

Making a Difference Across the Lifespan



National Center on Birth Defects and Developmental Disabilities (NCBDDD)

MESSAGE FROM THE DIRECTOR



The Children's Health Act of 2000, signed into law by President Clinton, was aimed at improving research and programs related to multiple aspects of children's health. One of the provisions of the law required CDC to establish the National Center on Birth Defects and Developmental Disabilities (NCBDDD). Since then, we have been working to save babies, help children, protect people, and improve the health of those most vulnerable.

Today, I am delighted to share with you an important milestone in the Center's history—celebrating 20 years since this now historic step/act! Not only is 20 years a critical milestone for the Center, it is also a chance to reflect on the Center's accomplishments, with an eye toward charting the path forward.

In my first years at CDC, 35 years ago, my work focused on Agent Orange and its resulting birth defects and other poor infant health outcomes. I have a special place in my heart for those who serve our country and are exposed to things that have very real and negative health consequences for themselves and their children. This is as important today as it was all those years ago.

Excited, humbled, and honored is the way I felt when, later in my career, in 2011, I was selected to serve as Director of this critically important

Center. I have had the privilege of leading brilliant staff whose work focuses on preventing birth defects and developmental disabilities and helping people living with blood disorders and disabilities live the healthiest life possible.

I can only imagine that NCBDDD's founding Director, Dr. Jose Cordero, was both excited and a bit humbled by the enormous task that lay before him—leading the newly established Center charged with creating pioneering programs to serve vulnerable populations. It would eventually become the comprehensive and successful Center we all know today.

If we stop for a moment to take a collective look back at just how far NCBDDD has come over the past 20 years, it is incredible. However, standing still and resting on our accomplishments is simply not possible, as NCBDDD must grow and change to address new issues that continue to emerge.

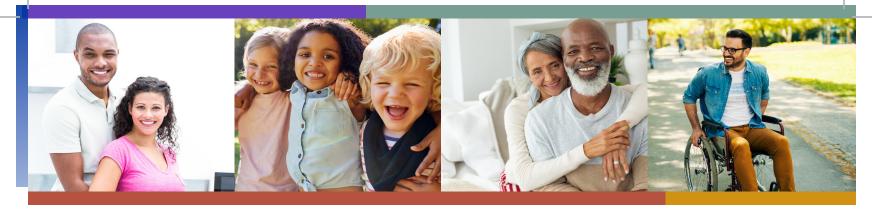
Today, our efforts continue to protect millions of our nation's most vulnerable, as demonstrated by the accomplishments highlighted in this year's *Annual Report*. Each year, new programs and opportunities to serve others are introduced that

are collaborative and creative and just simply were not on the radar/horizon back in 2000. I have been with NCBDDD since its inception, and the commitment to quality and innovative science and program demonstrated by NCBDDD staff has not waivered—I'm thankful to have been a part of it! As I approach my retirement, I am so very proud to be concluding my career with CDC during this momentous time as we embark on the next 20 years.

Thank you to all of you who have touched NCBDDD over the last two decades. As we look forward to the future of this great Center, I know that success is inevitable because of the combined strength of the wonderful people who comprise our staff and partners. And as we celebrate this important milestone together, I am eager to see what is in store for NCBDDD in the new decade.

Sincerely,

Coleen Boyle, PhD, MS (hyg) Director



Message from the Director

SAVING BABIES

Through Surveillance, Research, and Prevention
of Birth Defects and Infant Disorders | page 4

HELPING CHILDREN

Live to the Fullest by Understanding Developmental Disabilities | page 8

PROTECTING PEOPLE

and Preventing Complications of Blood Disorders | page 12

IMPROVING HEALTH

of People with Disabilities | page 16

Fiscal Year 2019 Budget | page 20

Select State-Based Activities and Funding | page 23

NCBDDD Top 20 Peer-Reviewed Publications | page 47

CONTENTS



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

Birth defects and infant disorders, such as neonatal abstinence syndrome, are common, costly, and critical. Our unique state-based birth defects tracking, 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 states, 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.

Data for Action

The 2016 Zika virus outbreak highlighted the need to collect high-quality, mother-infant linked surveillance data that track exposures during pregnancy and monitor health outcomes at birth and in early childhood. These data were essential to better understand this emerging threat to mothers and their babies. Collecting real-time, evidence-based, actionable information allows NCBDDD to inform clinical guidance, link families to medical and social services, and ensure state, local, and territorial public health agencies are ready and prepared to meet the needs of pregnant women and infants during public health emergencies.

 Data from NCBDDD's mother-infant Zika virus surveillance serve as a foundation to inform clinical guidance and travel and prevention recommendations, as demonstrated through Committee Opinions of the American College of Obstetricians and Gynecologists and CDC's travel and clinical guidance related to Zika virus.

- Surveillance data collected before and during the Zika virus outbreak demonstrated about a 30-fold increase in Zika-associated birth defects among pregnancies with laboratory evidence of confirmed or possible Zika virus infection, compared to a baseline prevalence and demonstrated an increased risk for neurodevelopmental abnormalities associated with congenital Zika virus infection in infants. This led to recommendations for continued monitoring and evaluation of all children with possible Zika virus exposure during pregnancy.
- The surveillance approach for Zika virus has been adapted to respond to other <u>emerging threats</u> that affect pregnant women and infants, such as congenital syphilis, hepatitis C virus, and <u>neonatal abstinence syndrome</u>.
- NCBDDD worked with the Council of State and Territorial Epidemiologists to establish a new standardized case definition for neonatal abstinence syndrome that will be used for state and national surveillance.







Looking to the Future

NCBDDD will continue its work to protect women and babies by tracking birth defects and infant disorders and through public health research. These activities provide knowledge about the factors that might increase or decrease the risk of having a baby with a birth defect or infant disorder. NCBDDD's work on Zika virus is a reminder of the medical vulnerability of mothers and babies to emerging infections and other health threats, such as the opioid crisis and natural disasters. NCBDDD's Surveillance of Emerging Threats to Mothers and Babies program will continue to leverage the innovative tracking and monitoring system developed to combat Zika virus, work to understand the full impact of Zika virus on infants and children, and adapt this system to capture data on other emerging threats that may affect mothers and babies. NCBDDD will expand work with states and partners to build upon birth defects surveillance systems and explore more accurate ways of estimating the number of infants diagnosed with neonatal abstinence syndrome, as well as the health needs for these children. NCBDDD also aims to improve our understanding of the spectrum of maternal, infant, and child health outcomes following treatment for opioid use disorder during pregnancy. This effort, known as MATernaL and Infant NetworK to Understand Outcomes Associated with Treatment for Opioid Use Disorder during Pregnancy (MAT-LINK), will establish a surveillance network of clinical sites to collect data toward these aims.

