

ENHANCING THE POTENTIAL FOR FULL AND PRODUCTIVE LIVING

The health and economic impact of infant and child health issues, bleeding disorders, and disabilities compels CDC to prioritize the promotion of health and well-being across the life-course. Recent estimates suggest that health care expenditures associated with disability were \$397.8 billion for 2006 alone, representing over a quarter of adult health care spending for that year.²⁶ CDC works to prevent birth defects, improve understanding of developmental disabilities, and promote the health of people with disabilities through surveillance, population-based epidemiology, and prevention efforts.

EPIDEMIOLOGY

Among women who may become pregnant, 69 percent do not take folic acid supplements, and during pregnancy, 11 percent smoke and about 10 percent consume alcohol. These behaviors contribute to poor birth outcomes in the United States where three percent of infants are born with major birth defects, the leading cause of infant mortality. Today, however, many children with birth defects are living longer and into adulthood. Over their lives they may face challenges to maximizing their health, development, and full participation in society. Overall, as children and adolescents mature into adulthood, the number reporting disabilities increases. In 2005, 22 percent of American adults, about 53 million individuals, reported having a disability.

Developmental disabilities affect approximately 13 percent of U.S. children, and can influence language, mobility, and learning. The most common developmental disabilities in the United States are intellectual disabilities, autism, and cerebral palsy. Children do not outgrow these conditions, and may require life-long support.

Bleeding disorders are also significant public health issues that can lead to ongoing health problems and functional limitations. For instance, some studies estimate that as many as two million women suffer from an undiagnosed bleeding disorder. It is estimated that 60 percent of these women, if properly diagnosed, could be treated non-invasively and avoid unnecessary surgical procedures, like hysterectomies.

HEALTH DISPARITIES/SOCIAL DETERMINANTS

While birth defects, developmental disabilities, blood disorders, and disabilities are cross-cutting in our society, certain groups are disproportionately affected. Data from the 2000 U.S. Census indicated that 33 percent of Americans with disabilities were from racial or ethnic minority groups, though these groups comprised only 25 percent of the population. This disparity is compounded by the fact that people with disabilities in general have higher rates of disease, fewer treatment options, more unhealthy behaviors, and less access to quality medical services and health promotion programs than do persons without disabilities.

EVIDENCE-BASED INTERVENTIONS

Effective measures exist to alleviate the health and economic burdens of these conditions. CDC supports states and localities, academic institutions, and other partners to develop best practices and evidence-based priorities. CDC also conducts evaluation and surveillance to collect high-quality data that can inform our efforts to improve health. Noted below are selected examples of best practices supported by CDC.

- MD STARnet is a research network developed to identify those with Duchenne or Becker muscular dystrophy (DBMD) born after 1981 in five locations in the country. The goals of the project are to estimate DBMD national prevalence and gather medical information to identify treatment options.

²⁶ Anderson, W. L., Armour, B. S., Finkelstein, E. A., & Wiener, J. M. (2010). Estimates of state-level health-care expenditures associated with disability. *Public Health Reports*, 125(1), 44-51.

NARRATIVE BY ACTIVITY
 ENHANCING THE POTENTIAL FOR FULL AND PRODUCTIVE LIVING
 BUDGET REQUEST

- In collaboration with the Iowa and Georgia Public Health Departments, CDC is conducting enhanced surveillance of stillbirths, building on existing birth defects surveillance infrastructures. CDC has published information on the challenges and priorities for stillbirth surveillance to guide future activities.
- CDC entered into an interagency agreement with the National Heart Lung and Blood Institute (NHLBI) to support the Registry and Surveillance System in Hemoglobinopathies (RuSH) project, which is a state-based data system, registry, and biospecimen repository that will provide data to describe the epidemiologic and clinical characteristics of people with hemoglobinopathies.

