

# NCBDDD

## Making a Difference Across the Lifespan



### From Saving Babies to Protecting People:

# 2018



National Center on Birth Defects  
and Developmental Disabilities





Coleen Boyle, PhD, MS (Hyg)  
Director

# MESSAGE FROM THE DIRECTOR

I am pleased to present the National Center on Birth Defects and Developmental Disabilities' (NCBDDD) Report for 2018: Making a Difference Across the Lifespan. As an organization, we strive to put our best foot forward

every day to serve the public in the most efficient and effective ways possible. In this year's Report, we are highlighting many, though certainly not all, of the Center's accomplishments and activities to advance our vision ensuring babies are born healthy, children reach their potential, and everyone thrives.

The past year, 2018, proved to be another eventful year for our Center. Most notably, Zika continued to dominate the headlines, with NCBDDD working extensively to respond to this emerging disease threat. We worked closely with our partners in Washington and members of Congress to support our first budget initiative in several years: Emerging Threats to Mothers and Babies. The Zika virus response brought stark attention to the threat public health emergencies pose to pregnant women and their infants, and this successfully funded budget initiative allows us to continue supporting state and local capacity to identify and track health outcomes due to the virus. Additionally, we have been working with jurisdictions most heavily impacted by the opioid epidemic to learn more about potential birth defects and other poor newborn outcomes linked to opioid use in pregnancy, as well as understand the long-term developmental outcomes that may be associated with this exposure. Building on our Zika surveillance program, we will support the foundation for a national system to rapidly identify potential threats to infant health, support care providers and families by improving our understanding of adverse outcomes, and tailor interventions that help children thrive.

This increase to our Center's budget would not have happened without the support of our partners across the public health community, and we will continue to work together to ensure this investment improves the lives of millions of babies and children. We remain committed to fighting on the frontlines protecting moms and babies from all emerging health threats.

I hope you enjoy reading this Report and that it gives you further insight into the work that we do and the progress we have made as an organization in partnership with others during 2018. Our staff are our greatest resource, and I'm proud to say we have a team committed to working together for the success of our Center. As we enter 2019, I would like to take a moment to thank retiring staff Julie Bolen, PhD, and J. Michael Soucie, PhD, for their incredible contributions to this Center and public health (rare disorders and bleeding disorders, respectively). I thank them for their service and tenacity and their dedication throughout the years. Lastly, I would like to thank all of our partners for their dedication and commitment to NCBDDD.

In 2020, we will be celebrating NCBDDD's 20<sup>th</sup> anniversary as a Center, focusing on all the incredible work we've done for the past 20 years. I invite our partners to join us in 2020 for this special celebration.

On behalf of NCBDDD,

A handwritten signature in black ink that reads "Coleen Boyle".

Coleen Boyle, PhD, MS (Hyg)  
Director

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# SAVING BABIES

Through Birth Defects Prevention and Research

*CDC's NCBDDD is working toward  
a day when all babies are born  
with the best health possible.*

Birth defects and infant disorders, such as fetal alcohol spectrum disorders, are common, costly, and critical. Our unique state-based birth defects tracking, public health research, and world-renowned expertise provide a wealth of information used to

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

Together with states, academic centers, healthcare providers, and other partners, we are working toward a day when all babies are born with the best health possible and every child thrives.

## Accomplishments

- **Contributed to what is known about Zika virus infection during pregnancy.** Information collected from the U.S. Zika Pregnancy and Infant Registry was used to advance public health action to protect mothers and babies from Zika virus infection. In addition, data from this innovative monitoring system led to

- Better understanding of the impact of Zika virus infection during pregnancy;
- Updated clinical care recommendations;
- Planning for medical and social services for families affected by Zika virus; and
- Improved prevention of Zika virus infection during pregnancy.

- **Advanced the efforts examining the effectiveness of mandated screening for critical congenital heart defects (CCHDs) and the long-term outcomes and healthcare needs for children born with heart defects.** Mandated CCHD screening nationwide was estimated to potentially save the lives of 120 babies each year. NCBDDD estimated that 1 in 77 U.S. children were living with heart conditions in 2016 and that these children were more likely to have special healthcare needs, such as medication needs or physical or speech therapy. This research quantifies the impact of mandated CCHD screening, identifies the needs of those living with heart defects, and helps inform resource planning for this growing population.



- **Expanded research and delivered reliable information about the use of certain medications, such as antibiotics and medications for attention-deficit/hyperactivity disorder, among pregnant women and women of reproductive age.** These results from studies by NCBDDD researchers, using data from the National Birth Defects Prevention Study, provide a basis for further studies on medications identified as having a potential risk for birth defects. NCBDDD also provided new information on medication use during pregnancy through the *Treating for Two* website.
- **Focused new fetal alcohol spectrum disorder (FASD) activities on**
  - Implementing alcohol screening and brief intervention in health systems that provide women's health services;
  - Expanding capacity of national professional organizations in the prevention, identification, and management of FASDs; and
  - Promoting resources for FASD awareness and prevention.
- **Collaborated across CDC to evaluate a possible link between neural tube defects among infants born to women living with human immunodeficiency virus (HIV) and the use of the medication, dolutegravir, in early pregnancy.** This comprehensive evaluation considered all risks and benefits to both mother and baby for the use of dolutegravir in early pregnancy.



### Looking to the Future

NCBDDD will continue its work to protect women and babies through 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 or infant disorder. NCBDDD's work on Zika virus is a reminder of the medical vulnerability of mothers and babies to emerging infections and other health threats, such as the opioid crisis and natural disasters. With new funding received for fiscal year 2019 for Surveillance of Emerging Threats to Mothers and Babies, NCBDDD will continue to leverage the innovative tracking and monitoring system developed to combat Zika virus, work to understand the full impact of Zika virus on infants and children, and pilot this system to capture data on other emerging threats that may affect mothers and babies. With new funding received for fiscal year 2019 for neonatal abstinence syndrome, NCBDDD will expand work with states and partners to build upon birth defects surveillance systems and explore more accurate ways of estimating the number of infants who have neonatal abstinence syndrome and the health needs for these children.

### Notable Scientific Publications

Abouk R, Grosse SD, Ailes EC, Oster ME. Association of US state implementation of newborn screening policies for critical congenital heart disease with early infant cardiac deaths. *JAMA*. 2017;318(21):2111-2118.

Anderson KN, Ailes EC, Danielson M, et al. Attention-deficit/hyperactivity disorder medication prescription claims among privately insured women aged 15–44 years — United States, 2003–2015. *MMWR Morb Mortal Wkly Rep*. 2018;67(2):66–70.

Anderson KN, Dutton AC, Broussard CS, et al. ADHD medication use during pregnancy and risk for selected birth defects: National Birth Defects Prevention Study, 1998-2011. *J Atten Disord*. 2018 Mar. [Epub ahead of print]

Chen M, Riehle-Colarusso T, Yeung LF, Smith C, Farr SL. Children with Heart Conditions and Their Special Health Care Needs — United States, 2016. *MMWR Morb Mortal Wkly Rep*. 2018;67:1045–1049.

Crider KS, Qi YP, Devine O, Tinker SC, Berry RJ. Modeling the impact of folic acid fortification and supplementation on red blood cell folate concentrations and predicted neural tube defect risk in the United States: have we reached optimal prevention? *Am J Clin Nutr*. 2018;107(6):1027-1034.

Delaney A, Mai C, Smoots A, et al. Population-Based Surveillance of Birth Defects Potentially Related to Zika Virus Infection — 15 States and U.S. Territories, 2016. *MMWR Morb Mortal Wkly Rep*. 2018;67(3):91-96.

