From Saving Babies to Protecting People:

NCBDDD Making a Difference Across the Lifespan

in 2017

National Center on Birth Defects and Developmental Disabilities

MESSAGE FROM THE DIRECTOR

Coleen A. Boyle, PhD, MS (Hyg)
Director

It is with great pride and accomplishment that I present to you CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD), year in review entitled: *From Saving Babies to Protecting People: NCBDDD Making a Difference Across the Lifespan*. This report highlights many notable achievements. I am proud to celebrate these achievements and continued progress in the pursuit of improved programs, research, and knowledge for the millions of Americans who live with birth defects, disabilities, and blood disorders.

2017 marked an incredibly active year for CDC and NCBDDD. In addition to the many accomplishments featured in this report, I would like to highlight additional activities for which we are proud:

Development of New Strategic Plan: The mission of NCBDDD is to: save babies by studying and addressing the causes of birth defects; help children reach their potential by understanding developmental disabilities; reduce complications of blood disorders; and improve the health of people living with disabilities. To help guide this critical work over the coming years, we embarked on a process to complete our strategic plan. NCBDDD's strategic plan serves as a detailed road map for our organization, marking the health impacts we anticipate achieving in the coming years, and at a high-level, describing how we plan to do this. We are very excited to share our plan and welcome you to take a moment to review it and share within your networks.

Continued Response to Zika Virus: While CDC deactivated its Emergency Operations Center for Zika in September, 2017, NCBDDD's charge to protect mothers and babies from the virus and other emerging threats persists. Until we have an effective vaccine against Zika, it will continue to be a critical public health threat. We have learned a lot in a short amount of time through our surveillance systems and taken critical public health action. As we learn more about Zika, our concerns grow. Many questions remain about the full impact of the virus on children and the types of services needed to care for infants with congenital Zika syndrome are complex. Zika deserves our constant vigilance–for pregnant women, children and families.

As you read the report, I hope you will gain insight into the breadth and depth of our activities. As the director of NCBDDD, I pledge to continue the quest for greater knowledge, better programs, and enhanced capacity on behalf of every child and adult impacted by a birth defect, developmental or physical disability, blood disorder, or any obstacle keeping them from optimal growth and development. They deserve to see the promises of tomorrow become today's reality. The accomplishments over the past year and the work ahead depends on the support and contributions of our partners and dedicated staff. I am immensely grateful to those individuals and partners whose energy and support sustain us.

Thank you and I look forward to another amazing year at NCBDDD.

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SAVING BABIES

Through Birth Defects Prevention and Research

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

Birth defects are common, costly, and critical. Our unique state-based birth defects tracking and public health research provide a wealth of information that we use to identify causes of birth defects, find opportunities to prevent them, and improve the health of those living with birth defects. 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.

Accomplishments

- Contributed to what is known about Zika virus infection during pregnancy. Used information collected from the U.S. Zika Pregnancy and Infant Registry for public health action to protect mothers and babies from Zika virus infection. The information from this innovative surveillance answered questions related to Zika virus infection during pregnancy, resulted in updated recommendations for clinical care, guided planning for medical and social services for affected families, and improved prevention of Zika virus infection during pregnancy.

- Confirmed the link between maternal fever during early pregnancy and an increased chance for having a baby with a neural tube defect (NTD)

using two independent information sources: CDC funded National Birth Defects Prevention Study, which looked for a link between fever and 29 other birth defects and the Slone Epidemiology Center Birth Defects Study, which found that daily folic acid intake reduced the chance for an NTD.

- Supported research efforts to link a group of infants identified with neonatal abstinence syndrome (NAS) in Tennessee Medicaid claims information to Tennessee Department of Education information to understand the long-term neurodevelopmental outcomes potentially related to NAS. This pilot project is the first to look at connections between NAS and special education needs in U.S. children.

- Provided new information on alcohol screening and brief intervention (SBI) that showed most adults who drank at risky levels and were asked about their alcohol use during checkups were not advised to drink less. Supported CDC's Collaborative for Alcohol-Free Pregnancy to promote alcohol SBI, which included implementing a model in a large health system in Texas that engaged health professionals from multiple disciplines. Worked with partners to develop resources promoting the prevention and recognition of fetal alcohol spectrum disorders, such as the launch of an online PediaLink course from the American Academy of Pediatrics.

- Analyzed National Health and Nutrition Examination Survey information to predict the chances among various groups of U.S. women of having a pregnancy affected by a neural tube defect (NTD). About 1,300 NTDs are prevented each year through food fortification with folic acid. However, additional birth defects could be prevented if folic acid consumption is increased among women with low consumption. Worked with partners in Tanzania to increase market supply and demand for maize flour fortified with folic acid and other nutrients produced by small- and medium-scale mills. Worked with partners in Haryana State, India to assess the health impact of fortifying wheat flour with folic acid, vitamin B12, and iron.

Birth Defects are Critical

Birth defects cause

1 IN EVERY 5

deaths during the first year of life

Looking to the Future

NCBDDD will continue its work to protect women and babies through our birth defects tracking and 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. Our work in Zika virus is a reminder of the medical vulnerability of mothers and babies to emerging infections and other threats, and the impact of infectious diseases and other exposures during pregnancy. We will continue to leverage the innovative tracking and monitoring system developed to combat Zika virus and respond rapidly to other emerging threats that affect mothers and babies.

Notable Scientific Publications

Honein MA, et al. Birth Defects Among Fetuses and Infants of US Women With Evidence of Possible Zika Virus Infection During Pregnancy. JAMA. 2017;317(1):59-68.

Howley M, et al. Thyroid Medication Use and Birth Defects in the National Birth Defects Prevention Study. Birth Defects Res. 2017;109(18):1471-81.

Lind J, et al. Maternal Use of Opioids During Pregnancy and Congenital Malformations: A Systematic Review. Pediatrics. 2017;139(6):e20164131.

Lynch M, et al. Making Decisions About Medication Use During Pregnancy: Implications for Communication Strategies. Maternal Child Health J. 2017 Sep 12.

McKnight-Eily LR, et al. Screening for Excessive Alcohol Use and Brief Counseling of Adults — 17 States and the District of Columbia, 2014. MMWR Morb Mortal Wkly Rep. 2017;66(12):313-9.

Oduyebo T, et al. Update: Interim Guidance for Health Care Providers Caring for Pregnant Women with Possible Zika Virus Exposure — United States (Including U.S. Territories), July 2017. MMWR Morb Mortal Wkly Rep. 2017;66(29):781-93.

Parra-Saavedra M, et al. Serial Head and Brain Imaging of 17 Fetuses with Confirmed Zika Virus. Obstet Gynecol. 2017;130(1):207-12.

Reynolds MR, et al. Vital Signs: Update on Zika Virus-Associated Birth Defects and Evaluation of All U.S. Infants with Congenital Zika Virus Exposure - U.S. Zika Pregnancy Registry, 2016. MMWR Morb Mortal Wkly Rep. 2017;66(13):366-73.

Rosenthal J, et al. Folate Deficiency Is Prevalent in Women of Childbearing Age in Belize and Is Negatively Affected by Coexisting Vitamin B-12 Deficiency: Belize National Micronutrient Survey 2011. wwJ Nutr. 2017 Jun;147(6):1183-93.

Shapiro-Mendoza CK, et al. Pregnancy Outcomes After Maternal Zika Virus Infection During Pregnancy — U.S. Territories, January 1, 2016–April 25, 2017. MMWR Morb Mortal Wkly Rep. 2017;66(23):615-21.

SPOTLIGHT ON:

American Academy of Pediatrics & The National Birth Defects Prevention Network

Birth defects are common, costly, and critical. CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) saves babies by preventing birth defects. NCBDDD identifies causes of birth defects, finds opportunities to prevent them, and improves the health of those living with birth defects.