PROGRAM ACTIVITIES TABLE

(Dollars in Thousands)	FY 2009 Appropriation	FY 2009 Recovery Act	FY 2010 Appropriation	FY 2011 President's Budget Request	FY 2011 +/- FY 2010
Birth Defects, Developmental Disabilities, Disability and Health	\$138,022	\$0	\$143,368	\$143,539	+\$171
Birth Defects and Developmental Disabilities	\$62,459	\$0	\$64,697	\$65,442	+\$745
Birth Defects	\$21,123	\$0	\$21,342	\$20,819	-\$523
<i>Craniofacial Malformation (non- add)</i>	\$1,750	\$0	\$1,878	\$1,882	+\$4
<i>Fetal Death (non-add)</i>	\$844	\$0	\$846	\$848	+\$2
<i>Alveolar Capillary Dysplasia (non- add)</i>	\$246	\$0	\$247	\$0	-\$247
Fetal Alcohol Syndrome	\$10,112	\$0	\$10,140	\$9,990	-\$150
Folic Acid	\$2,818	\$0	\$3,126	\$3,110	-\$16
Infant Health	\$8,006	\$0	\$8,028	\$7,696	-\$332
Autism	\$20,400	\$0	\$22,061	\$23,827	+\$1,766
Human Development and Disability	\$55,706	\$0	\$58,759	\$57,854	-\$905
Disability and Health (includes Child Development Studies)	\$13,572	\$0	\$13,611	\$13,361	-\$250
Charcot Marie Tooth Disorders	\$0	\$0	\$1,000	\$1,002	+\$2
Limb Loss	\$2,898	\$0	\$2,906	\$2,908	+\$2
Tourette Syndrome	\$1,744	\$0	\$1,749	\$1,749	\$0
Early Hearing Detection and Intervention	\$10,858	\$0	\$10,888	\$10,689	-\$199
Muscular Dystrophy	\$6,274	\$0	\$6,291	\$6,021	-\$270
Special Olympics Healthy Athletes	\$5,519	\$0	\$5,534	\$5,545	+\$11
Paralysis Resource Center (Christopher Reeve)	\$5,727	\$0	\$6,882	\$6,886	+\$4
Attention Deficit Hyperactivity Disorder	\$1,746	\$0	\$1,751	\$1,755	+\$4
Fragile X	\$1,900	\$0	\$1,905	\$1,909	+\$4
Spina Bifida	\$5,468	\$0	\$6,242	\$6,029	-\$213
Public Health Approach to Blood Disorders	\$0	\$0	\$0	\$20,243	+\$20,243
Blood Disorders	\$19,857	\$0	\$19,912	\$0	-\$19,912
Hemophilia	\$17,155	\$0	\$17,203	\$0	-\$17,203
Thalassemia	\$1,860	\$0	\$1,865	\$0	-\$1,865
Diamond Blackfan Anemia	\$516	\$0	\$517	\$0	-\$517
Hemochromatosis	\$326	\$0	\$327	\$0	-\$327

BIRTH DEFECTS, DEVELOPMENTAL DISABILITIES, DISABILITY AND HEALTH

SUMMARY OF THE REQUEST

CDC requests \$143,539,000 for birth defects, developmental disabilities, and disability and health in FY 2011, an increase of \$171,000 above the FY 2010 Omnibus. FY 2011 funds will support CDC’s work to prevent birth defects and other disabilities, minimize the health impact of birth defects and developmental disabilities, and promote health among all people with disabilities.

The FY 2011 budget request for birth defects, developmental disabilities, and disability and health will support the major activities noted below.

- CDC requests \$65,442,000 for birth defects and developmental disabilities in FY 2011, an increase of \$745,000 above the FY 2010 Omnibus.
 - The request for birth defects and developmental disabilities includes an increase of \$1,766,000 for Autism.
- CDC requests \$57,854,000 for human development and disability in FY 2011, a decrease of \$905,000 below the FY 2010 Omnibus, which is inclusive of contract and travel savings (Please see page 17 for more information).
 - CDC’s request includes a request of \$1,002,000 for Charcot Marie Tooth Disorders and \$1,749,000 for Tourette Syndrome.
- CDC requests \$20,243,000 for a program realignment in FY 2011 that focuses a public health approach to blood disorders.

