

NCBDDD annual report 2011

National Center on Birth Defects and Developmental Disabilities • Centers for Disease Control and Prevention

PROMOTING THE HEALTH OF
BABIES, CHILDREN, AND ADULTS
and enhancing the potential for full, productive living



learn more: www.cdc.gov/ncbddd • 1.800.cdc.info • 1.800.232.4626

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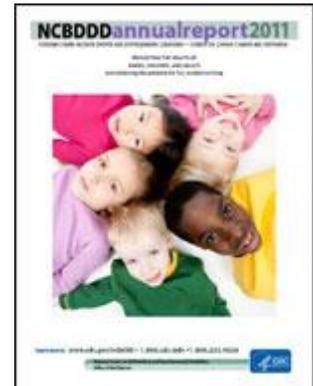
NCBDDDannualreport2011

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NCBDDD 2011 Annual Report

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- [Birth Defects and Developmental Disabilities](#)
 - [Autism and Other Developmental Disabilities](#)
Enhancing the monitoring and tracking of autism and other developmental disabilities and advancing research into the risk factors for these conditions.
 - [Birth Defects](#)
Preventing major birth defects from maternal risk factors.
 - [Fetal Alcohol Spectrum Disorders](#)
Preventing fetal alcohol spectrum disorders and other negative effects of alcohol-exposed pregnancies.
 - [Folic Acid](#)
Reducing folic-acid preventable neural tube defects.
 - [Newborn Screening](#)
Enhancing the quality and usefulness of newborn screening data and programs.
- [Blood Disorders](#)
 - [Preventing clotting disorders](#)
Venous thromboembolism (VTE) - a condition where a blood clot in one of the large veins of the lower leg, thigh or pelvis, known as a deep vein thrombosis (DVT), breaks up and moves to the lungs causing a pulmonary embolism (PE).
 - [Sickle Cell and Thalassemia](#)
Preventing and controlling complications resulting from hemoglobinopathies
 - [Hemophila and Von Willebrand Disease](#)
Preventing and controlling complications resulting from bleeding disorders
- [Human Development and Disability](#)
 - [Disparities in Health Among People with Disabilities](#)
Identify and reduce disparity in key health indicators, including obesity, among children, youth and adults with disabilities.



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- [Child Development](#)
Improve developmental outcomes of children.
- [Hearing Loss in Children](#)
Ensure that all newborns are screened and assessed for hearing loss and receive appropriate intervention.
- [Disparities in Health Care Access for People with Disabilities](#)
Reduce disparities in health care access for people with disabilities.
- [Incorporate Disability Status into Surveys, Policies and Practices](#)
Incorporate disability status as a demographic variable into all relevant CDC surveys, policies and practices.
- [10 Years of Service](#)
- [Notable Scientific Publications](#)
- [_____](#)

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About the Centers for Disease Control and Prevention (CDC)

CDC'S mission is to collaborate to create the expertise, information, and tools that people and communities need to protect their health – through health promotion, prevention of disease, injury, and disability, and preparedness for new health threats.

A Public Health Approach

What does it mean to take “a public health approach”? By definition, public health focuses on preventing disease, promoting health, and prolonging life. It addresses population-level health concerns rather than individual-level health issues. Tracking and monitoring of disease patterns and outbreaks are foundational to public health. Scientific research is the basis for development of health education and outreach programs as well as policy interventions.



NCBDDD Mission

Helping People Live Life to the Fullest

Through our efforts, we work to improve lives from childhood through adulthood. The mission of CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is to promote the health of babies, children, and adults, helping them live life to the fullest. We live out our mission in important ways:

- *We use science as the foundation* to reflect the impact that birth defects, disabilities, and blood disorders can have and to show us how we can understand their causes and learn to prevent them.
- *We translate science into action* providing health information, programs, tools, and resources to consumers, health care professionals, and policymakers.
- *We collaborate with partners* to increase our impact where people live, work, and play.

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Message from the Director

The mission of our Center has grown considerably since its inception on April 15, 2001. This became apparent to me as I engaged with many of you over the past year to mark our 10 year anniversary with a series of events titled 10 Years of Service. Our partners have also worked with us over the past 10 years to make a difference in the lives of so many impacted by birth defects, disabilities and blood disorders. Together, we have advanced science, changed policies and systems, and most importantly given people the opportunity to live the healthiest life possible. It's been an exciting year and is an exciting time.

I've been with the Center since its creation, but serving as center director has given me a new appreciation for how the work of my colleagues has changed the conversation about the populations that we serve and where we place our priorities. What I've seen is how we have successfully reframed the context in which people live. We've helped change the way people view many of the conditions we study.



We have three [center-level priorities](#) and these fit within the context of prevention opportunities with a focus on those issues that will have a health impact. They are independent, stand-alone priorities:

- Take what we know about the prevention of birth defects and move that along in terms of trying to have health impact. We've invested, over the last 13-14 years, in a fairly large research effort and through that effort have identified a number of preventable causes of birth defects. This includes things like alcohol, smoking and other lifestyle factors, a number of maternal health conditions like pre-gestational diabetes and obesity, use of medications in pregnancy, and our landmark work on folic acid.
- Reduce health disparities among people with disabilities. People with disabilities have a higher number of lifestyle risk factors and we'd like to work within the context of the programs here at CDC and our federal partners to try make sure the many prevention efforts are reaching people with disabilities and other vulnerable populations.
- Address venous thromboembolism and the fact that we know how to prevent it, particularly those associated with hospitalization and surgery. That means working to bring groups

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together to coalesce around appropriate guidelines, and then working within the context of policy to implement those guidelines. We're also starting a tracking component of that by working with the National Health Care Safety Network to monitor real-time venous thromboembolism (VTE) events.

As the director of the National Center on Birth Defects and Developmental Disabilities, I am proud to celebrate 10 years of continued progress in the pursuit of improved programs, research, and knowledge for the millions of Americans who live with birth defects, disabilities, and blood disorders. Though our work is far from over, the foundation we have built strengthens our quest for a better tomorrow. We're working across CDC to make sure that people are getting the health protection and promotion they need. No one group can do this. It has to happen with CDC and with our partners. The Center's mission and CDC's mission is not complete until the most vulnerable in our nation are also benefiting from our work.

Sincerely,



Coleen A. Boyle, PhD, MS(Hyg)

Director of the National Center on Birth Defects and Developmental Disabilities (NCBDDD)

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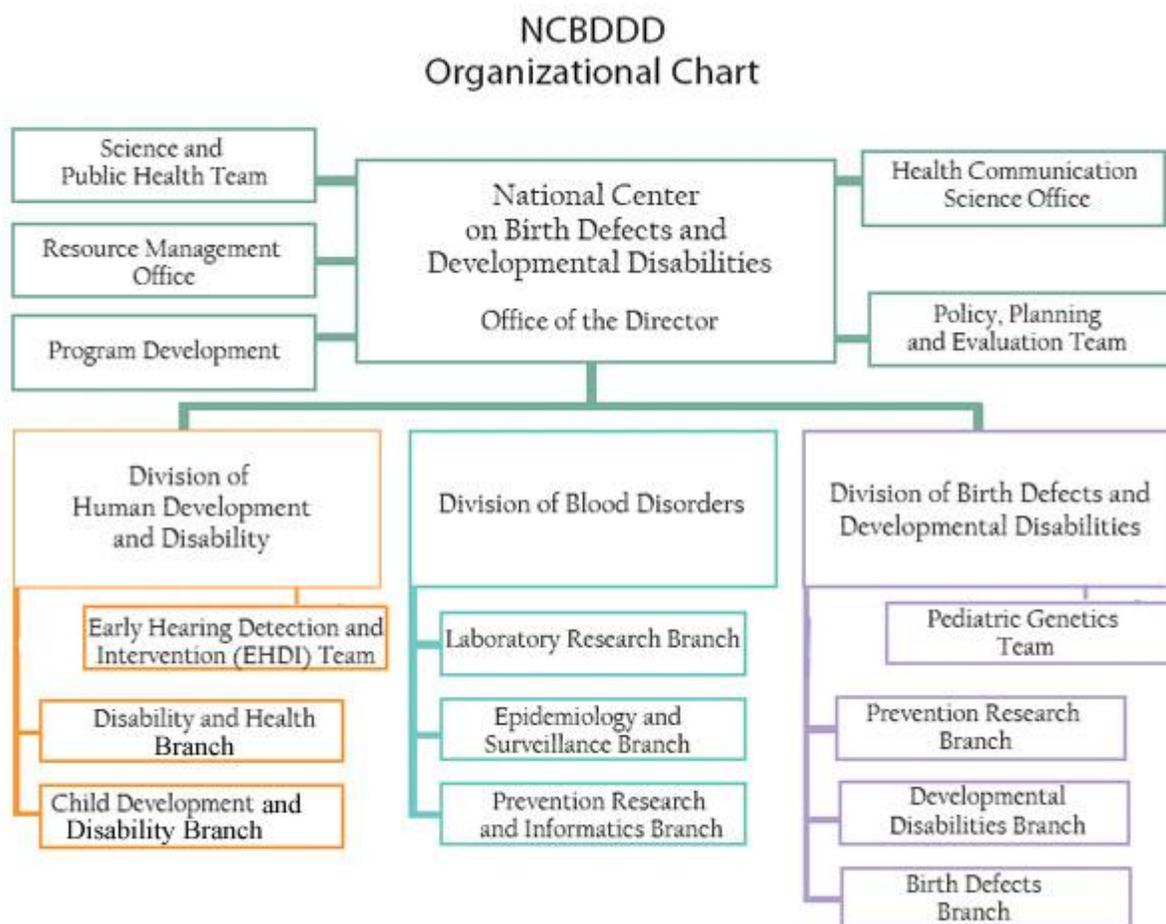


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NCBDDD Organizational Landscape

The Children's Health Act of 2000 established the National Center on Birth Defects and Developmental Disabilities. Our Center is organized into three divisions, which are focused on human development and disabilities, birth defects and developmental disabilities, and blood disorders. Our Center is comprised of about 375 dedicated employees and contractors working within multidisciplinary teams.



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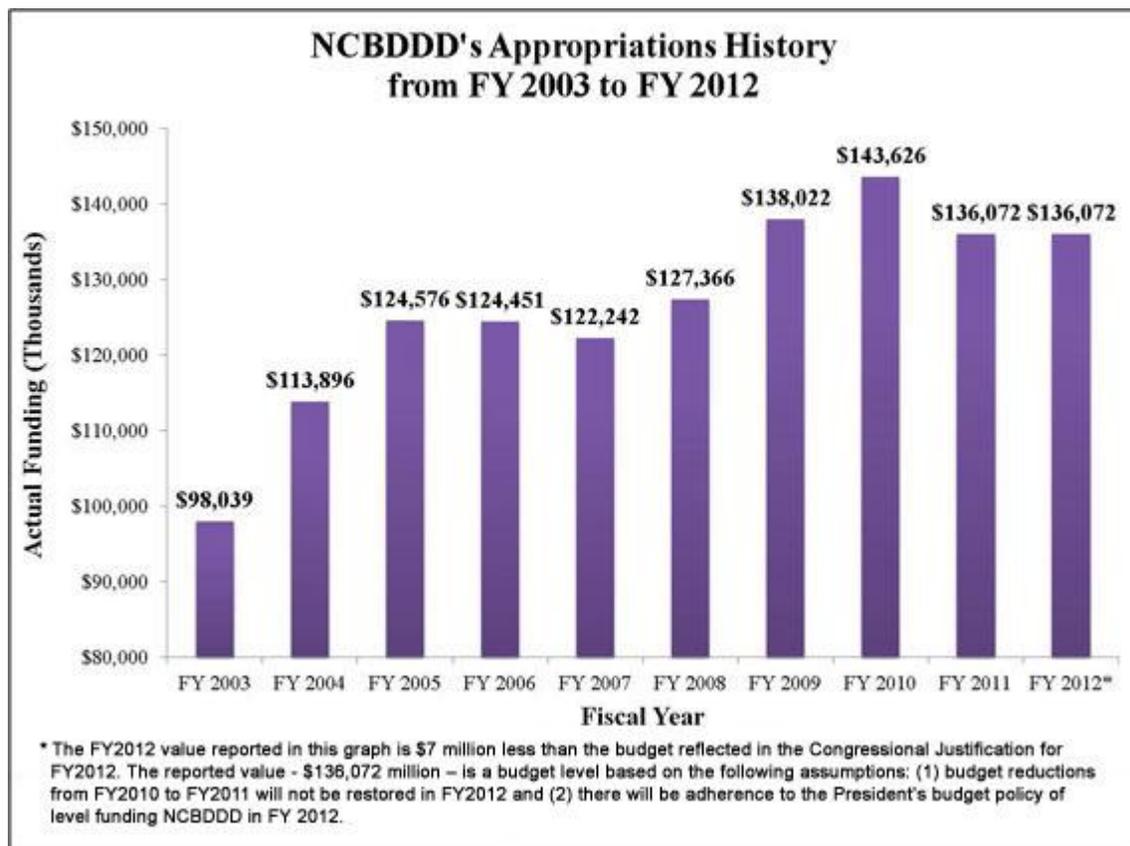
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Our Budget

As the United States faces substantial budgetary constraints, government agencies across the nation have been impacted including CDC. In the final fiscal year (FY) 2011 budget, CDC was required to absorb an 11 percent reduction in its base budget from the FY 2010 funding levels bringing the total FY 2011 budget to \$10.8 billion. As expected, programs across the agency have experienced budget reductions. CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) experienced a 5 percent reduction in its budget, bringing NCBDDD's operating budget to FY 2008 levels.

