

## Historical Timeline of National Center on Birth Defects and Developmental Disabilities and Its Critical Issues

1946	The Communicable Disease Center (CDC) is established in Atlanta (the precursor of the current Centers for Disease Control and Prevention). CDC's goal is to protect the public by quickly identifying diseases brought into the United States by soldiers returning from out of the country.
1961	CDC expands its reach into chronic disease with investigation of a cancer cluster in Niles, Illinois. Because of the connection between cancer and birth defects, CDC begins to explore birth defects research issues.
1967	After the thalidomide tragedy in Europe, the Metropolitan Atlanta Congenital Defects Program (MACDP)—the first population-based birth defects surveillance system in the United States—is born through the collaborative efforts of CDC, the Georgia Mental Health Institute, and the Emory University School of Medicine.
1972	President Richard M. Nixon signs the National Sickle Cell Anemia Control Act providing for the establishment of voluntary sickle cell screening and counseling programs.
1974	CDC begins the national Birth Defects Monitoring Program with grants from the National Institute for Child Health and Human Development and the March of Dimes Birth Defects Foundation, using hospital discharge records of newborns from about 800 hospitals around the nation. The International Clearinghouse for Birth Defects Monitoring Systems is established with financial support from the March of Dimes and technical support from CDC.
1975	Congress passes the Individuals with Disabilities Education Act (IDEA), mandating that all children with disabilities receive a free, public education, regardless of the level of severity of their disability. Congress mandates establishment of a network of federally supported hemophilia treatment centers in the United States to provide comprehensive care for people with bleeding disorders.
1979	CDC sends an Epidemic Intelligence Service officer to investigate a cluster of infant deaths, which subsequently is linked to chloride-deficient infant formula. This investigation leads swiftly to public health action for regulation of infant formula ingredients, culminating with the Infant Formula Act of 1980.
1981	January is declared Birth Defects Prevention Month. Tragically, during the period 1981 through 1984, many hemophilia patients transfused with clotting factor in the United States become infected with HIV and eventually die of AIDS. Many also are infected with the yet-to-be-identified hepatitis C virus, which results in chronic liver disease.
1982	Researchers in France find that valproic acid, a drug used to treat epilepsy, causes spina bifida. It is the first teratogen discovered by a birth defect surveillance system. CDC quickly works with the U.S. Food and Drug Administration (FDA) to re-label the drug to warn women and their health care providers about this serious risk.
1983	President Ronald W. Reagan designates September as National Sickle Cell Awareness Month. CDC receives funding for HIV risk reduction services for people with hemophilia and others using blood products.
1984	CDC confirms that the acne medication isotretinoin (Accutane®) is linked with serious birth defects. CDC and the Georgia Department of Human Resources initiate the Metropolitan Atlanta Developmental Disabilities Study (MADDS) to provide population-based prevalence data on developmental disabilities. A CDC study supported by Congress and funded by the then-U.S. Veterans Administration (currently the U.S. Department of Veterans Affairs) shows that Vietnam veterans are at no higher risk than other men for fathering babies with birth defects, and produces the first of many publications on risk factors for birth defects.
1985	Heat-treated, blood-based clotting factor products used by people with hemophilia are introduced and shown to eliminate the transmission of HIV through infusion of clotting factor products.