(Dollars in Thousands)	FY 2009 Appropriation	FY 2009 Recovery Act	FY 2010 Appropriation	FY 2011 President’s Budget Request	FY 2011 +/- FY 2010
Budget Authority	\$138,022	\$0	\$143,368	\$143,539	+\$171
PHS Evaluation Transfers	\$0	\$0	\$0	\$0	\$0
Total	\$138,022	\$0	\$143,368	\$143,539	+\$171
FTEs	186	0	187	181	-6

AUTHORIZING LEGISLATION

PHSA §§ 301, 307, 310, 311, 317, 317C, 317J, 327, 352, 399G, 399H-J, 399M, 399Q, 1102, 1108

PHSA Title IV

FY 2010 Authorization.....Expired/Indefinite

Allocation Method.....Direct
Federal/Intramural; Competitive Grants, Cooperative Agreements and Contracts

PROGRAM DESCRIPTION

Fifty-four million people in the United States have a birth defect or disability and the number is rising. CDC has established monitoring and research programs that serve as models for state and local public health departments. CDC coordinates epidemiologic research efforts and provides technical assistance to states on surveillance for birth defects and developmental disabilities. CDC’s birth defects and disability prevention activities are conducted in three priority areas: 1) assure child health, 2) improve health of those with a disability, and 3) public health approach to blood disorders.

MECHANISMS AND FUNDING HISTORY TABLE

Ten percent of birth defects, developmental disabilities, and disability and health funds are administered through cooperative agreements with 49 states as well as contracts with NGOs and CBOs. An additional 46 percent of CDC’s birth defects and prevention funds are allocated through 139 cooperative agreements with academic research centers, hospitals, and other non-profit organizations. CDC estimates that 44 percent of birth defects and disabilities funding is spent on intramural research, surveillance, personnel, and programmatic costs.

Fiscal Year	Amount
FY 2006	\$124,451,000
FY 2007	\$122,242,000
FY 2008	\$127,366,000
FY 2009	\$138,022,000
FY 2010	\$143,368,000

Budget Request: Assure Child Health

CDC works to assure child health through a range of activities that address maternal, infant, and child health. Preparation for a healthy life starts before birth, and the health of the expectant mother impacts her child’s later health and life outcomes. Research shows that experiences in the earliest years of life play a critical role in a child’s ability to grow up healthy and ready to learn.

Good nutrition, healthy pregnancy, safe and nurturing parental relationships, and early intervention boost a child’s health and development. FY 2011 funds will support CDC’s work to assure child health through the following activities: 1) promote preconception health among women of childbearing age; 2) research and monitor birth defects and developmental disabilities; and, 3) promote early identification and intervention.

The FY 2011 request supports the President’s goal to expand support for children, families and communities affected by autism spectrum disorders. CDC’s FY 2011 request includes a \$1.8 million increase for Autism. The increase will be used to support the education and awareness campaign, “Learn the Signs. Act Early,” and to expand monitoring and surveillance. Additional information about CDC’s Autism activities is located in the following sections: Research and Monitor Birth Defects and Developmental Disabilities, and Promote Early Identification and Intervention.

Promote Preconception Health

In FY 2011, CDC will continue to support activities that promote preconception care. While not all birth defects and developmental disabilities are preventable, certain high-risk maternal behaviors reduce the chances of having a healthy baby. Two high-risk behaviors—inadequate consumption of folic acid and alcohol use during pregnancy—can lead to spina bifida and fetal alcohol syndrome (FAS), respectively. Evidence indicates that reducing these two high-risk maternal behaviors through work to promote preconception health can effectively decrease preventable birth defects. CDC will work to target folic acid consumption and maternal alcohol use during pregnancy through the activities noted below.

