

ISSUE REPORT

BIRTH DEFECTS AND
DEVELOPMENTAL DISABILITIES:

The Search for Causes and Cures



JULY 2005

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BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES:

The Search for Causes and Cures

Over the years, the public health and medical communities have learned a great deal about the birth defects and developmental disabilities that affect hundreds of thousands of children each year.¹ Prevention, cures, and treatments have allowed many of those who might have been seriously impaired to live rich, full lives. Continued medical advances and an enhanced understanding of how disorders impact those who live with them have led to significant progress with respect to health, education, social integration, and overall quality of life.

This report presents an overview of major birth defects and developmental disabilities, as well as an assessment of some recent public health successes, and a look at several ongoing challenges. By taking the lead on sound

policy development, research, public education, and medical care, U.S. public health agencies can and should address the serious public health implications presented by birth defects and developmental disabilities.





AN OVERVIEW:

Major Birth Defects and Developmental Disabilities

Birth Defects

Each year, about 120,000 babies -- one in 33 -- are born with a major birth defect. Birth defects are the leading cause of death in children during the first year of life and vary widely.² Although the causes of 60 to 70 percent of birth defects are unknown, genetic and environmental factors are likely to affect incidence and severity.

Birth defects encompass a wide range of abnormalities with varying levels of impact on a child's future physical and mental health. Some birth defects are extremely serious and result in stillbirth or infant death. Other defects are less severe and modern medicine prevents, detects, or treats these before birth or during infancy or childhood. Many birth defects fall somewhere in the middle, causing a range of disabilities, both mental and physical, that can affect children and their families for life.

Congenital heart defects are the most common structural birth defects. Children with heart defects can be severely affected and require complex surgical and medical treatment. These children are at risk of chronic illness and premature death. Children with less severe forms of heart defects can still be affected in their quality of life. As treatment and support continually improve, increasing numbers of affected individuals live longer and healthier lives. Adolescents and adults who have been successfully treated now represent a growing group in the population and may have specific health care needs.

Although the vast majority of birth defects involve structural malformations of one or more organ systems, there are other reasons for childhood disabilities. Less common types of birth defects include functional birth defects, which affect cognition, and metabolic birth defects, such as phenylketonuria (PKU).

The National Institutes of Health (NIH) conducts basic and clinical research into causes of and treatments for birth defects through the National Institute of Child Health and Human Development (NICHD), with additional research based in the National Institute of Neurological Disorders and Stroke (NINDS). The NIH conducts research on the full range of birth defects.

In 2001, the Centers for Disease Control and Prevention (CDC) established the National Center on Birth Defects and Developmental Disabilities (NCBDDD).

The NCBDDD:

- Conducts data collection, research, public education, and prevention campaigns for various birth defects.
- Runs the Metropolitan Atlanta Congenital Defects Program, a model for state-based birth defects surveillance and a source of data for in-depth epidemiological studies.
- Helps coordinate the activities of the National Birth Defects Prevention Network (NBDPN).

The CDC studies genetic and environmental risk factors for major birth defects in the National Birth Defects Prevention Study, an ongoing, population-based study conducted collaboratively with eight U.S. states. CDC continues to disseminate award-winning publications and public service announcements promoting folic acid consumption for the prevention of spina bifida and anencephaly. CDC also is addressing fetal alcohol syndrome and numerous other birth defects.

The Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) is active in developing national screening guidelines for new-

borns intended to identify treatable metabolic disorders not otherwise apparent at birth. These defects can lead to developmental disabilities and death if not detected and treated in the immediate newborn or infant period.

In March 2005, HRSA released a report entitled “Newborn Screening: Toward a Uniform Screening Panel” that recommends a specified set of disorders for screening, discusses the benefits of establishing a set of mandatory screenings for newborns, and the potential role for national oversight to guide states and localities in screening guidelines, analyses of rare disorders, and immediate follow-up to families of newborns with positive screening results.

Developmental Disabilities

Developmental disabilities are a diverse group of chronic functional limitations that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as communication, mobility, learning, self-help, and independent living. Developmental disabilities can begin anytime from development up to early adulthood and last throughout a person’s lifetime. An estimated 17 percent of children have some type of developmental disability, and two percent of school-aged children have a serious developmental disability.

CDC’s NCBDDD runs the Metropolitan Atlanta Developmental Disabilities Surveillance Program, a model program for monitoring

developmental disabilities in addition to monitoring birth defects. This program, in place since 1991, currently monitors five conditions: mental retardation, cerebral palsy, hearing loss, vision impairment, and autism spectrum disorders. In addition, NCBDDD sponsors the Autism and Developmental Disabilities Monitoring Network, a group of states that are developing or improving programs to track the number of children with autism spectrum disorders and other developmental disabilities. In addition, CDC funds the Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology, which focus on monitoring and epidemiologic research in the area of autism spectrum disorders and other developmental disabilities.

THE NATIONAL BIRTH DEFECTS PREVENTION NETWORK: KEEPING TRACK AND RAISING AWARENESS

The National Birth Defects Prevention Network (NBDPN) is a network of birth defect surveillance systems and individuals working at the local, state, and national level in birth defect surveillance, research, and prevention.³ The NBDPN seeks to establish and maintain population-based surveillance systems, assess the impact of birth defects upon children, families, and health care, identify primary prevention strategies, and assist families and their providers to prevent secondary disabilities.

The objectives of the NBDPN are to:

- Improve the quality of birth defects surveillance data.
- Promote scientific collaboration for the prevention of birth defects.
- Provide technical assistance for the development of uniform methods of data collection.

- Facilitate the communication and dissemination of information related to birth defects.
- Collect, analyze, and disseminate state and population-based birth defects surveillance data.
- Encourage the use of birth defects data for decisions regarding health services planning (secondary disabilities prevention and services).

The NBDPN raises awareness and works to reduce adverse pregnancy outcomes. It has created an in-depth guideline for conducting birth defects surveillance and established an on-going system to monitor neural tube defects to assess the impact of folic acid education and fortification. The NBDPN works closely with CDC and NCBDDD, produces an annual report of state surveillance data, and develops materials for and provides information to families.

MARCH OF DIMES: COMMITTED TO PREVENTING BIRTH DEFECTS AND INFANT MORTALITY

The March of Dimes was founded in 1938 to combat polio and has since been a national leader in research and treatment of birth defects of all kinds. In January 2003, the organization launched a multi-year nationwide premature birth campaign which has direct implications for the many forms of birth defects arising from incompletely developed organs, as well as for cerebral palsy, intellectual disabilities and mental retardation, learning and behavioral disorders, and hearing and vision impairments. The campaign aims to raise awareness of prematurity and to significantly reduce the effects of preterm birth through research funding, education, advocacy for health care access, and support to families with premature babies.

According to the March of Dimes, of those babies born with birth defects:

- Three to four out of every 1,000 newborns in the U.S. will experience hearing loss;
- Two to six out of every 1,000 U.S. children have an autism spectrum disorder;
- Two to three out of every 1,000 U.S. children over age 3 have cerebral palsy (about 500,000 nationwide);
- One in 800 to 1,000 U.S. babies born will have Down syndrome;
- One in 4,000 U.S. males and one in 8,000 U.S. females will be born with Fragile X syndrome.