Given the continued tight budget climate, the FY 2012 President's Budget proposes consolidation of budget lines to increase efficiencies and savings across programs.



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Fiscal Year 2011

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) fiscal year (FY) 2011 operating plan includes \$136 million for Child Health, Disabilities, and Blood Disorders, which is \$7.5 million below FY 2010. This 5 percent reduction eliminated the following programs:

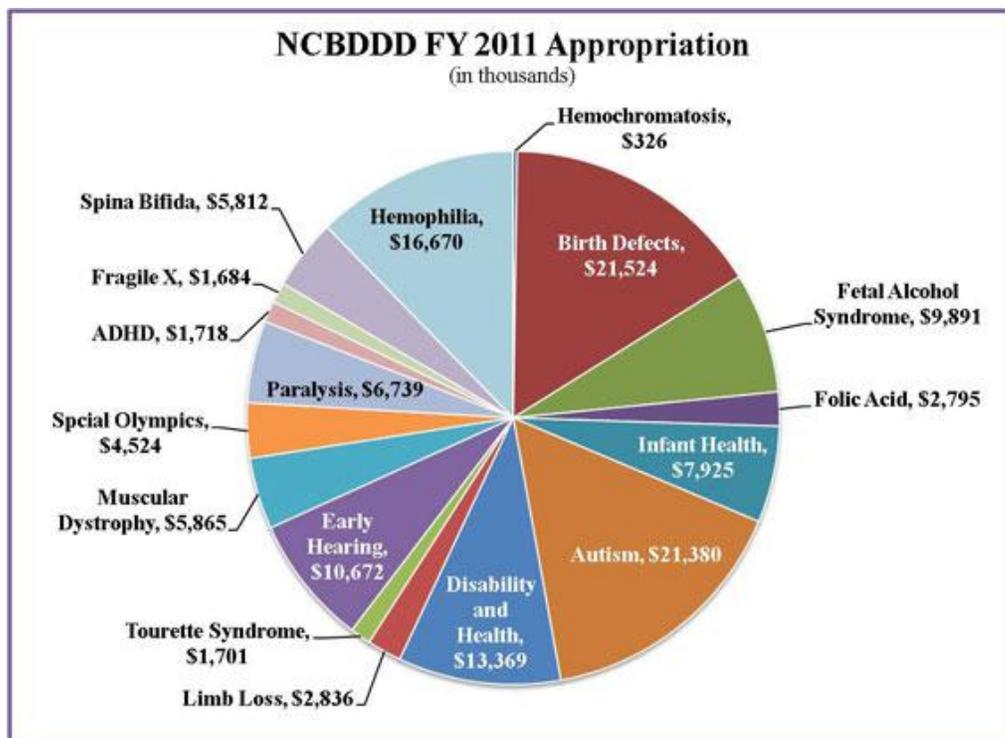
- Charcot Marie Tooth Disorders
- Alveolar Capillary Dysplasia
- Diamond Blackfan Anemia

The rationale used to identify reductions included:

- Consistency with National Center priorities
- Consistency with Agency priorities
- Demonstrated impact of public health programs
- Equitable reductions across broad programmatic activities

In addition, significant reductions have been taken from across the remaining program lines.

Funds are currently supporting surveillance, research, and prevention activities that are addressing issues with the greatest public health burden and implementing strategies to improve health outcomes.



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NCBDDD FY 2011 Appropriations (in thousands)

Child Health and Development	\$62,295
Birth Defects	\$20,304
<i>Craniofacial Malformation</i>	\$1,809
<i>Fetal Death</i>	\$808
Fetal Alcohol Syndrome	\$9,891
Folic Acid	\$2,795
Infant Health	\$7,925
Autism	\$21,380
Health and Development with Disabilities	\$54,920
Disability and Health (includes Child Development Studies)	\$13,369
Limb Loss	\$2,836
Tourette Syndrome	\$1,701
EHDI	\$10,672
Muscular Dystrophy	\$5,865
Special Olympics	\$4,524
Reeve Paralysis Resource Center	\$6,739
ADHD	\$1,718
Fragile X	\$1,684
Spina Bifida	\$5,812
Blood Disorders	\$18,857
Hemophilia	\$16,670
Thalassemia	\$1,861
Hemochromatosis	\$326
NCBDDD Total	\$136,072

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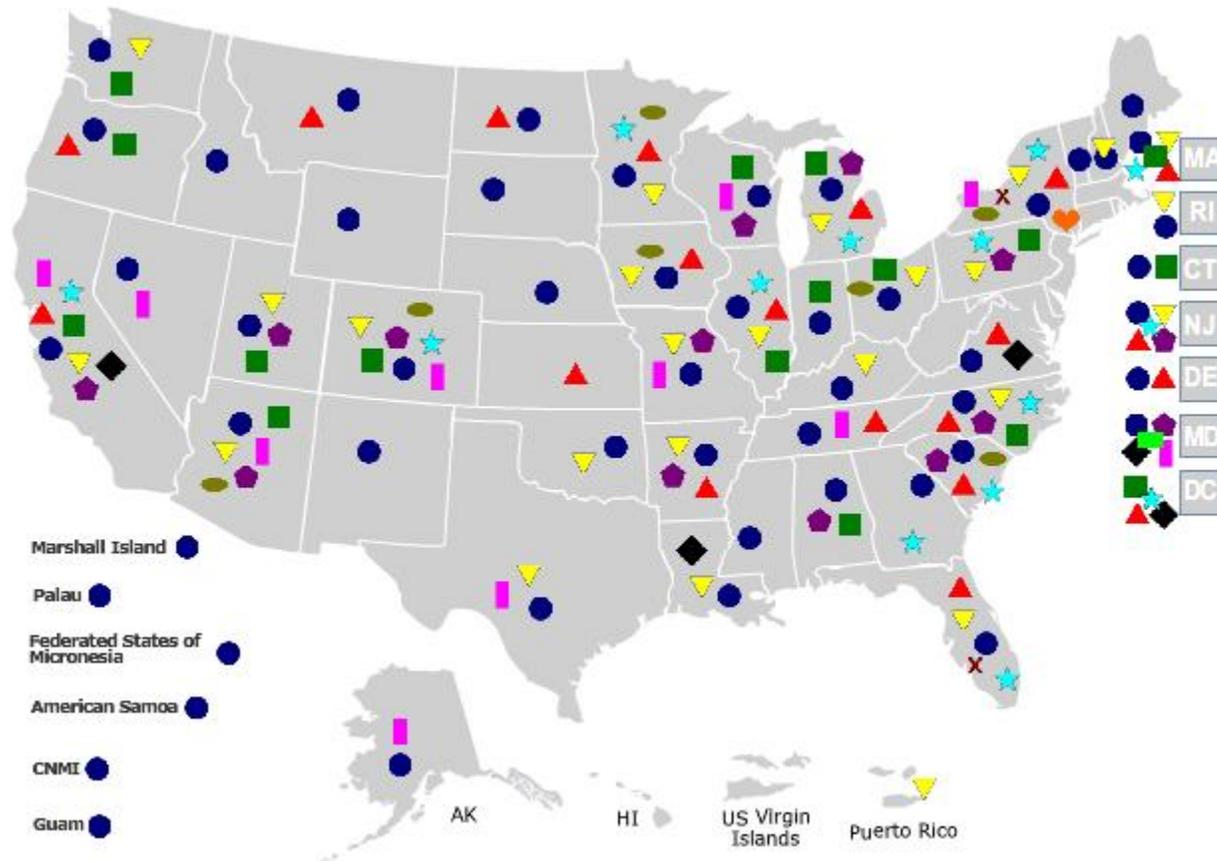


Select State-Based Activities and Funding

CDC's National Center on Birth Defects and Developmental Disabilities

Each colored dot on a state represents a category of funding as listed in the legend below (there may be multiple programs within a category of funding for a particular state). Please note: This map is based on Fiscal Year 2011 funding levels of extramural programs. This map does not include discrete funding activities, including conference support grants.

To use the interactive map, visit our website: <http://www.cdc.gov/NCBDDD/AboutUs/map/index.html>



Legend: Categories of Funding

- Autism Research and Tracking
- FASD Research, Tracking and Training Activities
- Disability and Health Research and Tracking
- Spina Bifida Research and Tracking
- Muscular Dystrophy Research and Tracking
- Fragile X Research and Tracking
- Birth Defects Research and Tracking
- Early Hearing Detection Research and Tracking
- Blood Disorders Research and Tracking
- ADHD Research and Tracking
- Tourette Syndrome Research and Tracking
- NCBDDD Partnerships

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Select State-Based Activities and Funding

(Based on Fiscal Year 2011 funding level.)

Alabama

Autism and Developmental Disabilities Monitoring (ADDM) Network

Surveillance Non-Research

University of Alabama, Birmingham (DD10-1002, 000678)

\$354,025

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Alabama Department of Public Health (DD11-1101, 000793)

\$147,030

National Spina Bifida Registry Longitudinal Data Collection & Evaluation

University of Alabama, Birmingham (DD11-005, 000773)

\$50,000

Alaska

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Alaska Department of Health (DD11-1101, 000780)

\$156,933

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Centers

University of Alaska, Anchorage (DD11-1107, 000886)

\$300,000

Arkansas

Autism and Developmental Disabilities Monitoring (ADDM) Network

Surveillance Non-Research

University of Arkansas (DD10-1002, 000679)

\$352,880

Birth Defects - Centers for Birth Defects Research and Prevention-Research

Arkansas Children's Hospital Research Institute (DD09-001, 000491)

\$870,000

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Arkansas Department of Health (DD11-1101, 000789)
\$154,440

▲ Disability and Health

State capacity building / health promotion

University of Arkansas (DD07-702, 000286)
\$399,372

Arizona

◆ Autism and Developmental Disabilities Monitoring (ADDM) Network

Surveillance Non-Research

University of Arizona (DD10-1002, 000680)
\$478,975

▼ Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Arizona Department of Health Services (DD10-1001, 000609)
\$180,000

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Arizona Department of Health Services (DD11-1101, 000826)
\$157,372

■ Surveillance of Fetal Alcohol Syndrome Utilizing the Infrastructure of Existing Surveillance Programs – Non-Research

University of Arizona (DD09-910, 000557)
\$215,000

● MD STARnet: Feasibility of Expansion to other Muscular Dystrophies

University of Arizona (DD11-006, 000830)
\$550,000

■ Developing a Prospective Assessment of the Development, Health, and Condition Progression in Children with Spina Bifida

University of Arizona (DD10-004, 000691)
\$248,185

California

◆ CADDRE: A Case-Cohort Study

Kaiser Foundation Hospitals (DD11-002, 000748)
\$900,000

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▼ **Birth Defects - Centers for Birth Defects Research and Prevention - Research**

Stanford University (DD09-001, 000489)

\$945,000

● **Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs**

California Department of Health Care Services (DD11-1101, 000816)

\$148,800

▲ **Disability and Health**

State Capacity Building /Health Promotion

California Department of Public Health (DD07-702, 000259)

\$250,000

■ **National Spina Bifida Patient Registry Clinic Demonstration Project**

Children's Hospital & Research Center @ Oakland (DD11-001, 000743)

\$40,000

■ **National Spina Bifida Registry Longitudinal Data Collection and Evaluation**

Children's Hospital Of Los Angeles (DD11-005, 000770)

\$50,000

★ **Population Based Surveillance for Hemoglobinopathies (RuSH)**

Public Health Foundation Enterprises Inc. (DD09-909, 000568)

\$545,442

★ **Research Initiatives for the Prevent of Complications of Thalassemia**

Children's Hospital and Research Center at Oakland (DD07-010, 000310)

\$200,000

Children's Hospital at Los Angeles (DD07-010, 000309)

\$150,000

■ **Reducing Risks for Alcohol Exposed Pregnancy in Women attending Federally-Funded Community Health Centers**

AltaMed Health Service Corp (DD10-1006, 000726)

\$275,000

■ **Intervention for Youth and Young Adults with Fetal Alcohol Spec Disorders**

University Of California, Los Angeles (DD09-006, 000504)

\$299,999

◆ **The Norman Lear Center Entertainment Education Program**

University of Southern California (HM07-702, 000205)

\$20,000

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Colorado

Autism and Developmental Disabilities Monitoring (ADDM) Network

Surveillance Non-Research

Colorado Department of Public Health & Environment (DD10-1002, 000686)
\$324,870

CADDRE: A Case-Cohort Study

University of Colorado Denver (DD11-002, 000750)
\$900,000

Birth Defects - Population Based Surveillance and Utilization of Surveillance Data by Public Health Departments - Non-Research