- By September 2011, CDC will issue recommendations on corn masa flour fortification and/or the concentration of folic acid in wheat flour fortification.
- CDC will expand a targeted health education program to promote folic acid consumption in predominantly Hispanic communities to encourage preconception folic acid supplementation among Hispanic women of childbearing age.
- In FY 2011, CDC will implement the Atlanta FAS Surveillance Pilot Project in five Atlanta counties to collect population-based information on the occurrence of FAS and determine the feasibility of collecting these data using existing surveillance infrastructure.

- CDC will fund four states to conduct population-based surveillance of FAS to develop the preliminary population-based prevalence estimates of FAS.

Rationale and Recent Accomplishments: Despite the 26 percent reduction in spina bifida and anencephaly that has occurred since fortification of the cereal grain supply with folic acid in 1998, Hispanic Americans continue to have a higher prevalence of neural tube defects (NTDs). A comprehensive review by “The Community Guide” recommends both fortification of food products and community-wide campaigns to increase folic acid supplement use as effective interventions to reduce the number of pregnancies affected by neural tube defects. CDC’s work in preconception health targets this disparity in total folic acid intake, particularly among newly immigrant populations, where the NTD risk is highest. Recent CDC accomplishments in assuring child health include the following activities discussed below.

- In 2009, CDC conducted an analysis, which suggests that fortification would effectively target Mexican American women without substantially increasing folic acid intake among other populations.
- In 2009, CDC released a preliminary analysis that estimates the number of NTDs that may be averted with additional fortification of corn masa flour.

Prenatal alcohol exposure is a leading preventable cause of birth defects and developmental disabilities. In the United States, approximately 12 percent of pregnant women report alcohol use and two percent report binge drinking in the past 30 days. This percentage translates to approximately 480,000 alcohol-exposed pregnancies, roughly 80,000 of which are exposed to binge drinking. Selected information on CDC’s recent accomplishments to reduce the number of alcohol-exposed pregnancies is noted below.

- CDC established baseline rates of screening and intervention practices among key healthcare providers, in order to identify women at risk of alcohol-exposed pregnancies.
- CDC implemented the Atlanta FAS Surveillance Pilot Project in five Atlanta counties. As a result, progress was made on developing methodologies to more accurately estimate the prevalence of FAS.

Health Impact: CDC anticipates that the FY 2011 preconception care activities will result in: 1) 0.1 percent decrease in the birth prevalence of folic acid-preventable spina bifida and anencephaly among Hispanics, and 2) 0.5 percent increase in provider-based screening and intervention for FAS among at-risk women of childbearing age. Based on previous fortification efforts, it is anticipated that a 0.1 percent decrease in the birth prevalence of folic acid-preventable spina bifida and anencephaly among Hispanics will result in a decrease in spina-bifida affected births among Hispanic women. *(Please see output 6.C and outcomes 6.1.3-6.1.4 for specific information.)*

Research and Monitor Birth Defects and Developmental Disabilities

Every four and a half minutes a baby is born with a birth defect in the United States, yet the major causes of most birth defects and developmental disabilities remain unknown. With nearly 70 percent of birth defects having unknown causes, CDC uses epidemiologic research to identify risk factors (e.g. genetic, environmental, medical) that contribute to birth defects and developmental disabilities. In FY 2011, funding will support the research and monitoring of birth defects and developmental disabilities as noted below.

- CDC will collect data from eight National Birth Defects Prevention Study (NBDPS) sites on priority birth defects for which there is no currently-known cause and conduct analyses of maternal exposures such as medications used during pregnancy for maternal conditions and occupational exposures.
- CDC will support expedited analyses in the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) and analysis of biologic and genetic samples in order to research the of causes of autism.