McClung N, Glidewell J, Farr SL. Financial burdens and mental health needs in families of children with congenital heart disease. *Congenit Heart Dis*. 2018;13(4):554-562.

Polen KD, Gilboa SM, Hills S, et al. Update: Interim guidance for preconception counseling and prevention of sexual transmission of Zika virus for men with possible Zika virus exposure — United States, August 2018. *MMWR Morb Mortal Wkly Rep*. 2018;67(31):868-871.

Raut JR, Simeone RM, Tinker SC, et al. Proportion of orofacial clefts attributable to recognized risk factors. *Cleft Palate Craniofac J*. 2018 Jan. [Epub ahead of print]

Rice ME, Galang RR, Roth NM, et al. Vital Signs: Zika-associated birth defects and neurodevelopmental abnormalities possibly associated with congenital Zika virus infection — U.S. territories and freely associated states, 2018. *MMWR Morb Mortal Wkly Rep*. 2018;67(31):858-867.

# SPOTLIGHT ON:

## American Academy of Pediatrics

### *Zika Response*

Since 2016, the American Academy of Pediatrics (AAP) has worked hand-in-hand with the Centers for Disease Control and Prevention (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD) to ensure that infants impacted by Zika virus were identified, reported, and provided immediate and long-term treatment and care. This included input on updated clinical guidance, articles, and resources for clinicians, such as psychosocial support materials and an AAP Periodic Survey of Fellows to learn about pediatricians' experiences with, and attitudes toward, infectious disease and disaster preparedness, with a focus on Zika virus. The AAP also partnered with the American College of Obstetricians and Gynecologists (ACOG) to conduct a national survey of its membership and focus groups, and evaluation of AAP/ACOG support to Zika contractual field assignees within local health departments. The AAP continues to express that

- Clinicians remain vigilant in preventing Zika during pregnancy;
- Healthcare providers provide consistent and clear presentation of information from provider-to-provider and from provider-to-patient; and
- Developing babies with suspected or possible congenital Zika virus infection need continued monitoring within a medical home.

The AAP believes this work and these collaborations are important to ensure the optimal health and development of infants with congenital Zika virus exposure.

### *Fetal Alcohol Spectrum Disorders*

Prenatal exposure to alcohol is the leading preventable cause of birth defects, intellectual disabilities, and neurodevelopmental disorders. The non diagnostic umbrella term fetal alcohol spectrum disorders (FASDs) is used to characterize the full range of diagnoses resulting from prenatal alcohol exposure. Research and other published data continue to document missed and underdiagnosed FASDs. Early identification of a child at risk for an FASD is facilitated by screening for prenatal alcohol exposure. Information to support pediatricians is available at [www.aap.org/pae](http://www.aap.org/pae).

Through grant funding from NCBDDD, AAP has worked with the National Organization on Fetal Alcohol Syndrome and two university-based Practice and Implementation Centers at the University of California-San Diego and the University of Wisconsin-Madison. Through these partnerships, the centers developed multiple educational resources to ensure pediatric clinicians have the capacity to identify and manage the care for children with FASDs. These are available at [www.aap.org/fasd](http://www.aap.org/fasd).

## NCBDDD's Birth Defects Topics

- Alcohol Use in Pregnancy
- Before Pregnancy
- Birth Defects
- Congenital Heart Defects
- Diabetes and Pregnancy
- Folic Acid
- Folic Acid: Birth Defects COUNT

Visit [www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd) to learn more.



# HELPING CHILDREN

Live to the Fullest by Understanding  
Developmental Disabilities

*CDC's NCBDDD is committed to helping children with developmental disabilities and their families get the support they need to thrive.*

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

- Monitoring common developmental disabilities,
- Identifying factors that can put children at risk for disabling conditions,
- Exploring possible causes of developmental disabilities, and
- Improving identification of developmental delays.

## Accomplishments

- **Published updated ASD characteristics and prevalence among 8-year-old children in 11 communities in the United States from data collected by the Autism and Developmental Disabilities Monitoring Network.** This study identified about 1 in 59 children with ASD in 2014 compared to about 1 in 69 children in 2012. These data have been used to
  - Promote early identification of children with ASD;

- Plan for service needs of children with ASD and their families; and
- Guide research and inform policy.
- **Supported deaf/hard-of-hearing children to have a healthy launch into school.** Ensuring that children have received hearing screening, diagnosis, and intervention services early is critically important for their learning and development. CDC's Early Hearing Detection and Intervention (EHDI) Program tracks the 1-3-6 milestones (on page 9) to confirm timely receipt of these critical services. However, some children are lost to the system. CDC partnered with the EHDI Program in Texas to understand how to prevent loss-to-follow-up and loss-to-documentation of receiving services among infants who do not pass a newborn hearing screening. The team identified
  - Potential reasons children do not receive services;
  - Barriers to documenting the diagnosis and intervention status of infants who did not pass their hearing screening; and
  - Recommendations to reduce these challenges.Findings will help states increase the number of deaf/hard of hearing children who receive the appropriate hearing services at the appropriate time so they are ready to learn in school.



- **Published more than 10 peer-reviewed articles using data from the Study to Explore Early Development (SEED)**, the largest study in the United States that focuses on identifying factors that may put children at risk for ASD and examining common characteristics among children with ASD. SEED researchers found
  - A possible link between shorter and longer time periods between births and having a child with ASD;
  - Self-injurious behaviors were more common among children with ASD than in children with developmental disabilities *without* ASD symptoms; and
  - A link between immune conditions in mothers and ASD and other developmental disabilities in their children.

CDC also began enrolling participants in SEED Teen, a follow-up study to help broaden our understanding of the health and development of individuals with ASD as they reach adolescence and adulthood.

- **Conducted the Zika Outcomes and Development in Infants and Children (ZODIAC) investigation** through CDC's partnership with Brazil's Ministry of Health, via support from the U.S. Agency

for International Development. This follow-up assessment of children aged 12-24 months who were conceived during the 2015-2016 Zika virus outbreak in Brazil provided a first-ever description of the longer-term health and developmental effects of congenital Zika virus infection in children with microcephaly. ZODIAC findings are being used to

- Understand the full range of potential healthcare problems;
  - Educate parents and healthcare providers;
  - Prepare communities for long-term medical and social service needs; and
  - Assist children in developing to their full potential.
- **Launched the *Learn the Signs. Act Early.* Milestone Tracker App in Spanish and English** to help parents monitor their child's development and get tips for taking action when there is a concern. Since its launch, the Milestone Tracker App was downloaded more than 140,000 times in 2018. Additionally, to promote developmental monitoring and screening for young children, CDC increased the number of state and territorial Act Early Ambassadors (55 total), who help identify and connect young children with developmental delays with the appropriate services and support as early as possible.



## HELPING CHILDREN

### Looking to the Future

Children with developmental disabilities and their families often face personal, social, and financial challenges. CDC and its partners work across systems to improve identification of developmental delays, increase the connection of these children and their families to medical, developmental, and behavioral intervention services, and provide tools and resources to help families facing these challenges. NCBDDD's mission extends to understanding optimal development at each stage of life, from promoting school readiness to the health of teens with ASD, as well as helping families and children get the support they need.

#### CDC's Early Hearing Detection and Intervention (EHDI) Program

- 1** Before one month of age: **Hearing Screening**
- 3** Before three months of age: **Hearing Evaluation**
- 6** Before six months of age: **Early Intervention**

### Notable Scientific Publications

Baio J, Wiggins L, Christensen DL, et al. Prevalence of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014. *MMWR Surveill Summ*. 2018;67(6):1-23.

