Birth Defects Tracking and Prevention: Too Many States Are Not Making the Grade

Trust for America's Health
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Trust for America's Health
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Trust for America's Health (TFAH) is a national non-profit organization whose mission is to protect the health and safety of all communities, especially those most at risk of environmental and other public health threats. Our goal is to strengthen the nation's public health system through science-based research, community partnerships, education, and advocacy.

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Executive Summary

Birth Defects Are the Leading Cause of Death Among Infants

Birth defects are the leading cause of death among infants in the United States, accounting for approximately one out of every five infant deaths per year. Birth defects also account for a similar proportion of total deaths for children ages one to fourteen. Every year, about 150,000 babies are born in the United States with some kind of birth defect. While many birth defects can be surgically treated, a child affected by a birth defect may often need frequent and painful medical care and suffer serious health, emotional and social burdens. These burdens affect not only the child but also that child's family and society as a whole.

Beyond the direct emotional and health impacts on affected children and their families, medical treatment and support services are a tremendous financial burden. For example, for children born in 1988, the lifetime expenses associated with 12 selected birth defects could amount to more than $8 billion in today's dollars, or anywhere from $140,000 to $700,000 per child.

Despite Reduced Infant Mortality, Birth Defects Persist

Infant mortality has fallen dramatically in the last several decades. During this same period, infant death due to congenital malformations has proportionally been steadily increasing. Unfortunately, the causes of most birth defects are still unknown. Factors such as personal behaviors (e.g. alcohol or drug use by the mother) create well-known risks. Exposure to environmental hazards may play a role in some birth defects. However, researchers lack essential data to explore these and other links. Without knowing the causes of birth defects, we are helpless to prevent them.

Birth Defects Registries: A Key to Prevention

State monitoring programs and registries provide researchers with basic information about rates of birth defects and can help identify trends. When combined with studies of genetics, molecular biology, etiologic investigations and environmental exposures, the information provided by birth defects registries has the potential to help uncover the causes of these conditions and prevent future cases.

Too Many States Are Not Making the Grade

Despite the effectiveness and value of birth defects registries, too many states do not have adequate programs. In 2000, more than 600,000 births were not covered by a working registry and almost 300,000 births occurred in states with no registries at all. Today, about one million births—as many as 25%—are not covered in birth defects monitoring programs.

As part of its ongoing efforts to promote nationwide tracking of chronic diseases, the Trust for America's Health (TFAH) has examined birth defects registries on a state-by-state basis, giving each one a letter grade of A, B, C, D or F. Final grades were based on a number of criteria, including ability to carry out tracking, data use, prevention and research capacity, data sharing capacity and resources devoted to the task.

As shown in Table 4 and the map on page 11, only eight programs in the 50 states, the District of Columbia and the Commonwealth of Puerto Rico earned an A. Even among these registries, certain minimum standards were not always met. The majority of states did not make the grade. Nine states have no program at all, or a program so marginal that it received an F. Fourteen programs earned a B and 10 received a C. Another 11 received a D, indicating that they are only beginning to develop programs.

Two-thirds of states with registries do not explore any possible links between birth defects and environmental exposure information. That means that opportunities to learn about potential causes and prevention of birth defects are being lost.

TFAH has found that state health officials want to build capacity for birth defects surveillance, but they lack the necessary resources to do so. If we are to make progress in tackling the causes of birth defects, each state must have a technically solid, complete, and ongoing monitoring program and registry. For states to make progress, the Centers for Disease Control and Prevention (CDC) must more fully support tracking and monitoring efforts, and states must devote resources so that their registries are sustainable from year to year.

This report builds on the 1999 Pew Environmental Health Commission's report *Healthy from the Start: Why America Needs a Better System to Track and Understand Birth Defects and the Environment*. TFAH has expanded the grading system used by the Pew Commission and also established a set of minimum program standards. TFAH will be issuing a report examining birth defects monitoring programs every two years to chart progress in this important area, highlight gaps, and identify recommendations for improvement.

Recommendations

To help prevent future birth defects, state registries must be improved and established where they do not exist. TFAH urges the following steps be taken as rapidly as possible:

National Action Step

- The United States needs a nationwide health tracking network built on current and planned state efforts that provides researchers, policy makers and communities data about chronic diseases, including birth defects, and about environmental factors that might be linked to them. This system should protect confidentiality and encourage chronic disease prevention, not just identification and treatment. Birth defects monitoring programs should be a vital part of this nationwide health tracking network.

CDC Action Steps

- By 2003, CDC should finalize standards for birth defects registries and monitoring programs. The minimum standards outlined in this report provide CDC with a place to start. The new CDC Center on Birth Defects and Developmental Disabilities should provide leadership in ensuring that states reach or exceed minimum standards. The Center should also ensure that data from different states can be compared.

- By 2004, CDC should collaborate with the National Institute of Environmental Health Sciences, the Environmental Protection Agency, or other federal agencies to fund up to 10 state pilot studies that examine the links between the environment and birth defects.

- By 2004, CDC should fund birth defects programs in every state.

State Action Steps

- By 2004, every state should meet or exceed minimum registry standards established by CDC. States that currently do not meet the minimum standards should develop a plan at once to achieve them. States that are at or above minimum standards should develop a plan to ensure and maintain quality programs.

- By 2004, every state should identify or create sources of data about environmental exposures. Birth defects monitoring programs should use these data to explore the connections between environmental exposures and birth defects.

- By 2004, every state legislature should provide 25% of the funding for its birth defects monitoring program. This commitment is necessary to ensure that states can maintain sustainable programs in collaboration with CDC.

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Birth Defects – A Sobering National Picture

A birth defect is an abnormality of structure, function or body metabolism (inborn error of body chemistry) present at birth that results in physical or mental disability, or is fatal.

Source: March of Dimes, http://www.modimes.org/healthlibrary2/FactSheets/Birth-Defects.htm, 2002.

Every year, about four million babies are born in the United States. Approximately 150,000 of them—about 3-4%—are born with some kind of birth defect.[1]

Birth defects can create considerable health, emotional, and social burdens on affected children, families, and society.[2] Many birth defects can be surgically treated, such as diaphragmatic hernia (a hole in the diaphragm that causes the abdomen to protrude). However, children affected by birth defects may often need frequent and painful medical care.[3]

Birth defects are the leading cause of infant mortality in our nation, accounting for approximately 20% of all infant deaths each year. That means we can predict with some certainty that about 6,000 of the infants born in 2002 who die before their first birthday will die because of a birth defect.[i] On average, about half of the children who die from a birth defect have cardiovascular (heart and/or circulatory) defects; 15% have central nervous system defects; and 12% have chromosomal defects.[4]

What is Happening in Warren County?

In Warren County, Illinois, Jo Sorensen wonders why so many babies in her community are born with birth defects and developmental disabilities. Jo, a special education teacher with over 20 years of experience, became concerned because of the number of cases she was seeing. Because Warren County (located near the Illinois-Iowa border) does not have its own health department, Jo appealed to the federal Centers for Disease Control and Prevention (CDC) and the Illinois Department of Public Health (IDPH) for help. In her letter to the CDC, Jo noted that Warren County "is in the heart of agricultural land, so pesticides and herbicides are used in the area."

In September 2000, the Illinois Adverse Pregnancy Outcomes Reporting System, operated by IDPH, conducted an investigation that found a significant excess of birth defects in Warren County. Where 43 defects would have been expected during the period 1989-1998, 63 were found. The study also found a significant excess of genitourinary defects, which impair the urinary tract. Because Illinois had a statewide registry, at least Jo could get a partial answer to her question. She and her community now know that a higher than expected number of birth defects are being seen.

But what caused these cases? Most likely, public health officials cannot tell Jo why these birth defects occurred, or what can be done to prevent them. Until states and the federal government make a greater investment in birth defects monitoring programs and registries, nationwide health tracking and studies to examine the causes of diseases such as birth defects, these vital questions will go unanswered.

Source: Illinois Department of Public Health, Incidence of Birth Defects in Warren County, Illinois. September 2000. Jo Sorensen, letter to CDC, IDPH, Knox County Health Department. August 9, 2000.

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[i] Projection based on figures from Hoyert DL, Arias E, Smith BL, Murphy SL, Kochanek KD. Deaths: Final Data for 1999. National Vital Statistics Report; 49(8). Hyattsville, Maryland: National Center for Health Statistics. 2001.

