, we are promoting awareness of the importance of blood donations for both sickle cell disease and thalassemia.

Notable Scientific Publications

- Abe K, et al. [Higher rates of bleeding and use of treatment products among young boys compared to girls with von Willebrand disease](#). *Am J Hematol*. 2020;95(1):10–17.
- Aluc A, et al. [Using surveillance to determine the number of individuals with sickle cell disease in California and Georgia, 2005–2016](#). *Pediatr Hematol Oncol*. 2020;1–5.
- Badawy S, et al. [Association between clinical outcomes and metformin use in adults with sickle cell disease and diabetes mellitus](#). *Blood Adv*. 2019;3(21):3297–3306.
- Bender M, et al. [Newborn screening practices for alpha-thalassemia detection in the United States](#). *MMWR Morb Mortal Wkly Rep*. 2020;69(36):1269–1272.
- Gupta S, et al. [Potential of the Community Counts Registry to characterize rare bleeding disorders](#). 2019;25(6):1045–1050.
- Majumdar S, et al. [Parvovirus B19 infection in sickle cell disease: An analysis from the CDC Hemoglobinopathy Blood Surveillance Project](#). *Transfus Med*. 2020;30(3):226–230.
- Panepinto J, 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, et al. [Evaluation of pre-analytic heat treatment protocol used in the CDC Nijmegen-Bethesda assay for heat inactivation of extended half-life hemophilia treatment products](#). 2020;26(1):e28–e30.

- Schieve L, et al. [Evaluation of CDC's hemophilia surveillance program: Universal Data Collection \(1998–2011\) and Community Counts \(2011–2019\)](#). *MMWR Surveill Summ*. 2020;69(5):1–18.
 - Soucie J, et al. [Occurrence rates of hemophilia among males in the United States based on surveillance conducted in specialized hemophilia treatment centres](#). 2020;26(3):487–493.
-

Improving Health of People with Disabilities



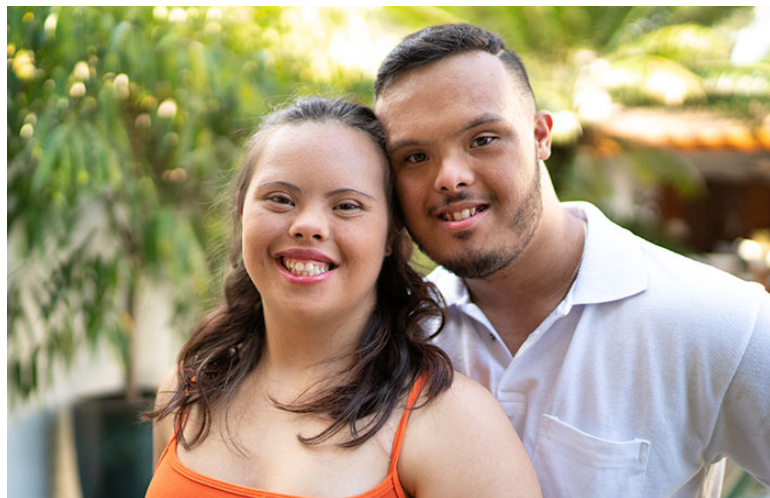
CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) works to ensure that people with disabilities have the same opportunities for good health as people without disabilities.

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 not healthy 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 part of their communities. CDC works to ensure that people of all abilities can live their lives to the fullest.

Accomplishments

- Coordinated and hosted a CDC Public Health Grand Rounds (PHGR) titled "[Addressing Gaps in Health Care for Individuals with Intellectual Disabilities.](#)"

Partners presented on efforts to improve health outcomes for people with intellectual disabilities (ID) and discussed how enhanced data can be a useful tool to help communities and healthcare professionals reach this goal. A [Beyond the Data](#) interview was produced and recorded during this PHGR, featuring prominent partners discussing disability inclusion and how to better understand the needs of people with ID. This PHGR was a first in many ways; namely, it was the first time a CDC guest hosted *Beyond the Data*, the first time PHGR included local disability partner organizations in an information fair, and the first time PHGR included a person with ID as a panel speaker.