Birth Defects Are Critical

Birth defects cause

1 IN EVERY 5

deaths during the first year of life

Notable Scientific Publications

Chen MY, Rose CE, Qi YP, Williams JL, Yeung LF, Berry RJ, Hao L, Cannon MJ, Crider KS. <u>Defining the plasma folate concentration associated with the red blood cell folate concentration threshold for optimal neural tube defects prevention: A population-based, randomized trial of folic acid supplementation. *Am J Clin Nutr.* 2019;109(5):1452–1461.</u>

Crider KS, Devine O, Qi YP, Yeung LF, Sekkarie A, Zaganjor I, Wong E, Rose CE, Berry RJ. <u>Systematic review and Bayesian meta-analysis of the dose-response relationship between folic acid intake and changes in blood folate concentrations</u>. *Nutrients*. 2019;11(1).

Denny CH, Acero CS, Naimi TS, Kim SY. <u>Consumption of alcohol beverages and binge drinking among pregnant women aged 18–44 years—United States</u>, 2015–2017. MMWR Morb Mortal Wkly Rep. 2019;68:365–368.

Frey MT, Meaney-Delman D, Bowen V, Yazdy MM, Watkins SM, Thorpe PG, Honein MA. <u>Surveillance for emerging threats to pregnant women and infants</u>. *J Womens Health (Larchmt)*. 2019;28(8):1031–1036.

Glidewell J, Grosse SD, Riehle-Colarusso T, Pinto N, Hudson J, Daskalov R, Gaviglio A, Darby E, Singh S, Sontag M. Actions in support of newborn screening for critical congenital heart disease—United States, 2011–2018.

MMWR Morb Mortal Wkly Rep. 2019;68:107–111.

Lind JN, Ailes EC, Alter CC, Fornoff JE, Broziceyic P, Garcia Saavedra LF, Tomedi LE, Gambatese M, Carroll B, Orantes L, Brennan M, Horne AA, Reefhuis J. <u>Leveraging existing birth defects surveillance infrastructure to build neonatal abstinence syndrome surveillance systems—Illinois, New Mexico, and Vermont, 2015—2016</u>. *MMWR Morb Mortal Wkly Rep.* 2019;68:177—180.

Olson SM, Delaney A, Jones AM, Carr CP, Liberman RF, Forestieri NE, Tong VT, Gilboa SM, Honein MA, Moore CA, Cragan JD. <u>Updated baseline prevalence of birth defects potentially related to Zika virus infection</u>. *Birth Defects Res.* 2019;111(13):938–940.

Raesima MM, Ogbuabo CM, Thomas V, Forhan SE, Gokatweng G, Dintwa E, Petlo C, Motswere-Chirwa C, Rabold EM, Tinker SC, Odunsi S, Malima S, Mmunyane O, Modise T, Kefitlhile K, Dare K, Letebele M, Roland ME, Moore CA, Modi S, Williamson DM. <u>Dolutegravir use at conception—additional surveillance data from Botswana</u>. *N Engl J Med*. 2019;381:885–887.

Short TD, Stallings EB, Isenburg J, O'Leary L, Yazdy MM, Bohm MK, Ethen M, Chen X, Tran T, Fox DJ, Fornoff J, Forestieri N, Ferrell E, Ramirez CM, Kim J, Shi J, Cho SJ, Duckett K, Nelson N, Zielke K, St. John K, Martin B, Clark C, Huynh M, Benusa C, Reefhuis J. Gastroschisis trends and ecologic link to opioid prescription rates—United States, 2006—2015. MMWR Morb Mortal Wkly Rep. 2019;68(2):31—36.

Tinker SC, Gilboa SM, Moore CA, Waller K, Simeone RM, Kim SY, Jamieson DJ, Botto LD, Reefhuis J. Specific birth defects in pregnancies of women with diabetes: National Birth Defects Prevention Study, 1997–2011. Am J Obstet Gynecol. 2019;222:176.



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

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

Data for Action

- CDC launched the <u>Autism Data Visualization Tool</u>, an interactive, web-based platform that gives users the opportunity to explore data on the prevalence of ASD among children. This platform provides clear, transparent information on ASD prevalence estimates nationally and by state or site (when data are available) for years 2000 to 2017.
- The goal of the Autism Data Visualization Tool is to provide the most current ASD prevalence estimates available from CDC and other surveillance sources in order to show the most comprehensive picture of ASD among children in the United States.

- The data presented through the platform highlight changes over time in reported ASD prevalence estimates and in the characteristics of children identified with ASD.
- The information provided can help state epidemiologists, researchers, public health professionals, and everyone interested in children with ASD better understand the different methods used for tracking ASD prevalence. It also provides an easy way to access national as well as state- and community-specific information that may be of interest to public health researchers, state health officials, and members of the public.
- The data come from four different sources: <u>CDC's Autism</u> and <u>Developmental Disabilities Monitoring (ADDM)</u> <u>Network</u>, Special Education, the National Survey of Children's Health, and Medicaid.





Looking to the Future

Children with developmental disabilities, and their families, often face personal, social, and financial challenges. CDC and its partners work across systems to improve early identification of children with developmental 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, as well as helping families and children get the support they need.



Notable Scientific Publications

Barger B, Squires J, Greer M, Noyes-Grosser D, Martin Eile J, Rice C, Shaw EM, Surprenant KS, Twombly E, London S, Zubler J, Wolf RB. <u>State variability in diagnosed conditions for IDEA Part C eligibility</u>. *Infants & Young Children*. 2019;32(4):231–244.

Christensen DL, Maenner MJ, Bilder D, Constantino JN, Daniels J, Durkin MS, Fitzgerald RT, Kurzius-Spencer M, Pettygrove SD, Robinson C, Shenouda J, White T, Zahorodny W, Pazol K, Dietz P. Prevalence and characteristics of autism spectrum disorder among children aged 4 years—Early Autism and Developmental Disabilities Monitoring Network, seven sites, United States, 2010–2014. MMWR Surveill Summ. 2019;68(2):1–19.

Cordero C, Schieve LA, Croen LA, Engel SM, Maria Siega-Riz A, Vladutiu CJ, Seashore CJ, Daniels JL. <u>Neonatal</u> jaundice in association with autism spectrum disorder and <u>developmental disorder</u>. *J Perinatol*. 2020;40:219–225.

Cree RA, Bitsko RH, Robinson LR, Holbrook JR, Danielson ML, Smith C, Kaminski JW, Kenney MK, Peacock G. <u>Health care</u>, family, and community factors associated with mental, behavioral, and developmental disorders and poverty among children aged 2–8 years—United States, 2016. MMWR Morb Mortal Wkly Rep. 2018;67(50):1377–1383.

Croen LA, Qian Y, Ashwood P, Zerbo O, Schendel D, Pinto-Martin J, Daniele Fallin M, Levy S, Schieve LA, Yeargin-Allsopp M, Sabourin KR, Ames JL. <u>Infection and fever in pregnancy and autism spectrum disorders: Findings from the Study to Explore Early Development</u>. *Autism Res*. 2019;12(10):1551–1561.