Deaths from birth defects continue to take their toll among older children too. They account for approximately 15.5% of deaths among children one to four years old; 8% among the five to nine year-old age group; and 6% in the ten to 14 year-old category. In fact, among children aged one to 14, one study estimated that birth defects could account for 21.5% of total deaths.[5]

Beyond their direct impact on the children who suffer from them, birth defects also exact an enormous emotional and social toll on American families and communities. While the emotional burden is impossible to quantify, scientists have been able to calculate some of the economic costs. A recent study looked at costs associated with medical treatment, developmental services, special education and lost productivity as a result of death or disability from certain birth defects.[6] For the children born in just one year (1988), the lifetime expenses associated with just 12 of these birth defects could amount to over $8 billion in today's dollars. This estimate does not include other economic burdens, such as lost wages for families caring for these children[7] (see Appendix One).

Table 1: Average Lifetime Cost Per Child with Selected Birth Defects, 2001[ii]

Birth Defects	**Estimated Cost**
Genetic Defects	
Down Syndrome	$647,200
Heart Defects	
Truncus arteriosus	$724,692
Transposition of the great vessels	$383,154
Tetralogy of Fallot	$375,979
Limb Defects	
Reduction defect-lower limbs	$285,572
Reduction defect-upper limbs	$142,068
Muscle Defects	
Diaphragmatic hernia	$358,759
Esophageal atresia/tracheoesophageal fistula	$208,080
Colon, rectal or anal atresia	$176,509
Gastroschisis	$156,419
Neural Tube Defects	
Spina bifida	$421,900
Oral-Facial Defects	
Cleft lip or palate	$144,938

Note: Figures are based on lifetime cost estimates for the 1988 California birth cohort (adjusted for differences in costs and numbers of births between California and the nation and for cost inflation between 1988 and 1992. The 1992 cost figures were adjusted for inflation and are presented in 2001 dollars.).

[ii] John Harris and James Levy. State-by-State Cost of Birth Defects -- 1992. *Teratology* 56(1-2):11-16 (1997).

Table 2: Estimated Incidences for Selected Birth Defects, 2000[iii]

Birth Defect	**Estimated Incidence**
Heart and circulation	1 in 115 births
Muscle and skeleton	1 in 130 births
Down Syndrome	1 in 900 births
Cleft lip/palate	1 in 930 births
Spina bifida	1 in 2,000 births

Note: Figures are based on available estimates, which underestimate true incidence of many birth defects.

Preventing Birth Defects: Are We Doing What It Takes?

Given the enormous economic, social and emotional costs that birth defects impose, we should expect that our local, state and federal institutions would respond swiftly and effectively to find the causes of birth defects and reduce or eliminate them whenever possible. But the numbers show we are not doing all we can.

Prevention Works: Reducing Neural Tube Defects by Folic Acid Fortification

Public health research and practice has demonstrated that prevention works.

In the early 1990s, public health scientists confirmed that consuming about 400 micrograms of folic acid before conception and during early pregnancy prevents the occurrence of neural tube defects (NTDs) such as spina bifida. In 1996, the U.S. Food and Drug Administration authorized the addition of folic acid to enriched grain products to ensure that women of childbearing age get the folic acid they need. Mandatory folic acid fortification of enriched grain products began in January 1998.

Birth prevalence of NTDs has decreased 19% since folic acid fortification began, according to a study published in the *Journal of the American Medical Association* (June 20, 2001). As an editorial in the same issue pointed out: “the study … provides important information – food fortification works.”

Source: US Public Health Service. Recommendations for the use of folic acid to reduce the number of cases of spina bifida and other neural tube defects. *Morbidity and Mortality Weekly Report*, 1992. 41(RR-14): p. 1-7.
James L Mills and Lucinda England. Food Fortification to Prevent Neural Tube Defects: Is It Working? *Journal of the American Medical Association* 285(23):3022-23 (June 20, 2001).

Today the causes of between 65% and 80% of birth defects are unknown.[8] Without knowing the causes of birth defects, we are helpless to prevent them. Our lack of knowledge about how to prevent birth defects is surprising in light of the advances we have made in combating diseases and death in infants over the past 50 years. Particularly in the last several decades, infant mortality has fallen dramatically, mainly due to improvements in medical care right before and after birth. During this same time period, however, infant death due to congenital malformations has proportionally been steadily increasing.[9]

[iii] Adapted from March of Dimes “Leading Categories of Birth Defects” available at http://www.modimes.org/HealthLibrary2/InfantHealthStatistics/bdtable.htm.

Many Questions, Few Answers

Despite the lack of overall progress, public health scientists have identified many of the factors that can affect the health of developing babies. These include social, behavioral and environmental factors, such as smoking, prescription medication and alcohol use by pregnant women; conditions that cause injury that are outside of personal control, such as motor vehicle accidents; and the presence of toxic agents in the environment such as radiation, chemicals and metals.[10] Some factors (consumption of alcohol or tobacco during pregnancy, for example) create well-known risks for developing babies.[11] Other factors – deficiencies in folic acid, for instance – are being addressed by adding supplements to the diets of women of childbearing years.[12] However, according to the CDC, two-thirds of women in the U.S. still do not get enough folic acid (0.4 milligrams) every day.[13]

While information is available on some of the most significant social and behavioral factors that may cause birth defects, much less is known about how exposure to toxic substances in water, air, food and soil could potentially affect developing babies. We know that many of the compounds used in agriculture and in our homes and gardens have been shown to cause birth defects in animal tests.[14] Of the top 20 agricultural and household use pesticides in this country (based on 1995 data), four are recognized developmental toxicants and five are suspected developmental toxicants. These pesticides include 2,4-D, the number one ranked household pesticide by millions of pounds used, which is a suspected developmental toxicant. In 1995, an estimated seven to nine million pounds of 2,4-D were used in American homes (see Appendix Two).

Table 3: Selected Birth Defects for Which Environmental Factors Are Suspected to be a Cause[iv]

Birth Defect	Definition
Anencephaly	Absence/near absence of brain
Atrial septal defect	Opening(s) in wall between two upper heart chambers
Cleft lip	Failure of lip components to join
Cleft palate	Failure of palate components to join
Gastroschisis	Opening in wall of intestines
Hypospadias/epispadias	Urinary outlet on males is in abnormal position on penis
Spina bifida	Failure of spinal cord to close
Tetralogy of Fallot	Four serious heart defects combined
Transposition of the great arteries	Heart defect; pulmonary artery, aorta switched
Ventricular septal defect	Opening(s) in wall between two lower heart chambers

Note: This list is not exhaustive.

[iv] Pew Environmental Health Commission. *Healthy from the Start: Why America Needs a Better System to Track and Understand Birth Defects and the Environment*. Baltimore, MD. 1999.

Beyond pesticides, recent research has uncovered a link between exposure to air pollution and the occurrence of certain birth defects.[15]

To understand more fully what environmental factors threaten developing babies, much additional information is needed. Some of that information could come from birth defects monitoring programs, if they were up to the task. At present, only 33% of the 52 jurisdictions examined (all 50 states, Puerto Rico and the District of Columbia) conduct or collaborate on studies of birth defects and environmental exposures (see Appendix Three). Increasing the number and quality of these types of etiologic studies could be very valuable in uncovering the causes of birth defects and determining how birth defects can be prevented. If solid evidence is uncovered linking environmental factors and birth defects, it might be possible to control or eliminate these exposures. In other words, conditions caused by environmental exposures are potentially preventable.

Does Air Pollution Cause Birth Defects?

In the first rigorous study to look at air pollution and birth defects, a group of California researchers, including scientists at the University of California at Los Angeles, discovered evidence that air pollution might play a role in causing some birth defects. Researchers conducted the study by matching extensive air pollution monitoring data from the US Environmental Protection Agency with information from the California Birth Defects Monitoring Program.

Mothers' exposure to four air pollutants—carbon monoxide, ozone, nitrogen dioxide and particulates—was estimated. Children with birth defects were compared to children without birth defects based on their exposure to air pollution. Pregnant women living in areas with higher levels of ozone and carbon monoxide pollution were as much as three times more likely to have had babies with serious birth defects, and the greater a mother's exposure to these pollutants in the critical second month of pregnancy, the greater the chance that the baby would have a serious cardiac defect. While this evidence is compelling, researchers caution that additional studies are essential. Unfortunately, too few states can link birth defects and environmental exposure data to carry out confirming studies.

