



National Center on Birth Defects  
and Developmental Disabilities

# Strategic Plan 2017 - 2022

A roadmap to a world  
where babies are born healthy,  
children reach their potential,  
and everyone thrives.





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# Strategic Direction

## **Mission**

We work to save babies by studying and addressing the causes of birth defects; help children reach their potential by understanding developmental disabilities; reduce complications of blood disorders; and improve the health of people living with disabilities.

## **Vision**

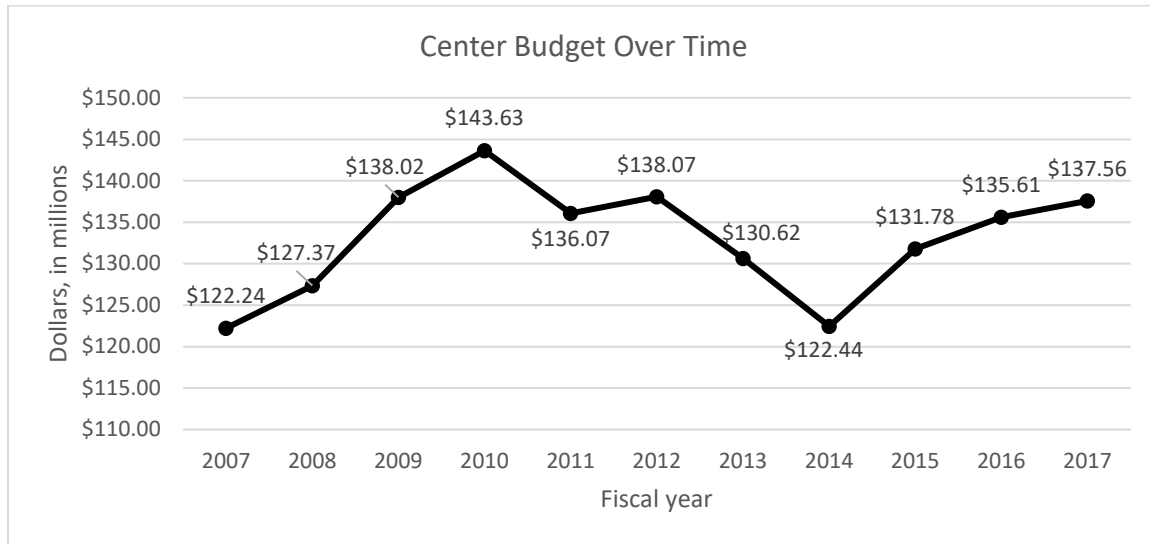
Babies are born healthy. Children reach their potential. And everyone thrives.

## **CDC Pledge to the American People**

1. Be a diligent steward of the funds entrusted to our agency.
2. Provide an environment for intellectual and personal growth and integrity.
3. Base all public health decisions on the highest quality scientific data that is derived openly and objectively.
4. Place the benefits to society above the benefits to our institution.
5. Treat all persons with dignity, honesty, and respect.

## **Context and Trends**

The National Center on Birth Defects and Developmental Disabilities was established at CDC in April 2001 as a result of the Children's Health Act of 2000. Currently, the center includes three divisions—the Division of Congenital and Developmental Disorders, the Division of Human Development and Disability, and the Division of Blood Disorders. While sister agencies and operating divisions have essential roles to play in helping Americans thrive, CDC's unique role includes detecting and responding to new and emerging health threats; tackling the biggest health problems causing death and disability for Americans; putting science and advanced technology into action to prevent disease; promoting healthy and safe behaviors, communities and environments; developing leaders and training the public health workforce, including disease detectives; and taking the health pulse of our nation. The center's budget peaked in FY 2010 at \$143.6 million.



The FY 2017 appropriated budget for the center is \$137.56 million dollars allocated across 19 specific funding lines:

<b>Child Health and Development</b>	<b>\$65,800,000</b>
Birth Defects	\$19,000,000
Fetal Death	\$900,000
Fetal Alcohol Syndrome	\$11,000,000
Folic Acid	\$3,150,000
Infant Health	\$8,650,000
Autism	\$23,100,000
<b>Health and Development with Disabilities</b>	<b>\$56,660,000</b>
Disability and Health	\$22,050,000
<i>Healthy Athletes Initiative (non-add)</i>	\$6,700,000
Tourette Syndrome	\$2,000,000
Early Hearing Detection and Intervention	\$10,760,000
Muscular Dystrophy	\$6,000,000
Attention Deficit Hyperactivity Disorder	\$1,900,000
Fragile X	\$2,000,000
Spina Bifida	\$6,000,000
Congenital Heart Failure	\$4,000,000
<b>Blood Disorders</b>	<b>\$15,100,000</b>
Public Health Approach to Blood Disorders	\$4,400,000
Hemophilia	\$3,500,000
Hemophilia Treatment Centers	\$5,100,000
Thalassemia	\$2,100,000
<b>Total</b>	<b>\$137,560,000</b>