Ghandour RM, Sherman LJ, Vladutiu CJ, Ali MM, Lynch SE, Bitsko RH, Blumberg SJ. <u>Prevalence and treatment of depression, anxiety, and conduct problems in US children</u>. *J Pediatr*. 2019;206:256–267.e3.

Kotzky K, Allen JE, Robinson LR, Satterfield-Nash A, Bertolli J, Smith C, Ornelas Pereira I, Faria e Silva Santelli AC, Peacock G. <u>Depressive symptoms and care demands among primary caregivers of young children with evidence of congenital Zika virus infection in Brazil</u>. *J Dev Behav Pediatr*. 2019;40(5):344–353.

Perou R, Robinson LR, Danielson ML, Claussen A, Visser SN, Scott KG, Beckwith L, Katz L, Smith DC. <u>The Legacy for Children™ randomized control trial: Effects on cognition through third grade for young children experiencing poverty</u>. *J Dev Behav Pediatr*. 2019;40(4):275–284.

Shapira SK, Tian LH, Aylsworth AS, Elias ER, Hoover-Fong JE, Meeks NJL, Souders MC, Tsai AC, Zackai EH, Alexander AA, Yeargin-Allsopp M, Schieve LA. A Novel Approach to Dysmorphology to Enhance the Phenotypic Classification of Autism Spectrum Disorder in the Study to Explore Early Development. J Autism Dev Disord. 2019;49(5):2184–2202.

Rubenstein E, Croen L, Lee LC, Moody E, Schieve LA, Soke GN, Thomas K, Wiggins L, Daniels J. <u>Community-based service use in preschool children with autism spectrum disorder and associations with insurance status</u>. *Res Autism Spectr Disord*. 2019;66:101410.

Wolicki SB, Bitsko RH, Danielson ML, Holbrook JR, Zablotsky B, Walkup JT, Woods DW, Mink JW. <u>Children with Tourette syndrome in the United States: Parent-reported diagnosis, co-occurring disorders, severity, and influence of activities on tics</u>. *J Dev Behav Pediatr*. 2019;40(6):407–414.



and Preventing Complications of Blood Disorders

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

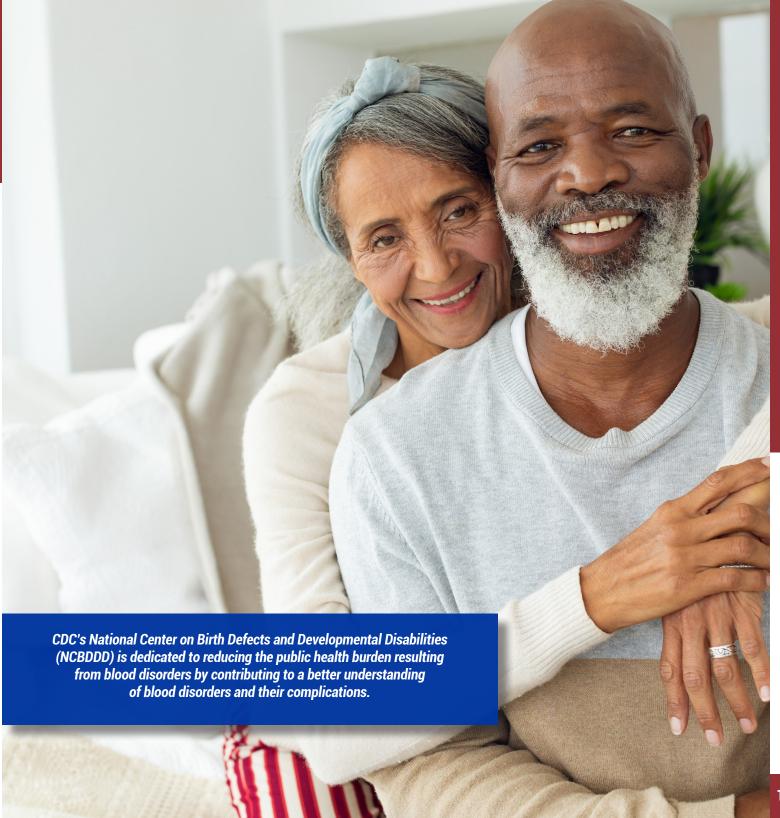
- Contributing to a better understanding of blood disorders and their complications;
- Working to develop, implement, and evaluate programs to prevent blood disorders and their complications;
- Helping consumers and healthcare providers get the information they need; and
- Encouraging action on behalf of individuals living with or affected by blood disorders.

Data for Action

Community Counts is a public health monitoring (surveillance) program designed to gather and share information about common health issues, medical complications, and causes of death that affect people with bleeding disorders cared for at U.S. hemophilia treatment centers (HTCs). Data collection began in 2012, but the bleeding disorder community expressed a need for real-time access to the data beyond standard surveillance reports.

In 2019, the Division of Blood Disorders developed and launched the <u>Community Counts Data Visualization</u>
<u>Tool</u>. The tool displays de-identified data—information in which all personally identifiable characteristics have been removed to protect identities and privacy—on patients with bleeding disorders in a new, interactive, visual format for clinicians, patients, policymakers, and the public to learn more about the burden of bleeding disorders in the United States. The tool includes the following:

- Data on more than 62,000 patients with bleeding disorders receiving care at approximately 140 federally funded HTCs participating in Community Counts;
- Information on more than 10 different patient characteristics (such as age, sex, race, and insurance status) and clinical characteristics (such as viral and vaccination status) that can be accessed by bleeding disorder diagnosis and severity; and
- The largest and most representative sample of patients with hemophilia (more than 25,000 shown in the Data Visualization Tool) in the United States.





Looking to the Future

The hemophilia treatment landscape is rapidly changing. Past CDC surveillance has shown that starting young children with severe hemophilia on preventive treatment with clotting factor products (also called prophylaxis) before age 4 years is the most effective way to preserve healthy joint function over the lifespan. New, longer-acting treatment products for patients with bleeding disorders are on the market. The data from CDC's Community Counts surveillance system will make it possible to track emerging trends in hemophilia treatments, the use of various treatment types across the lifespan, and associated impacts on long-term prevention of hemophilia complications, such as joint disease. We are also working to expand the <u>Sickle Cell Data Collection (SCDC) program</u> which collects health data about people with sickle cell disease (SCD) to study long-term trends in diagnosis, treatment, and healthcare access for people with SCD in the United States. The SCDC program will expand to other states and the data will be used to further delineate healthcare issues and barriers for those living with SCD.

Notable Scientific Publications

Abe K, Kuklina EV, Hooper WC, Callaghan WM. <u>Venous</u> thromboembolism as a cause of severe maternal morbidity and mortality in the <u>United States</u>. Semin Perinatol. 2019;43(4):200–204.