Source: Beate Ritz, Fei Yu, Scott Fruin, Guadalupe Chapa, Gary M Shaw, and John Harris. Ambient Air Pollution and Risk of Birth Defects in Southern California, *American Journal of Epidemiology.* 155(1):17-25 (2002).

Progress is Being Made, But Major Gaps Remain

As a nation, we should not accept the 150,000 or more birth defects that occur each year. Public health and medical scientists are just beginning to develop the tools and skills needed to combat birth defects, and the nation should be prepared to take immediate action. What's missing is the political will to boost resources devoted to such efforts.

The good news is that some of the steps needed to prevent birth defects are being taken. For instance:

- The CDC contains a new center dedicated to birth defects and developmental disabilities that promises to provide leadership for prevention and research efforts. In addition, CDC has established eight state centers for birth defects research throughout the country.
- Based on clinical trials and epidemiologic research, the Food and Drug Administration (FDA) has required that folic acid supplements be added to enriched grain products, which research shows is likely to continue to cut down the number of neural tube defects (NTDs).
- A substantial national investment has been made in studying the molecular and genetic components of birth defects.[16] Genetics and molecular biology are obviously important because, at its core, conception is a series of molecular reactions and a mixing of genes. Also, as the embryo and fetus develop, genes play a paramount role in controlling and orchestrating growth.

The CDC's National Center on Birth Defects and Developmental Disabilities

In 2001, Congress established the National Center on Birth Defects and Developmental Disabilities (NCBDDD) within CDC to promote optimal fetal, infant and child development, prevent birth defects and developmental disabilities, and enhance quality of life among those living with a disability.

NCBDDD is a key player in the fight to prevent birth defects and improve state birth defects monitoring programs. Among other things, it provides grants to state programs and university-based birth defects centers and promotes epidemiologic prevention-based research.

In January 2002, the three-year CDC cooperative agreements to 18 states expired. In March 2002, CDC will award 20 new cooperative agreements that will bring the total number of states with CDC funding for birth defects monitoring programs to 35. Currently, CDC is funding eight cooperative agreements until 2003 (Arizona, Connecticut, Illinois, Louisiana, Puerto Rico, Rhode Island, Washington and Wisconsin) plus seven Centers for Birth Defects Research and Prevention (see below).

Source: CDC, http://www.cdc.gov/ncbddd/dd/default.htm and TFAH contacts with CDC.

State Centers for Birth Defects Research and Prevention

Established in 1996 by the CDC, the Centers for Birth Defects Research and Prevention (CBDRP) carry out research to find the causes of birth defects. The Centers are located in Arkansas, California, Iowa, Massachusetts, New Jersey, New York, Texas and at CDC in the NCBDDD. They participate in the National Birth Defects Prevention Study (NBDPS), one of the largest studies conducted on the causes of birth defects, including both genetic and environmental risk factors. The NBDPS involves three parts: 1) a case-control study to compare infants with birth defects and those without birth defects to identify any factors that increase the risk for or protect against birth defects; 2) 12,000 interviews with mothers over a five-year period to obtain detailed medical history, potential exposures in the home and workplace, and pregnancy information; and 3) collection of infant and parental cheek cells to identify genetic factors. The results of the NBDPS are expected to have wide- and far-reaching significance in preventing birth defects.

Source: CDC, "Centers for Birth Defects Research and Prevention," available at http://www.cdc.gov/ncbddd/pub/cbdrpbk.pdf.

While we can expect studies about molecular biology and genetics to yield valuable insights, without other public health data about exposure to possible risk factors and birth defects monitoring information, we cannot carry out effective studies to help us unravel the mysteries of what *causes* birth defects. Molecular interactions and genetic makeup are only pieces of a much larger puzzle. In order to understand the events that lead to birth defects—and develop strategies to prevent them—we have to understand the factors that affect developing babies and their mothers.[17] The capacity to carry out epidemiologic research—public health science aimed at prevention—is essential. Large-scale studies in human populations aimed at uncovering the causes of birth defects—etiological studies—also represent a productive scientific avenue for finding risk factors. TFAH found that only 40% of state birth defects programs reported that they conduct or collaborate on such research (see Appendix Three).

Several states have on-going birth defects studies that look at environmental factors. Three are highlighted below:

> **California**: The California Birth Defects Monitoring Program's (CBDMP) mission is to find causes of birth defects. In addition to maintaining a registry, the Program conducts large, population-based case-control studies with concentration on uncovering gene-environment interactions. In addition to interviewing mothers, biologic and environmental samples are collected to determine risk factors. The Program has published findings on such environmental exposures as hazardous waste sites, drinking water contaminants, pesticides, and air pollution. Collaborations with state environmental programs include Department of Pesticide Regulation, Drinking Water and Environmental Management Division, Environmental Health Investigations Branch and Office of Environmental Health Hazard Assessment. These studies can be found on the CBDMP website at http://www.cbdmp.org.[18]
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> **Iowa**: Part of the mission of the Iowa Birth Defects Registry (IBDR) is to conduct research to identify genetic and environmental risk factors for birth defects. The IBDR has collaborated with the Iowa Department of Public Health to conduct geographic information systems (GIS) studies of potential environmental risk factors and birth defects. In addition, it has worked with the University of Iowa Center for Health Effects of Environmental Contamination to investigate risk of orofacial clefts associated with certain drinking water contaminants. Other studies assessing risk of selected birth defects and agricultural pesticides are underway between the IBDR and this Center.[19] More information about the studies that IBDR is conducting can be found on its website at http://www.public-health.uiowa.edu/birthdefects/.
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> **Missouri**: The Missouri Birth Defect Registry was developed, in part, to provide birth defects data for environmental tracking. The Registry has collaborated with the Division of Environmental Health and Communicable Disease Prevention and the Department of Natural Resources to study birth defects and other adverse health

effects in areas containing hazardous waste.[20] Information about this registry can be found at http://www.health.state.mo.us/Publications/MOSRVSYS.pdf on pages 121-122.

Tracking Birth Defects—A Key to Prevention

To truly make progress in preventing birth defects, this country needs to do a first-class job of tracking birth defects state-by-state. State-by-state tracking of birth defects is usually carried out by state health departments, which apply public health science to set up monitoring programs that look for birth defects cases in the state and follow them, while protecting privacy, through a centralized registry or database. With top-notch scientific information about birth defects, public health practitioners can more rapidly answer questions that communities are asking about risk factors and more readily study the causes of birth defects and how to prevent them.

For similar reasons, the United States needs a nationwide system for tracking chronic diseases, such as cancer and asthma. Without such a system, health officials have little chance of determining what causes many chronic diseases.

State monitoring programs and registries and a nationwide health tracking network are two of the foundations on which this country should build efforts to reduce the number of birth defects. Registries provide public health scientists with basic information about what birth defects are occurring, in what areas, and whether there is a trend. The information can be used to better target resources, provide services to affected families and study the causes of birth defects and the risk factors involved. Registries can also help to determine whether public policy changes have led to a reduction in birth defects.

While the value of birth defects programs and registries are clear, the establishment and maintenance of such systems are complicated matters. In carrying out the research for this report, TFAH learned that there is no such thing as a “perfect” state monitoring program or registry. In fact, when it comes to monitoring programs and registries, one size definitely does not fit all. States need flexibility to design birth defects programs that work for them, given the unique geography, population base, environmental exposures and resource limitations they confront. TFAH also learned that states are doing a yeoman’s job of establishing and running birth defects programs, often without adequate resources and attention. Nevertheless, this flexibility does not preclude the need to meet certain minimum standards so that the registry can collect, analyze and disseminate useful data. Moreover, our nationwide need to compare trends across states means that monitoring programs must have enough in common so that the information they generate can be pieced together to get a picture of how we, as a nation, are doing.

The CDC must take the lead in getting states to adopt minimum standards. The failure to establish national standards to date has resulted in a patchwork of registries across the nation. As one of its first acts, CDC’s new birth defects center should establish minimum standards for states. It is also critical that CDC’s new center develop ways that birth defects information can be compared across states so that a nationwide picture can be drawn.