NCBDDD's previous strategic plan covered the years 2011 to 2015. This new strategic plan will guide the center until 2022. It was formulated with the assumption that funding for current activities and staffing levels within the center will remain relatively stable, with the exception of a rise in resources at CDC for work related to responding to the ongoing threat from congenital Zika virus infection.

### **Approach**

The intention of this strategic plan is to provide an overarching map for our organization, marking where we want to be in the coming years and, at a high-level, describing how we plan to get there. This plan is meant to pair with division-maintained implementation plans and science agendas that will outline more granular plans for execution. The process of developing this strategic plan involved four phases: (1) developing a prototype plan based on existing documents that project our activities and objectives for the coming years; (2) soliciting additional content and strategic considerations through interviews with division leaders on strengths, weaknesses, opportunities, and threats; (3) developing aspirational goals through open group brainstorming; and (4) conducting multiple rounds of document review and revision engaging stakeholders throughout the center. In January 2017, the center's Executive Leadership Team was provided with an advanced draft of the strategic plan and asked to propose revisions. In May of 2017, the center's leadership adopted the strategic plan contained herein.

### **Maintenance**

This plan includes strategies designed to accelerate our impact and identifies intended outcomes. To track and monitor progress toward our outcomes, we will have corresponding tasks in the Annual Center Performance Plans maintained in a separate database. The center commits to conducting bi-annual assessments of the Annual Center Performance Plans to monitor progress toward our desired goals and outcomes and to identify and address complications early.

## Thematic Areas

The four thematic areas contained in this plan were established in 2014 to help communicate NCBDDD's breadth of work, by which the center's mission and vision is advanced through a special focus on people who are particularly under-protected from health risks:



### **Saving babies through birth defects prevention and research**

Every 4 ½ minutes, a baby is born with a major birth defect in the United States. That's 1 in 33 babies. Birth defects are structural changes in one or more parts of the body that are present at birth. Examples include heart defects, neural tube defects, microcephaly, and gastroschisis.



### **Helping children live to the fullest by understanding developmental disabilities**

Developmental disabilities are some of the most significant child health issues facing families and our nation today. About 1 in 6, or roughly 15%, of children aged 3 through 17 years have one or more developmental disabilities, such as attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), or hearing loss.



### **Protecting people and preventing complications of blood disorders**

Blood disorders - such as venous thromboembolism, hemophilia, and thalassemia - affect millions of people each year. Men, women, and children of all backgrounds live with the complications of these conditions, many of which are painful and potentially life-threatening.



### **Improving health of people with disabilities**

At any point in life, people can experience a disability. Functional disabilities can be acquired at birth or through illness, injury, or aging. They may include difficulty with walking or climbing stairs, making decisions, seeing or hearing, communicating, taking care of oneself, or living independently. Up to 57 million people are living with a disability in the United States today.



# Saving Babies

## Through Birth Defects Prevention and Research

### Background

Every 4 ½ minutes, a baby is born with a major birth defect in the US. That's about 1 in every 33 babies. Hospital costs for the treatment of birth defects are more than \$32 billion each year in the US, and birth defects cause 20% of all deaths in babies who die before their first birthday. Those who survive and live with a birth defect can have lifelong challenges, such as problems learning, playing, and interacting. Birth defects are caused by a range of genetic and environmental exposures (for example, alcohol use, Zika virus or other infections, or certain medications). CDC is committed to saving babies through birth defects prevention and research.

### Congressional Direction

In fiscal year 2017 CDC was appropriated \$42.7 million dollars to work on birth defects via the following budget lines: birth defects, fetal death, fetal alcohol spectrum disorders, folic acid, and infant health. Over the years, congressional direction has consistently supported surveillance, research, and prevention of birth defects. Congress has repeatedly noted CDC's leadership in assisting states in monitoring birth defects and encouraged CDC to expand the research being conducted by the regional Centers for Birth Defects Research and Prevention. A number of issues have been emphasized over the years, including promoting consumption of folic acid among women of reproductive age, researching the genetic and environmental causes of birth defects, expanding research on the link between medication use and adverse birth outcomes, and conducting prevention programs for fetal alcohol spectrum disorders.