- Guided the establishment of the "[Disability Data to Action](#)" [Community of Practice \(CoP\)](#) , which focuses on using disability data and information to educate and inform policymakers. The objective of the CoP is to move from simply describing health differences between people with and without disabilities to developing ways that existing disability data can be used to create policies and health promotion programs, and enable new public health efforts.
- Accelerated its surveillance and research to improve the lives of people living with congenital heart defects, muscular dystrophy, and spina bifida. Examining the 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 2020, NCBDDD
 - Provided critical data [characterizing adults with heart defects who access health care services](#), finding that those who access health care have certain characteristics in common, including being middle age, having multiple cardiac and non-cardiac health issues, and carrying public insurance. NCBDDD also found that [women with heart defects have a higher risk of pregnancy-related health issues but may not always receive recommended care](#). Additionally, NCBDDD established the Congenital Heart Defects Surveillance across Time And Regions (CHD STAR) project in seven sites to

- examine the health of people with heart defects over a 10-year time period.
- Expanded the Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet) to include two new surveillance sites. MD STARnet [collects sociodemographic, diagnostic, clinical, and mortality information for individuals with eight types of muscular dystrophy](#).
 - Advanced understanding of the health of individuals with spina bifida, including assessing [kidney function surveillance](#) in patients with spina bifida and reporting on differences in [continence rates](#) among people with spina bifida in relation to ethnicity.

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 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 in particular on healthy living (such as physical activity and nutrition) and

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 and desires. 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

- Chu DI, et al. [Kidney function surveillance in the National Spina Bifida Patient Registry: a retrospective cohort study](#). *J Urol*. 2020;204(3):578–586.
- Cree RA, et al. [Frequent mental distress among adults, by disability status, disability type, and selected characteristics—United States, 2018](#). *MMWR Morb Mortal Wkly Rep*. 2020;69(36):1238–1243.
- Downing KF, et al. [Adverse pregnancy conditions among privately insured women with and without congenital heart defects](#). *Circ Cardiovasc Qual Outcomes*. 2020;13(6):e006311.
- Gurvitz M, et al. [Characteristics of adults with congenital heart defects in the United States](#). *J Am Coll Cardiol*. 2020;76(2):175–182.

- Hollis ND, et al. [Physical activity types among US adults with mobility disability, Behavioral Risk Factor Surveillance System, 2017.](#) *Disabil Health J.* 2020;13(3):100888.
- Khavjou OA, et al. [National health care expenditures associated with disability.](#) *Med Care.* 2020;58(9):826–832.
- Leeb RT, et al. [Support for transition from adolescent to adult health care among adolescents with and without mental, behavioral, and developmental disorders—United States, 2016–2017.](#) *MMWR Morb Mortal Wkly Rep.* 2020;69:1156–1160.
- Smith KA, et al. [Differences in continence rates in individuals with spina bifida based on ethnicity.](#) *J Pediatr Rehabil Med.* 2019;12(4):361–368.
- Wallace B, et al. [Characterization of individuals with selected muscular dystrophies from the expanded pilot of the Muscular Dystrophy Surveillance, Tracking and Research Network \(MD STARnet\) in the United States.](#) *Birth Defects Res.* 2020 Jul 24.

