



**FISCAL YEAR 2010 ANNUAL REPORT**

**PROMOTING THE HEALTH OF  
BABIES, CHILDREN, AND ADULTS**  
*and enhancing the potential for full, productive living*

National Center on Birth Defects and Developmental Disabilities  
Office of the Director



## ABOUT THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

**CDC'S MISSION** is to collaborate to create the expertise, information, and tools that people and communities need to protect their health – through health promotion, prevention of disease, injury, and disability, and preparedness for new health threats.

### A PUBLIC HEALTH APPROACH

What does it mean to take “a public health approach”? By definition, public health focuses on preventing disease, promoting health, and prolonging life. It addresses population-level health concerns rather than individual-level health issues. Tracking and monitoring of disease patterns and outbreaks are foundational to public health. Scientific research is the basis for development of health education and outreach programs as well as policy interventions.

### OUR MISSION: HELPING PEOPLE LIVE LIFE TO THE FULLEST

Through our efforts, we work to improve lives from childhood through adulthood. The mission of CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is to promote the health of babies, children, and adults, helping them live life to the fullest. We live out our mission in important ways:

- *We use science as the foundation* to reflect the impact that birth defects, disabilities, and blood disorders can have and to show us how we can understand their causes and learn to prevent them.
- *We translate science into action* providing health information, programs, tools, and resources to consumers, health care professionals, and policymakers.
- *We collaborate with partners* to increase our impact where people live, work, and play.

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## LETTER FROM THE DIRECTOR

▶ *Each year, about 130,000 babies are born with a birth defect.*

▶ *More than 5,500 of these babies die in their first year of life, making birth defects a leading cause of infant death in the United States.*

▶ *About 13 percent of U.S. children younger than 18 years of age have a developmental disability.*

▶ *Approximately 1 in 5 people in the United States has some type of disability.*

▶ *Complications from deep vein thrombosis (DVT) kill more people each year than breast cancer, motor vehicle accidents, and HIV combined.*

These statistics are alarming and underscore the burden these conditions place on individuals and families living with birth defects, disabilities, or blood disorders. Here at the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD), we translate science into action to provide credible health information to consumers, health care professionals, and policymakers to help improve the lives of children and adults.

The year 2011 marks 10 years of service for us at NCBDDD, and we will be celebrating a decade of helping to promote the health of babies, children, and adults living with birth defects, disabilities, and blood disorders. Our dedicated partners, researchers, scientists, and public health experts strive to identify the risk factors and causes of these conditions to enhance the potential for full, productive living for many in these most vulnerable populations.

This report gives you a glimpse into some of the ways that we are advancing and translating science and collaborating with others to address our current strategic priorities of:

- Preventing major birth defects and poor infant outcomes attributable to maternal medical and lifestyle risk factors;
- Preventing death and disability associated with deep vein thrombosis/pulmonary embolism (DVT/PE); and
- Reducing disparities in obesity and other health indicators in children, youth, and adults with disabilities.

As the acting director of NCBDDD, I am proud to celebrate 10 years of continued progress in the pursuit of improved programs, research, and knowledge for the millions of Americans who live with birth defects, disabilities, and blood disorders. Though our work is far from over, the foundation we have built strengthens our quest for a better tomorrow.

Sincerely,



Coleen A. Boyle, PhD, MSHyg  
Acting Director, NCBDDD  
Centers for Disease Control and Prevention

## CELEBRATING 10 YEARS OF SERVICE



### SERVICE. PASSION. INNOVATION. IMPACT.

It's hard to believe that a decade has passed since the inception of the National Center on Birth Defects and Developmental Disabilities. In just 10 short years, our researchers, scientists, and public health practitioners have worked tirelessly with many experts in the fields of birth defects, disabilities, and blood disorders to develop prevention strategies addressing these conditions and improve the health of millions. From folic acid to DVT/PE to obesity, we are privileged to serve some of our nation's most vulnerable populations.

Throughout the coming year, we will be working with our partners across the country to celebrate accomplishments of the past decade and to strengthen our collective resolve to continue this work for years to come with a focus on having a measurable impact. We will honor the dedicated pioneers of public health who have helped to inspire generations of scientists, researchers, and health communicators to improve lives. It is because of these pioneers that we are poised for continued success and advancement in the near future.

As we enter the next decade of service, we look forward to working with our partners to help advance the priorities that are so critical for our populations. While we have made much progress in this decade, there are still lives to be impacted, scientific advancements to be made, and interventions to be created.

We extend our sincere thanks and gratitude for the collaboration and efforts of our Friends of NCBDDD. A coalition of government and private sector participants, Friends of NCBDDD works to enhance the mission and activities of NCBDDD. For more information about the group or how to join, please visit [www.friendsofncbddd.org](http://www.friendsofncbddd.org).

*Won't you join us?*

## OUR PRIORITY

*Preventing major birth defects and poor infant outcomes attributable to maternal medical and lifestyle risk factors.*



### WHAT IS THE PROBLEM?

▶ *Birth defects are a leading cause of deaths in the first year of life and can result in lifelong disability.*

▶ *Birth defects have accounted for more than 139,000 hospital stays during a single year, resulting in \$2.6 billion in hospital costs. To put this in context, hospitalizations for all types of childhood cancer combined total approximately \$1.7 billion each year.*

▶ *Many birth defects happen very early in pregnancy, sometimes before a woman even knows she is pregnant.*

### WHAT DO WE KNOW?

*Prevention of birth defects begins with identifying causes and risk factors.* The size and scope of NCBDDD's National Birth Defects Prevention Study provide the nation with a vast resource to look at possible causes of birth defects. The valuable information we get from the study guides development of effective programs to prevent birth defects. The study findings include the following preventable risk factors for major birth defects:

- **Diabetes and obesity:** Women who have poor control of diabetes or who are obese prior to and at the time of pregnancy have an increased chance of having a baby with a birth defect.
- **Smoking:** Women who smoke during pregnancy have an increased chance of having a baby born with certain birth defects such as cleft lip.
- **Medications:** Certain medications a woman takes before or during pregnancy can increase the risk for birth defects. The average number of medications used in pregnancy has increased over time, despite the limited data available on the safety or risk of specific medications.

These issues are particularly important given the significant increase in the number of women of reproductive age who have one or more of these risk factors.