The Grading System

This report builds on the 1999 Pew Environmental Health Commission's report *Healthy from the Start: Why America Needs a Better System to Track and Understand Birth Defects and the Environment*. The Commission's report (available at TFAH's website www.healthyamericans.org) explained the important role that birth defects registries play in public health prevention and also graded state registries.

TFAH is pleased to continue—and expand—the work begun by the Commission. TFAH built upon the grading system first used by the Commission and developed a set of minimum standards for registries (see Appendix Four). TFAH's goal is to release a report every two years that will chart progress in this important area, highlight gaps, and identify recommendations for improvement. This is TFAH's commitment to ensuring the overall quality of a comprehensive nationwide tracking network for chronic diseases, environmental factors and a public health system that can take action in preventing disease.

In this report, TFAH has examined the work that birth defects monitoring programs are doing and how they are doing it. Using an extensive database developed by the National Birth Defects Prevention Network (NBDPN),[v] birth defects tracking activities in all 50 states, the Commonwealth of Puerto Rico and the District of Columbia were graded. TFAH worked with the NBDPN to define and assign weights to important program criteria, including the states' tracking capacity, data use, collection and dissemination, and funding and resources (see Appendix Five).

The NBDPN, formed in 1997, is an organization of individuals involved in birth defects tracking, research and prevention. The NBDPN assisted us by:

- Providing access to NBDPN's updated electronic program directory database;
- Providing guidance on the interpretation and limitations of data elements in this database;
- Advising TFAH on developing a survey of additional questions; and
- Facilitating contact with state members of the NBDPN.

In grading the registries, TFAH researchers were guided by the program criteria we developed in conjunction with the NBDPN, the minimum standards and our follow-up research and interviews with state birth defects registry officials. TFAH knows that this grading process, while rigorous, is not perfect. For a number of reasons, minimum standards could not be established for every important criterion. Still, it is TFAH's belief that

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[v] This database is published in the journal *Teratology*. See *Teratology* 64:Supplement 1 (2001). TFAH updated and supplemented the information in the database.

these minimum standards will provide a foundation for the CDC to build upon, and we call on the new birth defects center to refine and finalize these standards by 2003.[vi]

TFAH researchers assigned a letter grade to 52 jurisdictions: the 50 states, the District of Columbia and the Commonwealth of Puerto Rico. Each jurisdiction was given a letter grade, from A to F, to present a snapshot of the program. A summary of each state program evaluation is contained in Appendix Seven.

Grade A states: Eight states received an A. All have programs that use active surveillance (i.e., staff seek out cases) and are distinguished by the detail paid to collecting, verifying, and ascertaining cases. These programs rely on high quality data sources and cover the full range of birth defects over an age range that extends to the first birthday. Seven of these states have studied the link between environmental factors and birth defects. Receiving an A grade does not mean that these programs are perfect. In fact, all could be improved—two do not publish data in a timely fashion, and two do not cover births in the entire state.

Grade B and C states: Twenty-four states received a B or C. These states achieved some of the criteria needed to be fully effective. They fall short in areas such as the ability to link data sources, the coverage of births (i.e., not statewide), the number of birth defects tracked, or the methods of data collection and quality assurance.

Grade D states: Eleven states received a D. These states have less than fully active programs, or report that they are now starting programs. Some of these programs have been launched since 1999. This group of "emerging" state programs has not yet reported on the data they have collected.

Grade F states: Nine states received an F. These states have marginal or no birth defects monitoring programs or registries.

Table 4: State Birth Defects Monitoring Programs Scorecard

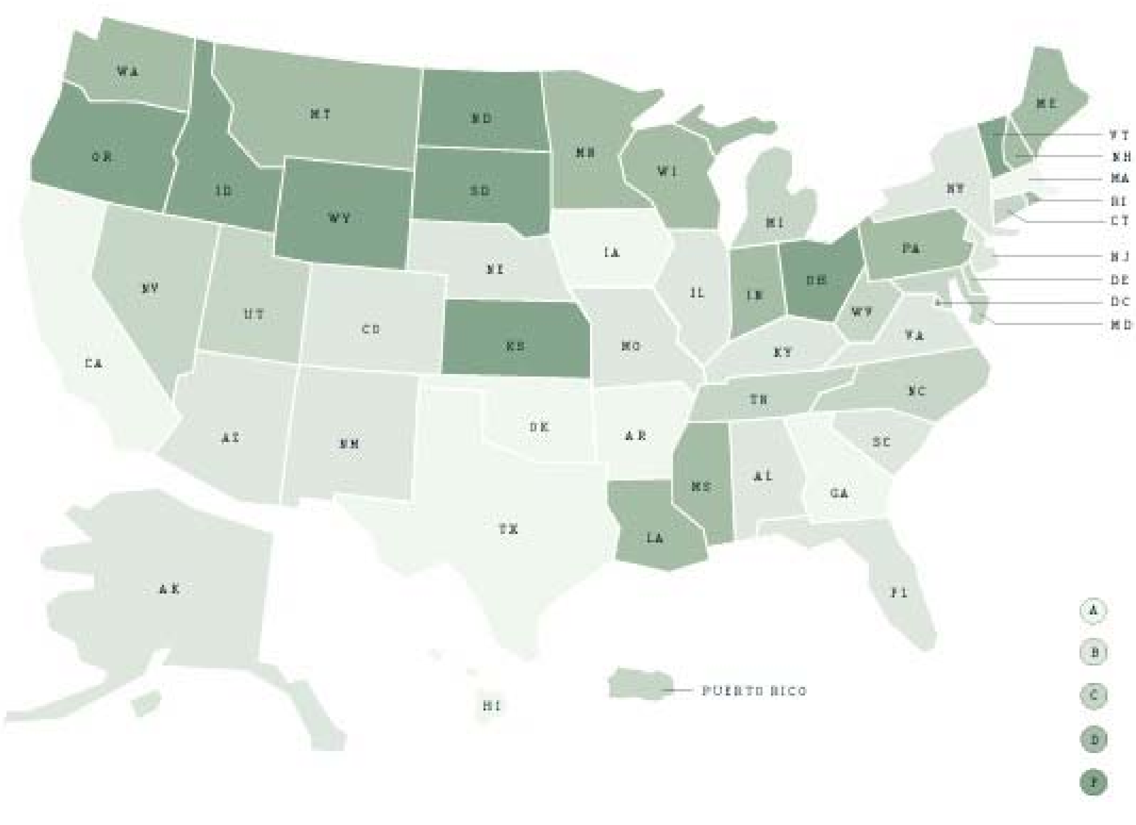
State	Grade	State	Grade
Alabama	**B**	Montana	**D**
Alaska	**B**	Nebraska	**B**
Arizona	**B**	Nevada	**C**
Arkansas	**A**	New Hampshire	**D**
California	**A**	New Jersey	**B**
Colorado	**B**	New Mexico	**B**
Connecticut	**C**	New York	**B**
Delaware	**C**	North Carolina	**C**
District of Columbia	**F**	North Dakota*	**F**
Florida	**B**	Ohio	**F**
Georgia	**A**	Oklahoma	**A**
Hawaii	**A**	Oregon	**F**

[vi] Appendix Six contains an evaluation of how each jurisdiction's birth defects program stacked up against TFAH's minimum standards.

Idaho	**F**	Pennsylvania	**D**
Illinois	**B**	Puerto Rico	**C**
Indiana	**D**	Rhode Island	**D**
Iowa	**A**	South Carolina	**B**
Kansas*	**F**	South Dakota	**F**
Kentucky	**B**	Tennessee	**C**
Louisiana	**D**	Texas	**A**
Maine	**D**	Utah	**C**
Maryland	**C**	Vermont	**F**
Massachusetts	**A**	Virginia	**B**
Michigan	**C**	Washington	**D**
Minnesota	**D**	West Virginia	**C**
Mississippi	**D**	Wisconsin	**D**
Missouri	**B**	Wyoming	**F**

Note: States marked with an asterisk (*) have vital records reporting only.

State Grades of Birth Defects Monitoring Programs, 2002



Conclusions and Recommendations

Conclusions:

- CDC has not set minimum national standards for registries. This has led to a patchwork of registries that prevents national studies and state-to-state comparisons.