### Summary of Progress

CDC is the world's leading organization in birth defects prevention and research. CDC's progress in saving babies has included accurately tracking birth defects and analyzing these data via the National Birth Defects Prevention Network and the Centers for Birth Defects Research and Prevention, which collaborate on large studies such as the National Birth Defects Prevention Study (NBDPS) and the Birth Defects Study To Evaluate Pregnancy exposureS (called BD-STEPS). Using data from NBDPS, CDC has identified many modifiable birth defect risk factors including the use of medications such as certain antibiotics and opioids. CDC has started to translate this knowledge into prevention activities to help women have healthy pregnancies. Building on the 36% reduction in neural tube defects in the US following folic acid fortification of enriched cereal grain products, CDC served as an instrumental partner in having folic acid added to corn masa flour primarily to reach Hispanic women. CDC has also helped lower-resource countries build their capacity for birth defects surveillance and for neural tube defect prevention through research in support of fortification strategies. With regard to fetal alcohol spectrum disorders, CDC has made great strides in implementing strategies to prevent exposure to alcohol during pregnancy, including training and systems-level support for healthcare professionals on alcohol screening and brief intervention approaches. In 2016 with the discovery that Zika virus was causally linked to microcephaly, CDC conducted outreach to clinicians and the public about protecting against Zika infection, issued clinical guidance for healthcare providers of pregnant women and women planning a pregnancy, educated women and providers about pregnancy in the context of Zika, and built Zika pregnancy registries and needed surveillance infrastructure.



## Strategic Aspiration

Despite our advances, there is still much work to be done to increase women’s chances of having a healthy baby:

- We still do not know the causes of most major birth defects that occur each year in the US, or how to prevent them.
- 1 in 10 pregnant women report using alcohol during the past 30 days, and 9 in 10 women report using one or more medications in pregnancy, despite the fact that we lack sufficient evidence on safety for 9 out of 10 medications.
- The majority of the world’s population today is not covered through folic acid fortification and efforts to implement fortification in lower-resourced countries face complex obstacles.

CDC will work steadfastly in the coming years to advance our science to inform and bolster individuals’ actions, support systems-level changes, and train future cohorts of experts to accelerate the prevention of birth defects.



Olivia, Age 8

## Pathways of Action

1

Prevent birth defects by reducing harmful exposures during pregnancy

- 1.1 Educate healthcare providers and women of reproductive age about ways to reduce harmful exposures of varying types and equip them with needed resources and tools
- 1.2 Increase use of alcohol screening and brief intervention approaches to reduce alcohol exposure in pregnancy

2

Prevent neural tube defects by increasing intake of folic acid among women of reproductive age worldwide

- 2.1 Monitor blood folate concentrations among women of reproductive age
- 2.2 Support effective implementation of food fortification with folic acid

3

Address critical data gaps regarding birth defects and their prevalence, distribution, and risk factors

- 3.1 Conduct targeted surveillance and monitoring to characterize the prevalence and distribution of major birth defects
- 3.2 Monitor known preventable or modifiable risk factors and conduct research to further understand their role in contributing to birth defects and the extent to which they might be minimized
- 3.3 Expand surveillance and research on emerging factors suspected to cause birth defects



## Helping Children

Live to the Fullest by Understanding Developmental Disabilities

### Background

Developmental disabilities are estimated to affect about 1 in 6 children. They include a diverse range of conditions that impact physical, learning, language, or behavior areas, begin during the developmental period, and usually last throughout a person's lifetime. For some developmental disabilities, we know the risk factors and causes. For many others, we do not. Early identification and intervention for developmental disabilities can have a significant impact on a child's ability to learn new skills as well as reduce the need for costly interventions over time. CDC is committed to helping children by understanding developmental disabilities.