Bitsko RH, Holbrook JR, Ghandour RM, et al. Epidemiology and impact of health care provider-diagnosed anxiety and depression among US children. *J Dev Behav Pediatr*. 2018;39(5):395-403.

Croen LA, Qian Y, Ashwood P, et al. Family history of immune conditions and autism spectrum and developmental disorders: Findings from the Study to Explore Early Development. *Autism Res*. 2018 Aug 10. [Epub ahead of print]

Danielson ML, Bitsko RH, Ghandour RM, Holbrook JR, Kogan MD, Blumberg SJ. Prevalence of parent-reported ADHD diagnosis and associated treatment among U.S. children and adolescents, 2016. *J Clin Child Adolesc Psychol*. 2018;47(2):199-212.

Deng X, Finitzo T, Aryal S. Measuring early hearing detection and intervention (EHDI) quality across the continuum of care. *EGEMS (Wash DC)*. 2018;6(1):18.

Kruger J, Brener N, Leeb R, Wolkin A, Avchen RN, Dziuban E. School district crisis preparedness, response, and recovery plans — United States, 2006, 2012, and 2016. *MMWR Morb Mortal Wkly Rep*. 2018;67:809-814.

Rubenstein E, Young JC, Croen LA, et al. Brief report: Maternal opioid prescription from preconception through pregnancy and the odds of autism spectrum disorder and autism features in children. *J Autism Dev Disord*. 2018 Sept 20. [Epub ahead of print]

Satterfield-Nash A, Kotzy K, Allen J, et al. Health and development at age 19–24 months of 19 children who were born with microcephaly and laboratory evidence of congenital Zika virus infection during the 2015 Zika virus outbreak — Brazil, 2017. *MMWR Morb Mortal Wkly Rep*. 2017;66:1347–1351.

Schieve LA, Tian LH, Drews-Botsch C, et al. Autism spectrum disorder and birth spacing: Findings from the Study to Explore Early Development (SEED). *Autism Res*. 2018;11(1):81-94.

Soke GN, Rosenberg SA, Rosenberg CR, Vasa RA, Lee LC, DiGuseppi C. Brief report: Self-injurious behaviors in preschool children with autism spectrum disorder compared to other developmental delays and disorders. *J Autism Dev Disord*. 2018;48(7):2558-2566.

# SPOTLIGHT ON:

## Association of Maternal and Child Health Programs

The Association of Maternal & Child Health Programs (AMCHP) is a national resource, partner, and advocate for state public health leaders and others working to improve the health of women, children, and families, including children and youth with special healthcare needs (CYSHCN). Recognizing the value of building high-quality systems of care for CYSHCN, AMCHP partnered with CDC, the Health Resources and Services Administration, and the Association of University Centers on Disabilities to support the *Learn the Signs. Act Early* (LTSAE) State Systems project and implement the State Public Health Autism Resource Center (SPHARC).

### *Helping State Grantees Improve Early Identification*

AMCHP supports state and jurisdiction LTSAE grantees to strengthen systems for the early identification and improved coordination of services for children at risk for autism spectrum disorder and other developmental disabilities (ASD/DD). With AMCHP grants and technical assistance, state teams promote the use of CDC's materials to help increase parental engagement of developmental monitoring. Successes include the production of culturally relevant cable access TV shows promoting LTSAE and the development and implementation of LTSAE trainings and materials for physicians, public libraries, hospitals, parents, and early childhood care providers (WIC, Head Start, etc.). To learn more, visit the LTSAE State Systems Grantees web page.

### *Peer-to-Peer Exchange (P2P) to Improve Systems of Care*

AMCHP's SPHARC convenes an annual P2P Exchange, which enables cross-state learning and capacity building for state programs implementing systems of care for children and youth with ASD/DD. The 2018 Exchange highlighted the importance of parents- and self-advocates, and featured the sharing of best practices and resources. The newsletter article relays the impactful stories told by a parent and self-advocate. Additionally, SPHARC released an interactive story wall featuring family navigators' stories on their experiences supporting families as they access comprehensive systems of care for CYSHCN. To learn more, visit the SPHARC web page.

## NCBDDD's Developmental Disabilities and 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
- Hearing Loss
- Intellectual Disability
- *Learn the Signs. Act Early.* Program
- Tourette Syndrome

Visit [www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd) to learn more.



# PROTECTING PEOPLE

and Preventing Complications of Blood Disorders

***CDC's NCBDDD is dedicated to reducing the public health burden resulting from blood disorders by contributing to a better understanding of blood disorders and their complications.***

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

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

## Accomplishments

- **Released new resources and potentially lifesaving information, through the CDC-funded *Stop the Clot, Spread the Word*<sup>™</sup> campaign** on the risks, signs, and symptoms of blood clots among women who are pregnant or recently gave birth.

These educational resources empower women to talk with their healthcare providers about the factors that increase their risk for blood clots as well as determine if they might benefit from a plan to prevent blood clots. The previous components of the campaign, which provide general information about blood clots and their risks related to hospitalization, have already achieved more than 300 million media impressions.

- **Published key articles and reports** using Community Counts data:
  - Community Counts: *Evolution of a National Surveillance System for Bleeding Disorders*, an article that describes the project's organization and components and provides a summary of patients enrolled through the end of September 2017.
  - *The 2014 Community Counts Registry Report*, a report that describes the project background, methods, and select baseline data collected during the project's first year.
  - Community Counts: *The HTC Population Profile Data through March 2018*, a report that contains a set of 12 data items collected on patients with



bleeding disorders or venous thromboembolism (blood clots) who receive care at U.S. hemophilia treatment centers.

- **Conducted a CNE/CME-accredited webinar titled “Improving Outcomes for Females with Bleeding Disorders in Non-Hematology Healthcare Settings.”** This webinar, funded through a cooperative agreement between the National Hemophilia Foundation and the Division of Blood Disorders, is intended to

- Help raise awareness among healthcare providers who are not blood disorders specialists about bleeding disorders in women and how best to care for these women;
- Encourage provider collaboration with hemophilia treatment centers;
- Influence clinical practice;
- Reduce reproductive system-related diseases in women; and
- Improve health outcomes.

- **Worked with partners to produce or collaborate on numerous education and outreach materials** through the Sickle Cell Data Collection (SCDC) program including:

- *The Bloodline*: the SCDC Program quarterly newsletter;
- SCDC Program Report: *Data to Action*;
- California SCDC webinars; and
- Videos for individuals with sickle cell disease who are transitioning from pediatric to adult care.
- **Developed educational materials, published research articles, and captured personal stories** about therapeutic blood transfusions for hemoglobinopathies (thalassemia and sickle cell disease), including:
  - An animated graphic about blood donations among racial/ethnic minorities;
  - An article describing a novel intervention in the primary care setting to improve management of transfusion-related iron overload; and
  - A personal story about Maria Hadjidemetriou’s journey living with thalassemia, which includes her advice for others living with inherited blood disorders.



### Looking to the Future

NCBDDD's important work will continue to include activities that increase understanding of blood disorders, advance medical care and treatments, and improve outcomes for all people with blood disorders by promoting health education, early detection, and medical referrals for this population. For thalassemia and sickle cell disease, NCBDDD invests in determining the number, health needs, and healthcare use of people living with these types of blood disorders. NCBDDD also works to understand more fully the complications resulting from blood transfusions. For those living with hemophilia, NCBDDD is researching how well treatment strategies are preventing disease-related complications, as well as learning the factors that place people with hemophilia at risk for inhibitors and other complications and studying and promoting the use of periodic inhibitor testing. NCBDDD also monitors complications arising from the use of blood products and new and existing treatment products; seeks to prevent blood clots; and works to improve laboratory techniques used to identify those at risk for clots.