- In 2000, there were close to 615,000 births not covered by working registries and almost 297,000 births in states with no registries at all. For 2002, it is estimated that close to one million births will not be included in birth defects monitoring programs.

- Of the 52 jurisdictions studied for this report, eight registries received an A, 14 received a B, 10 received a C, 11 received a D, and nine received an F.

- Two-thirds of the registries do not link data to environmental exposure information from other programs. This means that opportunities to learn about potential causes and prevention of birth defects are being lost.

- The federal government's funding of birth defects registries is inadequate. In March 2002, CDC will be funding registries in only 35 states. State government funding of registries is also inadequate. Currently, 33 states have yet to meet TFAH's suggested minimum funding level of 10% of costs.

Recommendations

National Action Step

- The nation needs a nationwide health tracking network built on current and planned state efforts that provides researchers, policy makers and communities data about chronic diseases, including birth defects, and about environmental factors that might be linked to them. This system should protect confidentiality and encourage chronic disease prevention, not just identification and treatment. Birth defects monitoring programs should be a vital part of this nationwide health tracking network.

CDC Action Steps

- By 2003, CDC should finalize standards for birth defects registries and monitoring programs. We believe that the minimum standards outlined in this report provide a good starting place for CDC. The new CDC Center on Birth Defects and Developmental Disabilities should provide leadership in ensuring that states reach or exceed minimum standards. The Center should also ensure that data from different states can be compared.

- By 2004, CDC should collaborate with the National Institute of Environmental Health Sciences, the Environmental Protection Agency, or other federal agencies to fund up to 10 state pilot studies that examine the links between the environment and birth defects.

- By 2004, CDC should fund birth defects programs in every state.

State Action Steps

- By 2004, every state should meet or exceed minimum registry standards established by CDC. States that currently do not meet the minimum standards should develop a plan at once to achieve them. States that are at or above minimum standards should develop a plan to ensure and maintain quality programs.

- By 2004, every state should identify or create sources of data about environmental exposures. Birth defects monitoring programs should use these data to explore the connections between environmental exposures and birth defects.

- By 2004, every state legislature should provide 25% of the funding for its birth defects monitoring program. This commitment is necessary to ensure that states can maintain sustainable programs in collaboration with CDC.

Appendix One: Estimated Lifetime Cost of Selected Birth Defects, for Babies with Selected Birth Defects Born in 1988 (2001 US$)

State	Estimated Lifetime Cost of Selected Birth Defects	State	Estimated Lifetime Cost of Selected Birth Defects
California	$1,199,302,221	Connecticut	$94,817,285
Texas	$639,473,053	Oklahoma	$94,785,395
New York	$573,784,785	Mississippi	$85,067,086
Florida	$382,101,318	Oregon	$83,779,551
Illinois	$381,469,511	Iowa	$76,672,191
Pennsylvania	$328,112,490	Kansas	$75,791,243
Ohio	$323,372,920	Utah	$74,142,959
Michigan	$287,182,386	Arkansas	$69,399,404
New Jersey	$238,989,464	New Mexico	$55,651,069
Georgia	$221,464,222	Nebraska	$46,632,334
North Carolina	$207,215,617	Nevada	$44,593,402
Virginia	$193,724,390	West Virginia	$44,186,815
Massachusetts	$173,859,259	Hawaii	$39,590,745
Indiana	$163,393,516	Idaho	$34,604,034
Washington	$158,351,026	Maine	$32,003,051
Maryland	$155,092,321	New Hampshire	$31,869,516
Missouri	$152,074,781	Rhode Island	$28,899,809
Tennessee	$146,719,350	Alaska	$23,370,977
Louisiana	$140,925,433	Montana	$22,864,731
Wisconsin	$140,851,694	South Dakota	$21,959,868
Arizona	$137,182,412	Delaware	$21,238,370
Minnesota	$130,760,673	North Dakota	$17,561,119
Alabama	$124,089,800	Vermont	$15,420,542
South Carolina	$111,995,727	Wyoming	$13,399,547
Colorado	$108,693,179	District of Columbia	N/A
Kentucky	$107,307,982	Puerto Rico	N/A
US	**$8,075,790,572**		

Source: John Harris and James Levy. State-by-State Cost of Birth Defects -- 1992. *Teratology* 56(1-2): 11-16 (1997).
These costs are calculated in 2001 dollars for the birth defects in Table 1 on page 2. The article containing this data presented costs in 1992 dollars. TFAH performed the calculation below to convert 1992 dollars into 2001 dollars.
Calculation: (1992 US$)(2001 CPI/1992 CPI) = 2001 US$
1992 CPI = 190.1
2001 CPI = 272.8
This information was based upon Bureau of Labor Statistics Data available at http://data.bls.gov/labjava/outside.jsp?survey=cu accessed on January 22, 2002. The information was found by using the following selection criteria on the site:

1) "Select an area:" US city average
2) "Select one or more items:" Medical care
3) "Select Seasonal Adjustment:" Not Seasonally Adjusted

To obtain the Consumer Price Index for All Urban Consumers, click "Get Data."

Appendix Two: Top 20 High-Use Agricultural and Household Use Pesticides that are Recognized or Suspected Developmental Toxicants

	Agricultural Use Ranking	Agricultural Usage (million lbs)	Household Use Ranking	Household Usage (million lbs)	Developmental Toxicity
Atrazine	1	68-73	-	-	-
Metolachlor	2	59-64	-	-	-
Metam Sodium	3	49-54	-	-	Recognized
Methyl Bromide	4	39-46	-	-	Recognized
Dichloropropene	5	38-43	-	-	-
2,4-D	6	31-36	1	7-9	Suspected
Glyphosate	7	25-30	2	5-7	-
Cyanazine	8	24-29	-	-	Recognized
Pendimethalin	9	23-28	-	-	-
Trifluralin	10	23-28	-	-	Suspected
Acetochlor	11	22-27	-	-	-
Alachlor	12	19-24	-	-	Suspected
EPTC	13	9-13	-	-	Recognized
Chloropyrifos	14	9-13	6	2-4	-
Chlorothalonil	15	8-12	-	-	-
Copper Hydroxide	16	7-11	-	-	-
Propanil	17	6-10	-	-	-
Dicamba	18	6-10	3	3-5	Suspected
Terbufos	19	6-9	-	-	-
Mancozeb	20	6-9	-	-	Suspected

Note: Reported in million pounds of active ingredients based on 1995 use data (United States). This list is limited to conventional pesticides and does not include sulfur usage and petroleum oil/distillate usage.

Source: Pew Environmental Health Commission, *Healthy from the Start: Why America Needs a Better System to Track and Understand Birth Defects and the Environment*, based on A. Aspelin, *Pesticide Industry Sales and Usage, 1994 and 1995 Market Estimates*, 1997.

Appendix Three: Birth Defects Programs that Conduct or Collaborate on Environmental Exposure Studies and Epidemiologic Research

State	Environmental Exposure Data	Epidemiologic Research
Alabama		
Alaska		Yes
Arizona		
Arkansas		Yes
California	Yes	Yes
Colorado		Yes
Connecticut		Yes
Delaware		
District of Columbia	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY	
Florida	Yes	
Georgia	Yes	Yes
Hawaii	Yes	Yes
Idaho	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY	
Illinois		
Indiana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT	
Iowa	Yes	Yes
Kansas	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY (VITAL RECORDS REPORTING ONLY)	
Kentucky		
Louisiana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT	
Maine	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT	
Maryland	Yes	Yes
Massachusetts	Yes	Yes
Michigan	Yes	Yes
Minnesota	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT	
Mississippi	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT	
Missouri	Yes	Yes
Montana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT	
Nebraska		
Nevada		
New Hampshire	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT	
New Jersey	Yes	Yes
New Mexico		
New York		Yes
North Carolina	Yes	
North Dakota	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY (VITAL RECORDS REPORTING ONLY)	
Ohio	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY	
Oklahoma	Yes	
Oregon	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY	
Pennsylvania	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT	
Puerto Rico		Yes
Rhode Island	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT	
South Carolina	Yes	Yes
South Dakota	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY	
Tennessee		Yes

Texas	Yes	Yes
Utah		Yes
Vermont	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY	
Virginia		Yes
Washington	Yes	
West Virginia	Yes	
Wisconsin	Yes	Yes
Wyoming	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY	
TOTAL (Percent of States)	**17 (32.7%)**	**21 (40.4%)**

The Environmental Exposure Data category refers to birth defects registries that conduct, or collaborate on, studies of birth defects and potentially associated environmental exposures (e.g., hazardous waste sites).