Colorado Department of Public Health and Environment (DD10-1001, 000596)
\$180,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Colorado Department Of Public Health And Environment (DD11-1101, 000822)
\$157,298

National Spina Bifida Registry Longitudinal Data Collection & Evaluation

University of Colorado at Denver (DD11-005, 000767)
\$50,000

Promoting Health of Individuals with Clotting Disorders

Vascular Disease Foundation (DD09-904, 000553)
\$217,497

Reducing Risk of Alcohol Exposed Pregnancy in High Risk Women Attending Sexually Transmitted Disease Clinics in Urban Settings

Colorado Department of Public Health and Environment (DD09-908, 000542)
\$260,274

Surveillance of Fetal Alcohol Syndrome Utilizing the Infrastructure of Existing Surveillance Programs – Non-Research

Colorado Department of Public Health and Environment (DD09-910, 000531)
\$215,000

Thrombosis and Hemostasis Centers Research and Prevention Network

University of CO at Denver (DD07-004, 000016)
\$175,000

MD STARnet: Feasibility of Expansion to other Muscular Dystrophies

Colorado Department Of Public Health And Environment (DD11-006, 000835)
\$450,000

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★ Public Health Research for the Prevention of Complications of Bleeding Disorders

University of Colorado Denver (DD11-009, 000757)
\$200,000

Connecticut

● Development, Maintenance & Enhancement of EHDl Info Systems (EHDl-IS) Surveillance Programs

Connecticut Department of Public Health (DD11-1101, 000817)
\$145,720

■ National Spina Bifida Registry Longitudinal Data Collection & Evaluation

Connecticut Children's Medical Center, Inc (DD11-005)
\$50,000

Delaware

● Development, Maintenance & Enhancement of EHDl Info Systems (EHDl-IS) Surveillance Programs

Delaware Department of Health and Social Services (DD11-1101, 000819)
\$122,047

▲ Disability and Health

State Capacity Building / Health Promotion

University of Delaware (DD07-702, 000277)
\$200,000

Florida

▼ Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Florida Department of Health (DD10-1001, 000608)
\$200,000

● Development, Maintenance & Enhancement of EHDl Info Systems (EHDl-IS) Surveillance Programs

Florida Dept of Health (DD11-1101, 000810)
\$145,561

▲ Disability and Health

State Capacity Building / Health Promotion

University of Florida (DD07-702, 000273)
\$374,876

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★ Population Based Surveillance for Hemoglobinopathies (RuSH)

Florida Dept of Health (DD09-909, 000580)
\$530,872

X Quality of Life, Co-Morbidities, Health Service Utilization in Youth with Tic Disorders

University of South Florida (DD09-004, 000509)
\$75,000

Georgia

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs



Georgia Dept of Community Health (DD11-1101, 000824)
\$159,909

★ Population Based Surveillance for Hemoglobinopathies (RuSH)

GA Dept of Community Health (DD09-909, 000582)
\$546,583

Hawaii

Idaho

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs



Idaho Dept of Health and Welfare (DD11-1101, 000801)
\$137,801

Illinois

▼ Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Illinois Department of Public Health (DD10-1001, 000598)
\$200,000

▼ Birth Defects - Public Health Program to Enhance Health and Development of Infants and Children through the AAP - Non-Research

American Academy of Pediatrics (DD09-907, 000587)
\$627,057

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● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Illinois Dept of Public Health (DD11-1101, 000825)

\$169,060

▲ Disability and Health

State capacity building / health promotion

Illinois Department of Public Health (DD07-702, 000271)

\$200,000

▲ Physical Activity for People with Disabilities Information Resource Center

University of Illinois (DD08-801, 000437)

\$925,000

★ Research Initiatives for the Prevent of Complications of Thalassemia

Children's Memorial Hospital – Chicago (DD07-011, 000307)

\$150,000

■ National Spina Bifida Patient Registry - Clinic Demonstration Project

Children's Memorial Hospital Chicago (DD11-001, 000744)

\$40,000

★ Public Health Research for the Prevention of Complications of Bleeding Disorders

American Thrombosis and Hemostasis Network (DD11-009, 000761)

\$200,000

★ Public Health Surveillance for the Prevention of Complications of Bleeding & Clotting Disorders

American Thrombosis and Hemostasis Network (DD11-1103, 000862)

\$3,700,000

Indiana

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Indiana State Department of Health (DD11-1101, 000790)

\$155,650

■ National Spina Bifida Registry Longitudinal Data Collection and Evaluation

Indiana University- Riley Hospital for Children (DD11-005, 000769)

\$50,000

Iowa

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▼ Birth Defects - Utilizing Existing Birth Defects Surveillance Program to include Surveillance Data on Stillbirths

Iowa Department of Public Health (DD10-1007, 000730)
\$270,000

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Iowa Dept of Public Health (DD11-1101, 000785)
\$175,000

▲ Disability and Health State capacity building / health promotion

Iowa Dept of Public Health (DD07-702, 000275)
\$425,000

● Surveillance and Epidemiologic Research of Duchene and Becker Muscular Dystrophy

University of Iowa (DD06-002)
\$19,638

▼ Centers for Birth Defects Research and Prevention

University of Iowa (DD09-001, 000492)
\$825,000

● MD STARnet: Feasibility of Expansion to other Muscular Dystrophies

University of Iowa (DD11-006, 000831)
\$749,999

Kansas

▲ Disability and Health

State capacity building / health promotion
Kansas Department of Public Health and Environment (DD07-702, 000284)
\$375,000

Kentucky

▼ Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Kentucky Cabinet for Health & Family Services (DD10-1001, 000606)
\$180,000

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Kentucky Cabinet for Health and Family Services (DD11-1101, 000828)
\$163,216

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Louisiana

▼ Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Louisiana Office of Public Health (DD10-1001, 000623)
\$185,000

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Louisiana Office of Public Health (DD11-1101, 000841)
\$166,461

◆ Strengthen and Improve the Nation's Public Health Capacity

National Network of Public Health Institutes (HM08-805, 000520)
\$5,000

Maine

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs - Non-Research

Maine Department of Health (DD11-1101, 000813)
\$157,334

Maryland

◆ Autism and Developmental Disabilities Monitoring (ADDM) Network Surveillance Non-Research

Johns Hopkins University (DD10-1002, 000675)
\$354,025

◆ CADDRE: A Case-Cohort Study

Johns Hopkins University School of Public Health (DD11-002, 000746)
\$1,650,000

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Maryland Department of Health and Mental Hygiene (DD11-1101, 000782)
\$146,651

■ CHADD – National Resource Center on ADHD

\$909,841 (DD07-714, 000335)
Association of University Centers on Disabilities
\$2,762,193 (DD07-003, 000231)

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Reducing Risk for Alcohol Exposed Pregnancy in High Risk Women Attending Sexually Transmitted Disease Clinics in Urban Settings

Baltimore City Health Department (DD09-908, 000555)

\$275,000

◆ PH Genetics Fellowship

American Society Human Genetics (DD09-901, 000588)

\$90,000

◆ Assure Hit Standards for Public Health

Public Health Data Standards Consortium (HM08-805, 000455)

\$131,031

◆ State Vital Records Jurisdictions

National Assoc of Public Health Stats and Information Systems (SH07-701, 000001)

\$8,500

Massachusetts

▼ Birth Defects - Centers for Birth Defects Research and Prevention - Research

Department of Public Health (DD09-001, 000493)

\$900,000

▼ Birth Defects - Down's Syndrome - Research

Boston University Medical Center (DD09-005, 000522)

\$150,000

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Commonwealth of Massachusetts Department of Public Health (DD11-1101, 000783)

\$156,470

▲ Disability and Health

State capacity building / health promotion

Massachusetts Department of Health (DD07-702, 000282)

\$275,000

▼ Birth Defects - Risk Factors for Folic Acid-Resistance Spina Bifida

Boston University Medical Campus (DD10-002, 000697)

\$196,180

★ Research Initiatives for the Prevent of Complications of Thalassemia

Children's Hospital Boston (DD07-011, 000308)

\$150,000

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Michigan

▼ Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Michigan Department of Community Health (DD10-1001, 000615)
\$200,000

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

 Michigan Department of Community Health (DD11-1101, 000798)
\$175,000

▲ Disability and Health

State capacity building / health promotion

Michigan Department of Community Health (DD07-702, 000290)
\$250,000

★ Population Based Surveillance for Hemoglobinopathies (RuSH)

Michigan Dept. of Community Health (DD09-909, 000567)
\$538,849

◆ Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE)

Michigan State University (DD09-002, 000498)
\$900,000

■ National Spina Bifida Patient Registry - Clinic Demonstration Project

Wayne State University (DD11-001, 000740)
\$39,464

Minnesota

▼ Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Minnesota Department of Health (DD10-1001, 000594)
\$175,000

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

 Minnesota Department of Health (DD11-1101, 000842)
\$126,376

▲ Disability and Health DD Prevention Research Center

University of Minnesota (DD09-001, 001939)
\$1,012,000

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★ Thrombosis and Hemostasis Centers Research and Prevention Network

Mayo Clinic (DD07-005, 000235)
\$175,000

● Development & Dissemination of Evidence Based Clinical Based Guidelines for Muscular Dystrophies

American Academy of Neurology (DD10-1012, 000723)
\$227,289

Mississippi

● Development, Maintenance & Enhancement of EHDl Info Systems (EHDl-IS) Surveillance Programs

 Mississippi Department of Health (DD11-1101, 000820)
\$138,245

Missouri

◆ Autism and Developmental Disabilities Monitoring (ADDM) Network Surveillance Non-Research

Washington University at St. Louis (DD10-1002, 000684)
\$422,305

● Development, Maintenance & Enhancement of EHDl Info Systems (EHDl-IS) Surveillance Programs

Missouri Dept of Health and Senior Services (DD11-1101, 000815)
\$140,255

■ Midwest Partners for Success Intervention for Youth and Young Adults with FASDs

Saint Louis University (DD09-006, 000512)
\$280,853

▼ Prevention Research Centers

Saint Louis University (DP09-001, 001903)
\$5,000

Montana

● Development, Maintenance & Enhancement of EHDl Info Systems (EHDl-IS) Surveillance Programs

Montana Department of Public Health and Human Services (DD11-1101, 000811)
\$154,998

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▲ Disability and Health

State capacity building / health promotion

Montana Department of Public Health (DD07-702, 000287)

\$400,000

Nebraska

● Development, Maintenance & Enhancement of EHDl Info Systems (EHDl-IS) Surveillance Programs

Nebraska Department of Health & Human Services (DD11-1101, 000797)

\$136,100

Nevada

● Development, Maintenance & Enhancement of EHDl Info Systems (EHDl-IS) Surveillance Programs

Nevada Department of Health and Human Services (DD11-1101, 000788)

\$132,985

█ Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center

Board of Regents, University of Nevada Reno (DD11-1107, 000888)

\$278,033

New Hampshire

▼ Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

New Hampshire Birth Conditions Program (DD10-1001, 000607)

\$160,000

● Development, Maintenance & Enhancement of EHDl Info Systems (EHDl-IS) Surveillance Programs

New Hampshire Department of Health and Human Services (DD11-1101, 000827)

\$164,900

New Jersey

◆ Autism and Developmental Disabilities Monitoring (ADDM) Network Surveillance Non-Research

University of Medicine and Dentistry of New Jersey (DD10-1002, 000674)

\$478,976

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▼ Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

New Jersey Department of Health and Senior Services (DD10-1001, 000599)
\$200,000

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

New Jersey Department of Health and Senior Services (DD11-1101, 000805)
\$172,000

▲ National Public Health Practice and Information Center on Paralysis

Christopher Reeve Paralysis Foundation (DD11-1102, 000838)
\$5,800,000

★ Thrombosis and Hemostasis Centers Research and Prevention Network

Univ of Medicine/Dentistry RW Johnson Medical School (DD07-004, 000017)
\$175,000

New Mexico

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

New Mexico Department Of Health (DD11-1101, 000807)
\$130,144

New York

▼ Birth Defects - Centers for Birth Defects Research and Prevention - Research

NYS Health Research, Inc/New York State Department of Health (DD09-001, 000487)
\$800,000

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Health Research Inc/NYS Dept of Health (DD11-1101, 000795)
\$156,338

▲ Disability and Health

State capacity building / health promotion

NY State Department of Health (DD07-702, 000269)
\$204,796

★ Promoting Health of Individuals with Clotting Disorders

National Alliance Thrombosis/Thrombophilia (DD09-904, 000545)
\$496,330

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★ Preventing Complications of Persons with Hereditary Blood Disorders Through Health Education and Outreach

National Hemophilia Foundation (DD09-905, 000534)
\$797,219

█ Surveillance of Fetal Alcohol Syndrome Utilizing the Infrastructure of Existing Surveillance Programs – Non-Research

NYS Health Research, Inc/New York State Department of Health (DD09-910, 000532)
\$203,200

█ Reducing Risks for Alcohol Exposed Pregnancy in Women attending Federally-Funded Community Health Centers