### Notable Scientific Publications

Anderst JD, Carpenter SL, Presley R, et al. Relevance of abusive head trauma to intracranial hemorrhages and bleeding disorders. *Pediatrics*. 2018;141(5):e20173485.

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

Boylan B, Miller CH. Effects of pre-analytical heat treatment in factor VIII (FVIII) inhibitor assays on FVIII antibody levels. *Haemophilia*. 2018;24(3):487-491.

Hulihan M, Hassell KL, Raphael JL, Smith-Whitley K, Thorpe P. CDC Grand Rounds: Improving the lives of persons with sickle cell disease. *MMWR Morb Mortal Wkly Rep*. 2017;66(46):1269-1271.

Kempton CL, Payne AB. HLA-DRB1-factor VIII binding is a risk factor for inhibitor development in nonsevere hemophilia: A case-control study. *Blood Adv*. 2018;2(14):1750-1755.

Manco-Johnson MJ, Byams VR, Recht M, et al. Community counts: Evolution of a national surveillance system for bleeding disorders. *Am J Hematol*. 2018;93(6):E137-E140.

Miller CH, Boylan B, Shapiro AD, Lentz SR, Wicklund BM, Hemophilia Inhibitor Research Study Investigators. 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):1971-1976.

Rampersad AG, Boylan B, Miller CH, Shapiro A. Distinguishing lupus anticoagulants from factor VIII inhibitors in haemophilic and non-haemophilic patients. *Haemophilia*. 2018;24(5):807-814.

Soucie JM, Monahan PE, Kulkarni R, Konkole BA, Mazepa MA, U.S. Hemophilia Treatment Center Network. The frequency of joint hemorrhages and procedures in nonsevere hemophilia A vs. B. *Blood Adv*. 2018;2(16):2136-2144.

Ullman M, Zhang QC, Grosse SD, Recht M, Soucie JM, Hemophilia Treatment Center Network Investigators. Prophylaxis use among males with haemophilia B in the United States. *Haemophilia*. 2017;23(6):910-917.

# SPOTLIGHT ON:

## National Hemophilia Foundation

The National Hemophilia Foundation (NHF) is committed to preventing the complications associated with hemophilia and other bleeding disorders. As part of NHF's cooperative agreement with CDC, NHF has focused on preventing joint damage for those living with a bleeding disorder. In 2017, NHF launched educational activities to encourage the community to "*Make Your Move*" through increased safe physical activity. In addition, NHF has

- Updated and revised its *Playing It Safe* guide (available in English and Spanish);
- Updated and revised its ratings on safe physical activities;
- Launched multiple *Make Your Move* webinars led by physical therapists promoting safe increased activity; and
- Continued educating the community through in-person workshops that bleeding disorders chapters around the country can bring to their local education events.

Through these efforts (distributed print materials, webinar views, workshop attendees, and website page views), NHF has garnered more than 17,000 touchpoints. To ensure better outreach to Spanish-speaking communities, NHF launched its *Guías Culturales* program, which trained nine Spanish-speaking community members in the TIPs to Improve Communication with Healthcare Providers workshop to facilitate local bleeding disorders events in Spanish and help address some of the cultural barriers faced when trying to get care for a bleeding disorder and prevent its complications.

## NCBDDD's Blood Disorders Topics

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

Visit [www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd) to learn more.



# IMPROVING HEALTH

of People with Disabilities

*CDC's NCBDDD works to ensure that people with disabilities have the same opportunities for good health as people without disabilities.*

Disabilities may include difficulty with movement, hearing, seeing, concentrating, remembering, or making decisions. Many people will experience a disability during their lifetimes, but having a disability does not mean that a person is not healthy or cannot be healthy. People with disabilities need healthcare services and health promotion programs for the same reasons everyone else does—to stay well, active, and part of the community. CDC works to make sure that people of all abilities are able to live their lives to the fullest.



## Accomplishments

- **Updated the clinical care considerations for individuals with Duchenne muscular dystrophy to improve their care and quality of life.** This set of three articles, funded by NCBDDD and published in *Lancet Neurology*, offers an update of the original articles from 2010, and outlines the latest clinical considerations. These consensus-based care considerations are intended to raise the standards

of care and provide physicians, families, and caregivers with information to provide and manage the best possible care for people with Duchenne. They cover 11 medical subspecialties, including three new topic areas:

- Endocrinology/bone health;
- Primary care and emergency care; and
- Healthcare transition from pediatric to adult care.

- **Helped advance better public health programs for people with disabilities by providing interactive, customizable access to state-level disability data via CDC's [Disability and Health Data System \(DHDS\)](#).** CDC updated DHDS to include the latest 2016 Behavioral Risk Factor Surveillance System (BRFSS) data on U.S. adults with disabilities, including cognitive (serious difficulty concentrating, remembering, or making decisions); mobility (serious difficulty walking or climbing stairs), vision, self-care, independent living; and—for the first time—deafness or serious difficulty hearing. DHDS provides state-level disability data on approximately 30 health indicators, such as smoking, heart disease, and receiving the flu vaccine. To promote the use of DHDS and show how the data can be used to plan for disability inclusive programs and services, NCBDDD developed, in collaboration with the National Association of Chronic Disease



Directors (NACDD), two webinars (“DHDS: Beginner’s Guide” and “DHDS: Beyond the Basics”) as well as one NACDD-sponsored podcast (Health Yeah!).

- **Disseminated the newest prevalence data on U.S. adults with disabilities** by disability type and healthcare access. Using 2016 BRFSS data, researchers found that 1 in 4 U.S. adults – 61 million Americans – have a disability, with mobility disability being the most common, followed by cognitive disability. Disability-specific differences in healthcare access are common, particularly among young and middle-aged adults. See the graphic on page 17 for more findings. This information enables healthcare professionals to address barriers to healthcare access, ensure inclusivity in public health programs, and improve the health of people with disabilities. These data were published in CDC’s *Morbidity and Mortality Weekly Report*.
- **Targeted various opportunities for improving the health of people with intellectual and developmental disabilities (IDD)** by funding, 10 State Disability and Health Programs to analyze Medicaid data and identify patterns of health and healthcare utilization among people with IDD.

Working with NCBDDD, awardees reviewed data showing the most common health conditions for outpatient care and emergency department visits. They have also begun to produce informational videos focused on diabetes self-management education and support for people with IDD, their caregivers, and healthcare providers.

- **Initiated efforts to help individuals with disabilities and/or potentially disabling long-standing conditions transition from pediatric to adult care.** CDC convened a coalition of 33 partners to develop actionable steps they could take to ensure that short-and long-term changes occur to achieve smooth transition for individuals with disabilities and/or with disabling, long-standing conditions. To further address this common goal of smoother healthcare transitions, the coalition will continue to meet to discuss
  - Clinical practice and coordination issues;
  - Access to care; and
  - Family and self-readiness for transition.



## IMPROVING HEALTH

### Looking to the Future

CDC is dedicated to promoting inclusive communities, programs, and policies that provide opportunities for people with disabilities to live full, healthy lives. CDC will continue to educate families and stakeholders about the need for public health programs that are fully accessible to all. By providing effective tools and resources to increase access to healthcare services and by promoting the healthy development of people with disabilities across the lifespan, CDC hopes to narrow health differences between people with and without disabilities.