Badawy SM, Payne AB, Rodeghier MJ, Liem RI. Exercise capacity and clinical outcomes in adults followed in the Cooperative Study of Sickle Cell Disease (CSSCD). Eur J Haematol. 2018;101(4):532–541.

Gupta S, Acharya S, Roberson C, Lail A, Soucie JM, Shapiro A. <u>Potential of the Community Counts Registry to characterize rare bleeding disorders</u>. *Haemophilia*. 2019;25(6):1045–1050.

Mainous AG 3rd, Carek PJ, Lynch K, Tanner RJ, Hulihan MM, Baskin J, Coates TD. Effectiveness of clinical decision support based intervention in the improvement of care for adult sickle cell disease patients in primary care. *J Am Board Fam Med.* 2018;31(5):812–816.

Okolo AI, Soucie JM, Grosse SD, Roberson C, Janson IA, Allen M, Shapiro AD. <u>Population-based surveillance of haemophilia and patient outcomes in Indiana using multiple data sources</u>. *Haemophilia*. 2019;25:456–462.

Ortel TL, Arnold K, Beckman M, Brown A, Reyes N, Saber I, Schulteis R, Singh BP, Sitlinger A, Thames EH. <u>Design and implementation of a comprehensive surveillance system for venous thromboembolism in a defined region using electronic and manual approaches</u>. *Appl Clin Inform*. 2019;10(3):552–562.

Payne AB, Miller CH, Ellingsen D, Driggers J, Boylan B, Bean CJ. Reagent substitution in the chromogenic Bethesda assay for factor VIII inhibitors. Haemophilia. 2019;25:e342–e344.

Pipe SW, Sabatino DE, Nugent DJ, Hooper WC, Soucie JM, Hoots WK, DiMichele DM. Executive Summary of the NHLBI State of the Science (SOS) Workshop: Overview and next steps in generating a national blueprint for future research on factor VIII inhibitors. Haemophilia. 2019;25(4):610–615.

Radke T, Paulukonis S, Hulihan MM, Feuchtbaum L. <u>Providers' perspectives on treating patients with thalassemia</u>. *J Pediatr Hematol Oncol*. 2019;41:e421–e426.

Tanabe P, Spratling R, Smith D, Grissom P, Hulihan M. <u>CE:</u> <u>Understanding the complications of sickle cell disease</u>. *Am J Nurs*. 2019;119(6):26–35.



IMPROVING HEALTH

of People with 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 on how they can be at their best 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.

Data for Action

CDC created the <u>Disability and Health Data System (DHDS)</u> to provide vital information at the state and national levels

needed to better understand the health needs of adults with disabilities. Equipped with these data, state epidemiologists, researchers, policymakers, public health professionals, and everyone interested in the health of adults with disabilities can plan for inclusive communities that offer



Use DHDS to help improve the health and the well-being of adults with disabilities.

Get started now! Visit DHDS at https://dhds.cdc.gov

the programs and services needed to improve the health of this population.

DHDS is an online, easy-to-use data tool that provides state- and national-level data from the Behavioral Risk

Factor Surveillance System (BRFSS) on approximately 30 health topics for adults with and without disabilities.

Users can access information on six disability types (cognitive ["difficulty" concentrating, making decisions, or "remembering"], vision, hearing, mobility, self-care, and independent living) and view data for "Any Disability" and "No Disability," as well as the difference between the two.

Users can explore data by indicator (for example, health conditions and health risks and behaviors) or by location—then make custom maps, charts, and tables, making it easy to view information for each state.

- According to DHDS, compared to adults without disabilities, adults with disabilities are more likely to be obese, smoke, have high blood pressure, and be physically inactive. These factors can increase the risk for chronic diseases, such as heart disease, stroke, diabetes, and some cancers. These chronic diseases are also more common among adults with disabilities.
- Data from DHDS were used to create NCBDDD's <u>Disability and Health State Profiles</u>.

| According to DHDS,* compared to adults without disabilities, | | | |
|--|--|--|--|
| adults with disabilities in the U.S are more likely to | | | |

| | | With Disabilities | Without Disabilities |
|----------|--------------------------|----------------------|-------------------------|
| | Have obesity | 39.5% | 26.3% |
| <u>u</u> | Smoke | 27.8% | 13.4% |
| | Have high blood pressure | 41.9% | 25.9% |
| Wil. | Be inactive | 42.2% | 24.3% |

^{*2017}

These fact sheets provide an overview of disability in each state, compared to national estimates. State epidemiologists, researchers, policy makers, public health professionals, and everyone interested in the health of adults with disabilities can use this information to learn more about the percentages and characteristics of adults with disabilities in their states.

- The Ohio Disability and Health Program used DHDS to create a fact sheet for use by healthcare professionals, educators, disability advocates, and community members. The fact sheet describes smoking data in Ohio, and includes resources for quitting smoking that are available to Ohioans with disabilities. The Ohio Disability and Health Program distributed the fact sheet through their website, email network, and social media. They then contracted with the American Association on Health and Disability to share the fact sheet with a national audience.
- David Ellsworth, a Health Services
 Policy Specialist with the Ohio
 Disability and Health Program,
 gave a presentation to trainees
 at the <u>Leadership Education in</u>
 Neurodevelopmental Disabilities (LEND)
 program about "big data." He discussed
 how databases, such as DHDS, can be
 used to convince partners to prioritize
 efforts that address the health needs of
 people with disabilities.
- The Kansas Disability and Health
 Program works to teach the public
 about health differences faced by
 Kansans with disabilities. They have distributed more than 400 copies of CDC's Kansas-specific "Disability Impacts All of Us" graphics page, which includes data from DHDS.



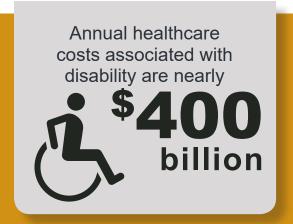
CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) works to ensure that people with disabilities have the same opportunities for good health as people without disabilities.



Looking to the Future

DHDS will be updated in 2020 to include 2018 BRFSS data. DHDS will then include disability and health data for years 2016, 2017, and 2018. With DHDS, you can answer questions such as:

- What percentage of my state's adult population has a disability?
- How does this population vary by age, sex, and race/ ethnicity?
- How does my state compare with other states and the nation as a whole?
- How does the percentage of diabetes, obesity, or heart disease vary by different disability types?



Notable Scientific Publications

Andrews JG, Lamb MM, Conway K, Street N, Westfield C, Ciafaloni E, Matthews D, Cunniff C, Pandya S, Fox D. Diagnostic accuracy of phenotype classification in Duchenne and Becker muscular dystrophy using medical record data.

J Neuromuscul Dis. 2018;5(4):481-495.

Cyrus AC, Royer J, Carroll DD, Courtney-Long EA, McDermott S, Turk MA. <u>Anti-hypertensive medication</u> use and factors related to adherence among adults with intellectual and developmental disabilities. *Am J Intellect Dev Disabil*. 2019;124(3):248–262.