- CDC will complete data collection on 2,500 families for the Study to Explore Early Development (SEED) in the six Centers for Autism and Developmental Disabilities Research and Epidemiology. CDC anticipates the release of SEED data analysis in FY 2012. SEED, the largest study of its kind, will explore a number of priority hypotheses, such as the role of infections and genetic, reproductive, and hormonal factors in Autism Spectrum Disorders (ASD) etiology. The study to help CDC learn more about the characteristics of children with ASDs, factors associated with developmental delays, and how genes and the environment may affect child development.
- CDC will expand the Autism and Developmental Disabilities Monitoring (ADDM) network to 17 sites. This expansion will increase the accuracy of population-based estimates of developmental disabilities as well as increase CDC's ability to monitor the occurrence of developmental disabilities in certain segments of the population. For example, the expansion will allow CDC to more effectively monitor younger children in order to improve ascertainment of autism spectrum disorders at younger ages. Additionally, the site expansion will allow CDC to more effectively monitor other developmental disabilities, such as cerebral palsy.

Rationale and Recent Accomplishments: CDC's birth defects and developmental disabilities monitoring provides reliable, population-based estimates of the number of infants affected by birth defects and school-aged children with developmental disabilities. These estimates are used to track the progress of intervention efforts and to plan for health and educational services. Recently, funds supported a range of successful research and monitoring activities, several of which are noted below.

- In 2009, CDC released the first-ever population-based prevalence estimates for cerebral palsy (surveillance years 2002 and 2004). These estimates will serve as meaningful baselines for understanding cerebral palsy prevalence in the future.
- CDC worked to inform health care providers about the risk of certain birth defects through the dissemination of more than 10 reports from the NBDPS on risk factors for birth defects, such as maternal smoking, obesity, and antidepressant use during pregnancy.
- In 2009, CDC restored three ADDM sites bringing the total number of ADDM sites from 11 to 14. As a result of the site restoration, CDC will be able to evaluate trends over time, across multiple geographic regions of the United States.
- In 2009, CDC released Autism prevalence data for surveillance years 2004 and 2006. These data provide key information on the prevalence of Autism Spectrum Disorders (ASDs) in the U.S. and trends over time.

Health Impact: CDC anticipates that FY 2011 birth defects and developmental disabilities activities will: 1) improve the quality and usability of birth defects monitoring data and 2) increase knowledge of the role of modifiable risk factors for birth defects and a statistically powerful data sample for developmental disabilities research. With the increase in the number of ADDM sites CDC will be available to monitor other developmental disabilities, such as cerebral palsy and that monitor younger children, in order to improve ascertainment of autism spectrum disorders at younger ages. FY 2011 funds will support expedited analyses in the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) and analysis of biologic and genetic samples in order to determine the of causes of autism. *(Please see outputs 6.B, and 6.D-6.E and objectives 6.1.1- 6.1.2 for specific information.)*

Promote Early Identification and Intervention

In FY 2011 CDC will work to promote early identification and intervention for birth defects and developmental disabilities. The early years of a child's life are crucial for cognitive, social, and emotional development. Children who grow up in environments where their developmental needs are not met are at an increased risk for compromised health, safety, learning and developmental delays. Early detection of developmental issues and appropriate intervention can significantly improve health outcomes in children.

CDC works to maximize all children's potential through: 1) early identification and interventions for children at-risk for developmental problems; 2) implementation of newborn screening to identify children with hearing loss and selected metabolic and genetic disorders; and, 3) awareness and identification of disabilities. Key activities to promote early identification and intervention are described below.

- CDC will continue "Learn the Signs. Act Early," a campaign aimed at increasing awareness of childhood developmental milestones, warning signs of autism and other developmental disabilities, and the importance of early action and intervention on developmental concerns.
- To address the 12,000 babies anticipated to be born with hearing loss in FY 2011, CDC will support state and territory public health departments and universities for the development and implementation of state and territory Early Hearing Detection and Intervention (EHDI) programs and surveillance systems. While the cause of hearing loss for many babies is unknown, and the EDHI program detects hearing loss early so that infants and children with hearing loss are found and receive help (e.g., intervention) as soon as possible.
- The FY 2011 request includes a program elimination of \$249,000 for Alveolar Capillary Dysplasia. CDC is gradually implementing a population-based comprehensive approach to address this condition rather than a disorder-specific approach.