Fetal Alcohol Spectrum Disorders

The American Academy of Pediatrics (AAP) Fetal Alcohol Spectrum Disorders (FASD) Regional Education and Awareness Liaisons (REAL) Champions Network was established in 2016 under a cooperative agreement between AAP and NCBDDD. The FASD REAL Champions Network supports the goals of CDC's FASD program through innovative education and awareness building activities. During its first year, the FASD REAL Champions Network reached over 1,200 pediatric clinicians with presentations on FASD screening, assessment and diagnosis; neurobehavioral disorder associated with prenatal alcohol exposure; and lifelong care for individuals with FASDs.

Recent studies indicate that from 2-5% of school aged children may have a FASD. Pediatric clinicians need an enhanced level of awareness, education, and guidance on the identification, treatment, and management of infants and children who were prenatally exposed to alcohol, some of whom may have one of the FASDs. The FASD REAL Champions Network aims to play a vital role in reducing alcohol exposed pregnancies and identifying and coordinating care for children with a FASD.

National Birth Defects Prevention

The National Birth Defects Prevention Network (NBDPN) was formed in 1997 as a non-profit organization of state-based programs, partner agencies, and other volunteers to advance science and its application to prevention through birth defects surveillance. The NBDPN assesses the impact of birth defects upon communities; identifies factors that can be used to develop primary prevention strategies; and assists families and their providers in secondary disabilities prevention.

Recently, NBDPN collaborated with NCBDDD to support state programs to conduct rapid tracking of Zika-related birth defects. A NBDPN Zika Response Group was formed to discuss case definitions for the defects to monitor, potential data variables to collect, rapid ascertainment methodologies, and other resources, such as assisting with a data collection tool development. The NBDPN published a state data brief on microcephaly and also worked with CDC to establish the baseline occurrence of microcephaly in the United States prior to Zika. These data provided crucial information to determine the elevated risk of Zika virus on developing babies. The NBDPN continues to assess and support state programs as they continue to monitor Zika-related birth defects and other major birth defects.

NCBDDD's Birth Defects Topics

- Birth Defects
- Congenital Heart Defects
- Fetal Alcohol Spectrum Disorders (FASDs)
- Folic Acid
  - Birth Defects COUNT
- Preconception Health and Health Care
- Pregnancy and Diabetes
- Pregnancy and Medication Use
  - Treating for Two
- Zika and Birth Defects

Visit **www.cdc.gov/ncbddd** to learn more.

HELPING CHILDREN

Live to the Fullest by Understanding Developmental Disabilities

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is committed to understanding developmental disabilities and other conditions in order to help children and their families get the help they need.

NCBDDD works to understand conditions that affect the development of children, such as attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), hearing loss and vision impairment, and other disorders (for example, fragile X syndrome and spina bifida). About 1 in 6 children in the United States have a developmental delay or disability. NCBDDD looks at how common these conditions are, possible causes and factors that put children at risk, how to keep children safe during an emergency, and ways to improve early identification of developmental delays so that children can get services and support as early as possible.

Accomplishments

- Educated healthcare providers about the effectiveness of the early hearing detection and intervention (EHDI) guidelines. The EHDI 1-3-6 guidelines recommend that children be screened for hearing loss by one month of age, diagnosed by three months of age, and enrolled in intervention by six months of age. A study published in the journal, *Pediatrics*, found that children with hearing loss were more likely to have larger vocabularies if they had received a diagnosis by three months and intervention by six months. This is the first study to explore whether meeting the 1-3-6 EHDI timeline can improve vocabulary outcomes of children with hearing loss in both ears.

- Developed innovative resources that promoted developmental monitoring and screening to help identify children with developmental delays and disabilities as early as

possible. Parents can use the *Learn the Signs. Act Early.* Milestone Tracker App to monitor their child's development and get tips for taking action when there is a concern. *Where is Bear? A Terrific Tale for Two-Year Olds* is an award-winning book that engages children while parents learn about important child development milestones. Thanks to the 45 state and territorial Act Early Ambassadors and other partners, *Learn the Signs. Act Early*. materials reach families through existing programs nationwide.

- Provided information to encourage better support of children with mental, behavioral, and developmental disorders. A new CDC study found that families in rural areas raising children with mental, behavioral, and developmental disorders might face greater challenges than those living in urban areas. CDC published a policy brief outlining potential policies and practices that could benefit families in rural areas and an article that examined the role of public health in identifying children at risk for delays in their development and learning.

- Hosted the first CDC pediatric-focused multi-state emergency preparedness exercise to help states across the nation prepare to take care of children's needs, including the needs of children with disabilities, during public health emergencies, such as disease outbreaks, earthquakes and weather-related emergencies. The exercise was evaluated and the results indicated that cross-state partnerships were established or strengthened, participation in the exercise enhanced emergency preparedness-related capabilities specific to children, and additional exercises of this type can enhance the capacity for local communities to be prepared for emergencies – ultimately protecting more children in times of crisis.

- Published seven peer-reviewed studies of data from the Study to Explore Early Development (SEED), the largest study in the United States to help identify factors that may put children at risk for autism spectrum disorder (ASD). These studies focused on a range of topics, including risk factors, genetic associations, and health conditions in children with ASD and other disabilities. CDC also collected information from 11 communities for the Autism and Developmental Disabilities Monitoring (ADDM) Network on the prevalence and characteristics of ASD among 8-year-old children during 2014.

HELPING CHILDREN

Early hearing screening and intervention for children with hearing loss **save approximately $200 million in additional education costs each year.**

Looking to the Future

Children with developmental or other disabilities and their families often face personal, social, and financial challenges. NCBDDD and its partners will work across healthcare, early learning, and other social service systems to improve the early identification of children with developmental delays, increase the connection of these children and their families to services, and provide tools and resources to help families facing personal, social, and financial challenges. Our mission extends to understanding optimal development at each stage of life, from early brain development and access to medical, developmental, and behavioral intervention services to the health of teens with autism spectrum disorder. NCBDDD paves the way to help families and children get the support they need.

Notable Scientific Publications

Danielson M, et al. A National Profile of Attention-Deficit Hyperactivity Disorder Diagnosis and Treatment Among US Children Aged 2 to 5 Years. J Dev Behav Peds. 2017;38(7):455-64.

Durkin MD, et al. Autism Spectrum Disorder Among U.S. Children (2002-2010): Socioeconomic, Racial, and Ethnic Disparities. Am J Public Health. 2017;107(11):1818-26.

Dziuban EJ, et al. A Child's Health is the Public's Health: Progress and Gaps in Addressing Pediatric Needs in Public Health Emergencies. Am J Public Health. 2017;107(S2):S134-S137.

Grosse S, et al. CDC Grand Rounds: Newborn Screening for Hearing Loss and Critical Congenital Heart Disease. MMWR Morb Mortal Wkly Rep. 2017;66(33):888-90.

Kaminski J, et al. Evidence Base Update for Psychosocial Treatments for Disruptive Behaviors in Children. J Clin Child Adolesc Psychol. 2017;46(4):477-99.

Maenner MJ, et al. Development of a Machine Learning Algorithm for the Surveillance of Autism Spectrum Disorder. PLoS One. 2016;11(12):e0168224.

Schieve LA, et al. Maternal and Paternal Infertility Disorders and Treatments and Autism Spectrum Disorder: Findings From the Study to Explore Early Development. J Autism Dev Disord. 2017;47(12):3994-4005.

Soke GN, et al. Factors Associated with Self-injurious Behaviors in Children with Autism Spectrum Disorder: Findings From Two Large National Samples. J Autism Dev Disord. 2017;47(2):285-96.

Tyler ET, et al. Behavioral Health Integration in Pediatric Primary Care: Considerations and Opportunities for Policymakers, Planners, and Providers. Milbank-Supported Report. 2017.