### WHAT CAN WE DO?

*Now is the time for action.* Our greatest strength is our ability to translate findings rapidly into prevention strategies that impact the most people. Because of our recent findings on diabetes, obesity, smoking, and medications, we are poised to develop and implement effective ways to reduce, control, and modify the risks associated with these exposures so that more babies are born healthy.

## **ASSURING CHILD HEALTH: PREVENTING BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES**

One in 33 babies born in the United States is born with a birth defect. Using science as the foundation of our efforts, we work to change this statistic. For example, thanks to ongoing research, we have learned that obesity, diabetes, and smoking increase the risk of congenital heart defects and other birth defects, so we are working to translate this information into prevention strategies. We're bringing together families, experts, and organizations to help prevent major birth defects attributable to maternal risk factors, ultimately leading to healthier babies and children who are able to reach their full potential.

Our work strives to:

- Decrease preventable birth defects and developmental disabilities due to known causes;
- Identify preventable risk factors for birth defects and developmental disabilities and develop appropriate interventions to reduce these risks; and
- Improve the quality of life of children with birth defects, autism, and other developmental disabilities.





## AUTISM AND DEVELOPMENTAL DISABILITIES MONITORING AND RESEARCH:

This year, we continued to develop scientific understanding about the magnitude, risk factors, and societal implications of autism and other developmental disabilities.

- Our Autism and Developmental Disabilities Monitoring (ADDM) Network provides data including prevalence estimates at a population level in order to increase our understanding of Autism Spectrum Disorders (ASDs) and other developmental disabilities. It also guides policies at the state and national levels that address the needs of affected families. The latest ADDM data were used to accomplish the following in 2010:
  - *Inform state policy.* As of January 2011, 23 states used the state-level prevalence data to guarantee that autism-specific services are covered by insurance companies.
  - *Identify significant racial/ethnic disparities in the recognition of ASDs.* We are working to understand why these disparities exist and increase recognition of early warning signs of ASDs among all families, particularly populations experiencing difficulty accessing care.
  - *Identify that the average age at which children*

*are diagnosed with an ASD is 4½ years old.* We want to move this average to a younger age because we know that ASDs can be recognized before the age of 3. Through the “Learn the Signs. Act Early.” program, we are helping professionals and parents learn how to recognize the early warning signs of ASDs and other developmental disabilities so that children receive services as early as possible.

- We continue our work to determine the prevalence of ASDs in younger children. In 2010, we funded six sites to expand monitoring of autism to include younger children. By tracking ASDs among 4-year-old children, we can increase our understanding of young children affected by ASDs and improve efforts at identifying the condition earlier.
- We are currently conducting one of the largest studies in the United States to help identify factors that may put children at risk for ASDs – the Study to Explore Early Development (SEED). By the end of 2010, SEED had enrolled more than 2,700 children and their families from six states. In 2012, we will begin analyzing initial results of the study, focusing on describing the children in terms of specific behaviors, developmental progress, medical issues, and demographics (age, race/ethnicity, gender, place of birth/residence).

- We are an active member of the federal committee charged with responding to autism, the Interagency Autism Coordinating Committee (IACC). Our autism activities correspond to those highlighted in the IACC’s strategic plan. In 2010, our research was used in the development of the IACC strategic research agenda for autism. Our data are critical and help determine the service needs for individuals and families living with autism.



## MONITORING BIRTH DEFECTS, UNDERSTANDING CAUSES, AND BUILDING PREVENTION CAPACITY

A key component to preventing birth defects is having an understanding of the risk factors and causes of these conditions. We worked throughout the year to advance our understanding of birth defects to build the capacity to prevent them.

- Influenza continues to be a concern for many high-risk populations that we serve, including pregnant women and children with high-risk medical conditions. Although vaccination is recommended in any trimester of pregnancy, typically only about 15–25 percent of pregnant women receive influenza vaccine for seasonal flu. Fortunately, uptake of vaccine was higher during the H1N1 pandemic with approximately 47 percent of pregnant women receiving the 2009 H1N1 pandemic flu vaccine. Through our research on how best to reach and educate the high-risk groups we serve, we hope to build on the positive momentum generated during the 2009 H1N1 pandemic.
- More than two-thirds of all pregnant women use at least one prescription or over-the-counter medication during pregnancy. For many

medications and herbal products, information on the safety of use during pregnancy is inadequate. In 2010, our research identified medications that might increase the risk of birth defects including some antidepressants. We will continue our efforts to understand which medications and herbal products are safe to take during pregnancy to help women and their doctors make the best decisions to protect both the mother and the baby.

- Poor control of diabetes during pregnancy increases the chances for birth defects and other problems for the baby as well as serious complications for the mother. We are collaborating with other CDC reproductive health and diabetes experts to develop a public health framework that will help prevent birth defects and other poor outcomes associated with pre-gestational and gestational diabetes.
- To reduce the occurrence of congenital heart defects (CHD) and improve the quality of life for children and adults with CHDs, we worked with experts, physician organizations, patient groups, and other federal agencies in

2010 to form the Congenital Heart Public Health Consortium. The consortium will work to address congenital heart defects with a public health approach, focusing on preventing disease, promoting health, and prolonging the lives of people with these conditions.

### *Did you know?*

**About 60 percent of women of childbearing age are either overweight or obese. Using data from our National Birth Defects Prevention Study, our researchers found that women who are overweight or obese are more likely to have a baby with a congenital heart defect.**

### CONGENITAL HEART DEFECTS: A MOTHER'S STORY

As Susan May welcomed the birth of her son Nick, she thought everything seemed normal; however, as she asked, "Is my baby fine?" the initial smiles surrounding her quickly changed to whispers and concerned looks. Soon, Nick was whisked away to specialists in a large children's hospital while Susan was left behind. Shortly afterward, she was released, leaving in a wheelchair with a balloon that read, "It's a BOY!" but she held no baby boy in her arms. Susan did not realize then that the adventure had only begun as tests revealed that her baby had a congenital heart defect.

Congenital heart defects are the most common type of birth defect, affecting nearly 1 in 100 or 40,000 babies born in the United States. They remain a leading cause of death from birth defects in the first year of life. Medical costs associated with congenital heart defects are substantial. \$1.2 billion is the estimated lifetime cost for U.S. children born in a single year with

one of four major heart defects (tetralogy of Fallot, transposition of the great arteries, single ventricle, truncus arteriosus). NCBDDD's tracking and research efforts through the National Birth Defects Prevention Study have identified important risk factors for congenital heart defects. For example, women who are obese when they become pregnant are more likely to have a baby with a congenital heart defect. But, we have more to learn.