Rationale and Recent Accomplishments: Recent studies have estimated that the lifetime cost to care for an individual with an Autism Spectrum Disorder is \$3.2 million. In the U.S. 13 percent of children have a developmental disability such as autism, mental retardation or AD/HD. However, less than 50 percent are identified before entering school, by which time significant time delays may have occurred and opportunities for treatment have been missed. CDC has promoted early identification and screening through activities noted below.

- Through the "Learn the Signs. Act Early." campaign, CDC supported the distribution of 171,000 resource kits to more than five million health care professionals, 46 million parents, and 140,000 child care providers. Pediatricians exposed to the campaign are more likely to believe that autism can be diagnosed as early as age 18 months and less likely to encourage a parent to "wait and see" if a developmental concern improves on its own. The campaign is reaching its goal of encouraging target audiences to "Learn the Signs." For example, about one out of two pediatricians and one out of four parents are aware of the campaign. CDC and its partners have distributed more than 203,000 resource kits for parents, health care professionals, child care providers and other early educators.
- Approximately 94 percent of U.S. births in 2007 were screened for hearing loss leading to the detection of approximately 67,659 children who did not pass their screening. Of those not passing, 4,016 were documented to have moderate to profound bilateral hearing loss.
- CDC funded 46 states/territories to develop or enhance a sustainable state-based EHDI tracking and surveillance system and to integrate the EHDI system with other state/territorial screening, tracking, and surveillance programs that identify children with special healthcare needs.

Health Impact: CDC's FY 2011 activities will help ensure that 95 percent of all infants are screened for hearing loss by on month of age. As a result of the "Learn the Signs. Act Early." campaign's education efforts to include allied health professionals and neonatal nurses. *(Please see outcome 6.2.3 for specific information.)*

Budget Request: Improve the Health of People with Disabilities

People with disabilities need health care and health programs to stay well, active, and part of the community. CDC works to increase participation and inclusion of people with disabilities in public health efforts as well as in everyday aspects of life. To accomplish this CDC conducts research on risk factors and measures of health, functioning, and disability and supports States to develop program infrastructure to promote the health

of all individuals with a disability. In FY 2011 funds will be used to improve the health of people with disabilities through the activities noted below.

- In order to ensure that individuals with disabilities are included in state disease prevention, health promotion, and emergency response activities. CDC will fund 16 state disability and health programs. These programs work to ensure that individuals with disabilities are included in state disease prevention, health promotion, and emergency response activities.
- CDC will develop and maintain a health surveillance repository with state specific information on key health indicators (such as obesity and use of preventive services) for people with disabilities. This repository will provide 50 states, DC, and three territories with timely data on comparable health status of people with and without disabilities at the state level on approximately 60 health outcomes.
- Three university projects will be funded by CDC to develop evidence-based health promotion interventions to improve health, and reduce health disparities and secondary conditions among people with disabilities. CDC funded research will address knowledge gaps in promoting health of people with disabilities in areas such as violence against people with disabilities, transition issues from childhood to adult in education and racial and ethnic disparities among people with disabilities.
- In order to address rare disorders (e.g., Duchenne/Becker muscular dystrophy, Fragile X, spina bifida), CDC will fund twenty-five programs. Specific projects will include implementing patient registries to gather clinical data to help depict disease progression, secondary conditions, and health care needs of this population.

Rationale and Recent Accomplishments: People with disabilities experience substantial health disparities compared to people without disabilities. These individuals report higher rates of poor or fair health than those without disabilities; and are more likely to smoke, be obese, and have higher risk of infections. To address these concerns CDC accomplished the following activities noted below.