Wiggins LD, et al. Homogeneous Subgroups of Young Children with Autism Improve Phenotypic Characterization in the Study to Explore Early Development. J Autism Dev Disord. 2017;47(11):3634-45.

SPOTLIGHT ON:

American Academy of Pediatrics & Autism Speaks

Developmental disabilities are some of the most significant child health issues facing American families. They include conditions, such as attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), and hearing loss. CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) helps children live life to the fullest by providing a better understanding of these conditions and helping parents and healthcare providers make smart decisions so that children and their families get the support they need.

Developmental Milestone Monitoring

The mission of the American Academy of Pediatrics (AAP) is to attain optimal physical, mental, and social health and well-being for all infants, children, and adolescents and young adults. The *Program to Improve Monitoring and Screening of Developmental Delays in Pediatric Practice*—supported by NCBDDD funding—aims to raise awareness about developmental monitoring and screening among pediatric clinicians, early child-care providers, and families.

One of the program's key activities was the successful implementation of a practice-based quality improvement project focused on improving developmental monitoring, screening, and referral in the pediatric primary care setting. One team stated, "As a result of this project, we communicate with families more concretely about what we're looking for at each stage of development." CDC's *Learn the Signs. Act Early.* (LTSAE) shared resources with practice teams, resulting in teams routinely using LTSAE resources with families, enhancing the support of developmental monitoring and screening activities in practice, and ultimately enhancing pediatric patient care.

Tracking Autism's Prevalence and Improving Screening Methods

Over the last ten years, Autism Speaks has joined with NCBDDD to support research that improves tracking of autism's prevalence. During this time, CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network tracked a steep rise in diagnosed autism from 1 in 150 children in 2007 to 1 in 68 children today. This work is crucial for guiding healthcare organizations, schools, public health agencies and policymakers in organizing appropriate support for people with autism.

ADDM measures autism prevalence based on indicators in the school and medical records of 8-year-olds in sample communities across the United States. Recent studies have found significantly higher rates when researchers directly screen and evaluate children for autism in a community. Autism Speaks looks forward to working with NCBDDD to better identify children with autism – and do so at younger ages – in order to make sure they get the services that can enhance their success in school, daily life, and adulthood.

Early Hearing Detection and Intervention Regional Network Liaison Program

The AAP Early Hearing Detection and Intervention (EHDI) program focuses on linking the physician community at the national, state, and local levels to activities that support early hearing screening, diagnosis, factor assessment, and early intervention and follow up for children who are deaf or hard of hearing (D/HH). Supported by funding from NCBDDD, the AAP works with its members and other national partners to educate and engage pediatric clinicians by establishing collaborative partnerships with other clinical professionals and state EHDI programs. Through an AAP EHDI Regional Network Liaison program, a pediatrician member, representing an AAP district and membership, provides leadership, mentoring, and support to AAP EHDI Chapter Champions.

NCBDDD's Developmental Disabilities & Child Development Topics

- Attention-Deficit/ Hyperactivity Disorder
- Autism Spectrum Disorder
- Caring for Children in a Disaster
- Cerebral Palsy
- Child Development
- Children's Mental Health
- Fetal Alcohol Spectrum Disorders
- Fragile X Syndrome
- Hearing Loss
- Intellectual Disability
- *Learn the Signs. Act Early.* Campaign.

Visit **www.cdc.gov/ncbddd** to learn more.

PROTECTING PEOPLE

and Preventing Complications of Blood Disorders

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

Blood disorders affect millions of people in the United States. Many of these disorders and their complications could be avoided with proper preventive actions and early intervention. 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 prevention programs;
- Helping consumers and healthcare providers get the information that they need; and
- Encouraging action to improve the quality of life for people living with or affected by these conditions.

Accomplishments

- Supported, developed, and promoted a supplement to the journal, *Journal of Hospital Medicine*, on venous thromboembolism (VTE) titled "Preventing Hospital-Acquired Venous Thromboembolism: Lessons from the Field." The executive summary within the supplement described the partnerships between CDC, the Joint Commission Center for Transforming Healthcare, and the Agency for Healthcare Research and Quality to advance patient safety by improving the prevention of healthcare-associated VTE. The remaining articles highlighted best practices and strategies for prevention of healthcare-associated VTE within five hospitals.

These hospitals were the 2015 CDC Healthcare-Associated VTE Prevention Challenge Champions.

- Coordinated a CDC Public Health Grand Rounds titled "Improving the Lives of People with Sickle Cell Disease," which featured a panel of four leaders in the field of sickle cell disease (SCD). Speakers discussed the importance of access to and use of healthcare services by people with SCD as key to decreasing illness and death. They discussed how CDC's Sickle Cell Data Collection Program provided important population-level information about how SCD progresses in people, the influence of interventions and use of healthcare services on improving health and quality of life for people with SCD, and the frequency of premature death from the condition.

- Worked with the National Hemophilia Foundation to launch "Better You Know," a public health education campaign to increase awareness about the signs, symptoms, and diagnosis of bleeding disorders among women. The campaign provided information for healthcare providers and women experiencing heavy menstrual bleeding who may be at risk for having a bleeding disorder. The campaign website has an online questionnaire, tools to help women determine their risk for a bleeding disorder, and next steps to seek care.

- Convened the Second Inhibitor Summit to discuss how inhibitors against clotting factor treatments for bleeding disorders are monitored and how this monitoring system can be better used or improved to prevent inhibitors. Prominent leaders in the bleeding disorders community attended the meeting, including care providers, researchers, patient advocacy partners, federal partners, and representatives of pharmaceutical companies.

- Coordinated the development of a four-module educational video series designed to help healthcare providers reduce the complications of blood transfusion when treating patients with SCD. Georgia State University and Emory University developed this video series. Continuing medical and nursing education credits are available for each module.

1 IN 10
people with
a blood clot
will die if it moves
to the lungs

Looking to the Future

NCBDDD will continue to learn about factors that place people with hemophilia at risk for inhibitors and other complications. We will study and promote the use of periodic inhibitor testing, monitor complications from blood and treatment products, and research how well treatment strategies prevent disease-related complications. We will work to prevent blood clots and improve laboratory techniques to identify factors that put people at risk for VTE. Health education, early detection, and medical referrals will remain part of this important work. We strive to better identify people living with thalassemia and sickle cell disease and better understand complications from blood transfusions.

Notable Scientific Publications

Beckman M, et al. Strategies and Partnerships Toward Prevention of Healthcare-Associated Venous Thromboembolism. J Hosp Med. 2016;11 Suppl 2:S5-S7.

Boylan B, et al. Survey of the Anti-Factor IX Immunoglobulin Profiles in Patients with Hemophilia B Using a Fluorescence-Based Immunoassay. J Thromb Haemost. 2016;14(10):1931-40.

Chaturvedi S, et al. Genome-Wide Association Study to Identify Variants Associated with Acute Severe Vaso-Occlusive Pain in Sickle Cell Anemia. Blood. 2017;130(5):686-8.

Deguchi H, et al. Low Level of Plasma Sphingolipid, Glucosylceramide, Is Associated with Thrombotic Diseases. Res Pract Thromb Haemost. 2017;1(1):33-40.

Kulkarni R, et al. Complications of Haemophilia in Babies (First Two Years of Life): A Report from the Centers for Disease Control and Prevention Universal Data Collection System. Haemophilia. 2017;23(2):207-14.

Manco-Johnson M, et al. Prophylaxis Usage, Bleeding Rates and Joint Outcomes of Hemophilia 1999 - 2010: A Surveillance Project. Blood. 2017;129(17):2368-74.

Miller CH, et al. Limit of Detection and Threshold for Positivity of the Centers for Disease Control and Prevention Assay for Factor VIII Inhibitors. J Thromb Haemost. 2017;15(10):1971-6.