VISUAL IMPAIRMENT AND HEARING LOSS

Visual impairment exists when a person's eyesight cannot be corrected to a "normal" level. While the impairment can be the result of any number of conditions, children's vision problems are most often related to structural birth defects (e.g., congenital cataracts and congenital glaucoma), prematurity, albinism, prenatal viral infection, lack of oxygen during birth, or excess fluid on the brain. Visual impairment encompasses loss of acuity, loss of visual field (in which vision is limited without moving the eyes or turning the head), and complete loss of vision. In an intensive CDC study of five counties in metropolitan Atlanta, Georgia, researchers found that about nine children in 10,000 between the ages of three and 10 experienced vision loss. In nearly two-thirds of cases, children with visual impairment also have another developmental disability. The average lifetime cost associated with visual impairment for one person is \$566,000.⁴

Hearing loss refers to the inability to hear certain types of sounds or an inability to hear sounds below a certain volume in one or both ears. Hearing loss may be due to a structural birth defect in the inner or outer ear, auditory nerve, or in the brain. Hearing loss also may be caused by prematurity, infection, injury, certain drugs, and exposures to loud noises. Ranging from mild to profound and in one or both ears, hearing loss can seriously impair a child's verbal abilities, particularly if it occurs before two years of age when the abilities to speak and understand language are in critical stages of development. In the same Atlanta study, the CDC found that about nine children in 10,000 had experienced moderate to profound hearing loss in both ears. In 30 percent of cases, children with hearing loss also had another disability. Newborn screening for hearing loss is recommended by the CDC and is being widely performed in all states. The average lifetime cost associated with hearing loss for one person is \$417,000.⁵

Autism Spectrum Disorders

Autism spectrum disorders (ASD), also known as pervasive developmental disorders, are a family of developmental disorders most commonly associated with autism. These disorders were first identified in the 1940s, but diagnoses for ASDs have ballooned since the early 1990s when a change in diagnostic criteria took place. Experts disagree whether the recent boom in ASD cases results from the changing definitions or higher incidence or greater awareness or a combination of factors, but some doctors and scientists believe that cases are still underreported. The CDC estimates the number of children affected by an ASD to be somewhere between two and six in 1,000. Therefore, as many as 1.77 million Americans may have an ASD.⁶

There is no single test for ASDs. The disorders share a group of symptoms including difficulty with verbal communication, unresponsiveness to social cues such as eye contact and body language, and a tendency toward unusual and repetitive behaviors. People with an ASD generally exhibit some combination of these symptoms, but a lack of definitive biological markers for these disorders contributes to challenges in categorizing and diagnosing ASDs. Other medical problems often accompany ASDs; one in four children with an ASD develops seizures, and other associated problems include mental retardation, and/or sensory disorders, a lack of response to pain stimulus, hypersensitivity, or both. Many children with an ASD have gastrointestinal problems as well.⁷

The most common forms of ASD are autism, Asperger's syndrome, and Pervasive Development Disorder – Not Otherwise Specified (PDD-NOS). These disorders normally appear during the toddler years, but before a child reaches school age. No cure for any ASD currently exists, despite increasing research. The most effective treatment currently available is intensive early intervention, ideally beginning at age two or three, focusing on communication and behavioral issues. Medications also may be used to address

symptoms such as anxiety, depression, and seizures. Special programs for pre-school and school-aged children with ASDs are highly resource intensive, presenting challenges for parents as well as for school systems facing expanding caseloads. The provision of a free, appropriate public education to school children with an ASD, as mandated by the federal Individuals with Disabilities Education Act of 1997 (IDEA) and amended in 2004, is a challenge for many school systems.

With rates of ASD diagnosis increasing, and patients, parents, and the medical community frustrated by a lack of understanding of how and why ASDs occur, a great deal of public and private attention has been focused on research into the disorders. In 1997, NIH formed an Autism Coordinating Committee (NIH/ACC) to enhance the quality, pace, and coordination of efforts at NIH to find a cure for autism. Headed by the National Institute of Mental Health, the committee also includes NICHD, the National Institute on Deafness and Communication Disorders (NIDCD), NINDS, and the National Institute of Environmental Health Sciences (NIEHS). The NIH/ACC sponsors national and international centers of excellence for autism research and funded research grants totaling nearly \$74 million in 2002. Advocates are calling on Congress to authorize \$176 million annually over the next five years to combat autism through research, screening, intervention, and education.

In addition to the NIH/ACC, the federal government in 2001 established the Interagency Autism Coordinating Committee (IACC) to coordinate efforts across federal agencies. Participants include NIH, the Food and Drug Administration, the Administration on Children and Families, the Agency for Healthcare Research and Quality, the Centers for Medicare and Medicaid Services, the CDC, the Department of Education, and HRSA. The IACC includes representation from some major advocacy groups as well as public members.

Numerous non-profit organizations also address the needs of people with autism and other ASDs. Some focus on research, while others focus on services for patients and families. Given the increased diagnoses of

ASDs, the need for intensive intervention services and inadequate resources, CDC has emphasized that ASDs are conditions that represent an urgent public health concern.

CHILDHOOD VACCINES

Patients, parents, doctors, and scientists in the ASD community have been frustrated by the lack of understanding of how and why these disorders develop. Many have sought clues in environmental factors, and extensive discussion and research have taken place regarding a possible link between ASDs and childhood vaccinations. A number of major research studies conducted in the U.S. and abroad have found no proof of an association between ASDs and vaccines. However, because of the timing of childhood immunizations and the development of signs of ASDs, some parents believe there is a link. This, in turn, has discouraged some parents from following recommended vaccination regimens for their children. Unfortunately, these concerns have contributed to outbreaks of vaccine-preventable infectious diseases, such as measles and pertussis among children.

The CDC maintains a Web site to inform the public health community and the public about

the latest research and developments on possible causes of autism. According to the CDC, “The weight of currently available scientific evidence does not support the hypothesis that vaccines cause autism. We recognize there is considerable public interest in this issue, and therefore support additional research regarding this hypothesis. CDC is committed to maintaining the safest, most effective vaccine supply in history.”⁸

In May 2004, a committee from the Institutes of Medicine found no “causal relationship” between thimerosal-containing vaccines, or the Measles, Mumps, and Rubella (MMR) vaccine, and autism.⁹ However, parents, some scientists and advocacy organizations disagree and believe more research is needed. They urge ongoing public sector and private research into the possible causes of autism, including viral infections, metabolic imbalances, exposures to heavy metals (e.g., mercury and lead), pesticides, and genetic factors.

Cerebral Palsy



Cerebral palsy is an umbrella term for a series of chronic disorders in which motor control is impaired by damage to certain parts of the brain. This brain damage can be caused by abnormal growth, birth trauma, or head injuries, and can occur before or after birth. In the most common forms of cerebral palsy the body's muscle tone is either too tight or too loose; a less common variant impairs balance and coordination.

Usually appearing by age two or three, cerebral palsy does not progress over time. Symptoms vary by patient and can include an inability to maintain posture or walk, involuntary muscle movements, balance problems, and impairments in the fine motor control required for tasks like writing. Some people with cerebral palsy also have other disorders including mental retardation and

seizures. Cerebral palsy is not currently curable; however, combinations of drug treatments, surgeries, medical assistance devices like specialized braces, and physical and occupational therapies can improve the quality of life for many people with this disorder.

Research has identified ways to prevent some causes of cerebral palsy, such as jaundice, Rh disease, and rubella. Infants born preterm are up to 30 times more likely to develop cerebral palsy. Research continues into ways to prevent preterm birth and other triggers for cerebral palsy. The origin of many cases remains unknown. The American College of Obstetricians and Gynecologists (ACOG) published an expert task force report in 2002, "Neonatal Encephalopathy and Subsequent Cerebral Palsy: Defining the pathogenesis and pathophysiology," emphasizing the importance of potential preventable prenatal factors such as maternal infection and thyroid disorder.¹⁰

The federal government conducts research into cerebral palsy causes and cures through various channels. At NIH, NINDS is the primary research organization dealing with the disorders. NINDS conducts research in areas including pre-natal cell development, neonatal stroke, and low birth-weight. The CDC tracks rates of cerebral palsy through the Metropolitan Atlanta Developmental Disabilities Surveillance Program, funds research through the North Atlantic Neuro-Epidemiology Alliance and has intensively studied the development of cerebral palsy during childhood. CDC also is working to understand the impact of untreated jaundice, leading to a severe disability known as kernicterus, which is associated with severe cerebral palsy. The March of Dimes funds research on prenatal brain development with implications for cerebral palsy and has launched a major education and research campaign on prematurity.