After three difficult open heart surgeries, Nick's doctors decided that he could only survive with a heart transplant. Just before his second birthday, Nick received his new heart. Although Nick is 21 years old now and doing well, he and his parents still worry about transplant rejection and the future. "I think about the pain and frustration we have been through, and my hope for other families is that we can find out what causes congenital heart defects so that we can prevent them," added Susan.



## REDUCING ALCOHOL-EXPOSED PREGNANCY

Despite prevention efforts, alcohol-exposed pregnancy remains a leading preventable cause of birth defects and developmental disabilities. We continue to work with partners and health care professionals to promote awareness of this issue.

- We know that alcohol screening and brief intervention programs are effective in reducing the risk of alcohol-exposed pregnancies. In collaboration with two state health departments, we are implementing alcohol screening and intervention programs to reduce alcohol-exposed pregnancies in women attending sexually transmitted disease clinics in Baltimore and Denver. We have also funded two sites in New York City and Los Angeles to assess the feasibility and impact of integrating these same programs into community health centers and family planning clinics serving women at risk for an alcohol-exposed pregnancy.
- Health care providers play a critical role in identifying and intervening with women at risk for an alcohol-exposed pregnancy and in identifying, referring, and treating children living with fetal alcohol spectrum disorders

(FASD). We work with five FASD Regional Training Centers to educate medical and allied health students and professionals on the prevention, identification, and treatment of FASDs. In 2010, the FASD Regional Training Centers conducted almost 300 trainings for more than 6,500 medical and allied health students and health care providers on the prevention, identification, and treatment of FASDs.



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## REDUCING FOLIC ACID-PREVENTABLE NEURAL TUBE DEFECTS

Another key issue for advancement in 2010 was preventing neural tube defects (NTDs) like spina bifida through folic acid fortification.

- We are providing technical assistance to a regional cooperative initiative in Central America to fortify foods with micronutrients including folic acid, iron, B complex vitamins, zinc, vitamin A, and iodine. Fortification will help prevent micronutrient deficiencies including NTDs, anemia, and other adverse health outcomes.
- We are providing guidance to a group that includes the March of Dimes, Spina Bifida Association, American Academy of Pediatrics, GRUMA (major manufacturer of corn masa flour products), and others to examine ways to fortify corn masa flour with folic acid. This would help reduce existing disparities in NTDs rates among Latinas in the United States.
- We began a global initiative to eliminate folic acid-preventable NTDs. Globally, 300,000 infants are born with NTDs each year, and current programs are preventing only about 9 percent of folic acid-preventable NTDs.



## LOOKING TO THE FUTURE

### IN 2011, OUR WORK WILL FOCUS ON ADVANCING OUR PRIORITIES:

**Priority 1.** Enhance surveillance and research for autism and other developmental disabilities to monitor changes in prevalence and contributing risk factors and better inform prevention policy and programs. Specifically, we will be:

- Publishing updated Autism Spectrum Disorder (ASD) prevalence data among 8-year-old children and assessing factors potentially contributing to changes in prevalence.
- Completing initial analyses from the Study to Explore Early Development (SEED) to examine risk factors for ASD.
- Identifying racial and ethnic disparities in the proportion of children identified and diagnosed with autism at an early age.
- Revising the “Learn the Signs, Act Early.” (LTSAE) materials to meet the current information needs of parents of young children.
- Working collaboratively with other federal agencies (i.e., Health Resources and Services Administration and Administration of Children and Families) to broadly disseminate LTSAE materials through organizations, systems, and professional and lay efforts serving young children and their families.

**Priority 2.** Prevent congenital heart defects and

other major birth defects associated with obesity, diabetes, and medications. Specifically, we will be:

- Researching practical strategies to help women have healthier pregnancies and healthier babies through activities such as moderate levels of exercise or changes in diet. These strategies could help women who are obese or who have diabetes before and during pregnancy.
- Improving the data available on safety of medications (both over the counter and prescription) that are most frequently used before and during pregnancy.

**Priority 3.** Prevent alcohol-exposed pregnancy among reproductive-aged women to prevent fetal alcohol syndrome and other adverse effects of prenatal exposure. Specifically, we will be:

- Adapting and promoting alcohol screening and brief interventions.
- Increasing awareness and promoting consistent messages regarding alcohol use and pregnancy among women and their health care providers.

**Priority 4.** Eliminate all folic acid-preventable neural tube defects (NTDs) in the United States and globally. Specifically, we will be:

- Determining optimal blood folate concentration for NTDs prevention.
- Developing a global strategy for elimination of folic acid-preventable NTDs.



## OUR PRIORITY

*Reducing disparities in obesity and other health indicators in children, youth, and adults with disabilities.*

### WHAT IS THE PROBLEM?

- ▶ *Obesity rates for children and adults with disabilities are 38 percent and 57 percent higher than rates for children and adults without disabilities.*
- ▶ *Adults with disabilities engage in physical activities on a regular basis approximately half as often as adults without disabilities (12 percent vs. 22 percent).*
- ▶ *Disparities have been found in access to health care with 29 percent of people with disabilities showing unmet need compared to 12 percent of people without disabilities.*

### WHAT DO WE KNOW?

The growing body of research on the link between obesity and disability indicates that, for both children and adults, those at greatest risk for obesity have mobility limitations, intellectual/learning disabilities, or both. Whether obesity is the result of disability or a contributing factor to disability, children, youth, and adults with disabilities are an important subgroup to address in reducing obesity in the United States.

Reasons for these disparities include:

- Lack of healthy food choices for many people with disabilities living in restrictive environments;
- Difficulty with chewing or swallowing food;
- Use of medications that can contribute to changes in weight and appetite;
- Physical limitations that can reduce a person's ability to exercise;
- Pain and/or lack of energy;
- Lack of accessible environments such as sidewalks, parks, and exercise equipment; and
- Lack of resources such as money, transportation, and social support from family, friends, neighbors, and community members.

### WHAT CAN WE DO?

*Now is the time for action.* Evidence shows that regular physical activity and good nutrition provide improved cardiovascular and muscle fitness, enhanced mental health, and a better ability to perform tasks of daily life for people with disabilities.