Paulukonis S, et al. Emergency Department Utilization by Californians with Sickle Cell Disease, 2005-2014. Pediatr Blood Cancer. 2017;64(6):e26390.

Soucie J, et al. The Effects of Joint Disease, Inhibitors and Other Complications on Health-Related Quality of Life Among Males with Severe Haemophilia A in the United States. Haemophilia. 2017;23(4):e287-e293.

Srivaths L, et al. Differences in Bleeding Phenotype and Provider Interventions in Postmenarchal Adolescents When Compared to Adult Women with Bleeding Disorders and Heavy Menstrual Bleeding. Haemophilia. 2017 Sep 5. [Epub ahead of print]

SPOTLIGHT ON:

American Society of Hematology & National Blood Clot Alliance

People with blood disorders are living longer than ever before, but with far too many medical complications that could be prevented. These complications have serious, sometimes fatal, health consequences and cost our healthcare system billions of dollars every year. CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) invests in activities that increase understanding of blood disorders, advance medical care and treatments, and improve outcomes for all people with blood disorders.

Sickle Cell Disease

The American Society of Hematology (ASH), an organization representing over 17,000 members dedicated to the study and treatment of blood and blood-related diseases and disorders, is committed to addressing the burden of sickle cell disease (SCD) and is undertaking a multi-faceted initiative to improve outcomes for individuals with the disease, both in the United States and globally. Activities include convening the Sickle Cell Disease Coalition (SCDC), developing up-to-date guidelines describing the management of acute and chronic complications of SCD, and educating hematologists and other healthcare providers in all settings to properly respond to SCD complications in their everyday practices.

NCBDDD and ASH worked collaboratively along with the Sickle Cell Disease Association of America to develop a Sickle Cell Trait Toolkit —a collection of resources to increase understanding of trait. CDC's Sickle Cell Data Collection (SCDC) program in California and Georgia continues to inform the ASH initiative by providing critical information on individuals with SCD over time, identifying major gaps in diagnosis, treatment, and healthcare access for people with SCD. CDC has also helped support the Society's efforts to raise awareness and education of the disease.

Venous Thromboembolism

The National Blood Clot Alliance (NBCA) is a 501(c)(3), non-profit, voluntary health organization dedicated to advancing the prevention, early diagnosis, and successful treatment of life-threatening blood clots. NBCA accomplishes its mission through programs that build public awareness, educate patients and healthcare professionals, and promote supportive public and private sector policy.

About 900,000 people are affected by blood clots each year, and 100,000 of these individuals will die due to a blood clot, which is more than the number of people who die each year due to AIDS, breast cancer, and motor vehicle crashes combined.

Launched in 2015, NBCA's *Stop the Clot, Spread the Word*™ campaign has reached more than 167 million people and is made possible through funding provided by the CDC. The centerpiece of the *Stop the Clot, Spread the Word*™ campaign involves a dedicated educational web portal that houses a suite of venous thromboembolism (VTE) educational tools, including videos, infographics, and downloadable checklists that people can review and share with their healthcare professionals. This important partnership between NBCA and CDC continues, and the program will expand to include information specific to other VTE risk groups and more high-profile public awareness activities, reaching more than 500 million people in the next two years.

NCBDDD's Blood Disorders Topics

- Hemophilia
- Sickle Cell Disease
- Thalassemia
- Venous Thromboembolism
- Vitamin K Deficiency Bleeding
- Von Willebrand Disease

Visit **www.cdc.gov/ncbddd** to learn more.

IMPROVING HEALTH

of People with Disabilities

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

One in five U.S. adults have some type of physical, sensory (for example, hearing or vision), or cognitive (for example, learning, thinking, or remembering) disability, and many people will experience a disability during their lifetimes. People with disabilities (PWDs) need health programs and health care for the same reasons anyone else does – to stay well, active, and a part of the community. Yet, programs, services, strategies, and interventions developed for millions of people to lower the risk for or prevent diseases are not always available, accessible, or effective for PWDs. CDC works to make sure that people of all abilities are able to live their lives to the fullest.

Accomplishments

- Developed, authored, and funded a supplement to the *Journal of Pediatrics*, that focused on fragile X syndrome. This wide-ranging resource for healthcare professionals and researchers assisted their efforts to advance knowledge, treatment, and quality of life for people who have fragile X syndrome and their families. The articles contain some of the latest research on fragile X-associated disorders.

- By increasing the number of State Disability and Health Programs funded in 2017 from four to seven, CDC has expanded the capacity to implement Medicaid data analysis activities toward improved monitoring of the health of people with intellectual and developmental disabilities (IDD). These analyses include

identifying patterns of health and healthcare utilization for people with IDD. For example, a recent analysis of Medicaid information, combined with information from other sources in South Carolina between 2001 and 2011, found Medicaid members with IDD experienced more than 21,000 potentially avoidable emergency department visits with costs exceeding $35 million.

- Expanded tracking of muscular dystrophies from two types (Duchenne and Becker) to eight to address gaps in knowledge about the percentage of people with each muscular dystrophy type, their survival, the care they receive, and differences in who receives care.

- Delivered 22 presentations in March 2017 at the Third World Congress on Spina Bifida Research and Care that highlighted spina bifida research projects that involved either participating CDC scientists or CDC information. Information from NCBDDD's National Spina Bifida Patient Registry was the foundation of the majority of these projects.

- Collected information and conducted surveys to understand the number of people living with congenital heart defects (CHDs) and their long-term health outcomes. This includes a pilot project to track adolescents and adults with a CHD and a second project looking at individuals' experiences with CHDs across the lifespan. Two of our funded sites – Emory University and New York State Department of Health – launched a survey of parents of adolescents with CHDs to assess barriers to appropriate transition from adolescent to adult heart care. In addition, the three sites in the Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG (CHSTRONG) are surveying young adults with CHDs and have received more than 1,000 completed surveys so far.

Annual healthcare costs associated with disability are nearly

$400 billion

Looking to the Future

NCBDDD is dedicated to promoting inclusive communities, programs, and policies that provide opportunities for people with disabilities to live a full, healthy life. NCBDDD plans to continue to educate families and other stakeholders about making programs fully accessible to all and providing effective tools and resources on improving accessibility of programs, particularly those focused on physical activity, nutrition, and obesity prevention. An important role for public health programs is addressing gaps in knowledge through each stage of life, such as the often difficult transition of health care for adolescents with mobility or intellectual disabilities into adulthood. NCBDDD will continue to promote the healthy development and inclusion of people with disabilities across their lifespans.

Notable Scientific Publications

Hinton CF, et al. The Guide Community Preventive Services and Disability Inclusion. Am J Prev Med. 2017;53(6):898-903.

Latimer R, et al. Secondary Conditions Among Males With Duchenne or Becker Muscular Dystrophy. J Child Neurol. 2017;32(7):663-70.

Phillips M, et al. PhenX Measures for Phenotyping Rare Genetic Conditions. Genet Med. 2017;19(7):834-37.

Riley C, et al. The Future of Fragile X Syndrome: CDC Stakeholder Meeting Summary. Pediatrics. 2017;139(Suppl. 3):s147-52.

Routh JC, et al. Bladder Reconstruction Rates Differ among Centers Participating in National Spina Bifida Patient Registry. J Urol. 2017;199:1-6.

Smith MG, et al. Capture-recapture Methodology to Study Rare Conditions Using Surveillance Data for Fragile X Syndrome and Muscular Dystrophy. Orphanet J Rare Dis. 2017;12(1):76.

Steele CB, et al. Prevalence of Cancer Screening Among Adults with Disabilities, United States, 2013. Prev Chronic Dis. 2017;14:e09.