Doyle KE, Sionean C, Paz-Bailey G, Hollis ND, Kanny D, Wejnert C; NHBS Study Group. <u>High prevalence of disability and HIV risk among low socioeconomic status urban adults</u>, 17 U.S. cities. *Disabil Health J.* 2020;13:100834.

Gilbertson KE, Jackson HL, Dziuban EJ, Sherman SL, Berry-Kravis EM, Erickson CA, Valdez R. <u>Preventive care services and health behaviors in children with fragile X syndrome</u>. *Disabil Health J.* 2019;12(4):564–573.

Nash R, Riley C, Paramsothy P, Gilbertson K, Raspa M, Wheeler A, Dziuban EJ, Peacock G. <u>A description of the educational setting among individuals with fragile X syndrome</u>. *Am J Intellect Dev Disabil*. 2019;124(1):57–76.

Sahay KM, Smith T, Conway KM, Romitti PA, Lamb MM, Andrews J, Pandya S, Oleszek J, Cunniff C, Valdez R. A review of MD STARnet's research contributions to pediatric-onset dystrophinopathy in the United States; 2002–2017. *J Child Neurol.* 2019;34(1):44–53.

Shapira SK, Tian LH, Aylsworth AS, Elias ER, Hoover-Fong JE, Meeks NJL, Souders MC, Tsai AC, Zackai EH, Alexander AA, Yeargin-Allsopp M, Schieve LA. <u>A Novel Approach to Dysmorphology to Enhance the Phenotypic Classification of Autism Spectrum Disorder in the Study to Explore Early Development.</u> *J Autism Dev Disord*. 2019;49(5):2184–2202.

Tanaka ST, Paramsothy P, Thibadeau J, Wiener JS, Joseph DB, Cheng EY, Tu D, Austin C, Koh CJ, Wallis MC, Walker WO, Smith KA, Routh JC, Baum MA. <u>Baseline urinary tractimaging in infants enrolled in the UMPIRE protocol for children with spina bifida</u>. *J Urol*. 2019;201(6):1193–1198.

Theis KA, Steinweg A, Helmick CG, Courtney-Long E, Bolen JA, Lee R. Which one? What kind? How many? Types, causes, and prevalence of disability among U.S. adults. Disabil Health J. 2019;12(3):411–421.

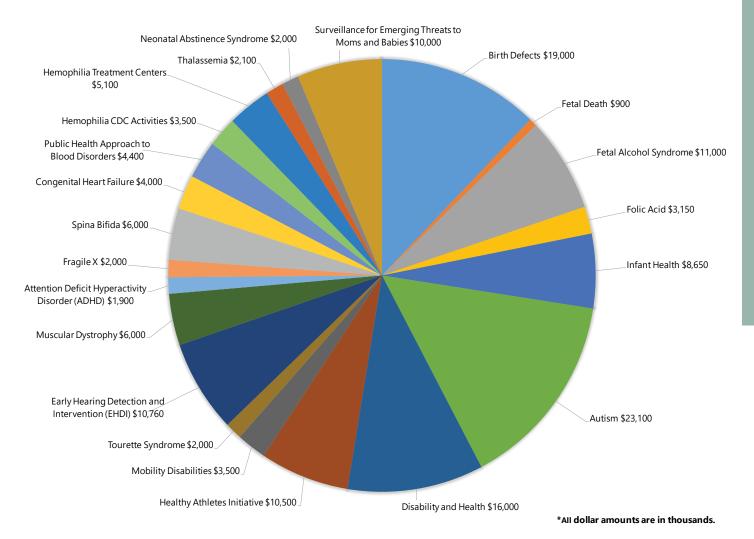
Wang Y, Ouyang L, Dicianno BE, Beierwaltes P, Valdez R, Thibadeau J, Bolen J. <u>Differences in length of stay and costs between comparable hospitalizations of patients with spina bifida with or without pressure injuries</u>. *Arch Phys Med Rehabil*. 2019;100(8):1475–1481.

Zhao G, Okoro CA, Hsia J, Garvin WS, Town M. 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 2019 BUDGET

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) fiscal year (FY) 2019 appropriation includes \$155.56 million for Child Health and Development, Health and Development with Disabilities, and the 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.





FISCAL YEAR 2019 BUDGET

| NCBDDD FY 2019 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 | |
| Health and Development with Disabilities | \$62,660 | |
| Disability and Health | \$16,000 | |
| Healthy Athletes Initiative | \$10,500 | |
| Mobility Disabilities | \$3,500 | |
| 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 | \$4,000 | |
| Public Health Approach to Blood Disorders | \$4,400 | |
| Hemophilia CDC Activities | \$3,500 | |
| Hemophilia Treatment Centers | \$5,100 | |
| Thalassemia | \$2,100 | |
| Neonatal Abstinence Syndrome | \$2,000 | |
| Surveillance for Emerging Threats to Moms and Babies | \$10,000 | |
| NCBDDD Total | \$155,560 | |

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) \$149,174

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 The University of Alabama at Birmingham (DD16-1602, 001157) \$3,142,429

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
The University of Alabama at
Birmingham (DD14-002, 001080)
Project ended 8/31/19

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
The University of Alabama at
Birmingham (DD14-002, 001079)
Project ended 8/31/19

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Alabama Department of Public Health (DD16-1605, 000002)
Project ended 7/31/19

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) \$85,000

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) \$150,000



Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers University of Alaska, Anchorage (DD14-1402, 001143) Project ended 9/29/19

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
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) \$150,000

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Arizona Department of Health Services (DD16-1605, 000020)
Project ended 7/31/2019

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) \$400,000

Surveillance for Emerging Threats to Mothers and Babies Arizona Department of Health Services (CK19-1904) \$316,458

Arkansas

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS); Stillbirth Risk Factor Pilot University of Arkansas for Medical Services (DD13-003 & DD15-004, 001039) Project ended 8/31/19

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) Arkansas Department of Health (DD17-1701, 000092) \$150,000

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

Enhancing Public Health Surveillance of Autism Spectrum Disorder and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network University of Arkansas (DD15-1501, 001163) Project ended 12/31/19

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Arkansas Children's Research Institute (DD17-1702, 000050)
Project ended 7/31/2019

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) II Arkansas Children's Research Institute (DD18-001, 001229) \$1,119,000

Enhancing Public Health Surveillance of Autism Spectrum Disorder Through the ADDM Network University of Arkansas (DD19-1901, 000006) \$543,657

California

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) Stanford University (DD13-003, 001033) Project ended 8/31/19

Characterizing the Complications Associated with Therapeutic Blood Transfusions for Hemoglobinopathies Children's Hospital and Research Center of Oakland (DD14-1406, 006093) Project ended 9/29/19 Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Children's Hospital of Los Angeles
(DD14-002, 001068)
Project ended 8/31/19