Intellectual Disabilities

Intellectual disabilities, often referred to as mental retardation, are characterized by significantly below-average intellectual functioning (generally regarded as an IQ below 70), combined with impairment in carrying out functions of daily life such as caring for oneself, communicating, and interacting socially. Appearing at any time before birth or during childhood (up to 18 years of age), intellectual disabilities can be caused by single causes or combinations of genetics, abnormal brain development, injury, infection or disease. They are the most common developmental disorder, affecting roughly three in 100 people. Intellectual disabilities can range from mild to profound, and mild and moderately-impaired people can often learn to live independently. When other disorders co-occur with intellectual disabilities, individuals are likely to experience more profound degrees of disability.¹¹

The cause of most intellectual disability is unknown. Some common cases are linked to genetics such as Down syndrome (the single most common chromosomal-related birth defect, in which a person has a partial or complete extra copy of chromosome 21) and Fragile X syndrome (an inherited condition impacting the X chromosome and hence, more commonly affecting males). Other less common causes include genetic conditions (such as cri-du-chat syndrome or Prader-Willi syndrome), infections (such as congenital cytomegalovirus), or birth defects that affect the brain (such as hydrocephalus or cortical atrophy). Other causes of intellectual disabilities (such as asphyxia) happen before, during, or soon after a baby is born. Still other causes may not happen until a child is older. These may include serious head injury, stroke, or certain infections such as meningitis.¹² Environmental factors like prenatal alcohol exposure (resulting in fetal alcohol syndrome, the most common preventable birth defect), malnutrition, or exposure to toxins such as lead or mercury can also cause intellectual disabilities. Newborn screening can be

effective in preventing intellectual disability from known causes such as phenylketonuria (PKU), a condition in which the body cannot process a protein found in many foods, and that can be treated through specialized diets. Some intellectual disabilities can be prevented. Preventive actions include:

- Iodization of salt to prevent iodine-deficiency hypothyroidism, which can result in intellectual disability;
- Abstinence from alcohol by women of child-bearing age to avoid fetal alcohol syndrome;
- Dietary control to prevent intellectual disabilities in people with phenylketonuria;
- Environmental control to prevent intellectual disabilities due to poisoning from heavy metals such as lead;
- Prevention of Kernicterus, a kind of brain damage that happens when a newborn has too much jaundice, by using special lights (phototherapy) or other therapies; and¹³
- Consistent use of infant and child safety precautions at home and restraints in automobiles.

A great deal of research on birth defects, genetic diseases, and other medical disorders has implications for preventing intellectual disabilities, but much more research targeted specifically to early recognition and treatment of intellectual abilities is needed. The majority of federal programs and non-profit organizations that address intellectual disabilities do so from a treatment perspective, and information and debate about specialized care, educational strategies, health care and financing, and assistance for affected adults abound.

Depending on the severity of the intellectual disability, medical interventions and/or “supports” are provided to the individual. The American Association on Mental Retardation defines “supports” as the resources and individual strategies necessary to promote the development, education, interests, and personal well-being of a person with mental

retardation. Supports can be provided by a parent, friend, teacher, psychologist, doctor, or by any appropriate person or agency.¹⁴ Providing individualized supports can improve personal functioning, promote self-determination and societal inclusion, and improve the well-being of a person with intellectual disabilities. Focusing on supports is a way to improve education, employment, recreation, and overall living environments.¹⁵ Additionally, pursuant to federal law, American children with intellectual disabilities are entitled to a free and appropriate education, including physical education, which may include special services.

Many individuals with intellectual disabilities live independently or semi-independently

with the support of family members or others. This option can allow for a more fulfilling life than many other disabilities permit, but also makes tracking systems that contribute to prevention research harder to implement. Some community groups also report difficulty in accessing high-quality, continuous health care, in part because intellectual disabilities have a lower urgency than other disabilities with which it might share support services. Additionally, people with intellectual disabilities are often dependent on sub-market payment rates like Medicaid. Further, few clinicians feel competent in their treatment of intellectually disabled patients, leading many to decide against serving that population.

WHY TERMINOLOGY MATTERS

In response to perceived negative stereotypes, the term mental retardation is often replaced today with the term intellectual disabilities. In some cases the word “mental” was confused with the term “mental illness” and the word “retardation” is often associated with offensive terms such as “retard” or “retarded.”¹⁶ For example, the Arc of the United States describes its work as providing services for “children and adults with cognitive, intellectual and developmental disabilities in every community.”¹⁷ In other parts of the world the terminology used may be intellectual disability, learning difficulty, or mental handicap.

Yet, notwithstanding the negative connotation associated with the term “mental retardation,” it does have certain legal and medical meanings, especially in the U.S. For example, within the purview of the law, the term “mental retardation” offers special protections in key areas of federal and state

policy, including death penalty prosecutions and Social Security administrative processes.

Self-advocates and those advocating on behalf of individuals with disabilities also provide these additional language guidelines:

- ▲ **Use “people-first language.”** Refer to individuals, persons or people with intellectual or developmental disabilities, rather than “intellectually disabled people” or “the developmentally disabled.”
- ▲ People **have** intellectual or developmental disabilities, rather than are “suffering from,” “afflicted with,” or “a victim of” intellectual disabilities.
- ▲ A person **“uses”** a wheelchair, rather than is “confined” or “restricted to” a wheelchair.
- ▲ **“Down syndrome”** has replaced “Down’s Syndrome” and “mongoloid.”
- ▲ A person is **physically challenged** or **disabled** rather than crippled.

SPECIAL OLYMPICS HEALTHY ATHLETES: A NEW MODEL FOR THE DELIVERY OF HEALTH AND WELLNESS SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITIES

People with intellectual and developmental disabilities have a markedly higher risk than the general public of preventable secondary health conditions. These include obesity, nutritional deficits, poor fitness, and untreated or poorly treated vision, dental, hearing or podiatric problems. For example, hearing loss is several hundred percent higher for people with intellectual disabilities when compared to other people their age.

These disparities in care result from lack of access and ability to pay for services, practitioners who are not adequately trained to care for this population, and poorly developed and supported behaviors to promote health.

Special Olympics is a world-wide leader in the field of athletics for people with intellectual disabilities, providing high quality sports training and competition opportunities, offering more than 1.7 million athletes from 150 nations the opportunity to participate in 26 Olympic-type summer and winter sports. Special Olympics programs also promote social competence and self-esteem, acceptance, and improved health outcomes. Recently, Special Olympics has been developing its Healthy Athletes program to address health disparities of its athletes.

Through Healthy Athletes, Special Olympics athletes with intellectual disabilities receive a



Photos courtesy of Special Olympics



variety of health screenings and services, including vision, dental, hearing, podiatric, and bone density screenings, surveys of exercise habits and aerobic fitness, and dissemination of information about health promotion and disease prevention. Additionally, Healthy Athletes has trained tens-of-thousands of health care professionals and students worldwide in an effort to educate them about the health needs and abilities of people with intellectual and developmental disabilities. Data obtained during Healthy Athletes screening events have informed a wide variety of health science and policy publications, scientific conferences and government advisory and legislative committees (www.specialolympics.org).

With the support of the CDC, the Special Olympics Healthy Athletes program conducted more than 425 screening events in 2004 in all U.S. states and another 54 nations around the world.



Birth Defects Surveillance Data from Selected States 1997-2001*

	Total Birth Defects	Total Live Births	Percent of Live Births Resulting in a Birth Defect
Alabama	983	42,267	2.33%
Alaska	2,745	49,835	5.51%
Arizona	1,753	75,563	2.32%
Arkansas	5,843	184,731	3.16%
California	3,491	283,066	1.23%
Colorado	12,215	310,632	3.93%
Delaware	1,554	42,533	3.65%
Florida	31,224	787,769	3.96%
Georgia	7,055	235,616	2.99%
Hawaii	2,936	86,743	3.38%
Illinois	15,336	914,204	1.68%
Iowa	6,820	187,312	3.64%
Kentucky	8,716	220,151	3.96%
Maryland	2,412	339,205	0.71%
Massachusetts	3,448	243,462	1.42%
Michigan	19,925	670,459	2.97%
Mississippi	1,753	86,352	2.03%
Missouri	12,516	300,876	4.16%
Montana	403	21,893	1.84%
New Jersey	21,508	571,846	3.76%
New Mexico	2,348	108,476	2.16%
New York	31,505	1,281,686	2.46%
North Carolina	16,642	452,582	3.68%
North Dakota	916	39,263	2.33%
Oklahoma	7,570	246,168	3.08%
Puerto Rico	521	299,859	0.17%
Rhode Island	1,835	59,422	3.09%
South Carolina	261	272,592	0.10%
Tennessee	4,915	157,857	3.11%
Texas	50,292	1,556,101	3.23%
Utah	4,002	229,626	1.74%
Virginia	7,991	375,277	2.13%
West Virginia	2,281	103,485	2.20%
Wisconsin	6,626	340,351	1.95%

SOURCE: Birth Defects Surveillance Data from Selected States, 1997-2001. Birth Defects Research (Part A) 70:677-771 (2004)¹⁸

*States were requested to report data from January 1, 1997 to December 31, 2001. However, time frames for reported data do vary. In most cases data refer to a full year, or some combination of years in the designated time period. Accordingly, some states may have under-reported the numbers of birth defects due to shortened reporting time periods. For any given year, a child may be counted twice, or more, depending on the number of birth defects. These numbers, therefore, are not absolute totals for the four year time period or absolute comparisons between the states. They should be used contextually and as an estimate of how prevalent birth defects are in the United States overall.