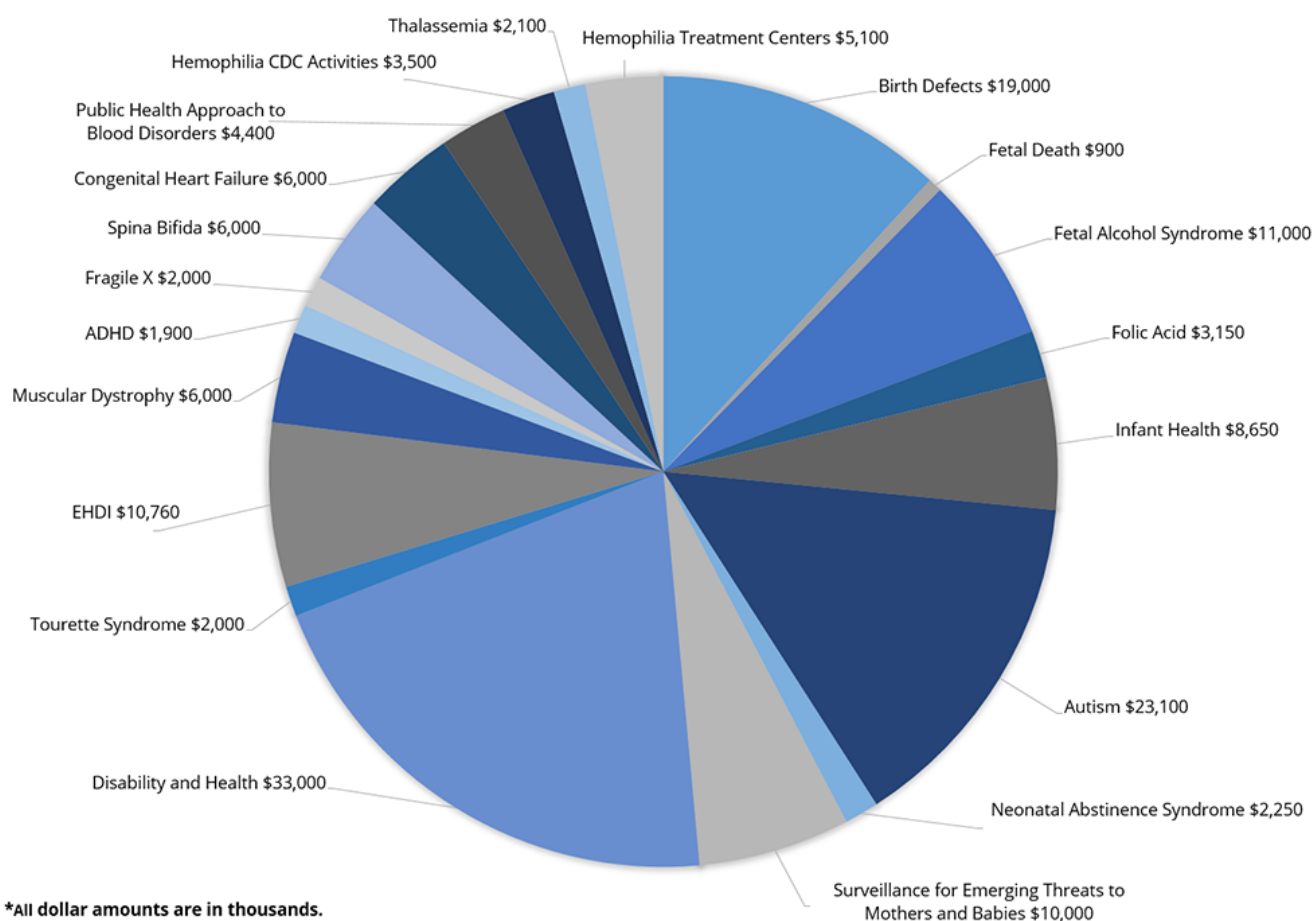
- Zhao G, et al. [Prevalence of disability and disability types by urban-rural county classification—U.S., 2016.](#) *Am J Prev Med.* 2019;57(6):749–756.

Fiscal Year 2020 Budget



CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) fiscal year (FY) 2020 appropriation includes **\$160,810,000** 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 are addressing issues with the greatest public health burden and implementing strategies to improve health outcomes.