NYC Health and Hospital Corp (DD10-1006, 000728)
\$275,000

X Tourette Syndrome National Education and Outreach

Tourette Syndrome Association (DD10-1004, 000727)
\$800,000

X Impact of Tics

University of Rochester (DD09-004, 000510)
\$75,000

★ Surveillance and Epidemiologic Research of Duchene and Becker Muscular Dystrophy

Prevention of the Complications of Thalassemia
Weill Medical College (DD07-010, 000311)
\$150,000

★ Thalassemia Prevention Education and Outreach

Cooley's Anemia Foundation Inc. (DD07-712, 000331)
\$200,000

★ State-Based Surveillance for Hemoglobinopathies

Health Research Inc/NYS Dept of Health (DD10-1017, 000722)
\$536,184

● MD STARnet: Feasibility of Expansion to other Muscular Dystrophies

Health Research Inc/NYS Dept of Health (DD11-006, 000836)
\$525,000

♥ Pilot Longitudinal Data Collection to Inform Public Health – Fragile X Syndrome

Research Foundation for Mental Hygiene, Inc. (DD11-007, 000753)
\$549,984

North Carolina

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Autism and Developmental Disabilities Monitoring (ADDM) Network

Surveillance Non-Research

University of North Carolina at Chapel Hill (DD10-1002, 000687)

\$344,170

Birth Defects - Centers for Birth Defects Research and Prevention - Research

University of North Carolina-Chapel Hill (DD09-001, 000488)

\$945,000

Birth Defects - The North Carolina Cleft Outcomes Study - Research

University of North Carolina-Chapel Hill (DD10-001, 000696)

\$400,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs



North Carolina Department Of Health And Human Services (DD11-1101, 000823)

\$163,962

Disability and Health

State capacity building / health promotion

NC Department of Health and Human Services (DD07-702, 000283)

\$250,000

Population Based Surveillance for Hemoglobinopathies (RuSH)

NC Depart Health & Human Services (DD09-909, 000577)

\$549,183

Thrombosis and Hemostasis Centers Research and Prevention Network

Duke University - \$175,000 (DD07-004, 000014)

University of North Carolina \$175,000 (DD07-005, 000292)

National Spina Bifida Patient Registry - Clinic Demonstration Project

Duke University (DD11-001, 000742)

\$39,731

New - CADDRE: A Case-Cohort Study

University of North Carolina at Chapel Hill (DD11-002, 000749)

\$900,000

Public Health Surveillance for the Prevention of Complications of Bleeding and Clotting Disorders

Duke University (DD11-1103, 000860)

\$200,000

North Dakota

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Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs



North Dakota - Minot State University (DD11-1101, 000802)

\$155,703

Disability and Health

State capacity building / health promotion

North Dakota - Minot State University (DD07-702, 000278)

\$200,000

Ohio

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Ohio Department of Health (DD10-1001, 000611)

\$180,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs



Ohio Department of Health (DD11-1101, 000804)

\$130,782

National Spina Bifida Registry Longitudinal Data Collection & Evaluation

Children's Hospital Medical Center (DD11-005, 000766)

\$50,000

Muscular Dystrophy Ed & Outreach

Duchenne and Becker Muscular Dystrophy Education and outreach Initiative (DD08-805, 000452)

\$100,000

National Spina Bifida Patient Registry - Clinic Demonstration Project

The Research Institute at Nationwide Children's Hospital (DD11-001, 000738)

\$40,000

Oklahoma

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Oklahoma Department of Health (DD10-1001, 000595)

\$185,000

Early Hearing Detection and Intervention Sureillance and Integration - Non-Research



Oklahoma State Department of Health (DD11-1101, 000814)

\$142,750

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Oregon

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs



Oregon State Dept of Human Services (DD11-1101, 000799)
\$162,365

Disability and Health

State capacity building / health promotion

Oregon Health and Science Center (DD07-702, 000266)
\$450,000

National Spina Bifida Registry Longitudinal Data Collection & Evaluation

Oregon Health & Science University (DD11-005, 000772)
\$50,000

Pennsylvania

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) Network - A Case-Cohort Study

University of Pennsylvania (DD11-002, 000752)
\$900,000

Birth Defects - Downs Syndrome - Research

Children's Hospital of Philadelphia (DD09-005, 000518)
\$279,916

Population Based Surveillance for Hemoglobinopathies (RuSH)

Penn Dept Health (DD09-909, 000578)
\$534,056

Research Initiatives for the Prevent of Complications of Thalassemia

Children's Hospital of Philadelphia (DD07-010, 000306)
\$150,000

National Spina Bifida Patient Registry - Clinic Demonstration Project

Pennsylvania State University Hershey Medical Center (DD11-001, 000736)
\$39,547

National Spina Bifida Patient Registry - Clinic Demonstration Project

University of Pittsburgh (DD11-001, 000737)
\$40,000

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Rhode Island

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Rhode Island Department of Health (DD10-1001, 000612)
\$160,000

Development, Maintenance & Enhancement of EHDl Info Systems (EHDl-IS) Surveillance Programs


Rhode Island Department of Health (DD11-1101, 000791)
\$143,474

South Carolina

Autism and Developmental Disabilities Monitoring (ADDM) Network Surveillance - Non-Research

Medical University of South Carolina (DD10-1002, 000682)
\$478,974

Development, Maintenance & Enhancement of EHDl Info Systems (EHDl-IS) Surveillance Programs


South Carolina Department of Health and Environmental Control (DD11-1101, 000779)
\$138,804

Disability and Health

State capacity building / health promotion
University of South Carolina (DD07-702, 000268)
\$300,000

Pilot for State-specific Cross-Sectional Surveillance of Persons with Rare Disorders & Longitudinal Assessment of Outcomes

South Carolina Research Foundation (DD11-004, 000776)
\$389,921

The Association of Genetic Biomarkers and Hereditary Hemochromatosis

Medical University of South Carolina (DD11-008, 000754)
\$150,839

South Dakota

Development, Maintenance & Enhancement of EHDl Info Systems (EHDl-IS) Surveillance Programs


South Dakota Department of Health (DD11-1101, 000794)
\$122,472

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Project CHOICES Pilot Implementation and Evaluation for American Indian and Alaska Native Women

Oglala Sioux Tribe (U58DP001608, Interagency Agreement with Indian Health Service)
\$150,000

Tennessee

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs



Tennessee Department of Health (DD11-1101, 000786)
\$156,873

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center

Meharry Medical College (DD11-1107, 000882)
\$275,000

Amputee Coalition of America

The National Limb Loss Information Center (DD07-710, 000347)
\$825,000

Texas

Birth Defects - Center for Birth Defects Research and Prevention - Research

Texas Department of State Health Services (DD09-001, 000494)
\$880,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs



Texas Department of State Health Services (DD11-1101, 000781)
\$162,852

CHOICES PLUS - Preconception approach to reducing alcohol & tobacco-exposed pregnancy

University of Texas at Austin (DD08-003, 000438)
\$499,995

Utah

Autism and Developmental Disabilities Monitoring (ADDM) Network

Surveillance Non-Research

University of Utah (DD10-1002, 000685)
\$473,044

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▼ Birth Defects - Centers for Birth Defects Research and Prevention - Research

Utah State Department of Health (DD09-001, 000490)
\$944,972

▼ Public Health Research on Craniofacial Malformations Research

Utah State University (DD10-001, 000698)
\$399,270

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs



Utah State Department of Health (DD11-1101, 000821)
\$154,950

■ Develop a Professional Assessment Development, Health and Condition Program in Young Children with Spina Bifida

University of Utah (DD10-004, 000690)
\$248,185

■ National Spina Bifida Patient Registry-Clinic Demonstration Project

IHC Health Services, Inc., Dba: LDS Hospital (DD11-001, 000745)
\$31,271

Vermont

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs



Vermont Department of Health (DD11-1101, 000818)
\$150,000

Virginia

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs



Virginia Department of Health (DD11-1101, 000812)
\$156,274

▲ Disability and Health

State capacity building / health promotion

Virginia Commonwealth University (DD07-702, 000270)
\$200,000

◆ Strengthen and Improve the Nation's Public Health Capacity

Association of State and Territorial Health Officials (ASTHO) (HM08-805, 000454),
\$20,000

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◆ Association of University Centers on Disabilities (AUCD)

DD07-003

\$2,762,193

◆ American Academy of Pediatrics (AAP)

Program to Enhance the Health and Development of Infants and Children

(DD09-907, 000587)

\$627,057

◆ Promoting Universal Access to Alcohol Screening and Brief Intervention through Collaboration with the American College of Obstetricians and Gynecologists

American College of Obstetricians and Gynecologists (200-2010-37560, Task Order 0001)

\$193,513

Washington

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs



Washington State Department of Health (DD11-1101, 000800)

\$170,257

■ National Spina Bifida Registry Longitudinal Data Collection & Evaluation

Seattle Children's Hospital (DD11-005, 000771)

\$50,000

▼ Surveillance, Natural History, Quality of Care and Outcomes of Diabetes Mellitus with Onset in Childhood and Adolescence

Seattle Children's Hospital (DP10-001, 002710)

\$649,848

West Virginia

Wisconsin

◆ Autism and Developmental Disabilities Monitoring (ADDM) Network

Surveillance - Non-Research

University of Wisconsin DD10-1002, 000677)

\$478,975

● Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs



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Wisconsin Department of Health and Family Services (DD11-1101, 000806)
\$165,205

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center
Board of Regents of the University of Wisconsin System (DD11-1107, 000885)
\$298,657

National Spina Bifida Registry Longitudinal Data Collection & Evaluation
Children's Hospital of Wisconsin (DD11-005, 000768)
\$50,000

Wyoming

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs 
Wyoming Department of Health (DD11-1101, 000787)
\$141,924

District of Columbia

National Spina Bifida Initiatives: Prevention, Resources, and Quality of Life
Spina Bifida Association of America
\$937,500 (DD07-709, 000318)

Preventing Complications of Persons with Hereditary Blood Disorders Through Health Education and Outreach
Hemophilia Federation of American (DD09-905, 000537)
\$345,194

Research Coop Agreement to Promote the Health of People with Intellectual Disability
Special Olympics (DD07-012, 000302)
\$450,000

Research Coop Agreement to Promote the Health of People with Intellectual Disability
Special Olympics (DD07-704, 000340)
\$3,500,000

Enhance Preparation of Public Health and Primary Care Physicians
Association of Teacher of Preventive Medicine
CD05-049, 300860, 22S9
\$67,946

Enhanced Resources for FASD Prevention and Intervention thru National Networking, Education and Dissemination

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National Organization on Fetal Alcohol Syndrome Prevention (DD10-1005, 000700)
\$300,000

★ [Public Health Surveillance for the Prevention of Complications of Bleeding & Clotting Disorders](#)

Hemophilia Federation of America (DD11-1103, 000859)
\$200,000

◆ **Strengthen and Improve the Nation's Public Health Capacity**

National Association of County & City Health Officials (NACCHO), HM08-805, 000449
\$189,450

◆ **Strengthen and Improve the Nation's Public Health Capacity**

American Public Health Association (APHA), HM08-805, 000459
\$19,050

◆ **Strengthen and Improve the Nation's Public Health Capacity**

Association of Maternal and Child Health Programs (AMCHP), HM08-805, 000
\$20,000

Puerto Rico

▼ [Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research](#)

Puerto Rico Department of Health (DD10-1001, 000600)
\$175,000

Guam

● [Development, Maintenance & Enhancement of EHDI Info Systems \(EHDI-IS\) Surveillance Programs](#)


University of Guam (DD11-1101, 000784)
\$139,735

American Samoa

● [Development, Maintenance & Enhancement of EHDI Info Systems \(EHDI-IS\) Surveillance Programs](#)

American Samoa Department Of Health (DD11-1101, 000777)
\$139,333

United States Virgin Islands

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Commonwealth of the Northern Mariana Islands

● **Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs** 

Commonwealth of the Northern Mariana Islands (DD11-1101, 000792)
\$122,350)

Palau

● **Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs**

Republic Of Palau Ministry Of Health (DD11-1101, 000809)
\$78,835

Federated States of Micronesia (FSM)

● **Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs**

Federated States of Micronesia Department of Health, Education and Social Affairs (DD11-1101, 000778)
\$83,056

Marshall Islands

● **Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs**

Marshall Islands Ministry of Health (DD11-1101, 000796)
\$77,663

Denmark

▼ **Epidemiologic Studies of Reproduction and Developmental Outcomes**

Aarhus Universitet (DD07-001, 000230)
\$575,000

China

▼ **China – US Collaborative Population-Based Surveillance and Research Programs**

National Center for Maternal and Infant Health (DD07-006, 000293)
\$50,000

International

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▼ [Birth Defects - Collaborative International Birth Defects Surveillance Program - Non Research](#)

International Centre for Birth Defects (DD09-902, 000524)

\$185,000

▼ [Birth Defects - Surveillance of Birth Defects in Low and Middle Income Countries - Non Research](#)

American University of Beirut (DD11-1104, 000843)

\$250,000

◆ **Global Prevention of Non-Communicable Disease Prevention & Promotion of Health**

World Health Organization (DP09-909, 002196)

\$443,828

◆ **Implementing Public Health Programs and Strengthening Public Health Science**

Universidad del Valle (GH07-703, 000011)

\$174,213

◆ **Addressing Emerging Infectious Diseases & Related Public Health Threats in the PR China**

Chinese Center for Disease Control and Prevention (GH09-002, 000029)

\$50,000

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Assuring Child Health

Preventing Birth Defects and Developmental Disabilities

National Center on Birth Defects and Developmental Disabilities (NCBDDD) focuses on birth defects and developmental disabilities, providing data for action, working on research to identify causes, and developing prevention activities that promote healthy births and optimal development for all children.