## Disability and COMMUNITIES



Disability is especially common in these groups:

**2 in 5**

adults age 65 years and older have a disability



**1 in 4**

women have a disability



**2 in 5**

Non-Hispanic American Indians/ Alaska Natives have a disability



### Notable Scientific Publications

Alabi NB, Thibadeau J, Wiener JS, et al. Surgeries and health outcomes among patients with spina bifida. *Pediatrics*. 2018;142(3):e20173730.

Birnkrant D, Bushby K, Bann CM, et al. Diagnosis and management of Duchenne muscular dystrophy, part 1: Diagnosis, and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management. *Lancet Neurol*. 2018;17(3):251-267.

Birnkrant D, Bushby K, Bann CM, et al. Diagnosis and management of Duchenne muscular dystrophy, part 2: Respiratory, cardiac, bone health, and orthopaedic management. *Lancet Neurol*. 2018;17(4):347-361.

Birnkrant D, Bushby K, Bann CM, et al. Diagnosis and management of Duchenne muscular dystrophy, part 3: Primary care, emergency management, psychosocial care, and transitions of care across the lifespan. *Lancet Neurol*. 2018;17(5):445-455.

Courtney-Long EA, Stevens AC, Carroll DD, Griffin-Blake S, Omura JD, Carlson SA. Primary care providers' level of preparedness for recommending physical activity to adults with disabilities. *Prev Chronic Dis*. 2017;14:E114.

Glidewell J, Book W, Raskind-Hood C, et al. Population-based surveillance of congenital heart defects among adolescents and adults: surveillance methodology. *Birth Defects Res*. 2018;1-9.

Hinton CF, Kraus LE, Richards TA, Fox MH, Campbell VA. The guide to community preventive services and disability inclusion. *Am J Prev Med*. 2017;53(6):898-903.

Kruger J, Hinton CF, Sinclair LB, Silverman B. Enhancing individual and community disaster preparedness: Individuals with disabilities and others with access and functional needs. *Disabil Health J*. 2018;11(2):170-173.

McDermott S, Royer J, Cope T, et al. Using Medicaid data to characterize persons with intellectual and developmental disabilities in five U.S. states. *Am J Intellect Dev Disabil*. 2018;123(4):371-381.

Okoro C, Hollis ND, Cyrus AC, Griffin-Blake S. Prevalence of disabilities and health care access by disability status and type among adults – United States, 2016. *MMWR Morb Mortal Wkly Rep*. 2018;67:882-887.

# SPOTLIGHT ON:

## Special Olympics

Special Olympics and NCBDDD have been working together for 16 years to prevent injury, illness, and premature death for people with intellectual disabilities by improving equitable access to quality health care, education, and services. This partnership for health is particularly powerful. In the United States, there are more than 675,000 athletes who compete in Special Olympics that are being reached through programming, education, prevention activities, and healthcare partnerships. Further, with more than 135,000 coaches and 686,500 volunteers, there are many community members influencing the health of the athletes.

Jackie Kennedy, an athlete with Special Olympics Connecticut, attended the 2017 Summer Games to compete in track and field. What she got was so much more than a medal. Jackie was one of 643 athletes who visited Special Olympics Healthy Athletes – a program that provides free health screenings in a fun, welcoming environment. During the dental screening, Jackie learned she had an abscessed tooth that needed immediate care. Through partnerships with the University of Connecticut School of Dental Medicine and the Department of Developmental Services, Special Olympics was able to refer Jackie for immediate follow-up treatment at a place where providers were trained to work with people with intellectual disabilities.

These providers worked to ensure it was a positive experience, helping Jackie become more trusting of doctors and dentists, ensuring her much-needed urgent care was of the highest quality. “I don’t get to go to the dentist and doctor as often as I need to. I look forward to Healthy Athletes screenings every year,” explained Jackie. “It’s the best thing that Special Olympics offers.”

Special Olympics Health is working to ensure Special Olympics athletes can perform at their best, on and off the field, and have equal access to quality health care, health education, and resources. Our impact on the health and well-being of Special Olympics athletes in the United States is substantial, in some cases saving lives by discovering unknown health issues or providing partnerships to health care that otherwise would not be available. We not only serve these athletes but also train healthcare professionals, who then return to their practices with increased knowledge of, and compassion for, people with intellectual disabilities.

## NCBDDD’s Disability Topics

- Congenital Heart Defects
- Disability and Health
- Fragile X Syndrome
- Muscular Dystrophy
- Living with Spina Bifida

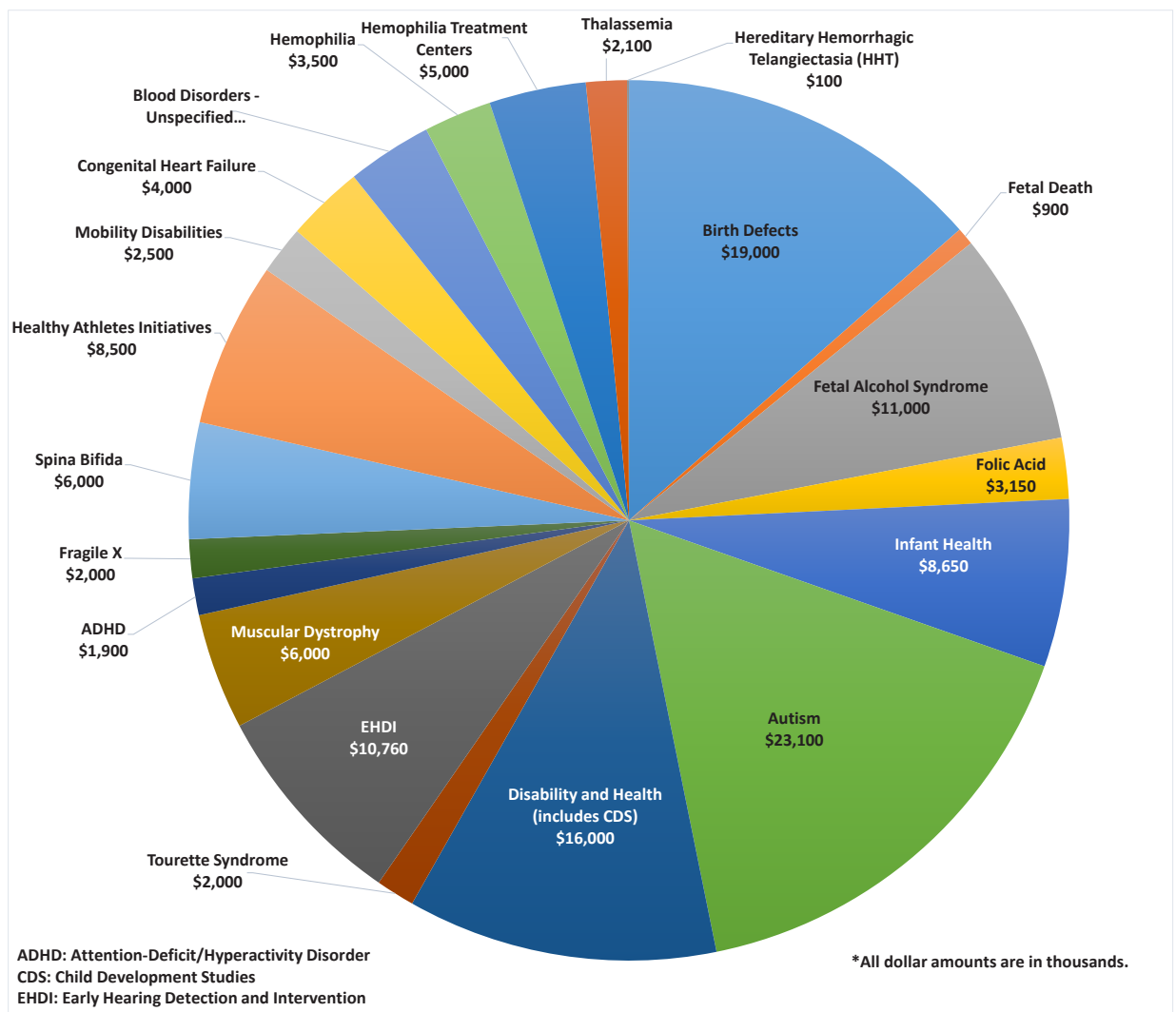
Visit [www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd) to learn more.