Thibadeau J, et al. Understanding the Natural Progression of Spina Bifida: Prospective Study. JMIR Res Protoc. 2017;6(9):e180.

Xinling X, et al. A Longitudinal Assessment of Adherence to Breast and Cervical Cancer Screening Recommendations Among Women With and Without Intellectual Disability. Prev Med. 2017;100:167-72.

NCBDDD's Disability Topics

- Disability and Health
- Fragile X Syndrome
- Hearing Loss
- Muscular Dystrophy
- Living with Spina Bifida
- Tourette Syndrome

Visit **www.cdc.gov/ncbddd** to learn more.

SPOTLIGHT ON:

National Association of County and City Health Officials, American Academy of Pediatrics, Spina Bfida Association & Tourette Association of America

Disabilities may include difficulty with movement, hearing, seeing, communicating or concentrating, remembering, or making decisions. CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) works to ensure that people of all different abilities are able to live their lives to the fullest.

Disability and Health

The National Association of County and City Health Officials (NACCHO) has worked closely with NCBDDD on efforts to support local health departments (LHDs). Recently, with funding support from NCBDDD, NACCHO completed an assessment of LHDs maternal and child health capacity in 10 high-priority jurisdictions for Zika virus infections, based on local virus transmission and travel-related infections. The results of this assessment will help NACCHO and NCBDDD provide training and technical assistance to LHDs as they respond to the needs of their communities.

NCBDDD has been integral in supporting NACCHO's Health and Disability program, which provides LHDs with the tools and resources needed to include people with disabilities in all department activities. In 2017, with funding support from NCBDDD, NACCHO launched an online e-learning training module, Health and Disability 101: Training for Health Department Employees. The purpose of the training is to educate health department staff about the benefits of including people with disabilities in all public health programs, products, and services.

Genetic-associated Conditions: Fragile X, Spina Bifida,and Tourette and Tic Disorders

Primary care pediatricians participated in a quality improvement learning collaborative aimed at increasing opportunities to diagnose fragile X syndrome and other genetic-associated conditions. Participating teams established and followed practice-specific protocols for the genetic testing of children with at least two domains of developmental delay. Of the number of children who had genetic testing completed during the course of this project, over 60% ended up with a confirmed genetic diagnosis. This finding was possible from the funding and support of NCBDDD.

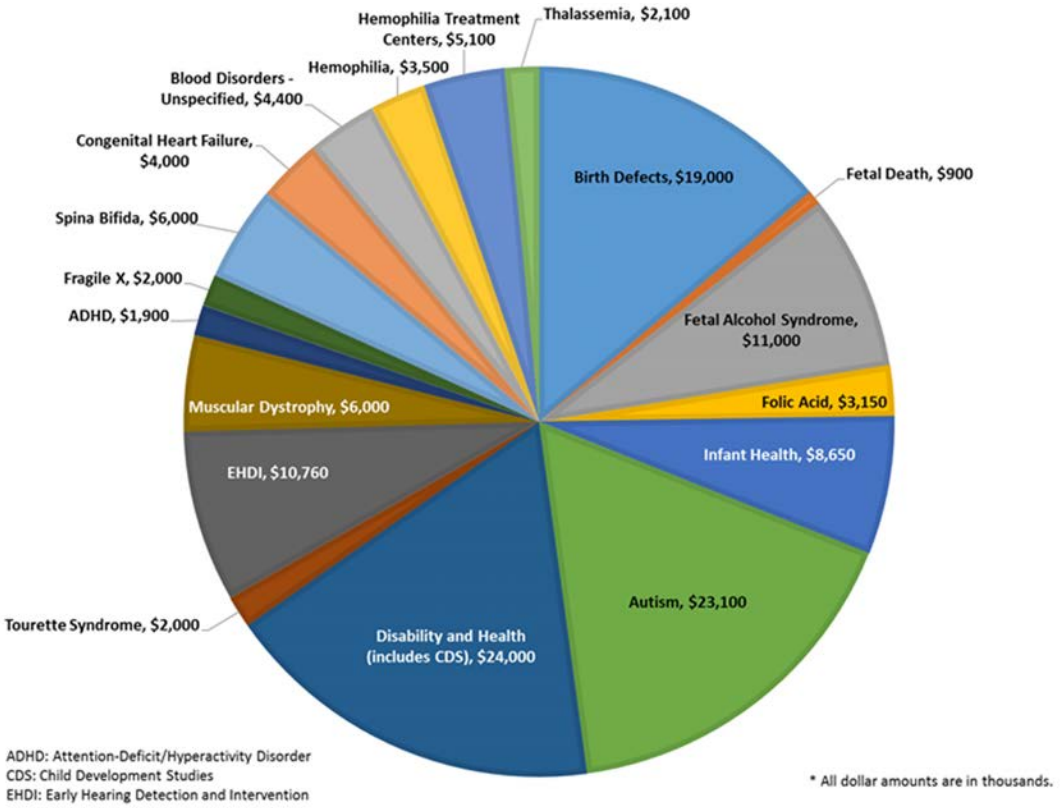
NCBDDD supports the only federal research that looks at spina bifida and considers the interdisciplinary teams necessary to treat people with spina bifida. The Spina Bifida Association (SBA) advocates and promotes NCBDDD's research and findings to advance care, and expand and strengthen research to accelerate new discoveries for people, including adults with spina bifida throughout their lifespans. SBA had numerous accomplishments that advanced care and expanded and strengthened research, such as hosting the 2017 World Congress on Spina Bifida Research & Care, launching the Adult Spina Bifida Survey, and developing Health Care Guidelines for Spina Bifida.

Comprehensive Behavior Intervention for Tics (CBIT) is a first-line medicine-free highly structured behavioral therapy for Tourette and tic disorders that has demonstrated to reduce tic severity and improve function in more than 50% of people, yet is not available to the vast majority of patients. NCBDDD's partnership with the Tourette Association of America (TAA) offers workshops at universities and hospitals across the country to inform practitioners about this important behavioral therapy. CDC funded CBIT introductory workshops can improve the lives of patients and families who undergo CBIT, and can result in health care and disability savings. TAA Youth Ambassador Trevor Harris completed CBIT training and Trevor no longer takes medicine for his Tourette Syndrome. "CBIT is hard work but so is living with Tourette. When I want to give up, my family reminds me that I am in control and I manage my tics through CBIT."

FISCAL YEAR 2017 BUDGET

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) fiscal year (FY) 2017 appropriation includes **$137.560 million** for Child Health and Development, Health and Development with Disabilities, and Public Health Approach to Blood Disorders.

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



NCBDDD FY 2017 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 w/ Disabilities	**$56,660**
Disability and Health (includes CDS)	$24,000
Tourette Syndrome	$2,000
EHDI	$10,760
Muscular Dystrophy	$6,000
ADHD	$1,900
Fragile X	$2,000
Spina Bifida	$6,000
Congenital Heart Failure	$4,000
Public Health Approach to Blood Disorders	**$15,100**
Blood Disorders - Unspecified	$4,400
Hemophilia	$3,500
Hemophilia Treatment Centers	$5,100
Thalassemia	$2,100
NCBDDD Total	**$137,560**

SELECT STATE-BASED Activities and Funding

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 thru State-based Public Health Programs
Alabama Department of Public Health (DD16-1603,000017)
$300,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
University of Alabama (DD14-002, 001080)
$66,943

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
University of Alabama (DD14-002, 001079)
$20,530

National Centers on Health Promotion for People with Disabilities
University of Alabama, Birmingham (DD16-1602, 001157)
$1,500,000

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Alabama Department of Health (DD16-1605, 000002)
Supplemental Funding $199,952*

Alaska

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

** Zika funding*

Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers
University of Alaska, Anchorage
(DD14-1402, 001143)
$343,000 ---------- **Supplemental Funding $151,200**