Learning Disabilities

A learning disability (LD) is distinct from an intellectual disability in that an individual with learning disabilities has normal or above-average intelligence, but has unexpected difficulty acquiring and mastering new skills or information in particular areas. Presumed to be neurobiological in nature, and therefore lifelong, learning disabilities include difficulties with reading, writing, listening, speaking, reasoning, and/or doing math. Dyslexia (a language-based disorder that affects reading) is the best understood of the specific learning disabilities. Physical impairments such as problems with vision and hearing may present challenges to learning, but are not considered learning disabilities. Learning disabilities are often inherited, though little is known about their direct causes. As many as one in seven people is thought to be affected by some form of learning disability.¹⁹

Since learning disabilities impair a child's ability to acquire new skills, they are often first detected at the onset of formal education. Special assistance can help a child to cope with or overcome the limitations and challenges posed by a disability, while failure to address the condition can lead a child to fall behind a grade level. Additionally, unaddressed learning disabilities sometimes can result in social/emotional and behavioral problems, such as low motivation, learned helplessness, diminished self-esteem, or disruptive behavior both at home and at school. Failure to properly recognize and treat learning disabilities can contribute to chronic underachievement as well as behavior and

discipline problems during a student's academic or vocational career.

Early intervention is crucial to effectively managing a learning disability, but identification and classification are often not carried out in a timely way. Moreover, learning disabilities might not become evident until a child is in school, delaying opportunities for early intervention. A learning disability label can stigmatize students among their peers and lead to tracking within the school system, so teachers sometimes hesitate to label a student if the problem is not severe. Wide disparities in who is tested and how they are tested can lead to differing outcomes and access to services.

Research into learning disabilities falls into two major categories: (1) studies of prevalence and disease burden, including how and why learning disabilities occur, and (2) studies that focus on effective means of teaching or intervening with children and adults who have learning disabilities. Prevalence and risk factor studies are conducted by the CDC through the National Center on Birth Defects and Developmental Disabilities. Studies about how and why learning disabilities occur are primarily undertaken by the NIH through NICHD, the National Institute of Deafness and Other Communication Disorders, and NIMH, while studies that focus on effective means of teaching or intervening with children and adults are conducted through the U.S. Department of Education Office of Special Education Programs, and most recently, the Institute for Education Sciences (IES).

ATTENTION DEFICIT-HYPERACTIVITY DISORDER (ADHD): MORE QUESTIONS THAN ANSWERS

Attention Deficit-Hyperactivity Disorder (ADHD) is a neurobehavioral disorder estimated to affect between three and five percent of all children.²⁰ A lifelong condition, its characteristics can include difficulty staying on task, following instructions, and paying attention to detail. ADHD can be disruptive in multiple settings in a person's life. Among children, ADHD can cause serious social consequences such as school failure, delinquency, increased risk for injury, and poor peer relations. Among adults, ADHD is less well-understood but has been related to frequent job loss/changes and difficulty in family functioning. There are three subtypes of ADHD, characterized by inattentiveness or hyperactivity and impulsiveness, and some people display elements of each.

The most common treatments for ADHD in children are psychostimulant medications that increase attention and decrease hyperactivity, structured classroom management, as well as educational and behavioral therapies at home and at school. Some people learn to manage the condition effectively and thereby minimize the challenges posed by their disability as adults. It is not known what causes ADHD. However, it is highly heritable and

environmental factors, such as lead and mercury exposures, have been implicated.

High prevalence rates and the lack of knowledge surrounding ADHD argue for high priority public and private research into the disorder. Improved data collection also is required, as is analysis of systemic implementation of research-based and promising practices to capture the full range of genetic, environmental, behavioral, and lifestyle factors to improve outcomes for these individuals.

Learning disabilities and ADHD may co-occur and are often confused as they share many of the same manifestation and behavioral characteristics, such as inattentiveness, poor task vigilance, and underachievement. In fact, based on major surveys, CDC estimates that nearly half of those with ADHD also have a learning disability.²¹

CDC/NCBDDD sponsors the National Resource Center on ADHD to provide accurate and valid information to the public, parents, affected adults, educators and health care providers. The center operates a toll-free hotline, a comprehensive Web site, and physical and virtual library holdings on ADHD diagnosis and treatment.

Number and Percentage of Children Ages 3 to 21 Served Under IDEA by State and Service Category As of 12/31/03