Our work includes:

- [Autism and Other Developmental Disabilities](#)
Enhancing the monitoring and tracking of autism and other developmental disabilities and advancing research into the risk factors for these conditions.
- [Birth Defects](#)
Preventing major birth defects associated with maternal risk factors.
- [Fetal Alcohol Spectrum Disorders](#)
Preventing fetal alcohol spectrum disorders and other negative effects of alcohol-exposed pregnancies.
- [Folic Acid](#)
Reducing folic-acid preventable neural tube defects.
- [Newborn Screening](#)
Enhancing the quality and usefulness of newborn screening data and programs.

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Autism and Other Developmental Disabilities

Enhancing the Monitoring and Tracking of Autism and Other Developmental Disabilities and Advancing Research into the Risk Factors for these Conditions

What is the problem?

- CDC estimates 1 in 88 children has been identified with an autism spectrum disorder (ASD).
- Annual medical expenditures per child with ASD range from \$2,100 to \$11,200. Additionally, we know that intensive behavioral interventions can cost between \$40,000 and \$60,000 per child with autism per year. We also know that nonmedical costs of educating a child with ASD as a qualifying condition for special education is about \$13,000 a year.
- Studies in Asia, Europe, and North America have identified ASD among the population to be 0.6% to over 1%. A recent study in South Korea reported ASD to be 2.6% among the population.
- We do not know all of the causes ASDs.
- There is currently no cure for ASDs.



What do we know?

- Cases of autism are reported to occur in all racial, ethnic, and socioeconomic groups, yet are on average 4 to 5 times more likely to occur in boys than in girls.
- Studies have shown that parents of children with ASDs notice a developmental problem before their child's first birthday. Concerns about vision and hearing were more often reported in the first year, and differences in social, communication, and fine motor skills were evident from 6 months of age.
- Early screening and diagnosis improve access to services during a child's most critical developmental period. However, a diagnosis is not necessary before a parent can get help for their child.
- Most children with autism are not diagnosed until after they reach age 4, when it's too late to get the full benefit of early intervention.

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What can we do?

- We will continue to monitor and track the number of people diagnosed with autism over time to determine if the number is rising, dropping, or staying the same. We can also compare the number of children with autism in different areas of the country and among different groups of people. This information can help us look for causes of autism and can help communities plan for services.
- Through our Study to Explore Early Development (SEED), we will:
 - Examine the physical and behavioral characteristics of children with autism, children with other developmental disabilities, and children without a developmental delay or disability.
 - Compare health conditions among children with and without autism.
 - Investigate factors associated with a child's risk for developing autism.
- In 2011, we began analyzing the initial results of SEED, focusing on describing the children in terms of specific behaviors, developmental progress, medical issues, genetic and pregnancy factors, and demographics (age, race/ethnicity, gender, place of birth/residence). We also initiated the second phase of SEED and completed enrollment of families for the largest study in the U. S. to help identify factors that may put children at risk for autism. This effort will increase the number of families enrolled in SEED, allowing us to get better estimates of risk.
- Most children who have autism are not diagnosed until after they reach age 4, even though many children can be identified before age 2. CDC supports recommendations that all children be screened by age 2, because early screening and diagnosis improve access to services during a child's most critical developmental period.

Did you know?

- Study to Explore Early Development (SEED) enrolled more than 3,700 children and their families in the largest study in the U.S. to help identify what puts children at risk for autism.
- SEED looks at autism risk factors across the population; a unique contribution to the Interagency Autism Coordinating Committee (IACC) Strategic Plan for Autism Research.



“The ‘Learn the Signs. Act Early.’ campaign fits perfectly with the work we do every day with families. The materials give our families a simple, concise overview of key milestones they can watch for in their children. And our staff is glad to have this additional support in talking with families about child development in a consistent, effective way.” Quote from a WIC manager in St. Louis related to the ‘Learn the Signs. Act Early.’ project

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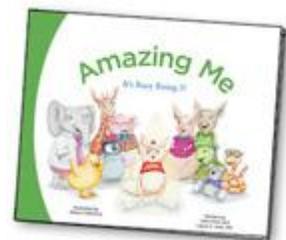
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- NCBDDD's "Learn the Signs. Act Early." program is working to improve awareness of developmental milestones and the importance of tracking them among parents, health care providers and early educators. We are currently funding four state demonstration grants in Utah, Washington, Missouri, and Alaska to help determine effective methods for reaching parents. One grantee in St. Louis, Missouri, has implemented "Learn the Signs. Act Early." messages and materials in 12 Women, Infants and Children (WIC) clinics. Milestone checklists are completed for every child who receives WIC benefits and parents are referred to health care providers as appropriate.
- We continue to track the occurrence of autism in younger children. By tracking autism among 4-year-old children, we can improve efforts at identifying the condition earlier.
- We will continue working with partners and stakeholders to develop ways to close the gap between when parents first have a concern about their child and when they receive a diagnosis. The earlier we can identify that a child has autism and the earlier we can get them into services, the more that child can benefit. However, parents do not need to wait for a diagnosis to get services and support.

Accomplishments

- NCBDDD and the Health Resources and Services Administration (HRSA) published a study showing that developmental disabilities are common: about 1 in 6 children in the U.S. had a developmental disability in 2006–2008. This tracking data also show that parent-reported developmental disabilities have increased 17.1% from 1997 to 2008. This study underscores the increasing need for health, education and social services, and more specialized health services for people with developmental disabilities.
- NCBDDD developed a mathematical model to estimate how changes in pregnancy and birth factors might have contributed to the subsequent increase in autism. The data showed that each pregnancy factor examined likely accounted for less than 1% of the total increase (pregnancy factors included preterm and very preterm delivery, low and very low birth weight, multiple birth, cesarean delivery, breech presentation, and use of in vitro fertilization or other assisted reproductive technologies).
- To increase awareness of developmental milestones, NCBDDD's "Learn the Signs. Act Early." program has created a new children's book, *Amazing Me: It's Busy Being 3!* The story of an amazing 3-year old kangaroo holds the child's attention and inspires an interest in books and reading while educating the parent-reader about different milestones that are important signs of a child's development. *Amazing Me* also encourages the parent-reader to look for milestones in their own child, provides parents a tool to track their child's development, and encourages parents to talk with their child's doctor about their child's development. Books will be distributed free to low-income parents of 3-year-olds through the Reach Out and Read pediatric network and in partnership with the American Academy of Pediatrics/Bright Futures. [The book is also available on CDC's website.](#)



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- NCBDDD's data on the burden of autism and descriptive characteristics of children with the condition are used to inform the Interagency Autism Coordinating Committee (IACC) Strategic Plan for Autism Research. Working in collaboration with the IACC, our autism activities complement the goals and objectives of the plan.
- NCBDDD conducted a workshop in partnership with Autism Speaks to understand identification issues and risk factors influencing increases in autism. The workshop brought together scientists and stakeholders from the autism community to increase knowledge about autism prevalence, to learn from other conditions, and to share ideas on how to move forward to better understand autism trends. An executive summary and the complete workshop summary are available for download on our website.
- NCBDDD worked with partners from other federal agencies to establish, for the first time, a Healthy People 2020 goal focused on autism screening, diagnosis, and enrollment in services. These measurable goals are important because the Autism and Developmental Disabilities Monitoring (ADDM) data show that caregivers or service providers typically have concerns about a child's development before they are 2, but most children are still being diagnosed much later, after 4.
- NCBDDD, HRSA, and the Association of University Centers on Disability established the Act Early Ambassadors program to strengthen state-level efforts to improve early identification of autism and other developmental disabilities. This program has created a network of champions to expand the reach of the "Learn the Signs. Act Early." program. Ambassadors use and promote "Learn the Signs. Act Early." messages and materials and serve as liaisons to their Act Early state teams. Act Early Ambassadors were funded in ten states during 2011: Hawaii, Illinois, Massachusetts, Montana, North Carolina, New Mexico, Ohio, Rhode Island, Tennessee, and Wisconsin. Additional Act Early Ambassadors were selected in 2012.

Did you know?

- Early intervention (before school age) can have a significant impact on a child's ability to learn new skills as well as reduce the need for costly interventions over time.
- In the United States, about 1 in 110 children has autism and about 1 in 6 children aged 3–17 has a developmental disability.



'Learn the Signs. Act Early'.
Ambassadors, June 23, 2011.

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- The Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee that coordinates all efforts within the Department of Health and Human Services (HHS) related to autism. Through its inclusion of both Federal and public members, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum.
- Each year, the IACC develops a strategic plan for autism research that takes into account all that we've learned about autism in the previous years and keeps the federal response to autism focused and informed.

Looking to the future

- Our ADDM Network will continue to help us learn more about autism, including understanding which children are more likely to have autism diagnosis and at what age that diagnosis is likely to be made.
- NCBDDD will continue collaborations with HRSA to implement and evaluate the "Learn the Signs. Act Early." campaign through four state demonstration grants (Utah, Washington, Missouri, and Alaska). Results on the feasibility and impact of these efforts will be available in early 2013.
- In 2012, through SEED, NCBDDD will investigate maternal medication use, infections, and lifestyle factors and whether they interact with some children's genes to put them at greater risk for autism.
- With the current infrastructure in place, we are well positioned to expand our work in the area of cerebral palsy by:
 - Increasing the tracking sample size to allow better examination of the characteristics of children with cerebral palsy, including socioeconomic factors and specific subtypes.
 - Conducting population-based research to identify additional strategies to prevent cerebral palsy and to detect the relationships between risk factors and cerebral palsy.
- NCBDDD will continue partnerships with National Institutes of Health and Autism Speaks to investigate autism in Somali children compared to other populations located in Minneapolis. Results could provide a framework for future studies on the risk factors and causes of autism and may also provide data that can be used for advocacy and service planning.
- NCBDDD began working through a public/private partnership with Autism Speaks to evaluate the use of direct screening and assessment to enhance the completeness of autism estimates. Through this partnership, Autism Speaks is providing supplemental funding to add complementary screening and assessment to one of the ADDM sites.

Notable 2011 NCBDDD Scientific Publications

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Featured Videos

[Baby Steps: "Learn the Signs. Act Early."](#)

[Learn the Signs. Act Early. Three Mothers - Television PSA](#)

[The Autism Developmental Disabilities and Monitoring Network](#)

[What is Autism?](#)

[Importance of the ADDM Network](#)

[What is SEED?](#)

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Birth Defects

Preventing Major Birth Defects Associated with Maternal Risk Factors

What is the problem?

- Birth defects are structural changes in one or more parts of the body. They are present at birth. They can have a serious, negative effect on the health, development, or functional ability of the baby.
 - Congenital heart defects are conditions that are present at birth and can affect the structure of a baby's heart and the way it works. They can affect how blood flows through the heart and out to the rest of the body.
- About one in every 33 babies is born with a birth defect. Birth defects are a leading cause of infant death, accounting for more than 1 of every 5 infant deaths. In addition, babies born with birth defects have a greater chance of illness and long term disability than babies without birth defects.
- We do not know the risks to pregnant women and their babies for most of the medications available today. Only about 2% of the medications approved by the FDA from 2000 to 2010 have sufficient data on the risk when used during pregnancy. We need more information about the safety or risk of medications that are commonly used in pregnancy.



What do we know?

- Some birth defects can be prevented, and prevention begins with identifying causes and risk factors.
 - Taking certain medications just before or during pregnancy might cause serious birth defects, but the safety of many medications taken by pregnant women.
 - Smoking in the month before getting pregnant and throughout pregnancy increases the chance of premature birth, certain birth defects (such as cleft lip, cleft palate, or both), and infant death.
 - Women who are obese when they get pregnant have a higher risk of having a baby with serious birth defects of the brain and spine (neural tube defects) and some heart defects.
 - Poor control of diabetes in pregnant women increases the chance for birth defects, and might cause serious complications for the mother, too.

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- Alcohol-exposed pregnancy remains a leading preventable cause of birth defects and developmental disabilities.
- Taking 400 micrograms of folic acid every day, starting at least one month before getting pregnant can help prevent neural tube defects, like spina bifida.
- The causes of congenital heart defects are mostly unknown. Some babies have heart defects because of changes in their genes or chromosomes. Congenital heart defects also are thought to be caused by a combination of genetic and other risk factors, such as exposures to things in the environment, maternal nutrition, or maternal medication use.

Did you know?

Congenital heart defects are:

- The most common type of birth defect.
- A leading cause of infant death.
- Present among nearly 40,000 births in the U. S. each year.

What can we do?

- As medical care and treatment have advanced, infants with congenital heart defects are living longer, healthier lives. This progress presents new challenges to families and the health care system to meet the special health needs of these individuals. We can improve monitoring and tracking of congenital heart defects in children and adults to get better estimates of the number of people affected, types of health services needed, and costs of such services.