Arkansas

Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)
Arkansas Department of Health
(DD17-1701, 000092)
$150,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs
University of Arkansas (DD16-1603, 000016)
$399,950 ---------- **Supplemental Funding $24,993**

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)
University of Arkansas for Medical Services
(DD13-003, 001039)
$1,025,000

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network
University of Arkansas for Medical Services
(DD15-1501, 001163)
$450,000

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)
$200,000*

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 Disorders and other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network
University of Arizona (DD15-1501, 001162)
$550,000

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)
Supplemental Funding $200,000*

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)
Arizona Department of Health Services
(DD17-1701, 000076)
$**150,000**

Behavior Risk Factor Surveillance System (BRFSS)
Alcohol SBI – DP15-1513
$35,500

California

Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers
University of California (DD14-1402, 001144)
$275,000 ---------- **Supplemental Funding $151,200**

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)
Stanford University (DD13-003, 001033)
$775,000

** Zika funding*

Characterizing the Complications Associated with Therapeutic Blood Transfusions for Hemoglobinopathies
Children's Hospital and Research Center at Oakland (DD14-1406, 001137)
$100,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Children's Hospital of Los Angeles (DD14-002, 001068)
$20,530

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Children's Hospital of Los Angeles (DD14-002, 001069)
$66,875

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)
Supplemental Funding $360,000*

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
California Department of Public Health (DD16-1605, 000040)
Supplemental Funding $360,000*

Colorado

Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action
Colorado Department of Public Health and Environment (DD16-1601, 004940)
$210,000

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network
Colorado Department of Public Health and Environment (DD15-1501, 001161)
$550,000

Advanced Alcohol Screening & Brief Intervention (aSBI) & CHOICES in American Indian & Alaska Native Population thru Training & Technical Assistance
Denver Health and Hospital Authority (DD13-1301, 001046)
Project Ended 7/31/17

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3
University of Colorado, Denver (DD16-001, 001210)
$800,000

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)
Colorado Department Of Public Health And Environment (DD17-1701, 000083)
$149,879

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders
Colorado State Department of Public Health and Environment (DD14-001, 001126)
$500,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
University of Colorado, Denver (DD14-002, 001093)
$67,082

Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to Improve Services and Outcomes
University of Colorado, Denver (DD15-003, 001190)
$99,984

Surveillance of Congenital Heart Defects across the Lifespan
University of Colorado (DD15-1506, 004935)
$450,000

Connecticut

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)
Connecticut Department of Public Health (DD17-1701, 000100)
$150,000

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Connecticut Department of Public Health (DD16-1605, 000010)
No cost extension project ends 12/31/17

** Zika funding*

Behavior Risk Factor Surveillance System (BRFSS)
Alcohol SBI – DP15-1513
$20,676

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

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 thru 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)
$99,987

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)
Supplemental Funding $360,000*

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)

$250,000
Surveillance of Congenital Heart Defects across the Lifespan
Emory University (DD15-1506, 004932)
$475,000

Characterizing the Complications Associated with Therapeutic Blood Transfusions for Hemoglobinopathies
Georgia State University Research Foundation (DD14-1406, 001138)
$550,000

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)
Supplemental Funding $280,000*

OSTLTS Partnerships CBA of the Public Health System Association of State and Territorial Chronic Disease Program Directors (OT13-1302, 00225)
$75,007

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 as a bona fide 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 as a bona fide for Marshall Islands (DD17-1701, 000072)
$124,584

** Zika funding*

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
State of Hawaii Department of Health
(DD16-1605, 000015)
Supplemental Funding $200,000*

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 Dept 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

Public Health Surveillance for the Prevention of Complications of Bleeding Disorders
American Thrombosis and Hemostasis Network
(DD15-1507, 000001)
$4,300,000 ---------- **Supplemental Funding $100,000**

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

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus-High Risk Local Areas
City of Chicago Department of Public Health
(DD16-1606, 000139)
Supplemental Funding $100,000*

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Illinois Department of Public Health (DD16-1605, 000006)
Supplemental Funding $180,000*

OSTLTS Partnerships CBA of the Public Health System
American Academy of Pediatrics (AAP)
(OT13-1302, 000167)
$85,000

OSTLTS Partnerships CBA of the Public Health System
American Academy of Pediatrics (AAP)
(OT13-1302, 000333)
$50,000

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Lurie Children's Hospital of Chicago (DD14-002, 001091)
$66,710

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Lurie Children's Hospital of Chicago (DD14-002, 001092)
$20,530

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

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)
$149,096

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Indiana State Department of Health
(DD16-1605, 000030)
Supplemental Funding $200,000*

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Indiana University/Purdue University at Indianapolis
(DD14-002, 001057)
$66,440

** Zika funding*

Iowa

Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)
Iowa Department of Public Health (DD17-1701, 000061)
$150,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs
Iowa Department of Public Health (DD16-1603, 000019)
$300,000 ---------- **Supplemental Funding $75,000**

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
University of Iowa (DD16-1605, 000005)
Supplemental Funding $100,000*

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)
University of Iowa (DD13-003, 001035)
$800,000

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders
University of Iowa (DD14-001, 001119)
$499,998

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders
University of Iowa (DD14-001, 001120)
$250,000

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders
University of Iowa (DD14-001, 001118)
$124,999

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)
$299,995

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)
No cost extension project end date 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

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 thru State-based Public Health Programs
Kentucky Cabinet for Health and Family Services (DD16-1603, 000010)
$150,000

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)
$145,821

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Kentucky Cabinet for Health and Family Services (DD16-1605, 000004)
Supplemental Funding $200,000*

** Zika funding*

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 Office of Public Health (DD17-1701, 000087)
$241,465

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Louisiana Office of Public Health (DD16-1605, 000026)
Supplemental Funding $200,000*

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) - Non-Research
Maine Department of Health (DD17-1701, 000074)
$149,999

Maryland

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network
Johns Hopkins University (DD15-1501, 001160)
$450,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs
Maryland Department of Health Mental Hygiene (DD16-1603, 000005)
$150,000

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3
Johns Hopkins University (DD16-001, 001214)
$1,009,100

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, 001049)
$850,000

OSTLTS Partnerships CBA of the Public Health System Sickle Cell Surveillance and Health Promotion
Association of University Centers on Disabilities (AUCD) (OT13-1302, 000140)
$100,000

OSTLTS Partnerships CBA of the Public Health System Association of University Centers on Disabilities (AUCD)
(OT13-1302, 000324)

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Maryland Department of Health and Mental Hygiene (DD16-1605, 000033)
No cost extension project end date 7/31/2019

Strengthening Public Health Laboratories Newborn Screening and Genetics – Hemoglobinopathies Project
Association of Public Health Laboratories (OE15-1501, 000103)
$52,104

Massachusetts

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 thru State-based Public Health Programs
Massachusetts Department of Public Health (DD16-1603, 000002)
$349,789 ---------- **Supplemental Funding $74,799**

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Commonwealth of Massachusetts Department of Public Health (DD16-1605, 000011)
Supplemental Funding
$100,000*

** Zika funding*

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)
Massachusetts Department of Public Health
(DD13-003, 001037)
$1,050,000

Public Health Research on Modifiable Risk Factors for Spina Bifida
Boston University Medical Campus (DD15-001, 001184)
$310,000

Michigan

Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action
Michigan Department of Health and Human Services
(DD16-1601, 004944)
$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 thru State-based Public Health Programs
Michigan Department of Health and Human Services
(DD16-1603, 000001)
$300,000

Improving Drug Safety for Pregnant Woman by Delivering Current and Authorization Information via Mobile Devices
Right Answer.Com, Inc. (PA16-302)
$499,961

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 Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network
University of Minnesota (DD15-1501, 001171)
$450,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru 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