	Autism		Hearing Impairments		Mental Retardation		Specific Learning Disabilities		Visual Impairments		All Disabilities	
	Ages 3-21	Percent of State 3-21 pop	Ages 3-21	Percent of State 3-21 pop	Ages 3-21	Percent of State 3-21 pop	Ages 3-21	Percent of State 3-21 pop	Ages 3-21	Percent of State 3-21 pop	Ages 3-21	Percent of State 3-21 pop
Alabama	1,479	0.12%	1,037	0.09%	12,652	1.05%	40,581	3.36%	476	0.04%	93,056	7.70%
Alaska	311	0.16%	158	0.08%	781	0.40%	8,368	4.27%	44	0.02%	17,959	9.16%
Arizona	2,288	0.16%	1,783	0.12%	8,383	0.58%	56,473	3.93%	635	0.04%	112,125	7.81%
Arkansas	1,114	0.15%	656	0.09%	11,641	1.60%	22,565	3.10%	243	0.03%	66,793	9.17%
California	24,863	0.26%	10,959	0.11%	42,991	0.44%	337,800	3.47%	4,261	0.04%	675,763	6.94%
Colorado	978	0.08%	1,442	0.12%	3,588	0.31%	32,232	2.76%	348	0.03%	82,447	7.06%
Connecticut	2,357	0.27%	864	0.10%	3,391	0.39%	27,035	3.09%	339	0.04%	73,952	8.46%
Delaware	475	0.23%	291	0.14%	2,363	1.13%	9,592	4.57%	52	0.02%	18,417	8.77%
D.C.	215	0.16%	124	0.09%	1,575	1.14%	6,253	4.54%	31	0.02%	13,242	9.60%
Florida	7,151	0.18%	3,881	0.10%	40,278	1.04%	180,278	4.66%	1,309	0.03%	397,758	10.28%
Georgia	4,383	0.19%	1,754	0.08%	29,003	1.26%	52,374	2.28%	628	0.03%	190,948	8.30%
Hawaii	770	0.24%	437	0.14%	2,004	0.64%	10,158	3.23%	72	0.02%	23,266	7.39%
Idaho	635	0.16%	303	0.08%	1,760	0.45%	12,849	3.26%	110	0.03%	29,092	7.37%
Illinois	6,961	0.20%	3,943	0.11%	28,292	0.82%	142,164	4.14%	1,166	0.03%	318,111	9.27%
Indiana	5,434	0.32%	2,143	0.13%	23,069	1.36%	63,314	3.74%	909	0.05%	171,896	10.14%
Iowa	1,331	0.17%	904	0.11%	12,632	1.57%	40,192	4.99%	182	0.02%	73,717	9.15%
Kansas	1,130	0.15%	615	0.08%	5,005	0.65%	24,172	3.15%	216	0.03%	65,139	8.50%
Kentucky	1,586	0.15%	687	0.06%	17,882	1.67%	17,957	1.67%	463	0.04%	103,783	9.68%
Louisiana	1,924	0.15%	1,403	0.11%	11,306	0.86%	35,190	2.67%	467	0.04%	101,933	7.75%
Maine	1,018	0.31%	286	0.09%	949	0.29%	12,688	3.91%	92	0.03%	37,784	11.66%
Maryland	4,084	0.29%	1,383	0.10%	6,822	0.48%	40,684	2.88%	574	0.04%	113,865	8.06%
Massachusetts	5,087	0.32%	1,217	0.08%	12,517	0.78%	71,868	4.47%	504	0.03%	159,042	9.90%
Michigan	7,259	0.26%	3,289	0.12%	25,938	0.94%	97,468	3.53%	929	0.03%	238,292	8.63%
Minnesota	5,838	0.42%	2,171	0.16%	9,718	0.71%	36,858	2.68%	368	0.03%	114,193	8.30%
Mississippi	680	0.08%	662	0.08%	4,959	0.59%	30,087	3.57%	300	0.04%	66,848	7.94%
Missouri	2,863	0.19%	1,334	0.09%	12,242	0.80%	59,848	3.91%	514	0.03%	143,593	9.38%
Montana	270	0.11%	198	0.08%	1,135	0.45%	9,409	3.76%	72	0.03%	19,435	7.78%
Nebraska	649	0.13%	674	0.14%	5,566	1.15%	15,363	3.17%	231	0.05%	44,561	9.19%
Nevada	1,164	0.22%	539	0.10%	2,031	0.39%	24,704	4.70%	175	0.03%	45,201	8.61%
New Hampshire	667	0.20%	291	0.09%	982	0.30%	13,391	4.04%	143	0.04%	31,311	9.45%
New Jersey	5,503	0.26%	1,703	0.08%	6,451	0.30%	108,997	5.09%	406	0.02%	241,272	11.26%
New Mexico	413	0.08%	553	0.10%	1,734	0.32%	25,726	4.78%	196	0.04%	51,814	9.63%
New York	9,486	0.19%	5,275	0.11%	14,721	0.30%	182,995	3.67%	1,792	0.04%	442,665	8.87%
North Carolina	4,687	0.22%	2,277	0.11%	27,781	1.32%	69,660	3.31%	701	0.03%	193,956	9.20%
North Dakota	240	0.13%	147	0.08%	1,142	0.63%	5,043	2.76%	56	0.03%	14,044	7.69%
Ohio	5,490	0.18%	2,867	0.09%	55,818	1.81%	94,309	3.06%	1,184	0.04%	253,878	8.25%
Oklahoma	991	0.10%	868	0.09%	7,233	0.75%	46,669	4.84%	407	0.04%	93,045	9.65%
Oregon	4,389	0.49%	914	0.10%	4,412	0.49%	31,711	3.50%	344	0.04%	76,083	8.41%
Pennsylvania	7,178	0.23%	3,002	0.09%	27,173	0.86%	139,083	4.39%	1,311	0.04%	273,259	8.62%
Rhode Island	655	0.24%	233	0.08%	1,264	0.45%	14,293	5.14%	76	0.03%	32,223	11.58%
South Carolina	1,523	0.14%	1,240	0.11%	14,913	1.36%	47,151	4.30%	418	0.04%	111,077	10.13%
South Dakota	391	0.18%	163	0.07%	1,299	0.59%	7,284	3.31%	39	0.02%	17,760	8.06%
Tennessee	1,958	0.13%	1,449	0.10%	13,623	0.91%	49,907	3.33%	756	0.05%	122,627	8.19%
Texas	11,940	0.19%	6,407	0.10%	27,544	0.44%	252,265	4.07%	2,980	0.05%	506,771	8.18%
Utah	1,179	0.15%	652	0.08%	3,155	0.41%	28,531	3.70%	310	0.04%	57,745	7.49%
Vermont	315	0.19%	130	0.08%	1,237	0.75%	4,353	2.65%	33	0.02%	13,670	8.34%
Virginia	3,951	0.21%	1,532	0.08%	14,084	0.76%	70,181	3.77%	506	0.03%	172,788	9.29%
Washington	3,112	0.19%	1,390	0.09%	5,743	0.36%	49,272	3.06%	315	0.02%	123,673	7.69%
West Virginia	534	0.12%	468	0.10%	9,131	2.05%	17,911	4.01%	276	0.06%	50,772	11.38%
Wisconsin	3,669	0.25%	1,649	0.11%	12,336	0.83%	48,843	3.29%	459	0.03%	127,828	8.61%
Wyoming	182	0.13%	166	0.12%	615	0.43%	5,118	3.62%	63	0.04%	13,430	9.50%
50 States & D.C.	162,750	0.21%	78,513	0.10%	592,864	0.77%	2,831,217	3.68%	28,481	0.04%	6,633,902	8.62%

SOURCE: Source: U.S. Department of Education, Office of Special Education Programs, Data Analysis System
 Percentages calculated based on 2000 Census State Population Data.

Number and Percentage of Infants and Toddlers (Under Age 3) Receiving Early Intervention Services Under IDEA As of 12/1/03

	0 to <12 Months	12 to <24 Months	24 to <36 Months	Total 0 to <36 Months	% of Population Receiving Services
Alabama	216	730	1,207	2,153	1.20
Alaska	90	219	332	641	2.17
Arizona	491	1,266	1,968	3,725	1.39
Arkansas	260	846	1,666	2,772	2.46
California	5,562	9,275	12,659	27,496	1.76
Colorado	444	1,034	1,670	3,148	1.56
Connecticut	419	1,088	2,194	3,701	2.96
Delaware	192	315	448	955	2.90
D.C.	24	75	152	251	1.13
Florida	2,219	4,525	7,975	14,719	2.28
Georgia	690	1,571	2,579	4,840	1.19
Hawaii	1,386	1,395	1,397	4,178	7.70
Idaho	272	457	761	1,490	2.44
Illinois	1,675	4,055	7,410	13,140	2.42
Indiana	1,585	3,002	4,683	9,270	3.62
Iowa	323	684	1,129	2,136	1.95
Kansas	413	805	1,531	2,749	2.40
Kentucky	320	1,214	2,352	3,886	2.37
Louisiana	460	1,088	1,950	3,498	1.75
Maine	98	304	703	1,105	2.77
Maryland	763	1,851	3,160	5,774	2.60
Massachusetts	2,391	4,569	7,447	14,407	5.92
Michigan	1,320	2,631	4,259	8,210	2.13
Minnesota	472	1,027	2,003	3,502	1.78
Mississippi	1,062	631	282	1,975	1.53
Missouri	465	1,067	1,891	3,423	1.51
Montana	131	219	278	628	1.95
Nebraska	176	374	710	1,260	1.70
Nevada	113	346	471	930	0.94
New Hampshire	155	329	662	1,146	2.61
New Jersey	688	2,382	5,021	8,091	2.36
New Mexico	455	804	1,068	2,327	2.89
New York	2,640	9,500	20,886	33,026	4.42
North Carolina	735	1,938	3,284	5,957	1.66
North Dakota	86	166	224	476	2.13
Ohio	1,233	2,641	4,230	8,104	1.81
Oklahoma	652	1,222	1,474	3,348	2.24
Oregon	184	591	1,063	1,838	1.38
Pennsylvania	2,009	4,000	6,420	12,429	2.94
Rhode Island	227	372	683	1,282	3.48
South Carolina	284	570	885	1,739	1.04
South Dakota	70	270	490	830	2.66
Tennessee	552	1,386	2,277	4,215	1.81
Texas	2,654	6,436	11,145	20,235	1.81
Utah	341	734	1,307	2,382	1.69
Vermont	64	171	387	622	3.42
Virginia	579	1,561	2,064	4,204	1.40
Washington	349	1,133	2,145	3,627	1.56
West Virginia	325	581	761	1,667	2.73
Wisconsin	607	1,554	3,256	5,417	2.66
Wyoming	100	214	358	672	3.57
50 States and D.C.	39,021	85,218	145,357	269,596	2.24

SOURCE: U.S. Department of Education, Office of Special Education Programs, Data Analysis System
Population Estimates from U.S. Census Bureau

Successes and Challenges

Coordinated Campaigns: A Model for Prevention

In 1992, the Department of Health and Human Services, through the U.S. Public Health Service, issued a recommendation that all women of child-bearing age consume at least 400 micrograms of folic acid daily. This recommendation was based on research showing that adequate consumption of folic acid before and during the first several weeks of pregnancy had the potential to reduce the incidence of spina bifida and anencephaly — birth defects in which the brain and spinal column are improperly formed, resulting in serious impairment or death — by as much as 70 percent. At that time, neural tube defects were estimated to affect an estimated 4,000 pregnancies annually, with annual medical costs associated with spina bifida alone exceeding \$200 million.²²

In 1998, the National Council on Folic Acid was formed as a partnership of more than 80 national organizations, federal agencies, and state councils. In 1996, the FDA issued a requirement that all foods containing enriched flour be fortified with folic acid by January 1998. This public health intervention was an important step to increase folic acid intake among women of childbearing age. The success of this effort has been documented by the 31 percent decline in spina bifida and 16 percent decline in anencephaly in the U.S. following folic acid fortification.²³ In 1999, the National Folic Acid Campaign was launched by CDC, the March of Dimes, and the National Council on Folic Acid. Today, CDC supports states and localities in developing and managing surveil-

lance systems, prevention programs, and epidemiological investigations.