To improve knowledge about congenital heart defects, NCBDDD supports the Congenital Heart Public Health Consortium (CHPHC), a group of organizations uniting efforts to promote public health activities to prevent the occurrence of congenital heart defects and to enhance and prolong the lives of those with heart defects.

Accomplishments

- NCBDDD created a new initiative to improve the available information about the safety or risk of medication use in pregnancy—TR_{eating} for Two. As part of this initiative, we are working to partner with relevant federal and external agencies to develop a formal review process to evaluate the quality and strength of evidence for safety or risks associated with the most commonly used medications during pregnancy. Better information on the safety or risk of specific medications will allow women and their doctors to make informed decisions about treatment during pregnancy.
- NCBDDD launched two websites on CDC.gov—one on [Medications in Pregnancy](#) and one on [Congenital Heart Defects](#)—to inform women, their health care providers, and families about important issues to consider related to these topics. These new websites contain easy-to-read, research-based information. Specific topics featured on these websites include compilations of key publications as well as overviews of the work NCBDDD and partners are doing in these fields of research.
- In 2011, the American College of Obstetricians and Gynecologists' (ACOG) Committee on Obstetric Practice used data from the NCBDDD's National Birth Defects Prevention Study published in 2009 to inform their professional opinion on certain antibiotics, particularly sulfonamides and nitrofurantoin, and

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the risk of birth defects. This information will affect how women are treated for infections during pregnancy.

ACOG concluded the following:

“Prescribing sulfonamides or nitrofurantoin in the first trimester is still considered appropriate when no other suitable alternative antibiotics are available. Pregnant women should not be denied appropriate treatment for infections because untreated infections can commonly lead to serious maternal and fetal complications...It is reassuring that commonly used antibiotics, namely penicillins, erythromycin, cephalosporins, and a less commonly used group, the quinolones, were not associated with an increased risk of birth defects in the 2009 study.”

- NCBDDD and other Congenital Heart Public Health Consortium members participated in a briefing on Capitol Hill entitled “Congenital Heart Defects: A Lifelong Disease,” which was sponsored by the American Academy of Pediatrics. This briefing focused on understanding the public health impact of congenital heart defects across the lifespan and the next steps for congenital heart defects research, tracking, and prevention.

Looking to the future

- In the next year, NCBDDD will estimate the medical costs of selected birth defects from infancy through childhood.
- NCBDDD researchers will conduct a cost-effectiveness analysis of universal screening for critical congenital heart defects in newborns using pulse oximetry.
- We will continue to research the impact of birth defects, including short- and long-term outcomes for affected individuals.
- We will enhance our communications plan for disseminating risk information on the most commonly used medications during pregnancy, focusing on increased accessibility to reliable information for women of reproductive age and their health care providers.

Did you know?

- Most women (about 90%) take at least one medication during pregnancy and 70% take at least one *prescription* medication.
- Over the last 30 years, first trimester use of prescription medications has increased more than 60%.
- Before and during pregnancy, a woman should talk to her health care provider about any medications she is taking or planning to take, including prescription and over-the-counter medications and dietary or herbal supplements. Women should also talk to a doctor before stopping any medications that are needed to treat health conditions.
- We have identified some medications that might cause birth defects if a mother takes them during pregnancy. In 2011, our research found that treatment with prescription pain killer medications might increase the risk for certain birth defects. We will continue to work on identifying the medications most commonly used during pregnancy and determining the risks of using those medications during pregnancy.

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- As medical care and treatment have advanced, infants with congenital heart defects are living longer, healthier lives. This progress presents new challenges to families and the health care system to meet the special health needs of these individuals. We will improve monitoring and tracking of congenital heart defects in children and adults to get better estimates of the number of people affected, types of health services needed, and costs of such services.
- The Patient Protection and Affordable Care Act included language authorizing CDC to expand tracking activities to include all individuals living with a congenital heart defect. Congress has provided additional funding for CDC in Fiscal Year 12 to address these challenges.

Did you know?

- The hospital costs alone for individuals with congenital heart defects in the U.S. in 2004 were about \$1.4 billion. Severe congenital heart defects accounted for about \$511 million, or about 37%, of the hospital costs associated with congenital heart defects.

Notable 2011 NCBDDD Scientific Publications

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Fetal Alcohol Spectrum Disorders

Reducing Alcohol-Exposed Pregnancies

What is the problem?

- The term “fetal alcohol spectrum disorders” (FASDs) is used to describe the many problems associated with exposure to alcohol before birth. **FASDs are 100% preventable if a woman does not drink alcohol during pregnancy.**
- Drinking alcohol during pregnancy can cause a wide range of physical and mental birth defects. Alcohol in the mother's blood passes through the umbilical cord and placenta to the baby. Drinking alcohol during pregnancy can cause miscarriage, stillbirth, and a range of FASDs.



What do we know?

- There is no known safe amount of alcohol to drink while pregnant. There is also no safe time during pregnancy to drink and no safe kind of alcohol. CDC urges pregnant women not to drink alcohol any time during pregnancy.
- Women also should not drink alcohol if they are planning to become pregnant or are sexually active and do not use effective birth control. This is because a woman could become pregnant and not know for several weeks or more. In the U.S. half of all pregnancies are unplanned.
- FASDs are 100% preventable. If a woman doesn't drink alcohol while she is pregnant, her child cannot have an FASD.

Did you know?

- About 1 in 8 pregnant women in the U.S. reports drinking alcohol in the past 30 days.
- About 1 in 50 pregnant women reports binge drinking (having five or more drinks at one time) in the past 30 days.

What can we do?

- NCBDDD continues to work with partners and health care professionals to promote awareness about this issue.
- The majority of non-pregnant women of reproductive age report alcohol use, with 12% reporting binge drinking (having five or more drinks at one time) in the past month. Since half of pregnancies in the U.S. are unplanned and some women continue to drink alcohol during pregnancy, it is important to address risky drinking among all women of reproductive age.

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- NCBDDD published *CHOICES: A Program for Women About Choosing Healthy Behaviors*, designed for use by professionals who will be conducting the CHOICES program and for trainers providing instruction on how to conduct the intervention. NCBDDD's CHOICES program is an intervention to prevent alcohol-exposed pregnancy among non-pregnant women of reproductive age by addressing risky drinking and ineffective contraception. The CHOICES materials are available for order at www.cdc.gov/fasd. NCBDDD continues to support the implementation of CHOICES in various settings, including clinics for sexually transmitted diseases and family planning, community health centers, and American Indian communities.

Accomplishments

- NCBDDD collaborated with the National Center for Health Statistics to include four additional alcohol questions on the National Survey on Family Growth in survey years 2011-2013 in order to obtain more accurate estimates of alcohol-exposed pregnancy risk among women of reproductive age. Data collection using the new alcohol questions began in September 2011.
- NCBDDD worked with the American College of Obstetricians and Gynecologists (ACOG) to revise previously developed educational materials for women's health care providers regarding alcohol use and reproductive health. Revised materials include a smart phone/hand-held application to screen women for at-risk drinking and a corresponding pocket card for providers.



Looking to the future

- In 2012, NCBDDD will work to advance implementation and adoption of alcohol screening and brief intervention (SBI) by:
 - Supporting the FASD Regional Training Centers in the development of plans to identify, recruit, and work with primary care systems in their regions to implement alcohol SBI.
 - Coordinating with the National Center on Chronic Disease Prevention and Health Promotion to develop, test, and implement a module to assess if people are being asked by their health care provider about their alcohol use and receiving feedback on this behavior as needed.
 - Partnering with ACOG and the National Organization on Fetal Alcohol Syndrome to hold a stakeholders meeting with employers, health plans and other key partners better understand how to increase routine use of alcohol screening and brief intervention in primary care settings.
 - Collaborating with ACOG to develop additional resources for women's health care providers and improve efforts to promote alcohol screening and brief intervention.

Notable 2011 NCBDDD Scientific Publications

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Folic Acid

Reducing Folic Acid-Preventable Neural Tube Defects

What Is the Problem?

- Each year in the United States, there are 3,000 pregnancies affected by spina bifida or anencephaly, which are neural tube defects (NTDs) caused by the incomplete closing of the spine and skull.
- In the United States, Hispanic women continue to have higher rates of neural tube defects than non-Hispanic white women, and rates of spina bifida are higher among Hispanic women whose primary language is Spanish.
- Globally, there are more than 300,000 babies born with neural tube defects each year.



What Do We Know?

- If a woman has enough folic acid in her body *before and during pregnancy*, it can help prevent major birth defects of the baby's brain and spine. Women who are capable of becoming pregnant need 400 micrograms (mcg) of folic acid every day.
- Folic acid is important because it can help prevent major birth defects of the baby's brain and spine (anencephaly and spina bifida). Spina bifida is a condition that affects the spine and is usually apparent at birth. Anencephaly is a serious birth defect in which a baby is born without parts of the brain and skull. Unfortunately, almost all babies born with anencephaly will die shortly after birth. Both spina bifida and anencephaly are neural tube defects (NTDs).
- For folic acid to help prevent some major birth defects, a woman needs to start taking it at least one month before she becomes pregnant and continue taking it while she is pregnant.
- By 1998, folic acid fortification of cereal grains labeled as enriched was fully implemented in the U.S., preventing an estimated 1,000 neural tube defects each year.
- Folic acid programs have been shown to be cost-effective in countries with varying levels of economic development. In the U.S., fortification of cereal grain products labeled as enriched

Did you know?

In the U.S. an estimated 1,000 more babies a year are born healthier since fortification.

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has resulted in \$4.5 billion in direct costs saved over the past decade, and for each dollar invested in fortification, more than \$45 in medical costs have been saved.

What can we do?

- Staple foods in Hispanic communities, such as tortillas and other products made from corn masa flour, are not included in the current FDA fortification regulation. Folic acid fortification of corn masa flour could selectively reach Mexican American women and have little impact among other race/ethnicities. NCBDDD is working to reduce ethnic disparities in the occurrence of folic acid-preventable neural tube defects, in part, by working with others to allow folic acid to be added to corn masa flour.
- Building on the success of preventing neural tube defects through folic acid fortification in the U.S., NCBDDD is working to strengthen and expand the reach of global folic acid fortification to prevent infant death and childhood disability.

Accomplishments

- NCBDDD identified countries with the high burden of neural tube defects in order to prioritize a strategy to eliminate folic acid-preventable neural tube defects globally.
- As part of its Global Initiative to Eliminate Folic Acid-Preventable Neural Tube Defects, NCBDDD began collaborations with the World Health Organization Regional Office of South-East Asia (WHO-SEARO) to develop a South-East Asia regional strategy for prevention of birth defects to reduce infant mortality. This strategy will help member countries develop and strengthen national birth defects prevention efforts.
- NCBDDD contributed toward efforts to reduce racial/ethnic disparities in NTD rates in the U.S. by providing technical assistance in the development of a food additive petition to fortify corn masa flour (CMF) with folic acid to the CMF Partner Group. The CMF Partner Group includes March of Dimes, Spina Bifida Association, GRUMA Corporation, American Academy of Pediatrics, Brigham Young University, Latin America/DSM Nutritional Products, University of Georgia, and the Council of La Raza. NCBDDD provided assistance in three major areas: safety, intake, and potential public health impact of CMF fortification. The CMF Partner Group plans to submit the petition to the U.S. Food and Drug Administration in 2012.



Global Initiative to Eliminate Folic Acid-Preventable Neural Tube Defects Expert Group Meeting



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Looking to the future

- NCBDDD will continue to strengthen in-country and regional capacity for tracking birth defects in the South-East Asia region. Plans include:
 - Developing a manual to track birth defects including NTDs and other external birth defects. The manual can be used by low – and middle-income countries for the development and oversight of a country-based birth defects tracking systems.
 - Conducting training on tracking birth defects in South-East Asia in April 2012 with WHO-SEARO.
 - Collaborating, with WHO-SEARO to convene a National Program Managers meeting with Ministries of Health in March 2012 in Thailand to finalize and approve a regional strategic framework for birth defects prevention.
 - Collaborating with WHO-Headquarters to convene a technical expert meeting in Atlanta, Georgia in 2012 to develop a framework for determining an optimal blood folate concentration for NTD prevention.
- Strengthening capacity in the field to accurately monitor blood folate concentrations is an important element of global fortification efforts to prevent neural tube defects. In 2012, NCBDDD will provide funding to support the development of easier, more sensitive, and inexpensive methods to better monitor blood folate concentrations. New field laboratory methods can ultimately be used in all regions where access to laboratory support is limited, for example in more isolated areas of the South-East Asia Region.

Notable 2011 NCBDDD Scientific Publications

- Hamner HC, Cogswell ME, Johnson MA. (2011). **Acculturation factors are associated with folate intakes among Mexican American women.** J Nutr, 141(10):1889-1897.
- Yeung LF, Cogswell ME, Carriquiry AL, Bailey LB, Pfeiffer CM, Berry RJ. (2011). **Contributions of enriched cereal-grain products, ready-to-eat cereals, and supplements to folic acid and vitamin B-12 usual intake and folate and vitamin B-12 status in US children: National Health and Nutrition Examination Survey, 2003-2006.** Am J Clin Nutr, 93(1):172-185.