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Minnesota Department of Health
(DD16-1605, 000007)
Supplemental Funding $100,000*

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Gillette Children's Specialty Healthcare
(DD14-002, 001074)
$67,090

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 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)
Supplemental Funding $200,000

Missouri

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network
Washington University at St. Louis
(DD15-1501, 001177)
$550,000

** Zika funding*

Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers
University of Missouri (DD14-1402, 001145)
$275,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs
Missouri Department of Health and Senior Services (DD16-1603, 000013)
$150,000

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

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)
Supplemental Funding $200,000*

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3
Washington University (DD16-001, 001216)
$800,000

Montana

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs
Montana Department of Public Health and Human Services (DD16-1603, 000018)
$300,000

Nebraska

Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)
Nebraska Department of Health & Human Services (DD17-1701, 000057)
$150,000

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Nebraska Department of Health & Human Services (DD17-1702, 000049)
$77,427*

Nevada

Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers
Board of Regents, University of Nevada Reno (DD14-1402, 001132)
$343,000 ---------- **Supplemental Funding $151,2000**

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)
$149,933

Behavioral Risk Factor Surveillance System
Nevada Department of Health DP15-1513
$12,500

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)
$200,000*

New Hampshire

Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)
New Hampshire Department of Health and Human Services (DD17-1701, 000068)
$150,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs
University of New Hampshire (DD16-1603, 000007)
$400,000 ---------- **Supplemental Funding $25,000**

** Zika funding*

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
New Hampshire Department of Health and Human Services (DD16-1605, 000009)
No Cost Extension project ends 7/31/2018

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)
$550,000

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)
New Jersey Department of Health (DD17-1701, 000081)
$248,837

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
New Jersey Department of Health (DD16-1605, 000008)
Supplemental Funding $280,000*

New Mexico

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 Mexico Department Of Health (DD17-1701, 000098)
$150,000

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)
No Funding in FY 17

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/New York State Department of Health (DD17-1701, 000066)
$150,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs
Health Research / NYSDOH (DD16-1603, 000004)
$350,000 ---------- **Supplement Funding $75,000**

Surveillance of Congenital Heart Defects Across the Lifespan
New York State Department of Health (DD15-1506, 004931)
$475,000

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorder
Health Research Inc. (DD14-001, 001054)
$100,000

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders
Center of Environment Health/Health Research Inc./ NYSDOH (DD14-001, 001123)
$500,000

Birth Defects Study To Evaluate Pregnancy exposures (BD-STEPS)
Health Research Inc./NYSDOH-Center for Environmental Health (DD13-003, 001032)
$775,000

National Public Health Practice and Resource Centers for Children with Attention-Deficit/Hyperactivity Disorder or Tourette Syndrome
Tourette Syndrome Association, Inc. (DD15-1505, 001050)
$900,000

OSTLTS Partnerships CBA of the Public Health System
March of Dimes Birth Defects Foundation (OT13-1302, 000199)
$818,029

** Zika funding*

Evaluation of Health Promotion and Prevention Programs for Blood Disorders
Cooley's Anemia Foundation, Inc. (DD14-1405, 001150)
$150,000

Evaluation of Health Promotion and Prevention Programs 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 (DD16-1606, 000144)
Supplemental Funding $352,287

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Health Research, Inc. NYSDOH (DD16-1605, 000021)
Supplemental Funding $359,999*

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 Res in Developmental Disabilities (DD15-003, 001189)
$349,861

Emerging Infections Program
New York Department of Health (CK12-1202)
$206,182

Surveillance of Congenital Heart Defects (CHDs) Adolescents /Adults
Health Research Inc./NYSDOH (DD12-1207, 001017)
No Cost Extension ending 5/31/17

North Carolina

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network
University of North Carolina at Chapel Hill (DD15-1501, 001175)
$550,000

Surveillance of Congenital Heart Defects across the Lifespan
Duke University (DD15-1506, 004933)
$450,000

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)
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)
Supplement Funding $280,000*

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3
University of North Carolina, Chapel Hill (DD16-001, 001205)
$1,050,000

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)
University of North Carolina, Chapel Hill (DD13-003, 001036)
$775,000

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders
Research Triangle Institute (DD14-001, 001116)
$449,608

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Duke University (DD14-002, 001082)
$66,718

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Duke University (DD14-002, 001087)
$20,483

** Zika funding*

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 thru State-based Public Health Programs
Ohio State University (DD16-1603, 000015)
$300,000

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Ohio Department of Health (DD16-1605, 000023)
Supplemental Funding $280,000*

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

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)
Supplemental Funding $108,262*

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)
$250,000 ---------- **Supplemental Funding $100,000**

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs
Oregon Health and Science University
(DD16-1603, 000014)
$400,000 ---------- **Supplemental Funding $25,000**

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Oregon Health and Science University
(DD14-002, 001071)
$67,099

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Oregon Health and Science University
(DD14-002, 001058)
$20,530

Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action
Oregon Health Authority (DD16-1601, 004951)
$175,000

Pennsylvania

Improving Fetal Alcohol Syndrome Disorder Prevention and Practice through National Partnerships
University of Pittsburgh
(DD14-1403, 001135)
$243,538

** Zika funding*

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)
Supplemental Funding $174,093

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, 000031)
Supplemental Funding $280,000*

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
University of Pittsburgh (DD14-002, 001078)
$66,985

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)
Philadelphia Department of Health
(DD17-1701, 000099)
$150,000

Rhode Island

Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action
Rhode Island Department of Health
(DD16-1601, 004943)
$160,000

Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)
Rhode Island Department of Health
(DD17-1701, 000073)
$150,000

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Rhode Island Department of Health
(DD16-1605, 000003)
Supplemental Funding $100,000*

South Carolina

Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)
South Carolina Department of Health and Environmental Control (DD17-1701, 000069)
$73,256

Coordinating Center for Research and Training to Promote the Health of People with Developmental and Other Disabilities
University of South Carolina, Columbia
(DD17-001, 001218)
$415,936

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs
University of South Carolina (DD16-1603, 000011)
$350,000 ---------- **Supplemental Funding $75,000**

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)
Supplemental Funding $200,000*

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorder
South Carolina Department of Health and Environmental Control (DD14-001, 001117)
$500,000

South 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)
South Dakota Department of Health (DD17-1701, 000097)
$148,459

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)
Supplemental Funding $200,000*

** Zika funding*

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Vanderbilt University Medical Center (DD14-002, 001073)
$67,188

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Vanderbilt University Medical Center (DD14-002, 001075)
$20,530

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)
$450,000 ---------- **Supplemental Funding $37,500**

Texas

Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action
Texas Department of State Health Services
(DD16-1601, 004942)
$200,000

Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers
Baylor College of Medicine (DD14-1402, 001131)
$342,960 ---------- **Supplemental Funding $145,826**

Improving Fetal Alcohol Syndrome Disorder Prevention and Practice through National Partnerships
University of Texas, Austin (DD14-1403, 001147)
$249,635

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)
Supplemental Funding $199,804*

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Texas Department of State Health Services
(DD16-1605, 000036)
Supplemental Funding $360,000*

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Baylor College of Medicine (DD14-002, 001072)
$66,776

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Baylor College of Medicine (DD14-002, 001070)
$20,530

Public Health Research on Modifiable Risk Factors for Spina Bifida
University of Texas Health Science Center, Houston
(DD15-001, 001179)
$240,000

Utah

Surveillance of Congenital Heart Defects Across the Lifespan
University of Utah (DD15-1506, 004934)
$450,000

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)
Utah Department of Health (DD17-1701, 000089)
$150,000

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Utah Department of Health
(DD16-1605, 000027)
Supplemental Funding $100,000*

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
IHC Health Services, Inc. (DD14-002, 001062)
$66,767