The Epidemiologic Research category refers to birth defects registries that conduct, or collaborate on, studies that attempt to find causes of birth defects.

Appendix Four: Standards for Birth Defects Programs

Category	Criteria	Description	Standards		
			Adequate or Minimum	Good	Better
Tracking Capacity	Quality Assurance	Ensure that data are accurate and valid	At least one tool (e.g., validity check on reports received)	At least one tool plus clinical review	At least two tools plus clinical review
	Timeliness	Makes sure that data are available for use	Data published within two years of collection	Data published within one year of collection	Data published less than one year after collection
	Case ascertainment	Methods used to identify and obtain information about cases	Passive (i.e., cases reported to program)	Passive, with active features	Active (i.e., program staff seek cases from hospitals and clinics)
	Data Sources	Facilities and institutions (e.g., hospitals) where programs get their information	At least 25% of sources are high quality sources or at least 10% are high quality sources plus disease discharge index (DDI)	At least 45% of sources are high quality or at least 25% are high quality plus DDI	At least 60% of the sources are high quality and DDI is used
	Pregnancy outcomes	What birth- and pregnancy-related events the program covers	Covers fetal death and live births	Covers fetal death, live births and deaths at less than twenty weeks gestation	
	Age range	What ages the program tracks	Newborn period -- Birth to age one month	Newborn period plus Infancy period -- Birth to age one year	Newborn and infancy periods, plus other pediatric age groups
	Birth defects covered	The types of defects upon which the program collects information	Major structural defects (ICD-9-CM 740 to 759.9)	Major structural defects plus one other condition	Major structural defects plus at least two other conditions or categories.
	Statewide coverage	Looks at whether birth defects data are collected from the entire state	Registry covers entire state		
	Population covered	Extent to which program collects birth defects data from entire population at risk	All (i.e., population-based)		

Data Use, Prevention and Research Capacity	Statistical Analysis and reporting	Looks at whether the program analyzes data and releases reports	One out of four criteria met	Two out of four criteria met	At least three out of four criteria met
	Prevention oriented initiatives	Looks at whether data is used in prevention efforts or in risk factor education	One out of two criteria met	Two out of two criteria met	N/A
	Intervention initiatives	Does program have way to link data to assessing needs, delivering services or case referral	One out of three criteria met	Two out of three criteria met	Three out of three criteria met
	Community and public concerns	Data is used to evaluate community and public concerns	One out of four criteria met	Two out of four criteria met	At least three out of four criteria met
	Epidemiological hypothesis testing	Data is used to look for causes of birth defects, or is used by others to study causes	No standards developed		
	Environmental exposure	Program collaborates with state environmental health division	No standards developed		
Data Sharing Capacity	Public Accessibility to information	Shows whether program makes data available to the public	Basic (eg., prevalence) reports are available either in print or electronic format	Basic reports are available plus at least one specialized report (eg., a report about NTDs in states)	Basic reports plus at least two specialized reports.
	Database linkages	Shows whether birth defects program data are used by other state programs or other state departments	No standards developed		
Legislation and Resources	Legislation	Looks at whether legislation has provisions that affect the functioning of the program	No standards developed		
	Funding type	Looks at distribution of funding for program	At least 10% state funding and at least one other funding source	At least 25% state funding and at least two other funding sources	At least 25% state funding and at least three other sources.
	Employees	Looks at how many public health staff work on the birth defects program	No standards developed		

Appendix Five: Definitions of Birth Defects Program Criteria

Tracking Capacity (35 points)
"Tracking" is synonymous with the CDC's concept of public health surveillance, which is defined as "the ongoing, systematic collection, analysis and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know"[vii]. States should have the ability to track successfully the types and numbers of birth defects, and make sure that this information is collected so that researchers and the public have confidence in the data. Also, registries should be able to publish basic information about birth defects (e.g., prevalence for various conditions) as soon as possible, preferably within the last two years. The public should have access to this data, too. Finally, state registries should be as complete as possible. They should cover the entire state (geographic coverage) and a broad range of birth defects (topical coverage).

The way in which registries identify their cases is important. There are two basic methods for collecting birth defects information. The first uses what are called "passive" sources of data – data that is reported to them by hospitals, vital statistics sources, or others. The second uses what are called "active" techniques – staff seek out this information from a variety of sources. Data abstractors are employed to code and check reported cases of birth defects.

a. Quality assurance (15%): Measures used to ensure that the accuracy and validity of data are maintained. Clinical review (defined as a clinician's routine review of the case record) is considered to be the best QA assessment tool.
b. Timeliness (15%): Timeliness measures whether complete analyzed data have been published within the last two years and are publicly accessible.
c. Case ascertainment (15%): The method by which a registry identifies its cases.
    i. Active case ascertainment refers to case investigators (data abstractors) conducting systematic reviews of medical and other records from hospitals, clinics, and other health-care facilities.
    ii. Passive case ascertainment refers to data being reported to the registry from participating hospitals, clinics and other health-care facilities.
    iii. Mostly passive case ascertainment means that data are reported to the registry from health-care facilities, and special cases are then investigated by registry staff (i.e., passive system with some active components).
d. Data sources (15%): Data sources refer to the facilities or institutions from which registries get their cases.
    i. Records from delivery hospitals and pediatric and tertiary care hospitals are considered to provide the largest number of cases. Delivery and pediatric/tertiary care hospital disease discharge index (defined as the set of discharge codes based on final diagnosis given by the physician(s) at

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[vii] Thacker, SB & Berkelman, RL (1988). Public Health Surveillance in the United States. *Epidemiologic Reviews*, 10:164-190.

    discharge) plus at least one other source is the minimum standard for this subcategory.
    ii. Specialty sources (including prenatal diagnostic facilities, cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities, physician reports, and other registries) provide fewer numbers of cases.
    iii. Vital records (e.g., birth certificates, death certificates, matched birth/death files, fetal death certificates and elective termination certificates), other state-based registries (e.g., programs for children with special health care needs, newborn genetic screening, newborn hearing screening, newborn biochemical screening, cancer registries, and AIDS/HIV registries), third party payers (e.g., Medicaid databases, HMO databases and Indian health services) and midwifery facilities provide the fewest number of cases.
e. Pregnancy outcomes covered (10%): Pregnancy outcomes include live births and fetal deaths. Fetal death is defined as the death of a fetus at greater than or equal to 20 weeks gestation, also known as stillbirth. Some states also include deaths at less than 20 weeks gestation.
f. Age range for case ascertainment (10%): The age range from birth or prenatal diagnosis for obtaining a case. The newborn period is birth to age one month. The infancy period is birth to age one year.
g. Categorical birth defects covered (10%): The range of birth defects that the registry defines as cases. The International Classification of Diseases (ICD) is the coding system for morbidity and mortality information used by hospitals. The International Classification of Diseases—9th Revision—Clinical Modification (ICD-9-CM) 740-759.9 codes major structural birth defects.
h. Statewide coverage (5%): The births included in the registry are obtained from all over the state, not just from certain regions within the state.
i. Population under coverage (5%): Segment of the population that is covered by the registry (e.g., hospital-based births). This category considers whether the program is population-based, meaning all births are considered potential cases.

Data Use, Prevention & Research Capacity (35 points)

This category assesses the ways in which data are used and the types of prevention, intervention and research programs the registry operates in addition to tracking.

a. Statistical analysis and reporting (20%): Registry analyzes data and releases tracking reports. This subcategory includes:
    i. data use for routine statistical monitoring;
    ii. data use for baseline rates;
    iii. data use for rates by demographic and other variables; and
    iv. published reports on file.
b. Prevention-oriented initiatives (20%): Activities or programs focused on prevention of birth defects and/or education of risk factors. This subcategory includes:
    i. data use for prevention projects; and
    ii. data use for education/public awareness.

c. Intervention initiatives (20%): Initiatives focused on care of children diagnosed with birth defects (i.e., follow-up services). This subcategory includes:
    i. needs assessment;
    ii. service delivery; and
    iii. referral of cases to necessary programs/services.

d. Evaluation of community and public health concerns (20%): Registry uses data in evaluating community and public health concerns. This subcategory includes:
    i. data use for time-space cluster analyses;
    ii. data use for epidemiologic studies using only program data;
    iii. data use for identification of potential cases for other epidemiologic studies; and
    iv. data use for monitoring outbreaks and cluster investigations.

e. Epidemiologic studies to test hypotheses (Research) (10%): Registry uses data to find causes of birth defects, or the data is released to other departments for epidemiologic research.

f. Environmental exposure data (10%): Birth defects registry collaborates with state environmental divisions.