**NCBDDD FY 2020 Appropriations
(in thousands)**

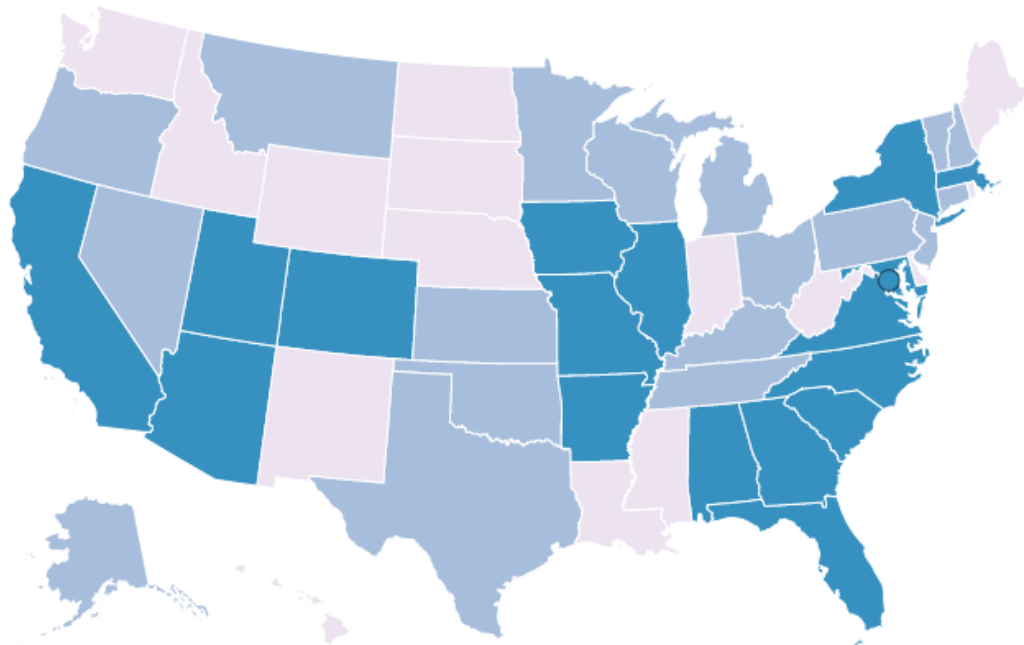
Child Health and Development	\$65,800
Birth Defects	\$19,000
Fetal Death	\$900
Fetal Alcohol Syndrome	\$11,000
Folic Acid	\$3,150
Infant Health	\$8,650
Autism	\$23,100
Neonatal Abstinence Syndrome	\$2,250
Surveillance for Emerging Threats to Moms and Babies	\$10,000
Health and Development with Disabilities	\$67,660
Disability and Health	\$33,000
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	\$6,000
Congenital Heart Failure	\$6,000
Public Health Approach to Blood Disorders	\$15,100
Public Health Approach to Blood Disorders	\$4,400
Hemophilia CDC Activities	\$3,500
Thalassemia	\$2,100
Hemophilia Treatment Centers	\$5,100
NCBDDD Total	\$160,810

Select State-Based Activities and Funding



View the National Center on Birth Defects and Developmental Disabilities' extramural program funding (based on Fiscal Year 2020 funding levels of extramural programs).

NCBDDD Select State-Based Activities and Funding



Territories **GU** **MP** **PR** **VI**



Funding Levels

(based on Fiscal Year 2020 funding levels of extramural programs).

- 0 - 320,000
- 325,000 - 1,483,146
- 1,485,641 - 13,595,503

Alabama

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)

Alabama Department of Public Health (DD17-1701, 000085)

Project ended 6/30/20

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)

\$300,000

National Centers on Health Promotion for People with Disabilities

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

\$4,142,429

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)

\$68,000

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)

\$20,500

Capacity Building for Sickle Cell Disease Surveillance

The University of Alabama at Birmingham (DD19-1906, 000009)

Project ended 9/29/20

Sickle Cell Data Collection Program

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

\$113,533 (Only \$8,000K from NCBDDD)

Alaska

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

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

\$400,000

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)

Alaska Department of Health and Social Services (DD17-1701, 000060)

Project ended 6/30/20

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)

\$200,000

Enhancing Public Health Surveillance of Autism Spectrum Disorder and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network

Arizona Board of Regents, University of Arizona (DD15-1501, 001162)