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Newborn Screening

Enhancing the Quality and Usefulness of Newborn Screening Data and Programs

What is the problem?

- In September 2011, HHS Secretary Sebelius approved adding critical congenital heart defects to the Recommended Uniform Screening Panel. Congenital heart defects (CHDs) account for 24% of infant deaths due to birth defects. In the United States, about 5,000 (or 12 per 10,000) babies born every year have critical congenital heart defects (CCHDs). Babies with a CCHD are at significant risk of disability or death if the condition is not diagnosed soon after birth. CCHDs can be detected in some babies using pulse oximetry, which is a test to determine the amount of oxygen in the blood.
- Long-term follow-up of children with confirmed newborn screening conditions ensures that these children receive the full benefits of early identification through newborn screening. Tracking these children is also important for public health. Efforts to systematically evaluate health outcomes, beyond long-term survival, with a few exceptions, are just beginning.



What do we know?

- In order to help states and health care providers as they implement the screening, it was recommended that the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children provide information to address the following issues:
 - What will be the impact on state health departments, including staffing needs, to implement this program? What are the roles of the state health departments?
 - What capability is present to ensure that all babies are screened and their results are communicated to providers, including assuring that those not screened at birth receive a screen?
- Technological improvements and partner collaboration have led to the expansion and increased uniformity of newborn screening as well as enhanced laboratory and data systems that provide better surveillance, tracking, and research.

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- Each year, more than 4 million newborns in the U. S. are screened for hearing loss and certain genetic, endocrine, and metabolic disorders. Through early identification and treatment, newborn screening provides an opportunity for significant reductions in morbidity and mortality while reducing health care costs associated with treatment of lifelong debilitating conditions. Newborn screening not only saves lives, it can make lives healthier.

What can we do?

- As screening for critical congenital heart defects (CCHDs) is implemented throughout the U.S., CDC will play an important role in the surveillance and tracking of babies with a CCHD identified through CCHD screening using pulse oximetry. Evaluating the effectiveness of screening for CCHD will provide states and health care providers with data to better understand the potential impact of implementation and to help make decisions about adding this condition to their existing newborn screening program.
- CDC provides data and expertise toward development of state and national policies on newborn screening (NBS). This screening data are used to prevent or reduce the negative consequences of birth defects, developmental disabilities, and pediatric genetic conditions. To improve long-term follow-up, CDC develops methodology and tools to improve data collection processes and data quality for long-term follow-up after NBS.
- NCBDDD participated in the establishment and management of the Interagency Coordinating Committee (ICC) on Newborn and Child Screening outlined in the Newborn Screening Saves Lives Act of 2008. The ICC provides input from federal agencies to the Secretary of Health and Human Services regarding recommendations from the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children.

Did you know?

- A 2011 MMWR article included newborn screening as one of the Ten Significant Public Health Achievements — United States, 2001-2010, citing the improvements in technology and endorsement of a uniform newborn screening panel as leading to earlier life-saving treatment and intervention for newborns.
- The newborn screening system is comprehensive, including not only screening and diagnosis, but also long-term follow-up care through the health system. Long-term follow-up of affected children identified through newborn screening means that these children and their families will have the best outcomes.

Accomplishments

- NCBDDD showed that rates reported for certain newborn screening conditions have not changed substantially despite changes in laboratory technology. State newborn screening laboratories have used different methods and criteria for newborn dried blood spot screening. To assure that changes in protocol were not affecting the number of babies identified,

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NCBDDD used data from the National Newborn Screening and Genetics Resource Center from 1991-2000 for congenital adrenal hyperplasia, phenylketonuria, and the sickle hemoglobinopathies. This study showed that there were no substantial changes in the birth prevalence rates of these conditions over the study period, which provided reassurance that changes in screening technologies over time did not negatively affect detection rates of diagnosed babies.

- NCBDDD has provided technical expertise and funded cooperative agreements with California, Iowa, New York, and Utah state health departments to incorporate newborn screening long-term follow-up into existing birth defects or newborn screening surveillance programs as part of a 3-year pilot project that began in September 2008. NCBDDD facilitates compilation and analysis of data from young children identified by newborn screening and disseminates methodology and results from multistate cooperative agreements to serve as a model for other state programs to conduct similar activities. Results will be available this year.
- NCBDDD collaborated with HRSA and the American Academy of Pediatrics (AAP) on a quality improvement project evaluating clinical support tools for newborn screening for use in the primary care setting. NCBDDD served on the Expert Group for the AAP Newborn Screen Positive Infant ACTION Project, in partnership with the American College of Medical Genetics, HRSA, and the AAP Quality Improvement Innovation Network. A summary of the project will be available this year. The Newborn Screen Positive Infant ACTION sheets were developed to guide primary care providers through short-term follow-up for newborns detected through public health screening for congenital conditions.
- NCBDDD published important considerations in the use of race and ethnicity to assess risk for certain blood disorders (hemoglobinopathies) in the newborn and prenatal settings. Certain blood disorders (hemoglobinopathies) differ among populations depending on their continent of origin, which is often thought of as race and ethnicity. Public health programs have debated the ethical and practical implications of targeted screening based on race/ethnicity versus screening everyone.
- NCBDDD worked with other federal agencies and partners to define and publish key questions that need to be addressed to achieve the long term follow-up goals of newborn screening, including care coordination, evidence-based treatment, continuous quality improvement, and new knowledge discovery.

Looking to the future

- NCBDDD has been tasked by the HHS Secretary to evaluate state surveillance and tracking systems to monitor the effectiveness of critical congenital heart defect (CCHD) newborn screening programs.

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- NCBDDD is assessing states' need for assistance with CCHD screening using pulse oximetry.
- NCBDDD will continue to collaborate with New Jersey, the first state in the U.S. with legislatively mandated screening.
- NCBDDD is working with New Jersey in early 2012 to assess surveillance and tracking of CCHD screening and to conduct a cost-effectiveness analysis of CCHD screening for the state.
- NCBDDD is surveying birth defects surveillance programs to assess their potential roles with CCHD screening. The results of this survey will be published in 2012.
- NCBDDD has been tasked by the HHS Secretary to conduct a cost-effectiveness analysis of newborn screening, for the early identification of CCHDs.
 - NCBDDD is developing a cost-effectiveness model to identify the impact and cost of universal CCHD screening, including the average and incremental cost of CCHD screening per newborn, the number of infants with critical congenital heart defects identified through CCHD screening, the number of infant deaths avoided due to CCHD screening and the associated cost, and the number of life years gained due to CCHD screening and the associated cost.
- Subject matter experts from CDC are collaborating with the Association of Public Health Laboratories and members of the Subcommittee on Laboratory Standards and Procedures from the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children to evaluate the utility of routine second testing in newborn screening for the endocrinopathies (congenital hypothyroidism (CH) and congenital adrenal hyperplasia (CAH)).
- NCBDDD is working with the American Academy of Pediatrics to develop a training module on newborn screening to educate pediatricians about developing quality measures to ensure screening results are received and communicated to families. It will also provide approaches to working with specialty providers to coordinate care for children who have positive screening results. This effort could lead to improved follow-up care for children affected by newborn screening conditions.

Notable 2011 NCBDDD Scientific Publications

- Hinton CF, Feuchtbaum L, Kus CA, Kemper AR, Berry SA, Levy-Fisch J, Luedtke J, Kaye C, Boyle CA. **What questions should newborn screening long-term follow-up be able to answer?: A statement of the United States Secretary for Health and Human Services' Advisory Committee on Heritable Disorders in Newborns and Children.** Genetics in Medicine; 2011; 13:861-865.

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- Hertzberg VS, Hinton CF, Therrell BF, Shapira SK. **Birth prevalence rates of newborn screening disorders in relation to screening practices in the United States.** Journal of Pediatrics; 2011; 159:555-560.
- Fisk Green R, Ehrhardt J, Ruttenber M, Olney RS. **Use of family history information for neural tube defect prevention: integration into state-based recurrence prevention programs.** American Journal of Health Education; 2011; 42: 296-308.
- Crider KS, Zhu J-H, Hao L, Yang Q-H, Gindler J, Maneval DR, Yang TP, Quinlivan EP, Li Z, Bailey LB, Berry RJ. **Methylenetetrahydrofolate reductase 677C→T genotype is associated with folate and homocysteine concentration in a large population-based double-blind trial of folic acid supplementation.** American Journal of Clinical Nutrition; 2011; 93:1365-1372.
- Hinton CF, Grant A, Grosse SD. **Ethical implications and practical considerations of ethnically-targeted screening for genetic disorders: the case of hemoglobinopathy screening.** Ethnicity and Health; 2011; 16:377-388.

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Blood Disorders

Protecting and Improving the Health of People with Blood Disorders

NCBDDD works to prevent and reduce complications experienced by people with certain blood disorders. Blood disorders affect millions of people each year in the United States, cutting across the boundaries of age, race, sex, and socioeconomic status. Men, women, and children of all backgrounds live with the complications associated with these conditions, many of which are painful and potentially life threatening. While millions of Americans carry genes for bleeding and clotting disorders, and hemoglobinopathies (a genetic defect), most will lead normal lives without experiencing any harm.



Our focus includes:

- [Preventing clotting disorders](#)
Venous thromboembolism (VTE) - a condition where a blood clot in one of the large veins of the lower leg, thigh or pelvis, known as a deep vein thrombosis (DVT), breaks up and moves to the lungs causing a pulmonary embolism (PE).
- [Sickle Cell and Thalassemia](#)
Preventing and controlling complications resulting from hemoglobinopathies
- [Hemophilia and Von Willebrand Disease](#)
Preventing and controlling complications resulting from bleeding disorders

Venous Thromboembolism

NCBDDD's work focuses on nonmalignant blood disorders such as deep vein thrombosis, or DVT, and pulmonary embolism, or PE. Together they are known as venous thromboembolism or VTE. It is estimated that 300,000-600,000 or more cases of VTE occur in the United States each year with a high case fatality rate. There are prevention opportunities that are not being fully taken advantage, particularly those associated with hospitalization and surgery.

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Sickle Cell

Another important public health issue is sickle cell disease (SCD), a hemoglobinopathy. Hemoglobinopathies are a group of blood disorders and diseases that affect red blood cells. These inherited disorders include both SCD and thalassemia and can cause lifelong disabilities and reduce life expectancy. People who have SCD have a 20-30 year lower life expectancy than people without SCD. This gap could be significantly diminished if there was continuity of care for these individuals over time.

Hemophilia

Bleeding disorders such as hemophilia can cause life and limb threatening bleeding. In addition, 15-20% of people with hemophilia develop an inhibitor (an antibody that prevents the action of clotting factor used to treat bleeding). Having an inhibitor increases hospitalization and the risk of an intracranial hemorrhage, compromises physical functioning, further limits joint mobility, and substantially increases the cost of care.

NCBDDD's comprehensive public health approach to blood disorders includes data collection, research to identify preventable or modifiable risk factors, and activities to develop, evaluate, and ensure widespread adoption of effective prevention strategies.



[View "Division of Blood Disorders: Building a Better Tomorrow" Video](#)

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Preventing Clotting Disorders

Venous Thromboembolism (VTE)

What is the problem?

- Venous Thromboembolism (VTE) is an underdiagnosed, serious, preventable medical condition.
- Approximately 100,000 people die each year from VTE.
- There are evidence-based clinical guidelines for preventing hospital-associated VTE; however, hospitals and practitioners are not using or fully implementing the guidelines.



What do we know?

- Many of the risk factors for VTE are well described and include: recent hospitalization, cancer, immobility, pregnancy, obesity, history of an inherited clotting disorder, and older age (over age 60).
- An estimated one-third to one-half of VTE events occur without any known risk factors.
- During pregnancy, a woman's risk of blood clots increases about four to five fold because of the extra clotting factors present which protect them at the time of childbirth.

What can we do?

- We are focusing on helping hospitals to follow recommended protocols that will reduce preventable conditions like VTE.
- We are working with the U.S. Department of Health and Human Services to reduce the incidence of hospital-associated conditions like VTE through the Partnership for Patients: Better Care, Lower Costs initiative. The initiative brings together, federal, state and local agencies, private sector businesses, hospitals and others to make hospital care safer.

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- We are developing a VTE event-reporting module for the Patient Safety Component of the National Healthcare Safety Network (NHSN). The reporting system will quantify the burden of VTE in hospital patients and evaluate and translate evidence of effective interventions. CDC's NHSN is a voluntary hospital reporting system for preventable hospital-associated conditions. Healthcare facilities in all 50 states report to NHSN and more than 4400 facilities are enrolled nationwide.