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Children's Hospital of Los Angeles
(DD14-002, 001069)
Project ended 8/31/19

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus—High-risk Local Areas Los Angeles County Department of Public Health (DD16-1606, 000142) Project ended 6/30/2019

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) II Stanford University (DD18-001, 001226) \$875,000

Strengthening Public Health Systems and Services Through National Partnerships to Improve and Protect the Nation's Health ChangeLab Solutions (OT18-1802, 000307) \$200,000 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

BRFSS Alcohol Screening and Brief Intervention Optional Module California Department of Public Health (DP15-1513) \$37,500

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) \$200,000



Surveillance for Emerging Threats to Mothers and Babies Los Angeles County Department of Public Health (CK19-1904) \$413,439

Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers University of California, San Diego (DD14-1402, 001144) Project ended 11/29/18

Colorado

Population-based Surveillance of Birth Defects and Data Utilization for Public Health Action Colorado State 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 State 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 ends 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

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders Colorado State Department of Public Health and Environment (DD14-001, 001126) Project ended 8/31/2019

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
University of Colorado, Denver
(DD14-002, 001093)
Project ended 8/31/2019

Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to Improve Services and Outcomes University of Colorado, Denver (DD15-003, 001190) \$99,981

Connecticut

Implementing Alcohol Screening and Brief Intervention in Healthcare Systems Providing Women's Health Services University of Connecticut Health Center (DD18-1802, 000004) \$391,591

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 Health and Social Services (DD17-1701, 000082) \$145,870

District of Columbia

National Public Health Practice and Resource Centers on Health Promotion for People with Disabilities Special Olympics (DD16-1602, 001156) \$9,882,425 Improving Fetal Alcohol Spectrum Disorders Prevention and Practice Through National Partnerships American College of Obstetricians and Gynecologists (DD14-1403, 001146) Project ended 4/30/19

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) \$400,000

Evaluation of Health Promotion and Prevention Program for Blood Disorders Hemophilia Federation of America (DD14-1405, 001151) \$550,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Spina Bifida Association
(DD14-002, 001077)
Project ended 8/31/19

Strengthening Public Health Systems and Services Through National Partnerships to Improve and Protect the Nation's Health Association of Maternal and Child Health Programs (OT18-1802, 000296) \$300,000

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) \$150,000

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

Characterizing the Complications Associated with Therapeutic Blood Transfusions for Hemoglobinopathies University of Florida (DD14-1406, 006094) Project ended 9/29/19

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Florida Department of Health (DD16-1605, 000013) Project ended 7/31/2019

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) \$425,000

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) \$200,000

Characterizing the Complications Associated with Therapeutic Blood Transfusions for Hemoglobinopathies Georgia State University, University Foundation, Inc (DD14-1406, 001138) Project ends 3/21/2020

Surveillance of Congenital Heart Defects Across the Lifespan Emory University (DD15-1506, 004932) Project ends 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 ends 7/30/2020

Strengthening Public Health Systems and Services Through National Partnerships to Improve and Protect the Nation's Health National Association of Chronic Disease Directors (OT18-1802, 000286) \$150,000

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) \$4,704,000

Strengthening Public Health Systems and Services Through National Partnerships to Improve and Protect the Nation's Health National Foundation for CDC (OT18-1802, 000288) \$375,000

Surveillance of Congenital Heart Defects Among Children, Adolescents, and Adults Emory University (DD19-1902, 000057) \$425,000

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) \$200,000

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) \$2,000,000

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)
\$141,925

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) \$124,584

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Hawaii Department of Health (DD16-1605, 000015)
Project ended 7/31/19

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) \$150,000

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) \$150,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Ann & Robert H. Lurie Children's Hospital of Chicago (DD14-002, 001091)
Project ended 8/31/19

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida Ann & Robert H. Lurie Children's Hospital of Chicago (DD14-002, 001092) Project ended 8/31/19 Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to Improve Services and Outcomes Rush University Medical Center (DD15-003, 001186) \$99,946

Public Health Surveillance for the Prevention of Complications of Bleeding Disorders American Thrombosis and Hemostasis Network (DD15-1507, 000001) \$4,300,000

Strengthening Public Health Systems and Services Through National Partnerships to Improve and Protect the Nation's Health American Academy of Pediatrics (OT18-1802, 000282) \$1,401,188

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) \$149,244

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida Indiana University/Purdue University at Indianapolis (DD14-002, 001057) Project ended 8/31/19

Capacity Building for Sickle Cell Disease Surveillance Indiana Hemophilia and Thrombosis Center (DD19-1906, 000006) \$75,000

lowa

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) University of Iowa (DD13-003, 001035) Project ended 8/31/19

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) Iowa Department of Public Health (DD17-1701, 000061) \$150,000

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) \$390.000

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders University of Iowa (DD14-001, 001119) Project ended 8/31/2019

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders University of Iowa (DD14-001, 001120) Project ended 8/31/2019

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) II University of Iowa (DD18-001, 001223) \$875,000

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

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Kansas Department of Health and Environment (DD16-1605, 000029)
Project ended 7/31/2019

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)
Kansas Department of Health and Environment (DD17-1701, 000075)
\$150,000

Reaching Healthcare Professionals in the Prevention of Fetal Alcohol Spectrum Disorders Through National Professional Organizations American Academy of Family Physicians (DD18-1803, 000010) \$248,617

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) \$147,191 Surveillance for Emerging Threats to Mothers and Babies Kentucky Department for Public 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) \$243.657

Strengthening Public Health Systems and Services Through National Partnerships to Improve and Protect the Nation's Health National Network of Public Health Institutes (OT18-1802) \$75,000

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) \$150,000

Maryland

Evaluation of Health Promotion and Prevention Programs for Blood Disorders National Blood Clot Alliance (DD14-1405, 001153) \$366,245

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

National Public Health Practice and Resource Centers for Children with Attention Deficit/Hyperactivity Disorder or Tourette Syndrome CHADD, Inc. (Children & Adults with Attention Deficit Hyperactivity Disorder) (DD15-1505, 005376) Project ended 8/31/19



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

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Maryland Department of Health (DD16-1605, 000033) Project ended 7/31/19

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) \$1,347,761

Enhancing Public Health Surveillance of Autism Spectrum Disorder Through the ADDM Network Johns Hopkins University (DD19-1901, 000004) \$556,538

Strengthening Public Health Laboratories Newborn Screening and Genetics – Hemoglobinopathies Project Association of Public Health Laboratories (0E15-1501, 000103) \$57,114

Small Business Innovation Research Grant (SBIR) Medial Decision Logic, Inc. (SBIR17-302, 001220) Project ended 11/29/19

Massachusetts

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS); Stillbirth Risk Factor Pilot Massachusetts Department of Public Health (DD13-003 & DD15-004, 001037) Project ended 8/31/19