Project ended 12/31/2019

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)

Arizona Department of Health Services (DD17-1701, 000076)

Project ended 6/30/20

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

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

\$387,806 - Supplemental Funding \$77,562

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)

\$316,458

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 (OT18-1802, 000279)

\$110,000

Arkansas

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)

Arkansas Department of Health (DD17-1701, 000092)

Project ended 6/30/20

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)

\$439,943

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 – Supplemental Funding \$104,874

Enhancing Public Health Surveillance of Autism Spectrum Disorder and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network

University of Arkansas for Medical Sciences (DD15-1501, 001163)

Project ended 12/31/2019

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)

\$500,000

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)

\$68,000

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)

\$20,500

Characterizing the Complications Associated with Therapeutic Blood Transfusions for Hemoglobinopathies

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

\$250,000

Capacity Building for Sickle Cell Disease Surveillance

Public Health Institute (DD19-1906, 000011)

Project ended 9/29/20

Sickle Cell Data Collection Program

Public Health Institute (DD20-2003, 000016)

\$366,750 (Funded from an external source)

Surveillance for Emerging Threats to Mothers and Babies

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

\$413,438

Surveillance for Emerging Threats to Mothers and Babies

Public Health Foundation Enterprises, Inc (CK19-1904)

\$528,731

Colorado

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

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

\$210,000

Enhancing Public Health Surveillance of Autism Spectrum Disorder and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network

Colorado Department of Public Health and Environment (DD15-1501, 001161)

Project ended 12/31/19

Surveillance of Congenital Heart Defects Across the Lifespan

University of Colorado, Denver (DD15-1506, 004935)

Project ended 9/29/20

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

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

\$770,377

Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to Improve Services and Outcomes

University of Colorado, Denver (DD15-003, 001190)

Project ended 8/30/20

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

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

\$800,000

Connecticut

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

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

\$396,513

Delaware

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)

Delaware State Department of Health (DD17-1701, 000082)

No cost extension until 11/30/20

Florida

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

Florida Department of Health (DD16-1601, 004946)

\$210,000

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)

Florida Department of Health (DD17-1701, 000077)

Project ended 6/30/20

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)

\$300,000

The Muscular Dystrophy Surveillance, Tracking and Research Network

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

\$349,882

Surveillance for Emerging Threats to Mothers and Babies

Florida Department of Health (CK19-1904)

\$465,759

Georgia

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)

Georgia Department of Public Health (DD17-1701, 000090)

Project ended 6/30/20

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

Characterizing the Complications Associated with Therapeutic Blood Transfusions for Hemoglobinopathies

Georgia State University Research Foundation, Inc. (DD14-1406, 001138)

Project ended 3/21/20

Surveillance of Congenital Heart Defects Across the Lifespan

Emory University (DD15-1506, 004932)

Project ended 9/29/20

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus

Georgia Department of Public Health (DD16-1605, 000019)

Project ended 7/31/20

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)

\$670,295

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)

\$150,000

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

Emory University (DD19-1902, 000057 – Comp A)

\$492,977

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

Emory University – (DD19-1902, 0000098- Comp B)

\$298,294

Characterizing the Complications Associated with Therapeutic Blood Transfusions for Hemoglobinopathies

Georgia State University, University Foundation, Inc (DD19-1903, 000003)

\$252,520

Capacity Building for Sickle Cell Disease Surveillance

Georgia State University, University Foundation, Inc (DD19-1906, 000031)

Program ended 9/29/20

Sickle Cell Data Collection Program

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

\$367,000 (Funded from an external source)

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)

\$1,315,000

Surveillance for Emerging Threats to Mothers and Babies

Georgia Department of Public Health (CK19-1904)

\$308,875

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

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)

Idaho Department of Health and Welfare (DD17-1701, 000079)

Project ended 6/30/20

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)

\$210,000

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)

Illinois Department of Public Health (DD17-1701, 000053)

Project ended 6/30/20

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

Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to Improve Services and Outcomes