1986	<p>CDC establishes cooperative agreements with seven states to track the occurrence of birth defects and low birth weight potentially related to toxic waste exposure.</p> <p>The National Council on Disability publishes a report on addressing the needs of people with disabilities in the United States. As 1 of 10 top priorities, the council identifies the creation of a program to address public health needs and the effects of people with disabilities on society, as well as the effects of society on people with disabilities.</p>
1987	<p>Congress appropriates \$3.8 million to CDC to provide technical assistance and short-term financial support for states and communities to establish programs for the prevention of disabilities. A disabilities prevention program is created within the CDC National Center for Environmental Health.</p> <p>CDC funds the first three disabilities prevention program research projects, all focusing on determining the prevalence of secondary conditions.</p> <p>A CDC study shows that periconceptional use of a multivitamin containing folic acid is associated with a reduced risk for neural tube defects (NTDs).</p>
1989	<p>CDC publishes a report that identifies birth defects as a leading cause of infant mortality. This report also notes that heart defects account for 38% of birth defects-related infant mortality.</p>
1990	<p>Congress passes and President George H.W. Bush signs into law the Americans with Disabilities Act. IDEA is enacted. It is a law ensuring services to children with disabilities.</p>
1991	<p>CDC works with state officials in Brownsville, Texas, to investigate a cluster of births of babies with anencephaly.</p> <p>CDC signs a memorandum of understanding with the Indian Health Service and the State of Alaska for a joint program to prevent fetal alcohol syndrome (FAS).</p> <p>CDC launches the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), an ongoing, population-based prevalence study of four developmental disabilities, based on the earlier MADDSP program.</p> <p>CDC issues a recommendation that women who have had a pregnancy affected by an NTD consume 4 milligrams of the B-vitamin folic acid daily, prior to pregnancy, for preventing the recurrence of NTDs.</p> <p>CDC signs a cooperative agreement with Beijing Medical University and the People's Republic of China to study the effectiveness of folic acid in community settings.</p> <p>CDC establishes the Fetal Alcohol Syndrome Unit in the Division of Birth Defects and Developmental Disabilities at the National Center for Environmental Health.</p>
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1994	<p>The U.S. Public Health Service recommends 400 micrograms of folic acid daily, before and during early pregnancy for the prevention of NTDs for all women capable of becoming pregnant. CDC, working closely with its partners, takes an active role in folic acid education, prevention, and advocacy.</p> <p>The National Institutes of Health Consensus Development Program recommends that all newborns be screened for hearing loss before they leave the hospital.</p> <p>CDC funds the Birth Defects Risk Factor Surveillance Study in California, Iowa, and metropolitan Atlanta, Georgia, with the primary objective of identifying risk factors for children born with multiple major birth defects.</p> <p>The Joint Committee on Infant Hearing position statement recommends that "all infants with hearing loss should be identified before 3 months of age and receive intervention by 6 months of age".</p>
1996	<p>A multistate study on limb defects among infants whose mothers had prenatal chorionic villus sampling (testing a sample of the placenta) leads to recommendations for counseling pregnant women about the</p>



	<p>risks and benefits of prenatal diagnostic procedures.</p> <p>Congress funds CDC \$3.14 million to conduct research on prevention of mental retardation. Contracts are awarded to 14 implementation sites for Project BEGIN (Bringing Early Growth and Development Into Neighborhoods), which later was to become the Legacy Project.</p> <p>CDC launches a six-state surveillance project to identify everyone in those states with hemophilia. The project collects important data on care and outcomes for people with hemophilia during the years 1993 through 1998 and provides the first population-based estimates of the burden of this bleeding disorder.</p> <p>CDC supports the FDA's rule that manufacturers fortify enriched grain products with folic acid for the prevention of neural tube defects. CDC develops a plan for a national program to educate women and health care providers on the need for folic acid before and during early pregnancy.</p>
1997	<p>CDC appropriates funding to establish at the state level Centers for Birth Defects Research and Prevention (CBDRP). Centers are established in states with existing birth defects surveillance programs and nationally recognized expertise in birth defects surveillance and research.</p> <p>A group of individuals involved in birth defects surveillance meets and begins to develop the National Birth Defects Prevention Network (NBDPN), an incorporated organization with participants from all 50 states.</p> <p>The Interagency Coordinating Committee on Fetal Alcohol Syndrome is created to coordinate federal FAS activities in response to a recommendation of an expert committee of the Institute of Medicine.</p> <p>CDC holds a national workshop on the benefits and risks of screening newborns for cystic fibrosis, leading to recommendations for public health policies for such screening.</p> <p>CDC convenes a group of organizations that becomes the National Council on Folic Acid (NCFA), dedicated to advocacy and education about folic acid-preventable birth defects.</p> <p>CDC begins Early Hearing Detection and Intervention activities as part of a national effort to promote the early detection of hearing loss, tracking of infants and children who have hearing loss, and initiation of effective intervention systems. This results in funding for programs in fiscal year 2000.</p> <p>CDC and the NBDPN publish the first annual Congenital Malformations Surveillance Report, with data on 47 categories of birth defects from 21 states. This is the first time population-based birth defects surveillance data from a number of states are presented together. NBDPN functions as a national clearinghouse on birth defects information.</p> <p>CDC partners with three universities to develop and test Project CHOICES (Changing High-Risk Alcohol Use and Increasing Contraception Effectiveness Study), a motivational intervention aimed at preventing alcohol-exposed pregnancies. Study results show that a brief motivational intervention can reduce the risk of an alcohol-exposed pregnancy. Project CHOICES becomes a model program embraced by researchers and used in other federal initiatives.</p>