Data Sharing Capacity (20 points)
Data sharing refers to the registry’s capacity to share data with other agencies, organizations, and the general public.

a. Public accessibility to information (60%): The registry has the capacity to share information with the public in electronic, print, and/or verbal form.

b. Database linkages (40%): Data sharing among departments within the state (intrastate) and between states (interstate).

Legislation and Resources (10 points)
This category assesses the type and extent of resources the registry has to perform its tracking activities.

a. Legislation (34%): The nature of the state legislation that has established a birth defects registry.

b. Funding Type (33%): Type of funding that the registry receives and the percentage breakdown by type. The following are the types of funding sources available:
    i. General state funds
    ii. Federal Title V Maternal-Child Health (MCH) Block Grants
    iii. Service Fees
    iv. Genetic screening revenues
    v. CDC grant
    vi. Other federal funding
    vii. Private
    viii. Other

c. Staff (33%): Number of staff, which can include administrative staff, epidemiologists, statisticians, computer programmers, data entry staff, contractors or others.

Appendix Six: State-by-State Evaluation of Minimum National Standards for Birth Defects Programs

Table 6-1: State-by-State Evaluation of Minimum National Standards—Tracking Capacity

State	Quality Assurance (15%)	Timeliness (15%)	Ascertainment (15%)	Data Sources (15%)	Outcomes (10%)	Age Range (10%)	BD Categories (10%)	Statewide (5%)	Population Covered (5%)
Alabama	Good	Below Minimum	Better	Better	Good	Good	Better	Below Minimum	Adequate
Alaska	Adequate	Below Minimum	Good	Adequate	Adequate	Better	Better	Adequate	Adequate
Arizona	Better	Below Minimum	Better	Better	Adequate	Good	Better	Adequate	Adequate
Arkansas	Better	Below Minimum	Better	Better	Good	Better	Adequate	Adequate	Adequate
California	Better	Adequate	Better	Better	Good	Good	Adequate	Below Minimum	Adequate
Colorado	Adequate	Adequate	Good	Good	Adequate	Better	Better	Adequate	Adequate
Connecticut	Adequate	Below Minimum	Adequate	Adequate	Below Minimum	Adequate	Good	Adequate	Adequate
Delaware	Below Minimum	Below Minimum	Good	Below Minimum	Adequate	Better	Better	Adequate	Adequate
District of Columbia	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY								
Florida	Adequate	Below Minimum	Adequate	Adequate	Adequate	Good	Better	Adequate	Adequate
Georgia	Better	Adequate	Better	Better	Good	Better	Better	Below Minimum	Adequate
Hawaii	Better	Adequate	Better	Better	Good	Good	Better	Adequate	Adequate
Idaho	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY								
Illinois	Adequate	Below Minimum	Good	Below Minimum	Adequate	Adequate	Adequate	Adequate	Adequate
Indiana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT								
Iowa	Better	Adequate	Better	Better	Good	Good	Adequate	Adequate	Adequate
Kansas	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY (VITAL RECORDS REPORTING ONLY)								
Kentucky	Better	Good	Good	Good	Adequate	Better	Better	Adequate	Adequate
Louisiana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT								
Maine	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT								
Maryland	Adequate	Adequate	Adequate	Good	Good	Adequate	Below Minimum	Adequate	Adequate
Massachusetts	Better	Adequate	Better	Better	Adequate	Good	Good	Adequate	Adequate

Michigan	Adequate	Below Minimum	Adequate	Good	Below Minimum	Better	Good	Adequate	Adequate
Minnesota	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT								
Mississippi	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT								
Missouri	Adequate	Adequate	Adequate	Adequate	Good	Good	Good	Adequate	Adequate
Montana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT								
Nebraska	Adequate	Adequate	Good	Better	Adequate	Good	Adequate	Adequate	Below Minimum
Nevada	Adequate	Good	Good	Good	Adequate	Better	Good	Below Minimum	Below Minimum
New Hampshire	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT								
New Jersey	Good	Good	Good	Better	Below Minimum	Better	Better	Adequate	Adequate
New Mexico	Adequate	Adequate	Good	Adequate	Good	Better	Better	Adequate	Adequate
New York	Adequate	Below Minimum	Good	Better	Below Minimum	Better	Adequate	Adequate	Adequate
North Carolina	Adequate	Adequate	Good	Good	Good	Good	Good	Adequate	Adequate
North Dakota	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY (VITAL RECORDS REPORTING ONLY)								
Ohio	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY								
Oklahoma	Adequate	Adequate	Better	Better	Good	Better	Good	Adequate	Adequate
Oregon	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY								
Pennsylvania	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT								
Puerto Rico	Better	Good	Better	Good	Good	Good	Below Minimum	Adequate	Adequate
Rhode Island	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT								
South Carolina	Better	Good	Better	Good	Good	Good	Below Minimum	Adequate	Adequate
South Dakota	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY								
Tennessee	Adequate	Below Minimum	Adequate	Good	Adequate	Better	Adequate	Below Minimum	Below Minimum
Texas	Better	Below Minimum	Better	Better	Good	Better	Good	Adequate	Adequate
Utah	Better	Below Minimum	Good	Better	Good	Better	Adequate	Adequate	Adequate
Vermont	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY								
Virginia	Better	Below Minimum	Adequate	Adequate	Below Minimum	Better	Good	Adequate	Below Minimum
Washington	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT								
West Virginia	Adequate	Good	Adequate	Below	Adequate	Better	Better	Adequate	Below

				Minimum					Minimum
Wisconsin	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT								
Wyoming	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY								

Table 6-2: State-by-State Evaluation of Minimum National Standards—Data Use, Prevention and Research*

State	Statistical Analysis & Reporting (20%)	Prevention (20%)	Intervention (20%)	Evaluation of Community and Public Health Concerns (20%)
Alabama	Good	Good	Better	Below Minimum
Alaska	Better	Good	Good	Adequate
Arizona	Better	Below Minimum	Adequate	Adequate
Arkansas	Better	Good	Below Minimum	Better
California	Better	Good	Good	Better
Colorado	Better	Good	Good	Better
Connecticut	Better	Adequate	Below Minimum	Adequate
Delaware	Adequate	Below Minimum	Below Minimum	Adequate
District of Columbia	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY			
Florida	Better	Good	Adequate	Better
Georgia	Better	Adequate	Below Minimum	Better
Hawaii	Better	Good	Adequate	Better
Idaho	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY			
Illinois	Good	Below Minimum	Better	Adequate
Indiana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT			
Iowa	Better	Good	Better	Better
Kansas	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY (VITAL RECORDS REPORTING ONLY)			
Kentucky	Better	Good	Better	Good
Louisiana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT			
Maine	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT			
Maryland	Better	Good	Better	Better
Massachusetts	Better	Below Minimum	Below Minimum	Better
Michigan	Better	Good	Better	Better
Minnesota	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT			
Mississippi	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT			
Missouri	Better	Good	Better	Better
Montana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT			
Nebraska	Good	Below Minimum	Adequate	Better
Nevada	Better	Good	Better	Better
New Hampshire	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT			
New Jersey	Better	Good	Better	Better
New Mexico	Better	Good	Adequate	Below Minimum
New York	Better	Good	Good	Better
North Carolina	Better	Good	Adequate	Good
North Dakota	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY (VITAL RECORDS REPORTING ONLY)			
Ohio	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY			
Oklahoma	Better	Good	Good	Good
Oregon	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY			
Pennsylvania	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT			
Puerto Rico	Better	Good	Better	Below Minimum
Rhode Island	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT			
South Carolina	Better	Good	Adequate	Adequate
South Dakota	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY			

Tennessee	Better	Good	Good	Good
Texas	Better	Good	Adequate	Better
Utah	Better	Good	Better	Good
Vermont	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY			
Virginia	Better	Good	Better	Adequate
Washington	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT			
West Virginia	Better	Good	Better	Adequate
Wisconsin	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT			
Wyoming	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY			

*Information regarding epidemiologic hypothesis testing and environmental exposure data linkage was collected, but no standards were established for these criteria.