Rush University Medical Center (DD15-003, 001186)

\$349,999

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

American Academy of Pediatrics (OT18-1802, 000282)

\$1,795,500

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)

\$67,999

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)

\$20,500

Indiana

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)

Indiana State Department of Health (DD17-1701, 000094)

Project ended 6/30/20

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 (DD19-1906, 000006)

Project ended 9/29/20

Capacity Building for Sickle Cell Disease Surveillance

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

\$113,533 (Funded from an external source)

Iowa

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)

Iowa Department of Public Health (DD17-1701, 000061)

Project ended 6/30/20

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)

\$399,141

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)

\$390,000

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders

University of Iowa (DD14-001, 001119)

Project ended 8/31/20

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders

University of Iowa (DD14-001, 001120)

Project ended 8/31/20

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)

\$374,999

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)

\$389,995

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)

Kansas Department of Health and Environment (DD17-1701, 000075)

Project ended 6/30/20

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)

\$160,000

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

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

\$249,642

Kentucky

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

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

\$210,000

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)

\$165,000

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)

Kentucky Cabinet for Health and Family Services (DD17-1701, 000080)

Project ended 6/30/20

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)

\$152,613

Louisiana

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)

Louisiana Department of Health (DD17-1701, 000087)

Project ended 6/30/20

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)

\$160,000

Maine

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)

Maine Department of Health and Human Services (DD17-1701, 000074)

Project ended 6/30/20

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

Maryland

Evaluation of Health Promotion and Prevention Programs for Blood Disorders

National Blood Clot Alliance (DD14-1405, 001153)

Project ended 9/29/20

Enhancing Public Health Surveillance of Autism Spectrum Disorder and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network

Johns Hopkins University (DD15-1501, 001160)

Project ended 12/31/19

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

Maryland Department of Health (DD16-1603, 000005)

\$165,000

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, 000019)

\$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)

\$1,020,377

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)

\$1,528,410 (\$300,000 from Chronic)

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, 000103)

\$50,000

Massachusetts

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

Boston Medical Center Corporation (DD18-1802, 000002)

\$397,258

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)

Massachusetts Department of Public Health (DD17-1701, 000095)

Project ended 6/30/20

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)

\$439,588

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)

\$69,910

Surveillance for Emerging Threats to Mothers and Babies

Massachusetts Department of Public Health (CK19-1904)

\$153,529

Michigan

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

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

\$210,000

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)

Michigan Department of Health and Human Services (DD17-1701, 000067)

Project ended 6/30/20

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)

\$390,000

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

Henry Ford Health System (DD18-1802, 000001)

\$356,621

Capacity Building for Sickle Cell Disease Surveillance

Michigan Department of Health and Human Services (DD19-1906, 000005)

Project ended 9/29/20

Sickle Cell Data Collection Program

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

\$366,525 (Funded from an external source)

Minnesota

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

Minnesota Department of Health (DD16-1601, 004939)

\$170,000

Enhancing Public Health Surveillance of Autism Spectrum Disorder and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network

Regents of the University of Minnesota (DD15-1501, 001171)

Project ended 12/31/19

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

Minnesota Department of Health (DD16-1603, 000009)

\$300,000

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)

Minnesota Department of Health (DD17-1701, 000062)

Project ended 6/30/20

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 – Supplemental Funding \$74,208

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

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

\$68,000

Capacity Building for Sickle Cell Disease Surveillance

Minnesota Department of Health (DD19-1906, 000008)

Project ended 9/29/20

Sickle Cell Disease Collection Program

Minnesota Department of Health (DD20-2003, 000017)

\$242,852 (Funded from an external source)

Small Business Innovation Research Grant (SBIR)

Aster Labs, Inc. (SBIR18-574, 001286)

\$341,409

Mississippi

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)

Mississippi State Department of Health (DD17-1701, 000096)

Project ended 6/30/20

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)

\$165,000

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)

Missouri Department of Health and Senior Services (DD17-1701, 000064)

Project ended 6/30/20

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

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

The Washington University (DD16-001, 001216)