1998	<p>The Fetal Alcohol Syndrome Surveillance Network is created in October and develops a multisource surveillance methodology to determine the prevalence of FAS within certain regions of the United States.</p> <p>A citizen's group in Brick Township, New Jersey, contacts the New Jersey Department of Health and Senior Services about what seems to be a larger-than-expected number of children with autism in Brick Township. CDC and the Agency for Toxic Substances and Disease Registry work together to find out how common autism is in Brick Township and to study the possible relationship of environmental factors to autism in the community. At this time, the prevalence of ASDs in the United States is 6.7 per 1,000 children. The prevalence of autism in Brick Township seems to be higher than that in other studies, particularly other studies conducted in the United States, but within the range of a few recent studies among smaller populations that used more thorough case-finding methods.</p> <p>The CBDRP begin collecting data as part of the National Birth Defects Prevention Study (NBDPS), a population-based case-control study to investigate genetic and environmental risk factors for birth defects.</p> <p>Congress passes the Birth Defects Prevention Act of 1998, directing CDC to implement programs to collect data on birth defects, operate regional centers for epidemiological research, and provide</p>



	<p>information to the public about the prevention of birth defects.</p> <p>A CDC-funded study concludes that screening newborns to identify children with sickle cell disease (SCD) reduces early childhood mortality from the disease to very low levels.</p> <p>In Atlanta, Georgia, CDC initiates one of the few programs in the world that conducts active, ongoing monitoring of the prevalence of autism spectrum disorders (ASDs) among children by adding ASDs as a condition monitored through MADDSP.</p> <p>CDC works with the FDA before the first U.S. rerelease of thalidomide, a well-known cause of birth defects, to develop usage guidelines in order to minimize the potential for future birth defects from this medication.</p> <p>NCBDDD initiates Legacy for Children™, a set of longitudinal, randomized, controlled studies examining the potential for improving child developmental outcomes through parenting programs designed to promote self-efficacy and a sense of community.</p> <p>CDC begins collaborating with approximately 140 federally funded hemophilia treatment centers in the United States and its territories through the Universal Data Collection (UDC) Program to monitor blood product safety and outcomes of care for people with bleeding disorders.</p> <p>The FDA approves hydroxyurea. It becomes the first drug proven to prevent complications of SCD.</p> <p>President William J. Clinton signs into law the Rehabilitation Act Amendments of 1998. These amendments provide details on access to federally funded programs and services. The law strengthens section 508 of the Rehabilitation Act of 1973 and requires access to electronic and information technology provided by the federal government. The law applies to all federal agencies when they develop, acquire, maintain, or use electronic and information technology. Federal agencies must ensure that this technology is accessible to employees and members of the public with disabilities to the extent it does not pose an "undue burden".</p>
1999	<p>CDC, the March of Dimes, and the NCFCA launch the National Folic Acid Campaign to promote the use of folic acid to prevent birth defects.</p> <p>Congress passes the Newborn and Infant Hearing, Screening, and Intervention Act of 1999. This Act authorizes funds and provides direction for CDC to assist states in establishing infant hearing screening, evaluation, and intervention programs.</p> <p>CDC funds 18 states to collect birth defects surveillance data and to use these data for prevention efforts.</p> <p>CDC publishes the results of a folic acid community intervention trial, conducted in China in collaboration with Beijing Medical University, showing an 85% reduction of cases of NTDs in northern counties and a 40% reduction in southern counties in China. This is the first study to show that 400 micrograms of folic acid alone (rather than included with other multivitamins) taken before and during early pregnancy can achieve dramatic reductions in the rates of these serious birth defects of the spine and brain.</p> <p>A CDC investigation shows that erythromycin given to newborns increases the risk for infantile hypertrophic pyloric stenosis. American Academy of Pediatrics guidelines for use of erythromycin for neonatal chlamydia exposure are modified based on the results of this investigation.</p> <p>Congress directs CDC to study hereditary hemochromatosis and other iron-related disorders.</p>