We need: research to build the evidence for interventions; effective communication to inform stakeholders; and implementation of public health programs, policies, and practices to reduce the disparity in obesity and other health indicators such as health care access.

With our partners, we are integrating disability into national efforts that address obesity and other health conditions and are identifying and measuring outcomes for persons with disabilities to evaluate effectiveness and monitor change.

## HUMAN DEVELOPMENT AND DISABILITY

More than 50 million Americans are living with some type of disability and more than 14 million children have a special health care need. From mobility to intellectual disabilities to vision and hearing impairments to mental health and social relationships, these conditions have significant impact on the lives of Americans of all ages and backgrounds. We know that people with disabilities are at greater risk for a number of preventable health conditions. Our research will inform strategies to help people with disabilities live healthier, fuller, and more engaged lives.

Through research, collaboration, health education, and programming, we:

- Increase early identification and intervention for infants and young children with disabling conditions to assure that referrals for needed services occur;
- Encourage the adoption of healthy behaviors in children, youth, and adults with disabilities to reduce health disparities compared to the general population;
- Improve health care access for children, youth, and adults with disabilities so that appropriate medical services are available and used; and



- Improve developmental outcomes for young children living in poverty through targeted, child-centered parent training.

### *Did you know?*

**Through the collaboration of CDC and HRSA, 95 percent of infants born in the United States have their hearing screened, most before one month of age.**

## IMPROVING NEWBORN HEARING SCREENING RATES

Hearing loss can affect a child's ability to develop communication, language, and social skills. The earlier children with hearing loss start getting services, the more likely they are to reach their full potential. We are focused on ensuring that all newborns are screened for hearing loss by the time they are one month old. We also want to help ensure that newborns who fail the screening receive an audiology exam by 3 months and are referred for intervention by 6 months if loss is detected. Our work in 2010 contributed to advancing this goal:

- We collaborated with state-based early hearing detection and intervention coordinators to recommend benchmark standards which have been incorporated into a new results-centered report designed to help states focus their intervention efforts. This new report will be distributed by Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA), a national partner association of hearing-related programs.
- To enhance reporting systems, we are partnering with organizations such as the Public Health Data Standards Consortium on the interoperability of clinical electronic health records and the public health Early Hearing Detection and Intervention (EHDI) information system.



## ACCOMPLISHMENTS

### REDUCING DISPARITIES IN OBESITY AMONG PEOPLE WITH DISABILITIES

We are working with other federal agencies, CDC programs, and our national and state partners to implement a public health approach that reduces the obesity disparity in children, youth, and adults with disabilities compared to the general population.

This approach includes:

- Promoting the inclusion of children, youth, and adults with disabilities in general obesity reduction campaigns;
- Identifying effective disability-specific interventions in obesity prevention and in weight loss;
- Developing communication campaigns for use by partners and others on the importance of addressing obesity among persons with disabilities;
- Supporting implementation of health promotion programs through our network of state disability and health programs;
- Providing support for online information, research opportunities, and summaries of public health practices related to improving the health of people with disabilities through partnerships

with the National Center on Physical Activity and Disability (NCPAD), the Association of University Centers on Disabilities (AUCD), the American Association on Health and Disability (AAHD), and the National Association of County and City Health Officials (NACCHO); and

- Partnering with organizations, such as the Christopher and Dana Reeve Foundation, which provide information about weight management and improved quality of life for persons with paralysis and other disabilities.

### IMPROVING HEALTH CARE ACCESS FOR PEOPLE WITH DISABILITIES

People living with a disability have unique health care needs, and accessibility to health care services is very important. We are engaged in the following areas this year:

- Funding a network of 16 state-based disability and health programs with the goal of improving health, well-being, and full participation in a society of people with disabilities. The programs address an array of issues including access to clinical preventive services, emergency preparedness, health promotion, disability monitoring, preparing professionals, and enhancing community livability.



- Collecting data starting in 2010 from the Natural History of Spina Bifida in Children pilot project, which engaged families with a child with spina bifida aged 3, 4, or 5 years old at the time of assessment. This project is the first step toward documenting the development, health status, and onset of complications affecting children with spina bifida, working in partnership with the Spina Bifida Association (SBA) to identify future effective interventions.

- Supporting the only national clearinghouse dedicated to sharing evidence-based information about identification, support, referral, and treatment for Attention Deficit/Hyperactivity Disorder (ADHD) through Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD). Through CHADD, we disseminate information on ADHD that helps the public understand diagnosis and treatment of the condition. At the same time, these efforts promote the health status of the growing number of American youth with ADHD by fielding more than 12,000 inquiries and 900,000 hits on the web site per year.
- Collaborating with partners, we help address issues encountered by people with limb loss. We partnered with the Amputee Coalition of America (ACA) to develop and disseminate fact sheets, podcasts, and training materials for clinicians and amputees impacted by the 2010 earthquake in Haiti.
- Partnering with the Tourette Syndrome Association (TSA) to provide health education and training of professionals on the standard diagnostic and treatment practices for Tourette Syndrome (TS) and related disorders, especially targeting practitioners working with underserved

and minority populations. TSA-funded activities have resulted in training of more than 26,000 professionals to date. As a result, more than 90 percent of professionals report better skills to improve diagnosis and treatment of TS and related conditions.

### **INCORPORATING DISABILITY IN CDC RESEARCH - PROMOTING DISABILITY INCLUSION**

To achieve the goal of having people with disabilities accurately represented in public health efforts, we worked this year on disability inclusion:

- CDC appointed its first Chief Disability and Health Officer who is the liaison from NCBDDD's Division of Human Development and Disability to CDC's Office of the Associate Director of Program and has developed a Disability and Health Workgroup. This group will incorporate disability status into CDC surveys to showcase best practices for health promotion among persons with disabilities and to ensure the relevance of our science, programs, and policies for persons with disabilities.



#### *Did you know?*

**People with disabilities are 2.5 times more likely than people without disabilities to report not getting the medical care they needed because of cost.**

## IMPROVING DEVELOPMENTAL OUTCOMES FOR CHILDREN IN POVERTY

In 2010, we continued to increase the knowledge base on how best to intervene in a child's early years to give at-risk families the best opportunities to raise healthy children who are ready to learn.