Public Health Research on Modifiable Risk Factors for Spina Bifida Trustees of Boston University (DD15-001, 001184) Project ended 4/30/19 Implementing Alcohol Screening and Brief Intervention in Healthcare Systems Providing Women's Health Services Boston Medical Center Corporation (DD18-1802, 000002) \$397,240

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) \$250,000

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

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Massachusetts Department of Public Health (DD16-1605, 000011) Project ended 7/31/2019

Birth Defects Study To Evaluate PregnancyexposureS (BD-STEPS) II Massachusetts Department of Public Health (DD18-001, 001224) \$1,119,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida The Children's Hospital Corporation (DD19-001, 001266- Comp B) \$68,000

Surveillance for Emerging Threats to Mothers and Babies Massachusetts Department of Public Health (CK19-1904) \$153,530

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) \$150,000 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) \$399,364

Capacity Building for Sickle Cell Disease Surveillance Michigan Department of Health and Human Services (DD19-1906, 000005) \$85,000

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) \$250,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida Gillette Children's Specialty Healthcare (DD14-002, 001074) Project ended 8/31/19



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) \$68,000

Capacity Building for Sickle Cell Disease Surveillance Minnesota Department of Health (DD19-1906, 000008) \$85,000

Small Business Innovation Research Grant (SBIR) Aster Labs, Inc. (SBIR18-574, 001286) \$620,862

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) \$150,000 Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Mississippi State Department of Health (DD16-1605, 000035) Project ended 7/31/2019

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) \$102,159

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3 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 in St. Louis (DD15-1501, 001177) Project ended 12/31/19

Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers University of Missouri (DD14-1402, 001145) Project ended 3/29/19

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Missouri Department of Health and Senior Services (DD16-1605, 000001) Project ended 4/30/19

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

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

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)
\$150.000

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) \$148,966

Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers Board of Regents, University of Nevada, Reno (DD14-1402, 001132)

Project ended 9/29/19

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

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Southern Nevada Health District (DD17-1702, 000047)
Project ended 7/31/2019

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) \$150,000

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) Projected 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) \$250,000

Enhancing Public Health Surveillance of Autism Spectrum Disorder Through the ADDM Network Rutgers, The State University of New Jersey (DD19-1901, 000008) \$400,729

BRFSS Alcohol Screening and Brief Intervention Optional Module New Jersey Department of Health and Senior Services (DP15-1513) \$25,000

New Mexico

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus New Mexico Department of Health (DD16-1605, 000016)
Project ended 7/31/2019

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) \$150,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities Through 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 Public Health (DD15-1506, 004931) Project ended 9/29/19

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorder Health Research Inc (DD14-001, 001054) Project ended 8/31/19 Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders Health Research Inc/New York State Department of Public Health (DD14-001, 001123) Project ended 8/31/19

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) Health Research Inc/New York State Department of Public Health (DD13-003, 001032) Project ended 8/31/19

National Public Health Practice and Resource Centers for Children with Attention-Deficit/Hyperactivity Disorder or Tourette Syndrome Tourette Syndrome Association, Inc (DD15-1505, 001050) Project ended 8/31/19

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

Strengthening Public Health Systems and Services Through National Partnerships to Improve and Protect the Nation's Health March of Dimes (OT18-1802, 000284) \$884,062 Evaluation of Health Promotion and Preventive Program for Blood Disorders Cooley's Anemia Foundation, Inc. (DD14-1405, 001150) \$150,000

Evaluation of Health Promotion and Preventive Program for Blood Disorders National Hemophilia Foundation (DD14-1405, 001154) \$593,000

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus-High-risk Local Areas New York City Department of Health and Mental Hygiene (DD16-1606, 000144) Project ended 8/31/19

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Health Research Inc/New York State Department of Public Health (DD16-1605, 000021)
Project ended 5/31/2019

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) \$199,004

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) \$350,000

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) II Health Research Inc/New York State Department of Public Health (DD18-001, 001227) \$875,000

Surveillance of Congenital Heart Defects Among Children, Adolescents, and Adults Health Research Inc/New York State Department of Public Health (DD19-1902, 000056) \$425,000

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 State Department of Public Health (DD19-002, 001252- Comp A) \$375,000

The Muscular Dystrophy Surveillance, Tracking and Research Network Health Research Inc/New York State Department of Public Health (DD19-002, 001250- Comp C) \$80,000

The Muscular Dystrophy Surveillance, Tracking and Research Network Health Research Inc/New York State Department of Public Health (DD19-002, 001251- Comp D) \$80,000

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

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, Chapel Hill (DD15-1501, 001175) Project ended 12/31/19

Surveillance of Congenital Heart Defects Across the Lifespan Duke University (DD15-1506, 004933) Project ends 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) \$200,000

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus North Carolina Department of Health and Human Services (DD16-1605, 000018) Project ended 7/31/19

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) University of North Carolina, Chapel Hill (DD13-003, 001036) Project ended 8/31/19

Surveillance and Research of Muscular Dystrophiesand Neuromuscular Disorders Research Triangle Institute (DD14-001, 001116) Project ended 8/31/19

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Duke University (DD14-002, 001082)
Project ended 8/31/19

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Duke University (DD14-002, 001087)
Project ended 8/31/19

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) II University of North Carolina, Chapel Hill (DD18-001, 001231) \$875,000 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) \$335,000

The Muscular Dystrophy Surveillance, Tracking and Research Network Research Triangle Institute (DD19-002, 001255 – Comp A) \$374,976

The Muscular Dystrophy Surveillance, Tracking and Research Network Research Triangle Institute (DD19-002, 001253 – Comp C) \$79,985

The Muscular Dystrophy Surveillance, Tracking and Research Network Research Triangle Institute (DD19-002, 001254 – Comp D) \$249,716 Capacity Building for Sickle Cell Disease Surveillance Duke University (DD19-1906, 000004) \$85,000

BRFSS Alcohol Screening and Brief Intervention Optional Module North Carolina Department of Health & Human Services (DP15-1513) \$13,000

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) \$150,000

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) \$150,000 Improving the Health of People with Mobility Limitations and Intellectual Disabilities Through 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) \$99,998

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) \$150,000

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Oklahoma State Department of Health (DD16-1605, 000038)
Project ended 1/31/19

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) \$150,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities Through State-based Public Health Programs Oregon Health and Science University (DD16-1603, 000014) \$440,000



Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Oregon Health and Science University (DD14-002, 001071)
Project ended 8/31/19

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida Oregon Health and Science University (DD14-002, 001058) Project ended 8/31/19

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

Improving Fetal Alcohol Spectrum Disorders Prevention and Practice Through National Partnerships University of Pittsburgh (DD14-1403, 001135) Project ended 9/29/19 Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus-High Risk Local Areas Philadelphia Department of Health (DD16-1606, 000042) Project ended 8/31/19

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Pennsylvania Department of Health (DD16-1605, 00003) Project ended 12/31/19

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida University of Pittsburgh (DD14-002, 001078) Project ended 8/31/19