# FISCAL YEAR 2018 BUDGET

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) fiscal year (FY) 2018 appropriation includes **\$140,560 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 2018 Appropriations (in thousands)

<b>Child Health and Development</b>	<b>\$65,800</b>
Birth Defects	\$19,000
Fetal Death	\$900
Fetal Alcohol Syndrome	\$11,000
Folic Acid	\$3,150
Infant Health	\$8,650
Autism	\$23,100
<b>Health and Development w/ Disabilities</b>	<b>\$59,660</b>
Disability and Health (includes CDS)	\$16,000
Tourette Syndrome	\$2,000
EHDI	\$10,760
Muscular Dystrophy	\$6,000
ADHD	\$1,900
Fragile X	\$2,000
Spina Bifida	\$6,000
Healthy Athletes Initiative	\$8,500
Mobility Disabilities	\$2,500
Congenital Heart Failure	\$4,000
<b>Public Health Approach to Blood Disorders</b>	<b>\$15,100</b>
Blood Disorders – Unspecified	\$4,400
Hemophilia	\$3,500
Hemophilia Treatment Centers	\$5,000
Thalassemia	\$2,100
Hereditary Hemorrhagic Telangiectasia (HHT)	\$100
<b>NCBDDD Total</b>	<b>\$140,560</b>



# 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 through State-based Public Health Programs*

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

**\$300,000**

*National Centers on Health Promotion for People with Disabilities*

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

**\$1,500,000**

**Supplemental Funding \$912,500**

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

University of Alabama, Birmingham (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**

*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)

**Project ends 7/31/19**

## Alaska

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

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

**\$400,000**

*Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)*  
Alaska Department of Health and Social Services  
(DD17-1701, 000060)  
**\$150,000**

*Fetal Alcohol Spectrum Disorders (FASO) Practice and Implementation Centers*  
University of Alaska, Anchorage (DD14-1402, 001143)  
**Project ended 9/29/18**

*Reaching Healthcare Professionals in the Prevention of Fetal Alcohol Spectrum Disorders through National Professional Organizations*  
University of Alaska, Anchorage (DD18-1803, 000006)  
**\$250,000**

## Arkansas

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

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

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs*  
University of Arkansas (DD16-1603, 000016)  
**\$439,943**

*Enhancing Public Health Surveillance of Autism Spectrum Disorder and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
University of Arkansas (DD15-1501, 001163)  
**\$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 (000050)  
**Project ends 1/31/2019**

*Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) II*  
Arkansas Children's Research Institute  
(DD18-001, 001229)  
**\$995,000**

## Arizona

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*  
Arizona Department of Health Services  
(DD16-1601, 004950)  
**\$200,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorder and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
University of Arizona (DD15-1501, 001162)  
**\$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)*  
Arizona Department of Health Services  
(DD17-1701, 000076)  
**\$150,000**

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



## SELECT STATE-BASED ACTIVITIES AND FUNDING

### California

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

Stanford University (DD13-003, 001033)

**Project ends 8/31/19**

*Characterizing the Complications Associated with Therapeutic Blood Transfusions for Hemoglobinopathies*

Children's Hospital and Research Center at Oakland (DD14-1406, 006093)

**\$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**

*Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers*

University of California (DD14-1402, 001144)

**Project ended 9/29/18**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus-High Risk Local Areas*

Los Angeles County Department of Public Health (DD16-1606, 000142)

**Project ended 6/30/2018**

*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)

**Project ended 4/2/18**

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

Stanford University (DD18-001, 001226)

**\$770,000**

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

Changelab Solutions (OT18-1802)

**\$200,000**

### 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 Disorder and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*

Colorado Department of Public Health and Environment

(DD15-1501, 001161)

**\$550,000**

*Surveillance of Congenital Heart Defects Across the Lifespan*

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

**\$450,000**

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

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

**\$770,377**

*Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders*

Colorado State Department of Public Health and

Environment (DD14-001, 001126)

**\$499,999**

*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)

**\$99,981**

## Connecticut

*Implementing Alcohol Screening and Brief Intervention in Healthcare Systems Providing Women's Health Services*  
University of Connecticut Health Center  
(DD18-1802, 000004)  
**\$399,954**

*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)  
**Project ended 12/29/17**

## Delaware

*Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*  
Delaware Health & 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 through State-based Public Health Programs*  
Florida Department of Health (DD16-1603, 000012)  
**\$300,000**

*Characterizing the Complications Associated with Therapeutic Blood Transfusions for Hemoglobinopathies*  
University of Florida (DD14-1406, 006094)  
**\$99,993**

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

## Georgia

*Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*  
Georgia Department of Public Health  
(DD17-1701, 000090)  
**\$200,000**

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

*Surveillance of Congenital Heart Defects Across the Lifespan*  
Emory University (DD15-1506, 004932)  
**\$475,000**

*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)  
**Project ended 11/30/2018**

*Strengthening Public Health Systems and Services Through National Partnerships to Improve and Protect the Nation's Health*  
Association of State and Territorial Public Health Nutrition Directors (OT18-1802)  
**\$250,000**

*Strengthening Public Health Systems and Services Through National Partnerships to Improve and Protect the Nation's Health*  
National Association of Chronic Disease Directors (OT18-1802)  
**\$277,200**



## SELECT STATE-BASED ACTIVITIES AND FUNDING

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

Task Force for Global Health (OT18-1802)

**\$757,881**

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

National Foundation for CDC (OT18-1802)

**\$150,000**

*Behavior Risk Factor Surveillance System (BRFSS) Georgia*  
Department of Public Health

(DP15-1513, 006036)

**\$30,000**

### 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 Systems – bona fide agent for American Samoa (DD17-1701, 000071)

**\$141,925**

*Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*

University of Hawaii Systems – Bona fide agent for Marshall Islands (DD17-1701, 000072)

**\$124,584**

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

State of Hawaii Department of Health

(DD16-1605, 000015)

**Project ends 7/31/19**

### Idaho

*Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*

Idaho Department of Health and Welfare

(DD17-1701, 000079)

**\$150,000**

### Illinois

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

Illinois Department of Public Health

(DD16-1601, 004947)

**\$210,000**

*Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*

Illinois Department of Public Health

(DD17-1701, 000053)

**\$150,000**

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

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)

**\$99,947**

*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**

*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)

**Project ended 8/31/2018**

*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)

**Project ended 2/28/18**

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

American Academy of Pediatrics (OT18-1802)

**\$1,042,595**

## 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)

**\$149,242**

*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**

*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)

**Project ended 7/31/2018**

## Iowa

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

University of Iowa (DD13-003, 001035)

**Project ends 8/31/19**

*Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*

Iowa Department of Public Health

(DD17-1701, 000061)

**\$150,000**

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

Iowa Department of Public Health

(DD16-1603, 000019)

**\$390,000**

*Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders*

University of Iowa (DD14-001, 001119)

**\$449,751**

*Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders*

University of Iowa (DD14-001, 001120)

**\$250,000**

*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)

**Project ended 9/30/2018**

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

University of Iowa (DD18-001, 001223)

**\$770,000**

## Kansas

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

University of Kansas Center for Research, Inc.