- *Legacy for Children™* is a CDC-developed program to support positive parenting among mothers living in poverty. Results through age 5 indicate improved child health and development. A follow-up study to assess the children's social-emotional, behavioral, cognitive, and academic outcomes in the school-age years is underway.
- We collaborated with the Administration for Children and Families (ACF) to develop, plan, and adapt the *Legacy for Children™* public health intervention curricula for community implementation in selected ACF Early Head Start sites across four states.
- We collaborated with the CDC/OD Office of the Associate Director for Policy, National Business Coalition on Health, National Business Group on Health, American Academy of Pediatrics, Health Resources and Services Administration (HRSA), and the Centers for Medicare and Medicaid Services (CMS) to operationalize the Bright Future standards in preventive health services (as mandated under the Affordable Care Act) that will improve the health and well-being of all children, including children with special health care needs.

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## PERSONAL STORY

### NOBODY LEFT BEHIND: CONSUMER EXPERIENCES OF EMERGENCIES AND DISASTERS

*Excerpts from the report by Catherine Rooney Howland, based on an online survey administered at the University of Kansas as part of the Nobody Left Behind: Disaster Preparedness for Persons with Mobility Impairments project.*

- I have juvenile rheumatoid arthritis and use a wheelchair. We had a bomb threat at work, which was very scary. Everyone evacuated, but I was still left on the third floor by the stairwell for the firefighters to come get me. But, no one came. Finally, I just struggled and I used pure fear to get myself down the stairs and outside. It was scary just to realize that there are not really any procedures in place to help someone like me in an emergency. – Los Angeles, CA
- [Disaster personnel after an earthquake] did not know whether any of the options were wheelchair accessible or if they had electricity to keep my ventilators running and batteries charged if the power outage lasted beyond my ventilators' battery life. – Alexandria, VA
- It is really difficult to get the utility company to understand power is a need, if disabled. – Knoxville, TN

These powerful statements provide insight into the shortcomings of the many current emergency management and response systems in the United States. Participants in an online consumer survey report that evacuation plans in public areas are often not addressing the evacuation needs of persons with mobility impairments. They were left behind without a plan of escape or left at stairwells or elevators while others escaped to safety. Other frightening and sometimes life-threatening situations occurred when infrastructures failed, such as electrical power outages for extended periods of time and non-accessible transportation, shelter, and temporary lodging.

Read more survey participants' statements at the Nobody Left Behind: Disaster Preparedness for Persons with Mobility Impairments Project web site at <http://www.nobodyleftbehind2.org>.



**ONE PARTNER MAKING A DIFFERENCE:  
SPECIAL OLYMPICS HEALTHY ATHLETES**

Special Olympics rhythmic gymnast Sara Abbott is accustomed to beating the odds. When she was an infant, doctors said she would never walk or talk; she was not supposed to live past the age of 30; and three years ago, she weighed well over 300 pounds.

Sara has a rare genetic disorder, Prader-Willi Syndrome, which results in intellectual disability and is frequently associated with insatiable appetite, low metabolism, and subsequent obesity. Yet today, at age 37, she is 150 pounds lighter and took home three gold and two silver medals in the summer 2010 Special Olympics USA National Games in Lincoln, Nebraska.

Obesity is a problem for most people with intellectual disabilities. Due to a health condition or the medications they take, the lack of opportunities to exercise, and other issues, approximately 75 percent of adult Special Olympics athletes are overweight. In response, Special Olympics issued a call to action during its National Games Health Symposium in July.

“We have a lot of work to do,” said Special Olympics Chairman and CEO Timothy Shriver. “The health condition for people with intellectual disabilities is nothing short of a crisis – one that will not improve on its own. All of us must act. This isn’t a problem for a few to handle. The solutions will come when everyone is engaged.”

In its call to action, Special Olympics details steps that should be taken and asks the public to donate their time and push their representatives to support policies that address these concerns. Health care providers should increase their knowledge of intellectual disability and welcome these patients into their practices.

For Sara and others just like her, Special Olympics is more than sports or a call to action – it allows people with intellectual disabilities the opportunity to be more fit, make more friends, and be a special part of a team. In the process, Sara has also become an inspiration to her family and fellow athletes.

“I want them to exercise like I did and lose weight and watch what they eat,” Sara added.

Special Olympics hopes that if more people join its fight against obesity, more athletes will be able to find the same healthier lifestyle that enabled Sara Abbott to achieve her goals.



## LOOKING TO THE FUTURE

### IN 2011, OUR WORK WILL FOCUS ON ADVANCING OUR PRIORITIES:

**Priority 1.** Reduce disparity in obesity and other health indicators in children, youth, and adults with disabilities. Specifically, we will be:

- Publishing a report that describes people with disabilities who are at greatest risk for obesity.
- Developing guidance for practitioners on how to address disability issues in obesity prevention and intervention programs.

**Priority 2.** Improve developmental outcomes of all children. Specifically, we will be:

- Conducting follow-up studies with children who live in poverty and identify modifiable factors associated with their developmental outcomes.
- Collecting and analyzing longitudinal data to understand service utilization, environmental factors, and developmental outcomes for children and youth with select disabling conditions.

**Priority 3.** Ensure that all newborns are screened and assessed for hearing loss and receive appropriate intervention according to established guidelines. Specifically, we will be:

- Enhancing state-based electronic case management in order to improve the timely follow-up of infants' care.

**Priority 4.** Identify and reduce disparities in health care access for persons with disabilities. Specifically, we will be:

- Developing and publishing reports on unmet health care needs and health care access of people with disabilities.
- Creating an interactive, publicly accessible web-based platform to display disability-related disparity data for more than 60 health care and health behavior variables.
- Assuring that State Disability and Health programs include components that focus on health care access.

**Priority 5.** Incorporate disability status as a demographic variable into all relevant CDC surveys, programs, and policies. Specifically, we will be:

- Incorporating disability status into current and future CDC surveys through participation in the CDC Disability and Health Workgroup and other inter-agency workgroups.

A man and a woman are walking hand-in-hand on a dirt path through a wooded area. The woman is on the left, wearing a light-colored patterned top, a dark vest, and dark shorts. The man is on the right, wearing a dark short-sleeved button-down shirt and light-colored cargo pants. They are both smiling and looking towards the camera. The background is filled with trees and foliage, with sunlight filtering through the leaves.