2000	<p>The Children's Health Act of 2000 is passed by Congress and signed into law by President William J. Clinton. It requires the establishment of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC by April 15, 2001. As specified in the act, the new center will include what heretofore were the programs, functions, and staff of the Division of Birth Defects and Developmental Disabilities, National Center for Environmental Health.</p> <p>Healthy People 2010 is published by the U.S. Department of Health and Human Services (DHHS). Chapter 6 addresses Disability and Secondary Conditions. This is the first time that people with disabilities have been addressed specifically as part of the Healthy People process.</p> <p>CDC convenes the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, a congressionally mandated committee created to promote coordination among governmental agencies, academics, clinicians, and community groups that conduct or support FAS research, programs, and</p>



	<p>surveillance and to address the needs of individuals living with FAS and their families.</p> <p>CDC organizes the Autism and Developmental Disabilities Monitoring (ADDM) Network, a surveillance program to collect data for determining prevalences of ASDs and other developmental disabilities at multiple sites across the United States.</p> <p>CDC establishes regional centers of excellence for ASDs and other developmental disabilities. Together they make up the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) Network.</p> <p>Congress mandates CDC to fund a national resource center on attention-deficit/hyperactivity disorder (ADHD) to conduct epidemiologic studies.</p> <p>Congress urges CDC to accelerate efforts geared toward the prevention of bleeding and clotting disorders, including von Willibrand disease and other women's bleeding disorders.</p>
2001	<p>In April, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) is established. Dr. Jose Cordero is named director of NCBDDD.</p> <p>NCBDDD publishes the first evaluation showing that folic acid fortification has reduced the prevalence of NTDs in the United States.</p> <p>The World Health Organization publishes the International Classification of Functioning, Disability and Health (ICF). The ICF provides a standard language for classifying changes in body function and structure, activity, participation levels, and environmental factors that influence health.</p> <p>Congress authorizes NCBDDD to develop public health programs related to muscular dystrophy under the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 (also known as the MD-CARE Act).</p>
2002	<p>Congress mandates that issues related to children's neurobehavioral disorders, including ADHD, be included as part of NCBDDD's research agenda. Tourette syndrome is added to this group of disorders in 2004.</p> <p>An NCBDDD study shows a major improvement in the survival of people with Down syndrome, but reveals substantial differences exist between racial groups.</p> <p>NCBDDD releases its first multistate, population-based report on the prevalence estimate of FAS: 0.3 to 1.5 cases of FAS per 1,000 livebirths in certain areas of the United States.</p> <p>Congress appropriates funding to create a thalassemia-based blood safety and surveillance program, modeled after the UDC Program used for hemophilia.</p> <p>NCBDDD and the FDA carry out two investigations to learn more about a possible association between cochlear implants and bacterial meningitis among children with cochlear implants. The study finds that children with an implant are 30 times more likely to get a type of bacterial meningitis than are children of the same age among the general population. The studies also find that children with an implant with a positioner (used with some implant models) are more likely to get meningitis than children who have an implant without the positioner. The implant model with a positioner voluntarily is removed from the market by the manufacturer in July 2002. Vaccination recommendations are changed to include cochlear implant recipients in the high-risk group for bacterial meningitis.</p> <p>NCBDDD convenes its first national conference.</p>
2003	<p>The Division of Blood Disorders joins NCBDDD.</p> <p>More than 60 organizations assemble at the Public Health Leadership Conference on Deep-Vein Thrombosis to discuss the urgent need to make deep-vein thrombosis (DVT) a major U.S. public health priority. As a result of this meeting, which is cohosted by NCBDDD, participants agree to establish a coalition of organizations committed to educating the public and health care community about DVT.</p> <p>NCBDDD issues the first ASDs prevalence report from MADDSP, verifying higher autism prevalences among populations at MADDSP sites than have been reported earlier among populations in other areas of the United States.</p>



2004	<p>NCBDDD issues the AUTISM A.L.A.R.M. with the American Academy of Pediatrics, summarizing the recent prevalence studies done that confirm that more children with ASDs are being identified than in the past.</p> <p>The “Learn the Signs. Act Early.” campaign is launched to raise awareness of the importance of monitoring a child’s development, knowledge of signs of ASDs and other developmental disabilities, and the importance of acting early if a delay is suspected.</p> <p>The Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children is chartered. The committee provides advice and recommendations to the United States Department of Health and Human Services to develop policies—such as recommendations for a uniform panel of conditions and a process by which new conditions will be considered—that will enhance the ability of health agencies to provide newborn screening.</p> <p>Congress directs NCBDDD to initiate a Diamond Blackfan anemia program.</p> <p>IDEA is reauthorized.</p>
2005	<p>March is declared Deep-Vein Thrombosis Awareness Month.</p> <p>The Surgeon General releases A Call to Action to Improve the Health and Wellness of Persons with Disabilities, and highlights disability as a major public health issue. The call to action appeals to all Americans to help improve the quality of life for people with disabilities through better health care and understanding.</p> <p>The Surgeon General releases the updated 2005 Advisory on Alcohol Use in Pregnancy, highlighting the importance of women’s abstaining from alcohol if they are pregnant or planning a pregnancy.</p> <p>NCBDDD establishes a pilot project to expand existing birth defects surveillance programs in Atlanta, Georgia, and Iowa to include all fetal deaths in their surveillance activities.</p>