- Sixteen state-based health programs were funded (at an average award amount of \$280,000) to promote the health of people with disabilities and include people with disabilities in disease prevention and emergency response activities. By working with states, CDC will impact the health and quality of life among people with disabilities including reducing the occurrence of complications and chronic diseases in those with disabilities.
- CDC supported nine university projects (at an average award amount of \$325,000) to assess emergency preparedness and develop evidence-based health promotion interventions to improve health, reduce health disparities, and prevent secondary conditions among people with disabilities. Recent research findings have highlighted a variety of diverse topics, including assessing the experience of Hurricanes Katrina and Rita on people with disabilities and chronic conditions. Findings indicated significant service disruption and psychological impact including social issues and separation from family.
- CDC funds supported comprehensive health screenings for 22,127 athletes at various Special Olympics events worldwide. Significant findings provided for athletes to receive care in their home communities.
- CDC developed a campaign, “Right to Know,” to promote breast cancer screening for women with physical disabilities. The percentage of women with a disability, aged 40 years or older, who received a mammogram in the last two years has reached 70 percent, the national goal established in Healthy People 2010.

Health Impact: By working with states and academic partners, CDC can impact the health and quality of life among people with disabilities including reducing the occurrence of complications and chronic diseases in those with disabilities. CDC funded research will address knowledge gaps in promoting health of people with

disabilities in areas such as violence against people with disabilities, transition issues from childhood to adult in education and racial and ethnic disparities among people with disabilities (*Please see outputs 6.G, 6.I and outcome 6.2.4 for specific information*).

Budget Request: Public Health Approach to Blood Disorders

CDC's FY 2011 request includes a proposal to realign CDC's Blood Disorders program to address the critical public health challenges associated with blood disorders and related secondary conditions. This realignment will allow CDC to focus its activities on population-based, public health programs targeting the blood disorders with the greatest risk of morbidity and mortality. CDC will utilize a comprehensive and coordinated public health agenda, which includes surveillance and epidemiologic research, laboratory investigation, and prevention research and awareness. FY 2011 resources will support a portfolio of activities that include work to improve access and application of scientific information about blood disorders, increase collaboration between members within the blood disorders and birth defects communities and advance science through surveillance and its application to public health efforts and resource allocation.

This proposed realignment supports initial, ongoing CDC efforts to shift the focus of this program away from its traditional clinical orientation and towards a population-based public health model. This realignment permits CDC to build on its initial steps toward a population-based public health model including:

- **Epidemiological Research/Surveillance:** Development of a population-based surveillance plan for deep vein thrombosis/pulmonary embolism (DVT/PE) to determine prevalence and burden and the basis for research on risk factors for DVT/PE and effectiveness of prevention efforts.
- **Laboratory Investigation:** Continued monitoring of blood product safety including a study of inhibitors (antibodies to blood products) which are the number one blood safety issue for these hemophilia patients and result in poor quality of life, increased mortality, and high costs for intensive medical care.
- **Prevention Research and Awareness:** Continuation of CDC's efforts to develop a national public health framework for the prevention of birth defects and complications from blood disorders.

Rationale and Recent Accomplishments: Millions of Americans have inherited disorders or acquired conditions of the blood that result in adverse health outcomes. In addition to affecting other organs, these conditions may also serve as risk factors for other diseases and, as a consequence, result in an underestimate of the real blood disorder burden to individuals, families, and communities.

Health Impact: FY 2011 funds will support activities that will increase the number of people with blood disorders who participate in the blood safety monitoring system, ensure better population-based estimates for risk factors, and secondary conditions associated with these disorders and prevention research and awareness through the continued development of a public health framework for addressing the prevention of blood disorders and their complications. FY2011 funds will also support the establishment of basic surveillance systems for women at risk for bleeding disorders, DVT/PE, and emerging chronic health conditions associated among hemophilia patients. These basic surveillance systems are critical to accurately establish the burden and prevalence of these diseases, prioritizing research on associated risk factors, and measuring the effectiveness of future prevention efforts (*Please see outputs 6.I and 6.J for specific information*).

IT INVESTMENTS

CDC Centers for Autism: This is an extramural Cooperative Agreement with Michigan State University to develop and maintain various data capture systems for the Study to Explore Early Development (SEED), a multi site case-cohort study that aims to gain information as to the natural history and causes of autism. The Data Coordinating Center at Michigan State also maintains all of the electronic data entered for this study and will produce analytic datasets for study researchers and eventually for the public. It supports the program goal and Congressional mandate for NCBDDD to conduct autism research. CDC PH Monitoring for Birth

Defects, Development Disabilities, Disabilities and Health: This investment is a rollup of several information technology systems for Capital Planning and Investment Control purposes.