Such coordinated campaigns are working. According to a 2004 Gallup Survey conducted for the March of Dimes, 24 percent of women of childbearing age knew that folic acid prevents birth defects, up from four percent in 1995.²⁴ Awareness of how and when to consume folic acid is increasing too, although a greater level of folic acid consumption will be required to realize the vitamin's full prevention potential. Initial data has allowed partners to fine-tune strategies for reaching high-risk populations, and new alliances are being formed based on feedback to date. One emerging challenge is the need to address disparities, such as higher rates of spina bifida and other neural tube defects among babies born to Hispanic women. In addition, there is a need to advance the understanding of how to promote the health and well-being of children and adults living with spina bifida neural tube conditions.

This campaign demonstrates that diverse groups -- national organizations, disease-specific associations, federal agencies, medical associations, local governments, state councils, and even unexpected partners like minority sorority councils -- can work together effectively when marshaled around a clear, specific health message. This success calls for coordinated, collaborative action by the public health and medical communities on other issues where concerted action can yield positive results.



Newborn Screening: Facilitating Early Detection and Treatment

For 40 years, state-based screening of newborn babies has been carried out to identify serious disorders that may not otherwise be detected before disability or death occurred. Newborn screening is typically carried out by taking a sample of blood from a newborn within 48 hours of birth, before the mother leaves the hospital, and analyzing it for as many as 44 different disorders. Every year some four million babies, virtually all of the nation's newborns, are tested through such state-based programs; about 3,000 are diagnosed with a severe disorder.²⁵ These screening programs have historically been highly effective in identifying medical problems and facilitating immediate, appropriate treatment, allowing many of these children to develop normally or with minimal health problems. Newborn screening is important because it leads to the detection of conditions, which in turn is critical to improving the outcomes of affected children, especially in preventing intellectual disabilities and death.

In 1999, the American Academy of Pediatrics (AAP) recommended that the federal government conduct a multi-stakeholder process to develop nationally recognized newborn screening standards and policies. While responsibility for screening rests with the individual states, a set of national standards could provide recommended minimum guidelines on how and what to test for, as well as assist in standardizing reporting procedures to enable nationwide data comparisons. Based on the importance of newborn screening for infant health, in 2000, the March of Dimes issued a set of nine core disorders for which every newborn should be screened.

In March, 2005, HRSA released a report by the American College of Medical Genetics entitled *Newborn Screening: Toward a Uniform Screening Panel and System*.²⁶ The report establishes criteria to evaluate conditions for potential inclusion in a national screening panel, and recommends screening for 29 core conditions for which effective tests and treatment regimens exist, as well as 25 secondary conditions that can be identified in the course of testing for the core group. The report also addresses guidelines for national oversight of such screening and highlights additional benefits that could occur by providing guidance to states following positive test results, particularly for rare conditions with which states may have limited experience. Both the March of Dimes and the American Academy of Pediatrics have formally endorsed this report.

The HRSA report was not issued in a vacuum; many agencies and organizations support the development of national newborn screening standards, and the existing screening programs in every state attest to the public and individual health benefits ascribed to such programs. Furthermore, the information and cost benefits of centralizing the process will allow individual states to significantly enhance the quality of screening provided to newborns while minimizing the cost entailed. To the extent that screening data can be collectively analyzed, researchers may also benefit from this initiative with more accurate, uniform, and extensive data sets on which to draw. Extended national screening thus constitutes a winning proposition for all.

THE 29 CONDITIONS RECOMMENDED FOR NEWBORN SCREENING

- 3-Methylcrotonyl-CoA carboxylase deficiency (3MCC)
- 3-OH 3-CH₃ glutaric aciduria (HMG)
- Argininosuccinic acidemia (ASA)
- Beta-ketothiolase deficiency (BKT)
- Biotinidase deficiency (BIOT)
- Carnitine uptake defect (CUD)
- Citrullinemia (CIT)
- Congenital adrenal hyperplasia (CAH)
- Congenital hypothyroidism (HYPOTH)
- Cystic fibrosis (CF)
- Galactosemia (GALT)
- Glutaric acidemia type I (GA I)
- Hb S/Beta-thalassemia (Hb S/Th)
- Hb S/C disease (Hb S/C)
- Hearing deficiency
- Homocystinuria (HCY)
- Isovaleric academia (IVA)
- Long-chain L-3-OH acyl-CoA dehydrogenase deficiency (LCHAD)
- Maple syrup urine disease (MSUD)
- Medium chain acyl-CoA dehydrogenase deficiency (MCAD)
- Methylmalonic acidemia (Cbl A,B)
- Methylmalonic acidemia (mutase deficiency) (MUT)
- Multiple carboxylase deficiency (MCD)
- Phenylketonuria (PKU)
- Propionic acidemia (PROP)
- Sickle cell anemia (SCA)
- Trifunctional protein deficiency (TFP)
- Tyrosinemia type I (TYR I)
- Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)

CHALLENGES AHEAD

Early Childhood Developmental Screening: Diagnosis Begins with the Primary Health Care Provider

Awareness of conditions that entail developmental delays like ASD and intellectual disabilities, as well as the risk for neurobiological disorders, such as learning disabilities and ADHD, has increased in part due to changes in how the health, medical, and educational communities address these problems. Most experts agree that early identification of developmental disabilities is important to managing them. Of the 17 percent of children with a developmental or behavioral disability in the U.S., less than 50 percent are recognized as having a problem before starting school. By this time, delays in language development have already occurred, and the affected children have missed out on potential early intervention opportunities.²⁷

The AAP, in recognition of this problem, has stated that “early identification of chil-

dren with developmental delays is important in the primary care setting.”²⁸ According to the CDC, “As many as 85 to 90 percent of children identified as having autism who participate in systematic intervention before they are five years of age gain the ability to talk, which helps them reach their full potential.”²⁹ CDC recently developed a program called “Learn the Signs. Act Early,” to increase parent and professional recognition of early developmental milestones and warning signs that may signal the need for further evaluation and possible early intervention.

In 2002, the HRSA Maternal and Child Health Bureau teamed up with the AAP and other private and public entities, including HMOs and universities, to administer the Bright Futures initiative. This effort aims to,

among other things, promote developmental screening in young children by developing and disseminating materials, fostering partnerships, and encouraging family participation in promoting health. Most experts agree that pediatricians are the professionals best suited to perform this screening, based on their repeated contact with children below school age at childhood wellness doctor visits. However, resource limitations may be a potential barrier to developmental screening for many families.

Currently, there is no coordinated system to establish the percentage of children who receive the benefits of early childhood developmental screening or to ensure that these services are universally available, and data do not exist to track screening efforts

National Health Tracking Network and Birth Defect Surveillance Systems: More Data are Needed

In 2002, the CDC established a National Environmental Public Health Tracking Program to begin work on building a national public health tracking network. Working through pilot projects and newly-established university centers of excellence, the program promises to significantly expand national capacity for tracking exposures to environmental hazards and related human health issues.

Birth defect surveillance and autism registries are a critical element of a national health tracking network, allowing states to assess the health and medical challenges of their newborn populations, and providing researchers with important data. More than 60 percent of birth defect causes are unknown, and currently, states track birth defects with significant variation in the standards set and achieved. In June 2004, the NBDPN published *Guidelines for Conducting Birth Defects Surveillance* in order to improve the quality and usefulness of birth defects data and to encourage and promote the use of the data in the design and delivery of services, prevention, and intervention.³⁰

around the country. Furthermore, many of the underlying causes for developmental disabilities are unknown, and quality data on distribution, area of concentration, age of onset, environmental exposures, and behavioral and lifestyle factors, are crucial to finding causes and cures for these conditions. As learning disabilities, autism, and other forms of developmental delay demand an increasing share of our health and education resources, it will become increasingly important to have systems in place that facilitate research and permit early identification and treatment. In addition, it is important to ensure a coordinated service delivery system where families can access validated, comprehensive, appropriate, and easy-to-use intervention services.