Table 6-3: State-by-State Evaluation of Minimum National Standards—Data Sharing Capacity*

State	Public Accessibility to Information (60%)
Alabama	Good
Alaska	Good
Arizona	Good
Arkansas	Good
California	Good
Colorado	Good
Connecticut	Good
Delaware	Below Minimum
District of Columbia	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY
Florida	Good
Georgia	Adequate
Hawaii	Good
Idaho	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY
Illinois	Good
Indiana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Iowa	Good
Kansas	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY (VITAL RECORDS REPORTING ONLY)
Kentucky	Below Minimum
Louisiana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Maine	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Maryland	Adequate
Massachusetts	Adequate
Michigan	Good
Minnesota	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY
Mississippi	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Missouri	Good
Montana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Nebraska	Adequate
Nevada	Below Minimum
New Hampshire	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
New Jersey	Good
New Mexico	Below Minimum
New York	Good
North Carolina	Adequate
North Dakota	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY (VITAL RECORDS REPORTING ONLY)
Ohio	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY
Oklahoma	Adequate
Oregon	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY
Pennsylvania	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Puerto Rico	Good
Rhode Island	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
South Carolina	Adequate
South Dakota	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY
Tennessee	Adequate
Texas	Good

Utah	Adequate
Vermont	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY
Virginia	Good
Washington	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
West Virginia	Below Minimum
Wisconsin	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Wyoming	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY

* Information about database linkages was collected, but no standards were established for this criterion.

Table 6-4: State-by-State Evaluation of Minimum National Standards—Legislation and Resources*

State	Funding Type (33%)
Alabama	Adequate
Alaska	Below Minimum
Arizona	Adequate
Arkansas	Adequate
California	Better
Colorado	Better
Connecticut	Below Minimum
Delaware	Below Minimum
District of Columbia	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY
Florida	Adequate
Georgia	Below Minimum
Hawaii	Better
Idaho	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY
Illinois	Better
Indiana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Iowa	Adequate
Kansas	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY (VITAL RECORDS REPORTING ONLY)
Kentucky	Adequate
Louisiana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Maine	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Maryland	Adequate
Massachusetts	Below Minimum
Michigan	Adequate
Minnesota	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Mississippi	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Missouri	Adequate
Montana	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Nebraska	Below Minimum
Nevada	Below Minimum
New Hampshire	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
New Jersey	Adequate
New Mexico	Adequate
New York	Below Minimum
North Carolina	Adequate
North Dakota	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY (VITAL RECORDS REPORTING ONLY)
Ohio	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY
Oklahoma	Good
Oregon	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY
Pennsylvania	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Puerto Rico	Below Minimum
Rhode Island	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
South Carolina	Better
South Dakota	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY
Tennessee	Below Minimum

Texas	Good
Utah	Below Minimum
Vermont	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY
Virginia	Below Minimum
Washington	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
West Virginia	Below Minimum
Wisconsin	MONITORING PROGRAM OR REGISTRY IN DEVELOPMENT
Wyoming	NO BIRTH DEFECTS MONITORING PROGRAM OR REGISTRY

* Information about legislation and staff was collected, but no standards were established for these criteria.

Appendix Seven: State Birth Defects Monitoring Programs and Registries at a Glance

This appendix, which contains brief descriptions of each state program, is available at TFAH's website, www.healthyamericans.org/state/birthdefects.

References

[1] Ventura SJ, Martin JA, Curlin SCF, Hamilton BE. Births: Final Data for 1999. *National Vital Statistics Reports*: 49(1). Hyattsville, Maryland: National Center for Health Statistics. 2001; March of Dimes, http://www.modimes.org/Programs2/FolicAcid/BirthDefectsMonth.htm, 2001; Pew Environmental Health Commission. *Healthy from the Start: Why America Needs a Better System to Track and Understand Birth Defects and the Environment*. Baltimore, MD. 1999.

[2] Pew Environmental Health Commission. *Healthy from the Start*. 1999.

[3] Pew Environmental Health Commission. *Healthy from the Start*. 1999. [Original source: Centers for Disease Control and Prevention, Years of potential life lost before age 65—United States, 1990 and 1991. *Morbidity and Mortality Weekly Report*, 1993. 42(13): p. 251-3.

[4] Quanhe Yang, Muin Khoury and David Mannino. Trends and Patterns of Mortality Associated with Birth Defects and Genetic Diseases in the United States, 1979-1992: An Analysis of Multiple-Cause Data. *Genetic Epidemiology* 14(5):493-505 (1997).

[5] *Ibid.*

[6] John Harris and James Levy. State-by-State Cost of Birth Defects -- 1992. *Teratology* 56(1-2):11-16 (1997). [Original Source: NJ Waitzman, PS Romano, RM Scheffler. Estimates of the economic costs of birth defects. *Inquiry* 31:188-205 (Summer 1994).]

[7] *Ibid.*

[8] March of Dimes, available at http://www.modimes.org/healthlibrary2/BirthDefects/Default.htm; Pew Environmental Health Commission. *Healthy from the Start*. 1999. [Original source: Nelson, K and Homes, L.B. Malformations due to presumed spontaneous mutations in new-born infants. *New England Journal of Medicine* 320(1):19-23 (1989).]

[9] Kwang-sun Lee, Babak Koshnood, Li Chen, Stephen Wall, William Cromie and Robert Mittendorf. Infant Mortality From Congenital Malformations in the United States, 1970 – 1997. *Obstretrics & Gynecology* 98(4): 620 – 27 (2001).

[10] Pew Environmental Health Commission. *Healthy from the Start*. 1999.

[11] Pew Environmental Health Commission. *Healthy from the Start*. 1999. [Original sources: Kleinman, J.C. and Madans, J.H., The effects of maternal smoking, physical stature, and educational attainment on the incidence of low birth weight. *American Journal of Epidemiology* 121(6):843-55 (1985). Windham, G.C., Eaton, A., and Hopkins, B., Evidence for an association between environmental tobacco smoke exposure and birthweight: a meta-analysis and new data. *Paediatric and Perinatal Epidemiology*, 1999. 13(1): p. 35-37. Day, N.L., et al., Effect of prenatal alcohol exposure on growth and morphology of offspring at 8 months of age. *Pediatrics*, 1990. 85(5): p. 748-52.

[12] JL Mills and L England. Food Fortification to Prevent Neural Tube Defects: Is It Working? *Journal of the American Medical Association,* 285(23):3022-23 (June 20, 2001).

[13] National Center on Birth Defects and Developmental Disabilities, CDC. “Why Folic Acid is so Important: Frequently Asked Questions.” Available at http://www.cdc.gov/ncbddd/folicacid/folicfaqs.htm#enough. (Accessed 9/12/01).

[14] Pew Environmental Health Commission. *Healthy from the Start*. 1999.

[15] Beate Ritz, Fei Yu, Scott Fruin, Guadalupe Chapa, Gary M Shaw, and John Harris. Ambient Air Pollution and Risk of Birth Defects in Southern California, *American Journal of Epidemiology.* 155(1):17-25 (2002).

[16] March of Dimes, *The Promise of Science: March of Dimes Annual Research Report 2000* available at www.modimes.org/Research2/ResearchAnnReport/Default.htm, 2000.

[17] March of Dimes, http://www.modimes.org/Programs2/FolicAcid/BirthDefectsMonth.htm, 2001; Pew Environmental Health Commission. *Healthy from the Start*. 1999.

[18] John Harris, California Birth Defects Monitoring Program, Personal Communication, January 21, 2002.

[19] Paul Romitti, Iowa Birth Defects Registry, Personal Communications, September, November, and December 2001.

[20] Janice Bakewell, Missouri Birth Defect Registry, Personal Communication, September 21, 2001.