### Congressional Direction

As of 2016, CDC was funded by Congress at a level of \$39.8 million dollars to work on five specific developmental disabilities: attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), fragile X syndrome, Tourette syndrome, and early hearing loss. Across these particular conditions, congressional direction has particularly emphasized improving awareness and early identification, supporting proper treatment for children living with developmental disabilities, and conducting research and surveillance. For ADHD in particular, congressional direction has emphasized early identification and proper treatment for the prevention of serious consequences as well as the need to provide information and educational tools. For ASD specifically, the focus of congressional direction has been support for epidemiological research, surveillance, and awareness efforts. Additional areas of interest that have received congressional support include early identification and the analysis of biological and genetic samples. For fragile X syndrome, Congress has encouraged CDC to expand surveillance and the epidemiological study of fragile X, as well as provide patient and provider outreach on fragile X. For Tourette syndrome, Congress has encouraged CDC to establish research programs to expand the scientific knowledge base on prevalence, risk factors, and co-morbidities of Tourette syndrome as well as public health education for parents, physicians, educators, and other health care workers about Tourette syndrome. For early hearing loss, congressional language has consistently emphasized supporting states with the development of newborn hearing screening systems and ensuring infants are referred from screening to receive appropriate diagnostic and early intervention services.

### Summary of Progress

CDC's tracking systems have helped provide an accurate picture of developmental disabilities across the US. One such system is the Autism and Developmental Disabilities Monitoring (ADDM) Network, which documented a rise in identified ASD prevalence from 1 in 150 (2007 report) to 1 in 68 (2015 report). Similarly, CDC's developmental disability research programs like the Study to Explore Early Development (SEED) have documented key findings about developmental disabilities, such as an association between ASD risk and hypertension and excessive weight gain in pregnancy. Through projects like SEED, CDC conducts research to better understand the risk factors, attributes, and outcomes associated with developmental disabilities. CDC also applies these data to raise awareness and drive early identification and intervention programs, such as the *Learn the Signs. Act Early.* campaign and the Early Hearing Detection

and Intervention (EHDI) program. Strides in early identification and awareness include that children born in 2006 received a comprehensive developmental evaluation 5 months earlier than children born in 2002 and that over 97% of newborns are now screened for hearing loss. CDC efforts to help children and their families get the services and supports they need have also included raising awareness of recommended ADHD treatment through a Vital Signs article that reached over 17 million readers and developing National Quality Forum-endorsed quality measures to improve early hearing care provision.

### Strategic Aspiration

Despite our advances, there is still much work to be done to help children with developmental disabilities thrive:

- Even though ASD can be diagnosed as early as age 2 years, most children are not diagnosed until after age 4 years. There are also important disparities as children with ASD who are of minority race/ethnicity or low socioeconomic status receive their initial evaluations later.
- Only 63% of jurisdictions collect, report, and use individually identifiable data in order to reduce the number of infants not passing hearing screening that are lost to follow-up.
- Only 41% of US children aged 2-5 years with a diagnosis of ADHD receive behavioral therapy (psychological services) for treatment, despite it being the American Academy of Pediatrics' recommended treatment.

In the coming years, CDC will work to better understand developmental disabilities to help children live to the fullest.



Rivers, Age 5

## Pathways of Action

1

Raise awareness of developmental disabilities and improve the proportion of young children who receive early identification and intervention

- 1.1 Educate parents, healthcare providers, and early educators about the importance of monitoring each child's development and acting early on concerns
- 1.2 Fund and provide technical assistance to states to screen all babies for hearing loss by 1 month and follow-up with those who do not pass by 3 months
- 1.3 Develop and promote quality measures to monitor and promote early identification and intervention

2

Inform and improve services and supports for children living with developmental disabilities

- 2.1 Increase the use of best practices in care and management of developmental disabilities, including childhood mental and behavioral health conditions
- 2.2 Provide information to states about the impact and cost-effectiveness of early intervention services, including those for early hearing loss
- 2.3 Provide information about the prevalence and distribution of ASDs in communities to inform the allocation of services and supports

3

Address critical data gaps regarding developmental disabilities such as ASD, ADHD, and hearing loss and their prevalence, distribution, risk factors, and outcomes

- 3.1 Conduct targeted surveillance and monitoring to characterize the prevalence and distribution of priority developmental disabilities
- 3.2 Conduct research on risk factors, outcomes, and the impact of services
- 3.3 Expand surveillance and research to additional developmental disabilities, particularly those associated with infectious causes of birth defects and developmental disabilities, including Zika



# Protecting People

## and Preventing Complications of Blood Disorders

### Background

Blood disorders affect millions of people each year in the US, cutting across the boundaries of age, race, sex, and socioeconomic status. Within the domain of blood disorders, CDC focuses particularly on bleeding disorders (like hemophilia), clotting disorders (like venous thromboembolism), and inherited red cell disorders (like thalassemia). Men, women, and children of all backgrounds live with the complications associated with these conditions, many of which are painful and potentially life threatening. While some blood disorders are passed down in families, others can be prevented. At current time, people in the US with bleeding, clotting, and inherited red cell disorders have reduced life expectancy and health-related quality of life compared to people without such disorders.