In 2002 and 2003, Trust for America's Health evaluated birth defect surveillance systems around the country and found that while most states were sensitive to the need to enhance birth defect registration and tracking, the majority of states had unsatisfactory programs in place, due in large part to resource limitations.³¹ Two thirds of all states did not explore possible links between birth defects and environmental exposures or between birth defects and other registries such as for cancer(s).³² For a fully-functioning national health tracking network to be realized, it is critical that the various components of health tracking -- birth defects surveillance systems, chronic disease registries, environmental health hazards, occupational influences, lifestyle, behavioral, and other health-related factors -- be systematically integrated and adequately funded.

Funding for birth defects programs has been inadequate at the state level for years and has become increasingly precarious with cuts in CDC's support to state birth defect surveillance programs. For example, there has not been sufficient funding to cre-

ate a birth defects network similar to that which exists for state-based newborn screening, wherein children are tracked throughout the entire process from identification to receipt of services. Birth defects prevention advocates and professionals argue that birth defects programs are similar in importance to newborn screening because they have the potential to identify an even larger number of children who are in need of health and support services.

Monitoring programs for autism and related developmental disabilities can also be an invaluable tool to give researchers the information they need to identify potential causes

for the disability. Tracking allows scientists to “detect changes in the prevalence of [autism], to understand the national impact of autism and related conditions, and to determine whether ASDs affect certain people or geographic areas more than others.”³³ Despite the need for coordinated monitoring systems for ASDs, these are relatively new endeavors and sites have faced significant challenges in accessing the information needed to most completely identify cases in the community. Lack of access to information on children’s developmental issues contained in educational records threatens the ability of these programs to provide accurate, ongoing information.

TRACKING BIRTH DEFECTS

“BIRTH DEFECTS RESEARCHERS USE EPIDEMIOLOGIC METHODS TO TRACK AND UNDERSTAND BIRTH DEFECTS AND THEIR CAUSES.... ALTHOUGH BIRTH DEFECTS RESEARCH AND MONITORING HAVE LED TO THE DISCOVERY OF EFFECTIVE PREVENTION METHODS FOR MANY BIRTH DEFECTS, THE CAUSES OF 66 [PERCENT] OF ALL BIRTH DEFECTS REMAINS UNKNOWN.... FOR THESE QUESTIONS TO BE ANSWERED ... THE UNITED STATES MUST DEVELOP AND MAINTAIN STRONG STATE- AND COMMUNITY-BASED MONITORING PROGRAMS.”³⁴ — CDC

According to the CDC, there are 47 states and territories operating or actively planning a surveillance program.³⁵ However, only 15 of these programs currently receive some financial support from CDC for birth defects surveillance and prevention, although technical assistance from CDC is available to all programs.³⁶ There are four states that do not have any form of birth defects monitoring program: Idaho, Oregon, South Dakota, and Wyoming.³⁷ Additionally, Kansas has a registry program that collects statistics, but the information is not used as part of a birth defects surveillance system. The monitoring systems and activities vary by state, including factors such as timeliness of data reporting, whether states study the linkages between the data and environmental factors, and the range of

birth defects about which information is collected.³⁸ Many states are in the process of planning new or expanding existing monitoring activities, but these efforts are largely contingent on the receipt of additional resources.

In 2005, CDC also provided funds for eight Centers for Birth Defects Research and Prevention (CBDRP) to assist states in their efforts to improve monitoring, conduct local research, and contribute to collaborative studies using data from the National Birth Defects Prevention Study (NBDPS).³⁹ These Centers include: Arkansas, California, Iowa, Massachusetts, New York, North Carolina, Texas, and Utah. CDC coordinates the CBDRP and participates in the NBDPS as the ninth study site.

States and Territories Operating or Actively Planning Birth Defects Surveillance Programs

(47 total)

(14 states and Puerto Rico receiving CDC funds for birth defects surveillance and prevention are noted in bold)

(Seven states in planning phase are noted with a “*”)

State	Funding Sources
Alabama	80% CDC grant; 20% university
Alaska	No specific funding source at present; currently operating on unexpended funds from 2002-2005 CDC grant
Arizona	40% CDC grant; 30% general state funds; 3% maternal and child health funds; 27% genetic screening revenues
Arkansas	100% general state funds
California	20% CDC grant; 35% general state funds; 20% maternal and child health funds; 15% other federal funds; 10% DHS/UC pass through
Colorado	70% CDC grant; 30% general state funds
Connecticut	100% maternal and child health funds
Delaware	(not reported)
D.C.*	100% Title V Block Grant
Florida	30% CDC grant; 70% general state funds
Georgia	60% general state funds; 40% other federal funds
Hawaii	73% State special funds; 27% private foundations
Illinois	27% CDC grant; 73% general state funds
Indiana	3% general state funds; 50% maternal and child health funds; 47% other federal funds
Iowa	65% CDC grant; 35% general state funds
Kentucky	25% CDC grant; 75% general state funds
Louisiana	100% Title V CSHCN funds
Maine	MCH Title V funds pending additional funding sources
Maryland	100% general state funds
Massachusetts	90% CDC grant; 10% general state funds
Michigan	25% CDC grant; 75% general state funds
Minnesota*	90% CDC grant; 5% general state funds; 5% March of Dimes in-kind match to CDC grant
Mississippi	5% maternal and child health funds; 95% genetic screening revenues
Missouri	37% maternal and child health funds; 54% service fees; 9% private foundation
Montana	100% CDC grant
Nebraska	100% maternal and child health funds
Nevada*	100% service fees
New Hampshire*	100% CDC grant
New Jersey	10% CDC grant; 85% maternal and child health funds; 5% genetic screening revenues
New Mexico	59% CDC grant; 16% general state funds; 25% maternal and child health funds
New York	45% CDC grant; 15% general state funds; 24% maternal and child health funds; 16% other federal funds
North Carolina	45% CDC grant; 55% general state funds
North Dakota	State Systems Development Initiative grant
Ohio*	100% CDC grant
Oklahoma	30% CDC grant; 13% general state funds; 57% maternal and child health funds
Pennsylvania*	100% maternal and child health funds
Puerto Rico	43% CDC grant; 57% maternal and child funds
Rhode Island	70% CDC; 30% maternal and child health funds
South Carolina	65% general state funds; 25% institutional funds; 10% March of Dimes
Tennessee	100% general state funds
Texas	51% general state funds; 33% maternal and child health funds; 16% preventive health block grant; Does not include CDC-supported research center funds
Utah	20% CDC grant; 80% maternal and child health funds
Vermont*	100% CDC grant
Virginia	30% CDC grant; 70% maternal and child health funds
Washington	40% general state funds; 60% maternal and child health funds
West Virginia	Title V and state appropriations
Wisconsin	50% CDC grant; 50% general state funds

TRACKING AUTISM

“THE CAUSES OF ASDs REMAIN UNKNOWN. BOTH GENETIC AND ENVIRONMENTAL FACTORS MIGHT PLAY A ROLE, THOUGH NO SINGLE GENE OR ENVIRONMENTAL FACTOR IS KNOWN TO CAUSE ASDs.”⁴⁰ – CDC

In 2004, only 16 sites in 18 states receive funds from the CDC to support tracking of Autism Spectrum Disorders.⁴¹ Most of these programs are relatively new and are at initial stages of development.

States with CDC Monitoring and Research Activities (seven total)	States with CDC Monitoring Activities (11 total)
Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology	Autism and Developmental Disabilities Monitoring Network
California Colorado Delaware (joint program with Maryland) Georgia (CDC’s program) Maryland (joint program with Delaware) North Carolina Pennsylvania	Alabama Arizona Arkansas Florida Illinois (joint program with Missouri) Missouri (joint program with Illinois) New Jersey South Carolina Utah West Virginia Wisconsin





CONCLUSIONS AND RECOMMENDATIONS:

Continued Progress Demands Data and Collaboration

Enormous progress has been made over the last two decades in research of causes and treatments for birth defects and developmental disabilities. Children with conditions that were once fatal are living into adulthood. Others with disabilities that affect academic progress and success are obtaining the assistance they need, thanks to enhanced supports and adaptive strategies.

However, these successes illustrate the need for further progress. Knowing that research has radically transformed the prospects for babies born with certain birth defects, the health community is compelled to find causes for the nearly 70 percent of birth defects that remain unexplained. Moreover, with the number of children now identified as having a developmental disability escalating, learning about the causes of these disabilities is essential to public health.