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida University of Pittsburgh (DD19-001, 001280- Comp B) \$67,873

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Pennsylvania State University
(DD19-001, 001270- Comp B)
\$66,510

Surveillance for Emerging Threats to Mothers and Babies Pennsylvania Department of Health (CK19-1904) \$370,968

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) \$150,000

BRFSS Alcohol Screening and Brief Intervention Optional Module State of Rhode Island Department of Health (DP15-1513) \$20,621

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)
\$73,256

Coordinating Center for Research and Training to Promote the Health of People with Developmental and Other Disabilities University of South Carolina (DD17-001, 001218) \$1,930,737

Improving the Health of People with Mobility Limitations and Intellectual Disabilities Through State-based Public Health Programs University of South Carolina (DD16-1603, 000011) \$440,000

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus South Carolina Department of Health and Environmental Control (DD16-1605, 000024)
Project ended 7/31/2019

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorder South Carolina Department of Health and Environmental Control (DD14-001, 001117) Project ended 8/31/2019

Surveillance of Congenital Heart Defects Among Children, Adolescents, and Adults South Carolina Department of Health and Environmental Control (DD19-1902, 000052) \$315,000

The Muscular Dystrophy Surveillance, Tracking and Research Network South Carolina Department of Health and Environmental Control (DD19-002, 001244) \$80,000

The Muscular Dystrophy Surveillance, Tracking and Research Network South Carolina Department of Health and Environmental Control (DD19-002, 001245) \$375,000

South Dakota

South Dakota has no "state-based activities and funding

Tennessee

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Tennessee Department of Health (DD16-1605, 000032) Project ended 7/31/19

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida Vanderbilt University Medical Center (DD14-002, 001073) Project ended 8/31/19

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Vanderbilt University Medical Center (DD14-002, 001075)
Project ended 8/31/19

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, 001170) 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



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) \$85,000

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) \$210,000 Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers Baylor College of Medicine (DD14-1402, 001131) Project ended 6/29/19

Improving Fetal Alcohol Spectrum Disorders Prevention and Practice Through National Partnerships University of Texas, Austin (DD14-1403, 001147) Project ended 9/29/19

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) \$150,000 Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus-High Risk Local Areas Houston Department of Health and Human Services (DD16-1606, 000045) Project ended 7/30/19

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida Baylor College of Medicine (DD14-002, 001072) Project ended 8/31/19

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida Baylor College of Medicine (DD14-002, 001070) Project ended 8/31/19

Public Health Research on Modifiable Risk Factors for Spina Bifida University of Texas Health Science Center, Houston (DD15-001, 001179) Project ended 12/31/18

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 andOutcomes 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) \$67,240

Utah

Surveillance of Congenital Heart Defects Across the Lifespan University of Utah (DD15-1506, 004934) Project ends 8/29/2020

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) \$150,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida IHC Health Services (DD14-002, 001062) Project ended 8/31/2019 Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida IHC Health Services (DD14-002, 001060) Project ended 8/31/2019

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorder University of Utah (DD14-001, 001108) Project ended 8/31/2019

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 Through 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 Surveillance of Congenital Heart Defects Among Children, Adolescents, and Adults University of Utah (DD19-1902, 000053) \$425,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida University of Utah (DD19-001, 001282) \$20,478

The Muscular Dystrophy Surveillance, Tracking and Research Network University of Utah (DD19-002, 001249 – Comp A) \$374,999

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) \$150,000



Improving the Health of People with Mobility Limitations and Intellectual Disabilities Through 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) \$122,290

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Virginia Department of Health (DD16-1605, 000014)
Project ended 7/31/2019

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Spina Bifida Association
(DD19-001, 001257- Comp A)
\$456,642

The Muscular Dystrophy Surveillance, Tracking and Research Network Virginia Commonwealth University (DD19-002, 001242- Comp B) \$348,689

Capacity Building for Sickle Cell Disease Surveillance Virginia Department of Health (DD19-1906, 0000007) \$53,113

Strengthening Public Health Systems and Services Through National Partnerships to Improve and Protect the Nation's Health Association of State and Territorial Health Officials (State)(ASTHO-S) \$250,000

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)
\$250,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida Seattle Children's Hospital (DD14-002, 001065) Project ended 8/31/2019 Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida Seattle Children's Hospital (DD14-002, 001064) Project ended 8/31/2019

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

Expanding Efforts & Strategies to Protect & Improve Public Health Globally Vysnova Partners, Inc (GH15-1632, 001732) \$564,839

West Virginia

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus West Virginia Department of Health and Human Resources (DD16-1605, 000012)
Project ended 7/31/19

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 Services (DD17-1701, 00055) \$250,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Children's Hospital of Wisconsin
(DD14-002, 001063)
Project ended 8/31/2019

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 12/31/2019

Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers Board of Regents of the University of Wisconsin System (DD14-1402, 001133) Project ended 3/31/2019 Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Wisconsin Department of Health Services (DD16-1605, 000025)Project ended 7/31/2019

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

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

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)
\$148,225

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)
\$150,000

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) \$65,040



Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Federated States of Micronesia (DD17-1702, 000051)
Project ended 1/31/2019

Puerto Rico

Population-based Surveillance of Birth Defects and Data Utilization for Public Health Action Puerto Rico Department of Health (DD16-1601, 004945) \$170,000

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes Linked with the Zika Virus Puerto Rico Department of Health (DD16-1605, 000037)
Project ended 7/31/2019

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) Puerto Rico Department of Health (DD17-1701, 000088) \$147,373 Surveillance for Emerging Threats to Mothers and Babies Puerto Rico Department of Health (CK19-1904) \$422,604

Switzerland

Global Noncommunicable Disease Prevention and Health Promotion World Health Organization (GH19-1954, 001235) \$570,930

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 ends 7/31/2020



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Gilboa SM, Salemi JL, Nembhard WN, Fixler DE, Correa A. Mortality resulting from congenital heart disease among children and adults in the United States, 1999 to 2006. Circulation. 2010;122(22):2254-2263.



Grosse SD, Waitzman NJ, Romano PS, Mulinare J. Reevaluating the benefits of folic acid fortification in the United States: economic analysis, regulation, and public health. Am J Public Health. 2005;95(11):1917–1922.



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Impact of folic acid fortification of the US food supply on the occurrence of neural tube defects.

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Peterson C, Grosse SD, Oster ME, Olney RS, Cassell CH. <u>Cost-effectiveness of routine screening for critical congenital heart disease in US newborns</u>. *Pediatrics*. 2013;132(3):e595-e603.



Kenneson K, Kolor K, Yang Q, Olney RS, Rasmussen SA, Friedman JM. <u>Trends and racial disparities in muscular dystrophy deaths in the United States, 1983–1998: an analysis of multiple cause mortality data</u>. *Am J Med Genet A*. 2006;140(21):2289–2297.



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