### Congressional Direction

In fiscal year 2017, CDC was appropriated \$15.1 million for blood disorders. Over the years, Congress has expressed support for research, surveillance and outreach to address key blood disorders, including bleeding disorders, thalassemia, clotting disorders, and hemoglobinopathies. Appropriations language has particularly emphasized support to maintain and expand the surveillance and research activities of the national network of Hemophilia Treatment Centers and CDC's national outreach and prevention programs on hemophilia. New appropriations language in 2017 encouraged CDC to also pilot ways to help people living with Hereditary Hemorrhagic Telangiectasia (HHT).

### Summary of Progress

CDC's progress in blood disorders over the past several years has established a solid foundation toward achieving our goals. CDC reached more than 70 million people with information about venous thromboembolism prevention and risk factors through the "Stop the Clot. Spread the Word." Campaign. We identified promising systems-level practices through an HHS Competes Challenge that uncovered best venous thromboembolism prevention practices at hospital systems around the world. CDC has also combated hemophilia complications by establishing a baseline rate of routine treatment inhibitor screening and pushing toward a goal rate of 100% screening in hemophilia treatment centers. With regard to surveillance and research, CDC provided the first-ever state-specific prevalence and characteristic information on people with sickle cell disease through the Registry and Surveillance System for Hemoglobinopathies and continues to fortify its Community Counts bleeding disorders surveillance system and to test methods for venous thromboembolism surveillance. For thalassemia, has worked to improve the quality of care that patients receive and decrease complications including those related to frequent transfusions.

### Strategic Aspirations

Although we have made many advances, there is still much work to be done to protect people and prevent complications of blood disorders:

- Despite the availability of known ways to reduce risk factors for venous thromboembolism they still affect as many as 900,000 people each year in the United States, killing up to 30% of them.
- Hemophilia treatment inhibitors, which are antibodies to the product used to treat or prevent bleeding episodes, are all-too-common, costly, and burdensome complications that can also result in limitation in physical activity that further compromise a person's health.
- The US still does not have nationally representative data on sickle cell disease, despite the fact that this condition reduces life expectancy by up to 30 years.
- People with thalassemia, who receive frequent blood transfusions, are at risk for iron overload. Red blood cells contain a lot of iron, and over time, the iron from all of the transfusions can build up in the body. When it builds up, the iron collects in places like the heart, liver, and brain, and can make it hard for these organs to work properly.

CDC will continue its work in blood disorder surveillance, research, and primary and secondary prevention in pursuit of our long-term goal of protecting people and preventing complications of blood disorders.



Rivers, Age 5

## Pathways of Action

### 1

#### Prevent venous thromboembolism

- 1.1 Conduct outreach and education on venous thromboembolism targeting healthcare providers and at-risk populations
- 1.2 Inform clinical decision-making and health system practices that can help prevent venous thromboembolism

### 2

#### Reduce complications of blood disorders

- 2.1 Provide inhibitor screening and support the dissemination of inhibitor screening methods to hemophilia treatment centers and labs
- 2.2 Increase the use of best practices in hemophilia care and management for the prevention of inhibitors and other complications
- 2.3 Increase the use of best practices in hemoglobinopathies care and management for the prevention of complications

### 3

#### Address critical data gaps regarding blood disorders and their prevalence, distribution, risk factors, and outcomes

- 3.1 Conduct targeted surveillance and monitoring to characterize the prevalence and distribution of blood disorders
- 3.2 Increase the proportion of hemophilia treatment centers participating in Community Counts that provide high quality data on all patients enrolled
- 3.3 Scale implementation and evaluation of venous thromboembolism surveillance modules in more hospital and electronic health record systems
- 3.4 Assess risk factors for venous thromboembolism as well as risk factors for blood disorder complications





## Improving Health for People with Disabilities

### Background

Up to 56 million Americans live with a disability. There are many types of disabilities that affect human development, functioning, and activity. Some are related to hearing, seeing, or moving, others to thinking and remembering, learning and applying knowledge, communicating, controlling thoughts, or interacting and socializing. Disabilities are associated with approximately \$400 billion in healthcare costs each year. People with disabilities can, and should, have the same opportunity for good health as people without disabilities. Currently, however, people with disabilities are more likely than others to be physically inactive, smoke, and have difficulty accessing preventive health services. CDC is committed to reducing these disparities and improving the health of people who live with disabilities.