(DD16-1603, 000006)

**\$389,995**

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

Kansas Department of Health and Environment (DD16-1605,000029)

**Project ends 7/31/2019**

*Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*

Kansas Department of Health and Environment

(DD17-1701, 000075)

**\$150,000**

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

American Academy of Family Physicians

(DD18-1803, 000010)

**\$248,593**



## SELECT STATE-BASED ACTIVITIES AND FUNDING

### *Behavioral Risk Factor Surveillance System*

Kansas Department of Health and Environment (DP15-1513,006025)

**\$29,379**

### **Kentucky**

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

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

**\$210,000**

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

Kentucky Cabinet for Health and Family Services (DD16-1603, 000010)

**\$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)

**\$147,191**

#### *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)

**Project ended 7/31/2018**

### **Louisiana**

#### *Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*

Louisiana Department of Health (DD17-1701, 000087)

**\$243,657**

#### *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)

**Project ended 7/31/2018**

### **Maine**

#### *Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*

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

**\$150,000**

### **Maryland**

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

Johns Hopkins University (DD15-1501, 001160)

**\$450,000**

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

Maryland Department of Health (DD16-1603, 000005)

**\$150,000**

#### *National Public Health Practice and Resource Centers for Children with Attention Deficit/Hyperactivity Disorder or Tourette Syndrome*

CHADD, Inc. (Children & Adults with Attention Deficit Hyperactivity Disorder) (DD15-1505, 005376)

**\$850,000**

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

Johns Hopkins University (DD16-001, 001214)

**\$1,020,377**

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

Maryland Department of Health (DD16-1605, 000033)

**Project ends 7/31/19**

#### *Strengthening Public Health Systems and Services Through National Partnerships to Improve and Protect the Nation's Health*

Association of University Centers on Disabilities (OT18-1802)

**\$1,164,250**

*Strengthening Public Health Laboratories Newborn Screening and Genetics - Hemoglobinopathies Project*  
Association of Public Health Laboratories  
(OE15-1501, 000103)  
**\$53,010**

*Behavioral Risk Factor Surveillance System*  
Maryland Department of Health  
(DP15-1513, 006039)  
**\$25,000**

*Small Business Innovation Research Grant (SBIR)*  
Medial Decision Logic, Inc. (SBIR17-302, 001220)  
**\$2,000**

## Massachusetts

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

*Public Health Research on Modifiable Risk Factors for Spina Bifida*  
Boston University Medical Center  
(DD15-001, 001184)  
**Project ends 4/30/19**

*Implementing Alcohol Screening and Brief Intervention in Healthcare Systems Providing Women's Health Services*  
Boston Medical Center Corporation  
(DD18-1802, 000002)  
**\$397,438**

*Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*  
Massachusetts Department of Public Health  
(DD17-1701, 000095)  
**\$250,000**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs*  
Massachusetts Department of Public Health  
(DD16-1603, 000002)  
**\$439,588**

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

*Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS) II*  
Massachusetts Department of Public Health  
(DD18-001, 001224)  
**\$995,000**

*Implementing Alcohol Screening and Brief Intervention in Healthcare Systems Providing Women's Health Services*  
Boston Medical Center Corporation  
(DD18-1802, 000002)  
**\$397,438**

## Michigan

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*  
Michigan Department of Health and Human Services (DD16-1601, 004944)  
**\$210,000**

*Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*  
Michigan Department of Health and Human Services (DD17-1701, 000067)  
**\$150,000**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs*  
Michigan Department of Health and Human Services (DD16-1603, 000001)  
**\$390,000**

*Implementing Alcohol Screening and Brief Intervention in Healthcare Systems Providing Women's Health Services*  
Henry Ford Health System (DD18-1802, 000001)Small Business Innovation Research Grant (SBIR)  
Rightanwer.com, Inc. (SBIR14-071, 001227)  
**\$532,664**



## SELECT STATE-BASED ACTIVITIES AND FUNDING

### Minnesota

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

Minnesota Department of Health

(DD16-1601, 004939)

**\$175,000**

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

Regents of the University of Minnesota

(DD15-1501, 001171)

**\$450,000**

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

Minnesota Department of Health

(DD16-1603, 000009)

**\$300,000**

*Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*

Minnesota Department of Health

(DD17-1701, 000062)

**\$250,000**

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

Gillette Children's Specialty Healthcare

(DD14-002, 001074)

**\$67,090**

*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)

**Project ended 7/31/2018**

*Behavioral Risk Factor Surveillance System*

Minnesota Department of Health

(DP15-1513, 006042)

**\$25,000**

### 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)

**Project ended 11/30/2018**

### Missouri

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

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

**\$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**

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

Washington University (DD16-001, 001216)

**\$770,377**

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

Washington University at St. Louis

(DD15-1501, 001177)

**\$550,000**

*Fetal Alcohol Spectrum Disorders (FASO) Practice and Implementation Centers*

University of Missouri (DD14-1402, 001145)

**Project ended 9/29/18**

Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus  
Missouri Department of Health and Senior Services  
(DD16-1605, 000001)  
**Project ends 1/31/19**

## Montana

Improving the Health of People with Mobility Limitations and Intellectual Disabilities through State-based Public Health Programs  
Montana Department of Public Health and Human Services  
(DD16-1603, 000018)  
**\$390,000**

Behavioral Risk Factor Surveillance System  
Montana Department of Public Health and Human Services  
(DP15-1513, 006044)  
**\$25,000**

## 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)  
**Project ended 7/31/2018**

*Behavioral Risk Factor Surveillance System*  
Nebraska Department of Health and Human Services  
(DP15-1513, 006027)  
**\$16,250**

## Nevada

*Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*  
Nevada Department of Health and Human Services  
(DD17-1701, 000086)  
**\$148,966**

Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers  
Board of Regents, University of Nevada Reno  
(DD14-1402, 001132)  
**Project ended 9/29/18**

*Strengthening Public Health Systems and Services Through National Partnerships to Improve and Protect the Nation's Health*  
Board of Regents, University of Nevada Reno  
(DD18-1802, 000008)  
**\$250,000**

*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)  
**Project ends 7/31/2019**

## New Hampshire

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



## SELECT STATE-BASED ACTIVITIES AND FUNDING

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

University of New Hampshire (DD16-1603, 000007)

**\$440,000**

*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 (DD16-1065, 000009)

**Project ends 7/31/19**

### 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)

**\$250,000**

*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)

**Project ended 7/31/2018**

### New Mexico

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

New Mexico Department of Health

(DD16-1605, 000016)

**Project ends 7/31/2019**

### New York

*Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)*

Health Research Inc./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)

**\$444,000**

*Surveillance of Congenital Heart Defects Across the Lifespan*

New York State Department of Health

(DD15-1506, 004931)

**\$465,024**

*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./New York State Department of Health (DD13-003, 001032)

**Project ends 8/31/19**

*National Public Health Practice and Resource Centers for Children with Attention-Deficit/Hyperactivity Disorder or Tourette Syndrome*

Tourette Syndrome Association, Inc

(DD15-1505, 001050)

**\$900,000**

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

March of Dimes (OT18-1802)