\$770,377

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network

Washington University at St. Louis (DD15-1501, 001177)

Project ended 12/31/19

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

The Washington University (DD19-1901, 000005)

\$418,911

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)

\$390,000

Nebraska

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)

Nebraska Department of Health & Human Services (DD17-1701, 000057)

Project ended 6/30/20

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

Nevada

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)

Nevada Department of Health and Human Services (DD17-1701, 000086)

Project ended 6/30/20

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

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

\$250,000

New Hampshire

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)

New Hampshire Department of Health and Human Services (DD17-1701, 000068)

Project ended 6/30/20

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)

\$440,000

New Jersey

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

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

\$210,000

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network

Rutgers, The State University of New Jersey (DD15-1501, 001172)

Project ended 12/31/19

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)

New Jersey Department of Health (DD17-1701, 000081)

Project ended 6/30/20

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 - Supplemental Funding \$79,510

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

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)

Health Research Inc (DD17-1701, 000066)

Project ended 6/30/20

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)

\$440,000

Surveillance of Congenital Heart Defects Across the Lifespan

Health Research Inc/New York State Department of Health (DD15-1506, 004931)

Project ended 9/29/20

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, 000017)

\$900,000

Evaluation of Health Promotion and Preventive Program for Blood Disorders

Cooley's Anemia Foundation, Inc. (DD14-1405, 001150)

Project ended 9/29/20

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 (DD14-1405, 001154)
Project ended 9/29/20

Evaluation of Health Promotion and Preventive Program for Blood Disorders
National Hemophilia Foundation (DD20-2002, 000006)
\$500,000

Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to
Improve Services and Outcomes
New York State Psychiatric Institute (DD15-003, 001188)
\$198,173

Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to
Improve Services and Outcomes
Institute for Basic Research in Developmental Disabilities (DD15-003, 001189)
Project ended 8/31/20

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)

\$895,346

Surveillance for Emerging Threats to Mothers and Babies

New York City Department of Health & Mental Hygiene (CK19-1904)

\$333,142

North Carolina

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network

University of North Carolina at Chapel Hill (DD15-1501, 001175)

Project ended 12/31/19

Surveillance of Congenital Heart Defects across the Lifespan

Duke University (DD15-1506, 004933)

Project ended 9/29/20

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)

North Carolina Department of Health and Human Services (DD17-1701, 000084)

Project ended 6/30/20

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)

\$1,020,377

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)

\$68,000

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

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

\$20,500

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

Duke University (DD19-1902, 000054)

\$399,995

The Muscular Dystrophy Surveillance, Tracking and Research Network

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

\$374,950

The Muscular Dystrophy Surveillance, Tracking and Research Network

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

\$79,840

The Muscular Dystrophy Surveillance, Tracking and Research Network

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

\$249,693

Capacity Building for Sickle Cell Disease Surveillance

Duke University (DD19-1906, 000004)

Project ended 9/29/20

Small Business Innovation Research Grant

TeleSage Inc (SBIR19-272, 001232)

\$60,875

Sickle Cell Data Collection Program

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

\$252,294 (Funded from an external source)

North Dakota

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)

Minot State University, North Dakota (DD17-1701, 000056)

Project ended 6/30/20

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

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)

Ohio Department of Health (DD17-1701, 000054)

Project ended 6/30/20

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

The Ohio State University (DD16-1603, 000015)

\$300,000

Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to Improve Services and Outcomes

Cincinnati Children's Hospital Medical Center (DD15-003, 001185)

Project ended 8/31/20

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)

\$68,000

Oklahoma

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

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

\$210,000

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)

Oklahoma State Department of Health (DD17-1701, 000065)

Project ended 6/30/20

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

Oregon

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)

Oregon Department of Human Services (DD17-1701, 000091)

Project ended 6/30/20

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)

\$440,000

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

Oregon Health Authority (DD16-1601, 004951)