## OUR PRIORITY

*Prevent death and disability associated with  
deep vein thrombosis/pulmonary embolism.*

## WHAT IS THE PROBLEM?

- ▶ *Deep vein thrombosis/pulmonary embolism (DVT/PE) is an underdiagnosed, serious, preventable medical condition.*
- ▶ *The precise number of people in the United States affected by DVT/PE is unknown; however, estimates range from 350,000 – 600,000 annually.*
- ▶ *DVT/PE is a leading cause of maternal death.*
- ▶ *For people who have a PE, about one quarter die suddenly.*

## WHAT DO WE KNOW?

Many of the risk factors for DVT/PE are well described and include: obesity, immobility, recent hospitalization, and history of inherited clotting disorders.

An estimated one-third to one-half of DVT/PE events occur without any known risk factors.

### *Did you know?*

Responses to a *HealthStyles* survey identified that although more than 60 percent of respondents identified pain and swelling as symptoms of a DVT, 60 percent did not identify tenderness (often the first sign of DVT) as a symptom. Only 38 percent of respondents knew that a DVT was a blood clot in a vein, and most could not identify common risk factors for DVT such as sitting for a long period of time (e.g., during air travel), having a leg or foot injury, having a family member who has had a DVT, taking birth control pills, or getting older.

## WHAT CAN WE DO?

*Now is the time for action.* Our comprehensive public health approach to blood disorders includes data collection, research to identify preventable or modifiable risk factors, and activities to develop, evaluate, and ensure widespread adoption of effective prevention strategies. These activities will help us:

- Clearly define the burden and challenges of DVT/PE;
- Define the risk factors in selected patient groups such as women during pregnancy and individuals who have had a surgical procedure; and
- Develop guidelines and policies for the prevention and treatment of DVT/PE.

## PROTECTING THE HEALTH OF PEOPLE WITH BLOOD DISORDERS

Nonmalignant blood disorders such as hemophilia, sickle cell disease (SCD), thalassemia, deep vein thrombosis/pulmonary embolism (DVT/PE), and von Willebrand disease (VWD) affect millions of people each year in the United States, cutting across the boundaries of age, race, sex, and socioeconomic status. Men, women, and children of all backgrounds live with complications associated with these conditions, many of which are painful and potentially life threatening. In addition to the numbers of people affected, blood disorders impose high costs on the U.S. health care system.

Through our work in prevention, research, and collaboration, we strive to:

- Understand the causes of and risk factors for blood disorders;
- Understand and minimize occurrence and complications of blood disorders;
- Develop and evaluate evidence-based interventions for blood disorders; and
- Ensure that people with, or at risk for, blood disorders have access to credible health information.

[www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd)





## ACCOMPLISHMENTS

At NCBDDD, our efforts focus on advancing and supporting scientific evidence surrounding primary, secondary, and tertiary prevention. We implement programs that increase awareness and promote education about risk factors, prevention tactics, and treatment options with the goal of substantially reducing the incidence of DVT/PE and preventing and controlling complications associated with other blood disorders.

### **PREVENTING CLOTTING DISORDERS: DEEP VEIN THROMBOSIS/ PULMONARY EMBOLISM**

- NCBDDD funded the National Blood Clot Alliance to develop an online curriculum to increase health care professionals' awareness about venous blood clots. "Stop the Clot®: What Every Healthcare Professional Should Know" has been launched and includes the basics of clotting and thrombophilia, medications, post-thrombotic syndrome and pulmonary hypertension, and prevention of DVT/PE.
- In 2010, we helped launch "This is Serious," a campaign to encourage women to be alert to DVT/PE symptoms and to talk to their doctors about their risks. This campaign was developed through a cooperative agreement with the Vascular Disease Foundation and in



Courtesy of the Vascular Disease Foundation

collaboration with the Spirit of Women hospital network, a national innovator of programs and events on women's health. The first phase of the campaign, Spirit Girls' Night Out, has been held at 25 sites and attended by an estimated 20,453 women.

- We convened an expert working group to collaborate on defining the need, objectives, stakeholders, case definitions, and indicators for DVT/PE surveillance. As a next step, pilot

programs will be funded, providing avenues for identifying and evaluating methods and utility of data sources such as inpatient and outpatient settings, vital statistics, and ambulatory care. Investing in surveillance and epidemiologic research is crucial to our understanding of the burden and challenges of DVT/PE.

- Through a CDC-wide initiative, we are defining the role and utility of electronic health records in public health activities such as monitoring of DVT/PE. Through the use of electronic health records, we can enhance our ability to more accurately define and monitor the public health burden associated with these disorders and assess the effectiveness of prevention activities. Electronic health records have the potential to improve the quality, effectiveness, and costs of health care and will play a vital role in health care reform.

### *Did you know?*

**Approximately 15–20 percent of hemophilia patients develop an inhibitor, where the individual's immune system destroys the clotting factor replacement products, making the treatments ineffective. This results in increased hospitalizations and decreased quality of life.**



## IMPROVING THE HEALTH OF PEOPLE LIVING WITH BLOOD DISORDERS

Throughout this year, we have also advanced the science and collaboration within the blood disorder community related to these serious conditions.

- On March 9, 2010, we convened the first-ever National Conference on Blood Disorders in Public Health. More than 350 federal, state, and local-level public health and medical professionals, health education and communications specialists, researchers, and policymakers attended the three-day conference. The event served as a catalyst for collaboration and the development of a nationally recognized public health framework promoting the health of and improved outcomes among people at risk for or affected by a blood disorder. Conference hosts included the Health Resources and Services Administration, the National Heart Lung and Blood Institute, the American Society of Hematology, and Hemophilia of Georgia.
- We completed a pilot inhibitor study in collaboration with Baxter Pharmaceuticals, Wyeth Pharmaceuticals, and our Universal Data Collection (UDC) system. While still in its initial stages, this study has already identified

several unique genetic mutations that might help identify which hemophilia patients have a higher risk for developing an inhibitor. These findings could have significant public health benefits – reducing treatment costs, the number of hospitalizations and co-morbidities, and improving the quality of life for people who have hemophilia.

- To learn more about hemochromatosis, an iron overload disorder in which extra iron gradually builds up in the body's tissues and organs, we funded the Medical University of South Carolina's survey of more than 5,000 adults who have been diagnosed with the condition.

### *Did you know?*

**Blood disorders pose an important challenge to the health and quality of life for women because of the relationship of these disorders to reproductive issues. These problems include heavy menstrual bleeding (termed menorrhagia), bleeding and clotting complications of pregnancy, and recurrent fetal loss.**

Investing in hemochromatosis research will help us gain a better understanding of how this diagnosis is made, leading to earlier detection and appropriate treatment.