**\$540,000**

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

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

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

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Health Research, Inc. NYSDOH  
(DD16-1605, 000021)  
**Project ends 5/31/2019**

*Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to Improve Services and Outcomes*  
New York State Psychiatric Institute  
(DD15-003, 001188)  
**\$199,004**

*Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to Improve Services and Outcomes*  
Institute for Basic Res in Developmental Disabilities (DD15-003, 001189)  
**\$349,862**

*Birth Defects Study To Evaluate Pregnancy exposureS (BD- STEPS) II*  
Health Research Inc/New York Department of Health (DD18-001, 001227)  
**\$770,000**

## 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)  
**\$359,987**

*Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)*  
North Carolina Department of Health and Human Services  
(DD17-1701, 000084)  
**\$200,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
North Carolina Department of Health and Human Services  
(DD16-1605, 000018)  
**Project ends 7/31/2019**

*Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3*  
University of North Carolina, Chapel Hill  
(DD16-001, 001205)  
**\$1,020,277**

*Birth Defects Study To Evaluate Pregnancy exposureS (BD- STEPS)*  
University of North Carolina, Chapel Hill  
(DD13-003, 001036)  
**Project Ends 8/31/19**

*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)  
**\$66,581**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Duke University (DD14-002, 001087)  
**\$20,520**

*Birth Defects Study To Evaluate Pregnancy exposureS (BD- STEPS) II*  
University of North Carolina- Chapel Hill  
(DD18-001, 001231)  
**\$770,000**



## SELECT STATE-BASED ACTIVITIES AND FUNDING

*Small Business Innovation Research Grant (SBIR) Innovation Research and Training, Inc.*  
(SBIR17-302, 001219)  
**\$2,000**

*Small Business Innovation Research Grant (SBIR) Innovation Research and Training, Inc.*  
(SBIR18-574, 001232)  
**\$2,000**

### North Dakota

*Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)*  
Minot State University – North Dakota  
(DD17-1701, 000056)  
**\$150,000**

### Ohio

*Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)*  
Ohio Department of Health (DD17-1701, 000054)  
**\$150,000**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities 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)  
**Project ended 4/30/2018**

*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)  
**\$99,992**

### Oklahoma

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*  
Oklahoma State Department of Health  
(DD16-1601, 004949)  
**\$210,000**

*Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)*  
Oklahoma State Department of Health  
(DD17-1701, 000065)  
**\$150,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Oklahoma State Department of Health (DD16-1605, 000038)  
**Project ends 1/31/2019**

### Oregon

*Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI-IS)*  
Oregon Department of Human Services  
(DD17-1701, 000091)  
**\$150,000**

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

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Oregon Health and Science University  
(DD14-002, 001071)  
**\$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)  
**\$210,000**

## Pennsylvania

*Improving Fetal Alcohol Syndrome Disorder Prevention and Practice through National Partnerships*  
University of Pittsburgh (DD14-1403, 001135)  
**Project ended 9/29/18**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus-High Risk Local Areas*  
Philadelphia Department of Health  
(DD16-1606, 000042)  
**Project ends 8/31/2019**

*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)  
**Project ends 7/31/2019**

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

## 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)  
**Project ended 7/31/2018**

## 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)  
**\$2,408,832**

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

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

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

*Behavioral Risk Factor Surveillance System*  
South Carolina Department of Health and Environment (DP15-1513, 00605)  
**\$27,500**

## South Dakota



## SELECT STATE-BASED ACTIVITIES AND FUNDING

### Tennessee

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

Tennessee Department of Health (DD16-1605, 000032)

**Project ends 7/31/2019**

*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**

### 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) Regional Training and Practice Centers*

Baylor College of Medicine (DD14-1402, 001131)

**Project ended 9/29/18**

*Improving Fetal Alcohol Syndrome Disorder Prevention and Practice through National Partnerships*

University of Texas, Austin (DD14-1403, 001147)

**Project ended 9/29/18**

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

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

**\$250,000**

*Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)*

Texas Department of State Health Services

(DD17-1701, 000052)

**\$150,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus-High Risk Local Areas*

Houston Department of Health and Human Services (DD16-1606, 000045)

**Project ended 10/15/2018**

*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)

**Project ended 7/31/2018**

*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)

**Project ended 12/31/18**

### 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)

**Project ended 9/30/18**

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

IHC Health Services, Inc. (DD14-002, 001062)

**\$66,767**

*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)

**\$449,751**

*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**

*Behavioral Risk Factor Surveillance System*

Utah Department of Health (DP15-1513, 006051)

**\$35,000**

## 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)

**Project ended 7/31/2018**

## Virginia

*Evaluation of Health Promotion and Prevention Programs for Blood Disorders*

National Blood Clot Alliance (DD14-1405, 001153)

**\$365,045**

*Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)*

Virginia Department of Health (DD17-1701, 000070)

**\$122,290**

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

Virginia Department of Health (DD16-1605, 000014)

**Project ended 1/31/19**

## 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**

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

Association of Maternal & Child Health Programs

(OT18-1802,000296)

**\$150,000**



## SELECT STATE-BASED ACTIVITIES AND FUNDING

*Expanding Efforts & Strategies to Protect & Improve Public Health Globally*

Vsynova Partners, Inc (GH15-1632, 001732)

**\$620,000**

### 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)

**Project ends 7/31/19**

### Wisconsin

*Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)*

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

**\$250,000**

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

Children's Hospital of Wisconsin (DD14-002, 001063)

**\$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) Regional Training and Practice Centers*

Board of Regents of the University of Wisconsin System (DD14-1402, 001133)

**Project ended 9/29/18**

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

Wisconsin Department of Health Services

(DD16-1605, 000025)

**Project ends 7/31/19**

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

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

**\$770,377**

### 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 Public Health Practice and Resource Centers on Health Promotion for People w/Disabilities*

Special Olympics (DD16-1602, 001156)

**\$4,500,000**

**Supplemental Funding \$1,800,000**

*Improving Fetal Alcohol Syndrome Disorder Prevention and Practice through National Partnerships*

American College of OB/GYN (DD14-1403, 001146)

**Project ended 9/29/18**

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

American College of OB/GYN (DD18-1803, 0000007)|

**\$250,000**

*Improving Fetal Alcohol Syndrome Disorder Prevention and Practice through National Partnerships*

National Organization on Fetal Alcohol Syndrome Prevention (DD14-1403, 001148)

**Project ended 9/29/18**

*Promoting Resources for Fetal Alcohol Spectrum Disorders Awareness and Prevention*

National Organization on Fetal Alcohol Syndrome Prevention (DD18-1801)

**\$400,000**

*OSTLTS Partnerships CBA of the Public Health System*

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

**\$13,712**

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

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Spina Bifida Association (DD14-002, 001077)  
**\$600,000**

## 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)  
**Project ends 7/31/2019**

*Documentation and Use of Follow up Diagnostic and Intervention Services Data Through the Maintenance and enhancement of the Early Hearing Detection and Intervention Information System (EHDI- IS)*  
Puerto Rico Department of Health (DD17-1701, 000088)  
**\$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)  
**Project ends 7/31/2019**

## 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)  
**Project ended 7/31/2018**

## 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)  
**Project ended 7/31/2018**

## 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)  
**Project ended 7/31/2018**

## Federated States of Micronesia

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

## Switzerland

*Global Prevention of NCD's Prevention and Promotion of Health*  
World Health Organization (DD14-1420, 001235)  
**\$540,140**



## OUR VISION

**Babies**  
*are born healthy.*

**Children**  
*reach their potential.*

**And everyone**  
*thrives.*

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