** Zika funding*

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
IHC Health Services, Inc. (DD14-002, 001060)
$20,530

Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorder
University of Utah (DD14-001, 001108)
$449,993

Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action
Utah Department of Health (DD16-1601, 004948)
$210,000

Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs
Utah Department of Health (DD16-1603, 000003)
$150,000

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 thru State-based Public Health Programs
Vermont Department of Health (DD16-1603, 000008)
$150,000

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Vermont Department of Health (DD16-1605, 000034)
No cost extension project end date 7/31/2018

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

Evaluation of Health Promotion & Prevention Program for Blood Disorders
National Blood Clot Alliance (DD14-1405, 001153)
$365,045

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)
No cost extension project end date 1/31/2019

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)
$66,429

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Seattle Children's Hospital (DD14-002, 001064)
$20,530

University of Washington Center for Mendelian Genomics
University of Washington (NIH Grant #2UM1HG006493)
$300,000

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)
Supplemental Funding $192,150*

Wisconsin

Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)
Wisconsin Department of Health and Family Services (DD17-1701, 00055)
$250,000

** Zika funding*

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Children's Hospital of Wisconsin
(DD14-002, 001063)
$67,060

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)
$550,000

Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers
Board of Regents of the University of Wisconsin System
(DD14-1402, 001133)
$273,739

Advanced Alcohol Screening & Brief Intervention (aSBI) & CHOICES in American Indian & Alaska Native Population thru Training & Technical Assistance
University of Wisconsin (DD13-1301, 001048)
Project ended 7/31/17

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)
Supplemental Funding $100,000*

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3
University of Wisconsin, Madison
(DD16-001, 001215)
$800,000

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

District of Columbia

National Centers on Health Promotion for People with Disabilities
Special Olympics (DD16-1602, 001156)
$4,500,000 ---------- Supplemental Funding $1,615,900

Improving Fetal Alcohol Syndrome Disorder Prevention and Practice through National Partnerships
American College of OB/GYN (DD14-1403, 001146)
$250,000

Improving Fetal Alcohol Syndrome Disorder Prevention and Practice through National Partnerships
National Organization on Fetal Alcohol Syndrome Prevention
(DD14-1403, 001148)
$300,000

OSTLTS Partnerships CBA of the Public Health System
American Public Health Association (APHA)
(OT13-1302, 000131)
$13,747

OSTLTS Partnerships CBA of the Public Health System
American Public Health Association (APHA)
(OT13-1302, 000203)
$300,000

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

CDC Collaboration with Academia to Strengthen Public Health Workforce Capacity
Association of Schools and Programs of Public Health
(OE12-1201, 0002)
University of Oklahoma
$204,996

CDC Collaboration with Academia to Strengthen Public Health Workforce Capacity
Association of American Medical Colleges
(OE12-1201, 00004)
Duke University
$205,000

** Zika funding*

CDC Collaboration with Academia to Strengthen Public Health Workforce Capacity
Association for Preventive Teaching and Research (OE12-1201, 0005)
$25,298

Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida
Spina Bifida Association (DD14-002, 001077)
$700,000

Expanding Efforts and Strategies to Protect and Improve Public Health Globally
Vysnova Partners, Inc. (GH15-1632)
$651,000

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)
Supplemental Funding $200,000*

Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)
Puerto Rico Department of Health (DD17-1701, 000088)
$143,373

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)
Supplemental Funding $199,885*

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

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Guam Department of Public Health and Social Services (DD16-1605, 000028)
Supplemental Funding $163,340*

American Samoa

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
American Samoa Department of Health (DD16-1605, 000039)
Supplemental Funding $200,000*

Commonwealth of the Northern Mariana Islands

Commonwealth of the Northern Mariana Islands Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)
Commonwealth Healthcare Corporation (DD17-1701, 00059)
$65,040

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus
Commonwealth Health Corporation (DD16-1605, 000017)
Supplemental Funding $200,000*

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)
$137,437*

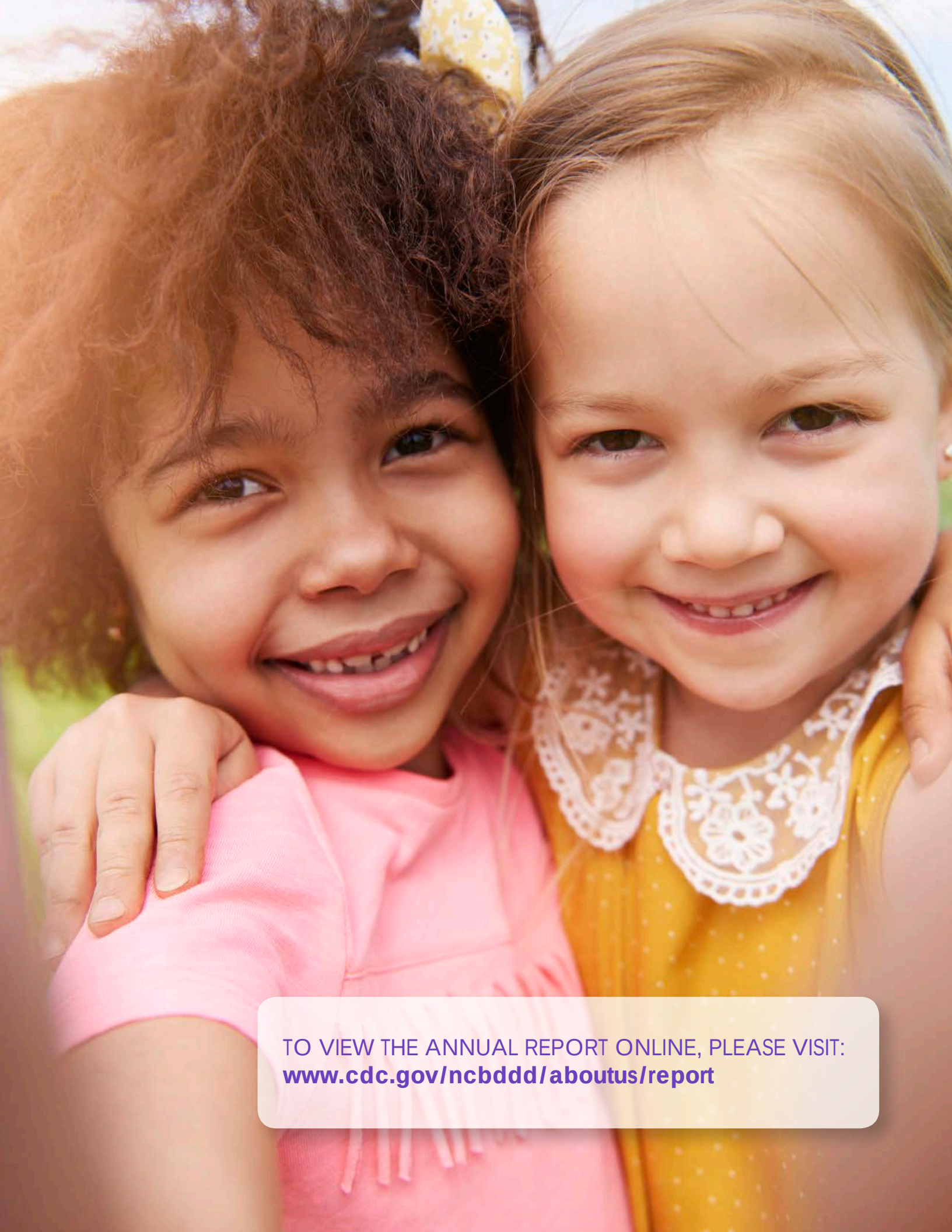
Marshall Islands

DD17-1702
$200,000

China

Conducting Public Research in China
Chinese Center for Disease Control and Prevention (GH12-005, 000636)
$50,000

** Zika funding*



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