\$210,000

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

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

\$68,000

Pennsylvania

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

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

\$68,825

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

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

\$66,507

Surveillance for Emerging Threats to Mothers and Babies

Pennsylvania Department of Health (CK19-1904)

\$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)

\$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)

Rhode Island Department of Health (DD17-1701, 000073)

Project ended 6/30/20

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

South Carolina

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)

South Carolina Department of Health and Environmental Control (DD17-1701, 000069)

Project ended 6/30/20

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)

\$1,261,000

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

University of South Carolina (DD16-1603, 000011)

\$440,000

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorder

South Carolina Department of Health and Environmental Control (DD14-001, 001117)

Project ended 8/31/20

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

South Dakota

N/A

Tennessee

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network

Vanderbilt University Medical Center (DD15-1501, 000001)

Project ended 12/31/19

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

Vanderbilt University Medical Center (DD19-1901, 000010)

\$416,369 – Supplemental Funding \$75,484

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

Vanderbilt University Medical Center (DD19-001, 001234- Comp C)

\$20,484

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

Vanderbilt University Medical Center (DD19-001, 001235- Compo B)

\$68,000

Capacity Building for Sickle Cell Disease Surveillance

University of Tennessee Health Science Center (DD19-1906, 000010)

Project ended 9/29/20

Sickle Cell Data Collection Program

The University Of Memphis (DD20-2003, 000019)

\$249,404 (Funded from an external source)

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)

\$253,371

Texas

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

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

\$195,000

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 Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)

Texas Department of State Health Services (DD17-1701, 000052)

Project ended 6/30/20

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)

\$68,000

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

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

\$20,500

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)

\$67,682

Utah

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)

Utah Department of Health (DD17-1701, 000089)

Project ended 6/30/20

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)

\$210,000

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

Utah Department of Health (DD16-1603, 000003)

\$165,000

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

University of Utah (DD19-1901, 000009)

\$570,129 – Supplement Funding \$111,376

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)

\$20,478

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

Vermont

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)

Vermont Department of Health (DD17-1701, 000063)

Project ended 6/30/20

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)

\$165,000

Virginia

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)

Virginia Department of Health (DD17-1701, 000070)

Project ended 6/30/20

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)

\$593,079

The Muscular Dystrophy Surveillance, Tracking and Research Network

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

\$348,540

Capacity Building for Sickle Cell Disease Surveillance

Virginia Department of Health (DD19-1906, 0000007)

Project ended 9/29/20

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)

\$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)

\$636,817 (\$50,000 from Chronic)

Washington

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)

Washington Department of Health (DD17-1701, 000078)

Project ended 6/30/20

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)

\$20,499

West Virginia

N/A

Wisconsin

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)

Wisconsin Department of Health and Family Services (DD17-1701, 00055)

Project ended 6/30/20

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network

Board of Regents of the University of Wisconsin System (DD15-1501, 001176)

Project ended 12/31/19

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

University of Wisconsin, Madison (DD16-001, 001215)

\$770,377

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 – Supplemental Funding \$76,986

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

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

\$68,000

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

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

\$20,500

Sickle Cell Data Collection Program

Medical College of Wisconsin (DD20-2003, 000013)

\$113,533 (Funded from an external source)

Wyoming

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)

Wyoming Department of Health (DD17-1701, 00058)

Project ended 6/30/20

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)

\$11,882,425

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, 0000003)

\$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)

429,366

Evaluation of Health Promotion & Prevention Program for Blood Disorders

Hemophilia Federation of America (DD14-1405, 001151)

Project ended 9/20/20

Evaluation of Health Promotion & Prevention Program for Blood Disorders

Hemophilia Federation of America (DD20-2002, 000008)

\$320,000

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

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

\$300,000

Puerto Rico

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

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

\$155,000

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)

Puerto Rico Department of Health (DD17-1701, 000088)

Project ended 6/30/20

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

Virgin Islands

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus

Virgin Islands Department of Health (DD16-1605, 000022)

Project ended 7/31/2020

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)

Cost Extension until 6/30/21- \$29,016

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)

No Cost Extension until 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