OUTCOME TABLE

Measure	Most Recent Result	FY 2010 Target	FY 2011 Target	FY 2011 +/- FY 2010
Efficiency Measure 6.E.2				
<u>6.E.2:</u> Increase the percentage of cost savings for CCHP as a result of the Public Health Integrated Business Services HPO. <i>(Efficiency)</i>	FY 2008: 65.0% <i>(Exceeded)</i>	38.0%	39.0%	+1.0%
Long Term Objective 6.1: Prevent birth defects and developmental disabilities.				
<u>6.1.3:</u> Reduce health disparities in the occurrence of folic acid-preventable spina bifida and anencephaly by reducing the birth prevalence of these conditions among Hispanics. <i>(Outcome)</i>	FY 2007: 5.7/10,000 <i>(Not Met)</i>	4.6	4.5	-0.1
<u>6.1.4:</u> Increase the percentage of health providers who screen women of childbearing age for risk of an alcohol-exposed pregnancy and provide appropriate, evidence-based interventions for those at risk. <i>(Outcome)</i>	FY 2009: Yes <i>(Met)</i>	Increase provider-based screening and intervention by 2% from baseline	Increase provider-based screening and intervention by 2.5% from baseline.	+0.5%
<u>6.1.5:</u> Improve the quality and usability of birth defects surveillance data. <i>(Outcome)</i>	FY 2008: Complete a collaborative multi-state study on the association of birth defects with preterm delivery. Evaluate the association of maternal diabetes and birth defects using a multi-site case control study based on surveillance data. <i>(Both Met)</i>	Estimate the prevalence of spina bifida by race and sex among children and adolescents in 10 regions of the U.S. Publish results of collaborative research projects on clubfoot and pyloric stenosis.	Disseminate guidelines for incorporating surveillance of stillbirth into birth defects monitoring systems. Evaluate the feasibility of conducting population-based surveillance for fetal alcohol syndrome.	N/A
Long Term Objective 6.2: Improve the health and quality of life of Americans with disabilities.				
<u>6.2.1:</u> Increase the number of people with blood disorders who participate in the monitoring system by 10% <i>(Outcome)</i>	FY 2009: 25,104 <i>(Exceeded)</i>	25,607	26,119	+512

NARRATIVE BY ACTIVITY
BIRTH DEFECTS, DEVELOPMENTAL DISABILITIES, DISABILITY AND HEALTH
BUDGET REQUEST

Measure	Most Recent Result	FY 2010 Target	FY 2011 Target	FY 2011 +/- FY 2010
6.2.2: Identify an effective public health intervention to ameliorate the effects of poverty on the health and well-being of children. (Outcome)	FY 2009: Yes (Met)	Data collection and analysis for age 5 year	Data collection and analysis for age 5 year	Maintain
6.2.3: Ensure that 95% of all infants are screened for hearing loss by 1 month of age. (Outcome)	FY 2006: 92% (Exceeded)	95%	95%	Maintain
6.2.4: Increase the mean lifespan of patients with Duchenne and Becker Muscular Dystrophy (DBMD) and carriers by 10% as measured by the Muscular Dystrophy Surveillance, Tracking and Research Network. (Outcome)	FY 2008: Yes (Met)	Increase the percentage of patients with DBMD who have access to treatments based on national standards of care to 80% as measured by MD STARnet and national or nationally representative data collection methods	Increase the percentage of patients with DBMD who have access to treatments based on national standards of care to 80% as measured by MD STARnet and national or nationally representative data collection methods	Maintain
6.2.5: Reduce the number of infants not passing the hearing screening that are lost to follow up. (Outcome)	FY 2007: 44.8%	37%	33%	- 4%