- In 2010, we collaborated with the National Hemophilia Foundation (NHF) in launching a Harris Poll survey of 1,600 young women to learn more about their perceptions of menstrual periods and measure their awareness and recognition of a bleeding disorder. The survey findings are helping us determine and develop effective and innovative ways to reach young women and encourage the early diagnosis of a bleeding disorder such as von Willebrand disease.
- Diamond Blackfan Anemia (DBA) is a rare blood disorder characterized by a failure of the bone marrow (the center of the bone where blood cells are made) to produce red blood cells and is associated with birth defects and abnormal features. Four years ago, no educational materials existed for patients with this extremely rare, complex syndrome. NCBDDD, together with nurses from DBA resource centers and representatives from the DBA Foundation and the Daniella Maria Arturi Foundation, developed a patient brochure and a series of fact sheets about DBA for families. The fact sheets focus on specific

treatment options, information for brothers and sisters of children with DBA, a parenting corner, and lists of other available resources, information, and support.

### *Did you know?*

**Von Willebrand disease (VWD) affects up to 1 million Americans, in particular women, and is commonly associated with persistent heavy menstrual bleeding.**



## PERSONAL STORY

Jane Cavanaugh Smith has always been familiar with hemophilia. Her father had hemophilia and she herself is a carrier of the gene. What she was not prepared for, however, was the struggles of being a parent of a child with hemophilia. Her son Leland was also born with the hereditary bleeding disorder. When Leland was 15 months old, his condition was further complicated by the development of an inhibitor, an antibody that posed difficulties for his treatment.

“The complications of long-term damage to his joints, of pain, just general quality of life, that’s been by far the biggest challenge...from mom’s perspective...[it is] real tough to watch the pain,” says Jane. She is determined to stay positive and ensure that Leland, now a teenager, lives a full life.

Her sense of helplessness as a parent, watching her child forced to sit out and miss important life experiences, has only strengthened her commitment to stay optimistic for the sake of her son. Yet, with annual medical bills exceeding \$3 million, Jane also recognizes that it will take more than power of will to help her son through his struggles. Leland’s care team from an NCBDDD-supported Hemophilia Treatment Center has been instrumental in providing the family with the support and information needed to live with hemophilia.

Jane and her family also rely on the shared information provided by the community of families living with hemophilia. “...one of our most important resources is other families in the community. [There is] so much to learn from each other...there’s something that comes from the other people living with hemophilia, the been there, done that factor...little tips or little suggestions.” Involving families like Jane’s in identifying education needs to better manage the complications of hemophilia is a critical component of NCBDDD’s “Steps for Living” program developed through a cooperative agreement with the National Hemophilia Foundation.

The importance of learning from each other is why the work of NCBDDD’s Universal Data Collection system is important, gathering information on treatment, care, and other issues affecting people living with hemophilia. The increase of available information and focus on research is what gives many people with hemophilia and their families the inspiration to keep fighting. And for Jane and Leland, the strength to stay positive.



### *Did you know?*

**Hemophilia affects approximately 20,000 people with an average cost of care of more than \$100,000 per year (can exceed \$1 million annually for those with an inhibitor) and a total impact on the health care system in excess of \$3 billion per year.**



## LOOKING TO THE FUTURE

### IN 2011, OUR WORK WILL FOCUS ON ADVANCING OUR PRIORITIES:

**Priority 1.** Prevent clotting disorders – deep vein thrombosis and pulmonary embolism. Specifically, we will be:

- Developing and implementing DVT/PE surveillance by assessing the strengths and limitations of existing datasets and supporting innovative pilot projects that will enable us to identify effective approaches for DVT/PE surveillance.
- Collaborating with various professional and community-based organizations to craft campaigns and materials that will inform and educate the public while improving the evidence-based practice of providers on preventing DVT/PE.

**Priority 2.** Prevent and control complications resulting from hemoglobinopathies with a focus on sickle cell disease (SCD) and thalassemia. Specifically, we will be:

- Increasing the geographic coverage and scope of our surveillance activities to better understand the burdens, challenges, and needs of the SCD and thalassemia populations.
- Evaluating models of health service delivery for people with SCD and thalassemia.

- Collaborating with professional and community-based organizations to develop campaigns and materials that will inform and educate the public while improving the evidence-based practice of providers.

**Priority 3.** Prevent and control complications resulting from bleeding disorders such as hemophilia and von Willebrand disease. Specifically, we will be:

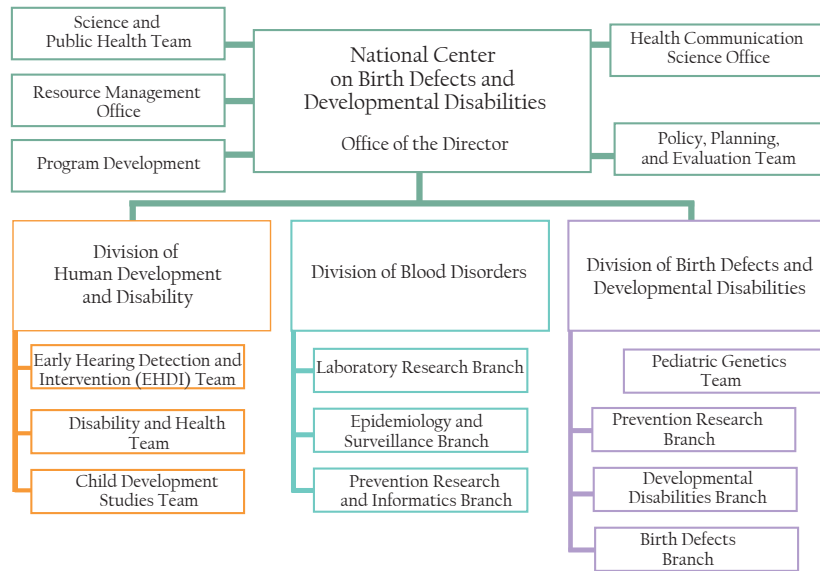
- Updating NCBDDD's current bleeding disorders surveillance system to collect information that will improve our research and prevention efforts.
- Identifying and increasing the use of intervention strategies to identify persons with hemophilia at highest risk for developing inhibitors.
- Collaborating with professional and community-based organizations to craft campaigns and materials that will inform and educate women about bleeding disorders and increase early identification and referral for care.