2006	<p>NCBDDD and its partners release a set of 10 recommendations for preconception health and convene the first national preconception conference.</p> <p>NCBDDD and the NBDPN release national prevalence estimates for 21 selected birth defects in the United States.</p>
2007	<p>Dr. Edwin Trevathan is named director of NCBDDD.</p> <p>The ADDM Network issues its first reports (study years 2000 through 2002), indicating a prevalence range of 1 in 100 to 1 in 300, with an average of 1 in 150 children affected by an ASD.</p> <p>The CADDRE Network implements the Study to Explore Early Development (SEED), one of the largest studies of its kind in the United States to help identify factors that might put children at risk for ASDs and other developmental disabilities.</p> <p>MACDP releases a technical report on 36 years of birth defects prevalence data.</p> <p>Data from the NBDPS show that maternal obesity might be a risk factor for certain birth defects. As detailed in a paper using these data, maternal obesity before pregnancy nearly doubles the risk for spina bifida, a major defect of a baby’s spine.</p> <p>Based on the results of an NCBDDD-sponsored clinical trial, prophylactic (preventative) treatment becomes the standard of care in the United States for people with hemophilia. Instead of waiting for bleeding to occur, clotting factor taken regularly to prevent bleeding is shown to prevent the development of joint disease among young boys with hemophilia.</p> <p>NCBDDD establishes the Thrombosis and Hemostasis Centers Research and Prevention Network to provide an opportunity for broad, population-based research on DVT and pulmonary embolism.</p> <p>The Institute of Medicine (IOM) releases The Future of Disability in America. In the report, the IOM committee identified continuing gaps in disability science and proposed steps to strengthen the evidence base for public and private actions to reduce the impact of disability and related conditions on individuals and society in the United States.</p>
2008	<p>The Acting Surgeon General issues A Call to Action to Prevent Deep Vein Thrombosis and Pulmonary Embolism.</p>



	<p>President George W. Bush signs into law the Americans with Disabilities Amendments Act, strengthening legislative language protecting the rights of people with disabilities in the United States.</p> <p>The Newborn Screening Saves Lives Act is enacted, which includes provisions to enhance, improve, or expand newborn screening programs and coordinate follow-up care once newborn screening has been conducted.</p> <p>Ten years after its establishment, CDC's UDC Program comprises more than 21,300 participants with bleeding disorders.</p>
2009	<p>NCBDDD's ADDM Network finds the average prevalence estimate for ASDs is 8 per 1,000 8-year-olds in 2004 and 9 per 1,000 8-year-olds in 2006 in several areas of the U.S. This is about 1 in 110 children.</p> <p>President Barack H. Obama authorizes signing the U.N. Convention of the Rights of Persons with Disabilities on behalf of the United States, supporting the following principles for people with disabilities: respect for inherent dignity, nondiscrimination, full inclusion in society, respect for differences and acceptance of people with disabilities as part of human diversity and humanity, equality of opportunity, accessibility, respect for the evolving abilities of children with disabilities, and respect for the right of children with disabilities to preserve their identities.</p>
2010	<p>Healthy People 2020 is published by DHHS. A new focus on blood disorders and blood safety addresses bleeding and clotting disorders, and hemoglobinopathies.</p> <p>The Patient Protection and Affordable Care Act is enacted. One of the requirements is that any federally conducted or supported health care or public health program, activity, or survey collect and report, to the extent practicable, data on disability status.</p> <p>President Barack H. Obama signs "Rosa's Law". The enactment of S. 2781 requires that the terms "mentally retarded" and "mental retardation" be replaced within federal policy with "intellectual disability" or "individual with an intellectual disability".</p> <p>NCBDDD works with many state and local health departments to investigate pandemic influenza among pregnant women, children, and people with disabilities. This work leads to swift action to develop guidance and recommendations for these vulnerable populations.</p> <p>The Duchenne muscular dystrophy (DMD) Care Considerations guide is published. This guide to the management of care for people with DMD is developed through the work of 84 national and international experts evaluating assessments and health care interventions. The Care Considerations provide a framework for recognizing the multisystem primary manifestations and secondary complications of DMD, and for providing coordinated multidisciplinary care.</p> <p>NCBDDD and the National Heart Lung and Blood Institute establish a pilot surveillance system for SCD and thalassemia called the Registry and Surveillance for Hemoglobinopathies (RuSH).</p> <p>NCBDDD convenes the first National Conference on Blood Disorders in Public Health.</p> <p>June is declared Hereditary Hemorrhagic Telangiectasia Awareness Month. 1</p>
2011	<p>Dr. Coleen A. Boyle is named director of NCBDDD.</p> <p>In 2011, NCBDDD and our partners launched a series of events and activities spanning the year to honor the achievement of this milestone of progress, and showcased the exceptional work of our collective organizations. We called the celebrations and acknowledgments 10 Years of Service.</p>