To ensure that progress towards identifying, treating and ultimately, preventing birth defects and developmental disabilities, TFAH recommends the following:

1. **Adequately fund birth defects surveillance systems and autism registries** at the state and federal levels. These tools provide the data necessary to perform several key public health functions, including referral of children to appropriate services; evaluation of the impact of birth defects and developmental disabilities on the medical system and on the communi-

ty; information for future research; and evaluation of the effectiveness of prevention programs. At the federal level, at least \$20 million should be appropriated for the CDC's state-based birth defects surveillance activities and the Center for Birth Defects Research and Prevention.

2. **With adequate privacy protections in place, ensure that birth defect and developmental disability surveillance systems have access to critical data.** To be effective, these prevention tools depend on access to multiple sources of data where children with these conditions are identified, including medical and educational settings which can be accomplished while maintaining individuals' confidentiality. In particular, developmental disability surveillance systems have faced significant challenges in accessing educational records, notwithstanding the fact that access is necessary to monitor local and national trends and to provide accurate ongoing information.

3. **Integrate key data systems** by linking existing high-quality data systems (e.g., vital records, birth defects surveillance systems, newborn screening programs, immunization registries, educational data, nationwide health tracking). Such integration would allow for additional public health uses of the information, such as linking environmental exposure data with developmental outcomes or examining the long-term health status of children with birth defects.
4. **Establish a national repository for blood samples that can help identify the causes of birth defects and developmental disabilities** that are due to the environment (e.g., elevated blood lead levels), infectious disease agents, or gene-environment interactions. Just like the CDC's nutritional studies have maintained biological samples for decades to help track changes in exposure, health

and nutrition over time, a similar national repository should be established for routine blood sampling conducted during a baby's birth. The establishment of a repository will ensure that the samples are properly cataloged and maintained, which in turn could be invaluable to prevention research.

5. **Realize the full potential of birth defects and developmental research** by continuing to invest in important ongoing studies, including the National Birth Defects Prevention Study, the National Children's Study, and the Centers for Autism and Developmental Disabilities Research and Epidemiology case-cohort study. These studies are at critical junctures and failure to fully implement them will not only delay important discoveries, but also result in loss of previous investments.

APPENDIX:

Glossary of Terms and Acronyms

AAP: *The American Academy of Pediatrics* is an “organization of 60,000 pediatricians committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents and young adults.” <http://www.aap.org>

ACF: *The Administration on Children and Families*, a part of *HHS*, funds “territory, local, and tribal organizations to provide family assistance (welfare), child support, child care, Head Start, child welfare, and other programs relating to children and families.” <http://www.acf.hhs.gov>

AHRQ: *The Agency for Healthcare Research and Quality*, a part of *HHS*, translates “research findings into better patient care and provid[es] policymakers and other health care leaders with information needed to make critical health care decisions.” <http://www.ahrq.gov>

ASD: *Autism spectrum disorders* (ASD), also known as pervasive developmental disorders, are a family of developmental disorders most commonly associated with autism

Asperger’s Syndrome: *Asperger’s Syndrome* is a form of ASD characterized by normal intelligence and language development, as well as autistic-like behaviors and marked deficiencies in social and communication skills.

Attention Deficit Hyperactivity Disorder (ADHD): *ADHD* is a neurobehavioral disorder characterized by difficulties in staying on task, following instructions, paying attention to detail, and sitting still.

Birth Defect: Also described by the term congenital, a birth defect is a structural, metabolic or functional abnormality that is present at birth, detected before birth, during the infant’s first year of life or even later in life.

CDC: *The Centers for Disease Control and Prevention*, a part of *HHS*, serves as the primary federal agency “for developing and applying disease prevention and control, environmental health, and health promotion and education activities designed to improve the health of the people of the United States.” <http://www.cdc.gov>

Cerebral Palsy: *Cerebral Palsy* is an umbrella term for a series of chronic disorders in which motor control is impaired by damage to certain parts of the brain.

CMS: *The Centers for Medicare and Medicaid Services*, a part of *HHS*, administers Medicare, Medicaid, and the State Children’s Health Insurance Program. <http://cms.hhs.gov>

Developmental Disabilities: A cognitive, intellectual, or behavioral impairment that presents itself during childhood.

Down syndrome: *Down syndrome*, also known as Trisomy 21, and characterized by an extra chromosome 21, is the most common chromosomal birth defect.

Dyslexia: *Dyslexia*, a learning disability, is a language-based disorder that affects reading.

FDA: *The Food and Drug Administration*, a part of *HHS*, works to ensure “the public health by assuring the safety, efficacy, and security of human and veterinary drugs, biological products, medical devices, our nation’s food supply, cosmetics, and products that emit radiation.” <http://www.fda.gov>

Fragile X syndrome: *Fragile X syndrome* is an inherited condition impacting the X chromosome that is a cause of mental retardation.

HMO: A *health maintenance organization* is a group insurance organization where members are often required to use certain health-care providers such as doctors and hospitals.

HRSA: The *Health Resources and Services Administration*, a part of *HHS*, “provides national leadership, program resources and services needed to improve access to culturally competent, quality health care.” <http://www.hrsa.gov/>

Intellectual Disabilities (IDs): *IDs*, often referred to as mental retardation, are a cognitive disability characterized by significantly below-average intellectual functioning (generally regarded as an IQ below 70), combined with impairment in carrying out functions of daily life such as caring for oneself, communicating, and interacting socially.

IACC: The *Interagency Autism Coordinating Committee* coordinates efforts across federal agencies. Participants include *NIH*, *FDA*, *ACF*, *AHRQ*, *CMS*, *CDC*, *HRSA*, and the Department of Education. <http://www.nimh.nih.gov/utismiacc/index.cfm>

IES: *The Institute for Education Sciences* is the research arm of the Department of Education. Its mission is to expand knowledge and provide information on the condition of education, practices that improve academic achievement, and the effectiveness of federal and other education programs.

Learning Disability (LD): A *learning disability* is distinct from mental retardation in that a diagnosed individual may have normal or above-average intelligence, but has difficulty acquiring new skills or information

MCHB: The *Maternal and Child Health Bureau*, a part of *HRSA* and *HHS*, is the government agency charged with “assuring the health of American mothers and children.” <http://mchb.hrsa.gov/>

NBDPN: The *National Birth Defect Prevention Network* is a group of birth defect surveillance programs and individuals interested in birth defect prevention, research and outreach for families and providers. <http://www.nbdpn.org>

NCBDDD: The *National Center on Birth Defects and Developmental Disabilities*, a part of the *CDC*, works to “promote the health of babies, children, and adults, and enhance the potential for full, productive living.” <http://www.cdc.gov/ncbddd/>

NICHD: The *National Institute of Child Health and Human Development*, a part of the *NIH*, ensures “that every person is born healthy and wanted, that women suffer no harmful effects from reproductive processes, and that all children have the chance to achieve their full potential for healthy and productive lives, free from disease or disability, and to ensure the health, productivity, independence, and well-being of all people through optimal rehabilitation.” <http://www.nichd.nih.gov>

NIDCD: *The National Institute on Deafness and Communication Disorders*, a part of the *NIH*, works to improve the lives of those who have communication disorders. <http://www.nidcd.nih.gov/>

NIEHS: The *National Institute of Environmental Health Sciences*, a part of the *NIH*, works to “the burden of human illness and dysfunction from environmental causes by understanding each of these elements and how they interrelate.” <http://www.niehs.nih.gov/>

NIH: *The National Institutes of Health*, a part of *HHS*, is the “steward of medical and behavioral research for the Nation.” <http://www.nih.gov/>

NIH/ACC: *The Autism Coordinating Committee* was formed by *NIH* to enhance the quality, pace, and coordination of efforts at *NIH* to find a cure for autism. <http://www.nidcd.nih.gov/>

NINDS: The *National Institute of Neurological Disorders and Stroke*, part of the *NIH*, is “the nation’s leading supporter of biomedical research on disorders of the brain and nervous system.” <http://www.ninds.nih.gov/>

Phenylketonuria (PKU): *PKU* is a condition in which the body cannot process a protein found in many foods; it can be treated through specialized diets.

Sensory Disorders: *Sensory Disorders*, an associated problem of *ASD*, are a lack of response to pain stimulus, hypersensitivity, or both.

Endnotes

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