## NCBDDD ORGANIZATIONAL AND FINANCIAL LANDSCAPE

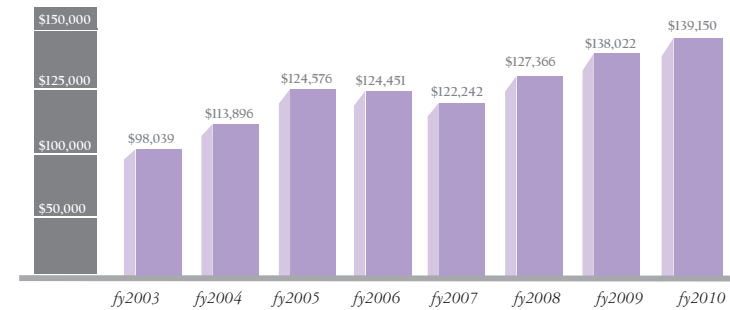
The Children's Health Act of 2000 established the National Center on Birth Defects and Developmental Disabilities. Our Center is organized into three divisions, which are focused on disabilities, birth defects and developmental disabilities, and blood disorders. Our Center is comprised of about **400 dedicated employees and contractors** working within multidisciplinary teams.

Below you will find information about our fiscal year 2010 budget as well as information about our budget trend since 2003.

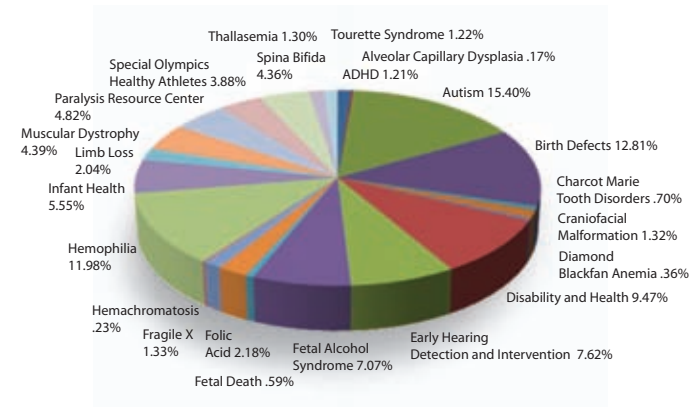
### NCBDDD ORGANIZATIONAL CHART



### NCBDDD APPROPRIATIONS HISTORY



### NCBDDD BUDGET AUTHORITY FY 2010 \$139.15M

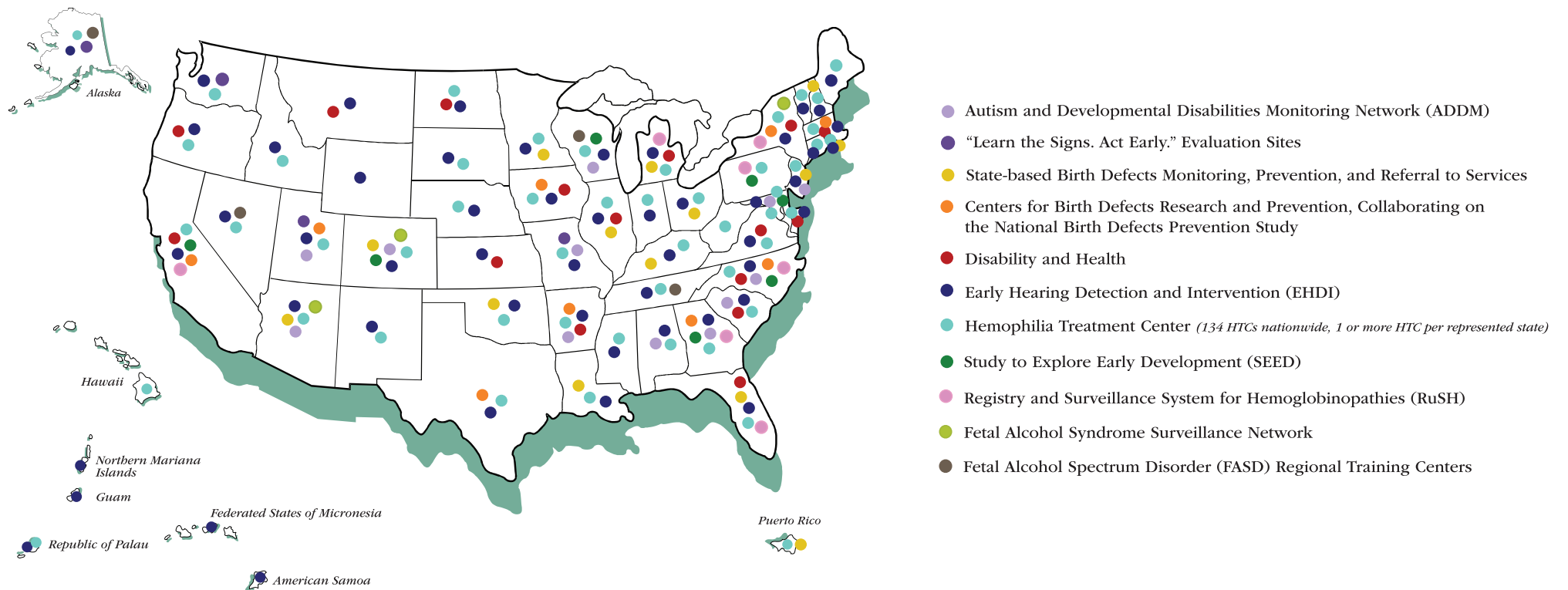


## A PICTURE OF NCBDDD'S REACH

The monitoring and research we conduct at NCBDDD impact the lives of people throughout the United States. Thanks to our collaborative

global initiatives, we are also touching lives in many other countries. Below is a map of some of our domestic monitoring and research activities.

### NCBDDD SELECT STATE-BASED ACTIVITIES



## NOTABLE 2010 NCBDDD SCIENTIFIC PUBLICATIONS

Each year, our scientists contribute to the development of numerous publications and articles demonstrating our commitment to advancing science. Below is a list of key publications that demonstrate the scientific scope of our work in 2010:

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[www.cdc.gov](http://www.cdc.gov)

National Center on Birth Defects and Developmental Disabilities  
Office of the Director