### Congressional Direction

In fiscal year 2017, Congress appropriated \$40 million to improving the health of people with disabilities via the following budget lines: disability and health, muscular dystrophy, spina bifida, and congenital heart disease. Congress has directed CDC to work on complex disabling medical conditions (including muscular dystrophy, spina bifida, and congenital heart defects) and on general disability health promotion and disease prevention for people living with disabilities. Specific emphases from Congress for muscular dystrophy include expanding surveillance, research, newborn screening, and standards of care. For spina bifida, congressional direction focuses on conducting surveillance and research, providing a resource center, improving care in the nation's spina bifida clinics, and mitigating the secondary effects of spina bifida by informing medical care. For congenital heart defects, congressional direction emphasizes gathering rigorous epidemiological and longitudinal data on individuals of all ages who are living with the condition. Congress has also supported activities to inform health promotion programs for persons with disabilities, including those with intellectual disability, and to support states and public health research centers to reduce the health risk factors for individuals living with disabilities.

### Summary of Progress

CDC's progress in improving health of people with disabilities has included gathering data on Duchenne and Becker muscular dystrophy through the Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet) and applying these data to deliver guidance for high-quality treatment such as MD Care Considerations, the Motor Developmental Delay Tool, and interventions promoting longer ability to walk. CDC has also gathered data on thousands of people living with spina bifida through the National Spina Bifida Registry and used these data to determine the most effective care for young children with spina bifida, especially practices to preserve renal function. In addition, CDC has published updated national estimates of the number of individuals living with congenital heart defects in the US, highlighting that adults with congenital heart defects now outnumber children and providing impetus for planning health services delivery.

Another key focus has been strengthening the evidence base on public health interventions that are effective at promoting the health of people with many disability types, and sharing these findings through publications and an evidence-based strategy menu to communicate the best ways we know how to improve the health of people living with disabilities (e.g. Public Health Strategies to Improve the Health of

Individuals with Disabilities, Living Well with a Disability, and GRAIDS – Guidelines, Recommendations, Adaptations, Including Disability).

### Strategic Aspirations

When children and adults with disabilities receive needed programs, services, and health care across their lifespan, they can reach their full potential, experience fewer health complications, have an improved quality of life, and experience independence. Today, many gaps still remain:

- Duchenne muscular dystrophy (the most common muscular dystrophy in children) often results in loss of ambulation between ages 7 and 13 years and death in the teens or 20s.
- The majority of people living with spina bifida experience impaired bladder function that can lead to kidney damage, and about 14% have experienced a pressure ulcer within the past year.
- At this time, even with improved treatments, many people with a CHD are not cured, even if their heart defect has been repaired. As a person with a heart defect grows and gets older, further heart problems may occur. Additional medications, surgeries, or other procedures may be needed after the initial childhood surgeries.
- Adults with disabilities have three times the risk of heart disease, diabetes, and cancer.

CDC will work to address these gaps and continue improving health of people living with disabilities.



Leona, Age 5

## Pathways of Action

### 1

#### Promote the health of people living with disabilities

- 1.1 Provide expertise to other parts of CDC and grantees on the inclusion of people with disabilities in public health promotion and protection initiatives
- 1.2 Fund and provide expertise to states to conduct health promotion and protection interventions for people living with disabilities
- 1.3 Fund and provide expertise to National Centers on Disability to address select health risk factors, particularly for people living with intellectual disability or mobility limitations

### 2

#### Reduce complications of select genetic disorders and birth defects, including muscular dystrophy, spina bifida, and congenital heart defects

- 2.1 Promote use of quality benchmarks identified in the muscular dystrophy care considerations
- 2.2 Increase uptake of key health care best practices in spina bifida such as skin breakdown preventive care and use of the spina bifida urologic protocol
- 2.3 Inform the prevention of long-term complications for people with congenital heart defects

### 3

#### Address critical data gaps regarding disabilities and their prevalence, distribution, risk factors, and outcomes

- 3.1 Conduct targeted surveillance and monitoring to characterize the prevalence and distribution of disabilities
- 3.2 Make disability data available to partners and stakeholders and encourage their use to inform policy and programs
- 3.3 Assess health status, outcomes, needs, costs, and leading health risks for people with disabilities
- 3.4 Inform the evidence base for which health promotion interventions are most effective for people with disabilities