Accomplishments

- The *"This is Serious"* campaign, developed in collaboration with the Venous Disease Foundation was the recipient of a Gold Aster Award (patient education category), one of the largest national competitions for outstanding excellence in healthcare advertising. The campaign encourages women to be alert to the symptoms of DVT. The first module targeting pregnant and postpartum women has been implemented. A new module is beginning development and will focus on the risk of VTE in surgery and trauma.
- Convened an expert panel meeting on the prevention of hospital-associated VTE to develop recommendations to improve VTE prophylaxis (measures to prevent a disease or condition), such as the use of blood thinners and compression stockings, in hospitalized patients.
- Provided \$875,000 to five thrombosis and hemostasis centers, the Thrombosis and Hemostasis Research and Prevention Network, to conduct research that will help identify risk factors for VTE and improve early diagnosis and treatment.
- Funded the National Blood Clot Alliance to conduct patient education forums on VTE through its *"Stop the Clot"* campaign.
- Funded research that will analyze data on surgical patients seen at Veterans Administration medical centers throughout the United States to determine patterns of VTE and VTE prophylaxis.

Did you know?

About 30-50% of VTEs occur among current patients or patients recently discharged from acute care hospitals, 20% are associated with cancer, and another 10% among residents of long-term-care facilities.

Caught early, DVT can be safely treated by a health care provider. Untreated it can be life-threatening.

Looking to the future

- Advance the prevention of clotting disorders.
- Complete development and begin testing a VTE event reporting module for the Patient Safety Component of the National Healthcare Safety Network.

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- Provide funding for two sites to conduct population-based tracking to identify the majority of VTE diagnoses that occur in outpatient settings, including people with recent hospital discharges.
- Publish public health recommendations in CDC's *MMWR* Recommendations and Report for decreasing the incidence of hospital-associated VTE.

Notable 2011 NCBDDD Scientific Publications

- Beckman MG, Grosse SD, Kenney KM, Grant AM, Atrash HK. **Developing surveillance activities for deep vein thrombosis and pulmonary embolism.** American Journal of Preventive Medicine 2011;41(6S4):S428-34.
- Boulet SL, Amendah D, Grosse SD, Hooper WC. **Health care expenditures associated with venous thromboembolism among children.** Thrombosis Research. Published online, August 25, 2011.



Featured Video

[View "A Look at Deep Vein Thrombosis and Pulmonary Embolism" Video>>](#)

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Sickle Cell Disease and Thalassemia

Preventing and Controlling Complications from Hemoglobinopathies

What is the problem?

- People with sickle cell disease (SCD) have a 20-30 year lower life expectancy than people without SCD.
- People with SCD, especially infants and children, are at risk for harmful infections. Pneumonia is a leading cause of death in infants and young children with SCD.
- An estimated 90% of people with SCD are unable to attain the resources they need for good management of their disease.
- Proven therapies are not being fully utilized. It is estimated that 30% or less of eligible patients are treated with hydroxyurea, a disease-modifying therapy for SCD.
- Because of the need for frequent blood transfusions, people with thalassemia are at increased risk for exposure to transfusion-related infections.
- Because there is no natural way for the body to eliminate iron, the iron in the transfused blood cells used to treat people with thalassemia can build up - iron overload - and become toxic to tissues and organs, particularly the liver and heart.



What do we know?

- Sickle cell disease (SCD) is one of the most common inherited blood disorders in the United States, with an estimated 100,000 Americans living with SCD.
- SCD occurs when a person inherits an abnormal gene from both parents. If both parents carry the sickle cell gene, there is a 25 percent chance that their baby will be born with the disease.
- It is estimated that 3 million people in the United States carry one sickle cell gene, that is, have sickle cell trait (SCT).
- SCD is more common in people of African, Southeast Asian, and Mediterranean descent.

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- There are several types of thalassemia. An estimated 1,000 people have Cooley's anemia (the most severe form of thalassemia) in the United States, and an unknown number are carriers – people who have the genetic trait and can pass it on to their children.
- Thalassemia is most common among people of Mediterranean descent, such as Italians and Greeks, and is also found among people from the Arabian Peninsula, Iran, Africa, Southeast Asia, and Southern China.

Did you know?

- Fewer than 10% of Americans with SCD have access to treatment centers that specialize in management of this disorder.
- Children with SCD can, and should, participate in physical activity to help stay healthy. However, it's important that they don't overdo it, rest when tired, and drink plenty of water, as is true for all children – those with and without SCD.
- Hydroxyurea has been reported to reduce pain crises, strokes, disability, and death in people with SCD.
- Some people with SCT have been shown to be more likely than those without SCT to experience heat stroke and muscle breakdown when doing intense exercise, such as competitive sports or military training under unfavorable temperatures (very high or low) or conditions. Studies have shown that the chance of this problem can be reduced by avoiding dehydration and getting too hot during training.
- Most patients with Cooley's Anemia, the most severe form of thalassemia, receive red blood cell transfusions every two to three weeks, amounting to as much as 52 pints of blood a year.

What can we do?

- Increase public awareness of risks for those with SCT and their children, and help with health-related decisions.
- Increase general awareness about SCD for the public and health care providers.
- Increase patients' and providers' awareness and knowledge about and use of the preventative measures proven to reduce secondary complications due to SCD such as vaccinations, early and continuous screening, and disease modifying therapies such as hydroxyurea.
- Increase efforts to improve SCD and thalassemia-related healthcare, education, and systems for delivering care through policy development, community engagement and partnerships.

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Accomplishments

- Co-hosted with the Sickle Cell Disease Association of America, “World Sickle Cell Awareness Day-Educate and Unite.” The event highlighted the need to increase awareness of the global impact of SCD and the importance of uniting global support for promoting and improving the health of persons with SCD through “increasing global action to reduce child mortality in SCD.”
- Launched “Living Well with Sickle Cell Disease-a Self-Care Tool Kit” to help people living with SCD manage their health and keep track of important information regarding medical care and treatment. Included in the toolkit are tracking sheets for vaccinations, immunizations, and hospitalizations and health provider information.
- Began a public health webinar series on hemoglobinopathies (SCD and thalassemia) to offer a learning collaborative platform for providers, consumers, educators, and scientists. Presenters are experts from a variety of disciplines, including the social sciences, clinical medicine, public health and community-based organizations.
- Convened the “International Public Health Learning Collaborative on Hemoglobinopathies” for countries, states, organizations, and others interested in learning more about public health tracking for SCD and thalassemia.
- In partnership with the Cooley’s Anemia Foundation, conducted five town hall meetings with patients with thalassemia to better understand the patient’s perspective on the challenges to fully adhering to prescribed treatments for thalassemia.
- Completed the first-ever environmental scan on educational materials for people with thalassemia which will help expand public access to an up-to-date and relevant collection of information resources on thalassemia.
- Provided input to a committee of thalassemia doctors and representatives from the Cooley’s Anemia Foundation, and the American Academy of Pediatrics on its proposal to expand the International Classification of Diseases (ICD) codes for thalassemia from one to six allowing for a more accurate diagnosis for thalassemia patients and enhance public health tracking activities. The proposal was accepted by the U.S. governmental agencies responsible (National Center on Health Statistics and the Centers for Medicare and Medicaid Services) for overseeing all changes and modifications and became effective October 1, 2011.

Looking to the future

- Increase the focus on preventing and controlling complications resulting from hemoglobinopathies.
- Publish reports that will track incidence and demographic characteristics, mortality rates, and health care utilization of people with SCD.

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- Fund 1-2 state health departments to establish a population-based tracking system for pediatric and non-pediatric populations with SCD to identify those receiving disease-modifying therapies, such as hydroxyurea, and SCD related secondary complications.
- Support the US Department Health and Human Services initiative to increase access and improve care of people with SCD by collecting information and conducting research to develop and disseminate evidence-based guidelines that will prevent and decrease complications associated with SCD.
- Partner with the American Society of Hematology to develop and launch a Sickle Cell Trait Education, Information and Resource Tool Kit that will provide general information about SCT (What is SCT, who's at risk) and information and resources concerning family planning, screening, genetic counseling, potential complications, prevention and management of complications, and psychosocial considerations. Information will be tailored to meet the education, information and resource needs of parents, children/adolescents/adults, health care providers, school coaches, teachers and administrators, athletes, state health departments, and US community advocates and health educators.
- Work with the Cooley's Anemia Foundation to develop a patient guide to living with thalassemia, a thalassemia toolkit for use in schools, and an emergency preparedness checklist specially designed for the thalassemia population.

Stories

Phyllis Zachery-Thomas

Phyllis Zachery-Thomas is 47 years old and was diagnosed with sickle cell disease at the age of six months old. She is a wife, mother, grandmother, and champion for the sickle cell community. She started the SCD Soldier Network, a non-profit organization [scdsoldiernetwork.com] whose mission is to support and mobilize the sickle cell community. Phyllis shared the following story with us:

“Sickle cell disease is unpredictable and you don’t know when it will attack. Although people with sickle cell disease are living longer, it is a battle to continue living. The disease has waged war against us. If you aren’t going to a specialty care system, you will likely find medical personnel who aren’t trained to treat sickle cell disease. I’ve had to educate my doctors. It took a long time for me to manage it. I’m someone who has gone through every phase of sickle cell and I’ve seen its many faces.”



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Stories like Phyllis' underscore the importance to improve access, quality of care, and length and quality of life for people living with SCD.

Terese Finitzo

"My name is Terese Finitzo. This is a picture of me and my two sisters, with me on the far right. I'm ten years old in this picture; long after I had experienced the shattered glass-like pain in my arms and legs that I eventually learned came from sickle cell disease. (People who have this form of SCD inherit a sickle cell gene ("S") from one parent and from the other parent a gene for an abnormal hemoglobin called "C." This is usually a milder form of SCD.)



In the early years, the pain came mostly in the summer after swimming, though our family doctors told my parents there was nothing wrong with me; that I was spoiled. I was diagnosed with sickle cell disease when I was 12, but we were not told of the diagnosis. Indeed, many years later at age 24, I asked, what was the explanation for why I had become so ill on my first ski vacation? The original pediatric hematologist was still in practice and he said, 'Oh yes, you're the young redheaded child with Sickle C disease.'" The family doctors decided not to tell my Italian immigrant father and my Scotch Irish mother living on the South side of Chicago in the late 1950's that their daughter had a disease found "only" in those of African ancestry.

We eventually learned my Mediterranean father carried the C trait and my mother, whose family had been in the US for nearly 200 years carried the S trait. They met during the war in California, and moved back to Chicago where they had three daughters. I am the only one with the disease, though my two sisters lived with the pain of seeing me suffer then and still do today when they see me fall ill.

It is time that there is universal newborn screening for sickle and other hemoglobinopathies, and also for identifying individuals with trait."

Terese's story is a poignant reminder of the many faces of SCD and that there is still a lot of work to be done to educate the public and health care providers about SCD.

Notable 2011 NCBDDD Scientific Publications

- Grant AM, Parker CS, Jordan L, Hulihan M, Creary M, Lloyd-Puryear MA, Goldsmith JC, Atrash H. **Public health implications of sickle cell trait: A Report of the Centers for Disease Control and Prevention Meeting.** American Journal of Preventive Medicine 2011;41(6S4):S435-39.

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- Yusuf H, Lloyd-Puryear MA, Grant AM, Parker CS, Creary MC, Atrash HK. **Sickle cell disease: the need for a public health agenda.** American Journal of Preventive Medicine 2011;41(6S4):S376-83.
- Hinton CF, Grant AM, Grosse SD. **The ethical and practical implications of ethnically-targeted screening for genetic disorders: The case of hemoglobinopathy screening.** Ethnicity & Health. 2011;16(4-5): 377–388.

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Hemophilia and Von Willebrand Disease

Preventing and Controlling Complications Resulting From Bleeding Disorders

What is the problem?

- Bleeding disorders such as hemophilia, and von Willebrand Disease (VWD) can lead to spontaneous internal bleeding and bleeding following injuries and surgery. Bleeding into joints can cause crippling and chronic pain if not appropriately treated with replacement blood products to facilitate blood clot formation.
- About 15% to 20% of people with hemophilia develop an inhibitor that results in the body's resistance to treatment products used to treat their bleeding disorder. Treatment for patients with inhibitors is extremely difficult and the cost of care can skyrocket. Patients with inhibitors often experience increased joint disease and other complications from bleeding that result in a reduced quality of life.
- VWD is an under-diagnosed blood disorder in which the blood does not clot properly.
- Current data estimate that as many as 1 percent of women in the United States may have a bleeding disorder, and many are unaware of their condition.
- Women with heavy menstrual bleeding (menorrhagia) and/or VWD are at increased risk for anemia, pain during menstruation, hospitalizations, blood transfusions, limitations in daily activities, time lost from work or school, and a reduced quality of life.



What do we know?

- Hemophilia affects 1 in 5,000 male births. About 400 babies are born with hemophilia each year.
- Currently, about 20,000 males in the United States have hemophilia.
- About half of those affected by hemophilia have the severe form. Hemophilia affects people from all racial and ethnic groups.
- People with hemophilia who develop an inhibitor are twice as likely to be hospitalized for a bleeding complication.

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- VWD is the most common bleeding disorder, found in up to 1% of the U.S. population. This means that 1.4 million (or about 1 in every 100) people in the United States have the disease. Although VWD occurs among men and women equally, women are more likely to notice the symptoms because of heavy or abnormal bleeding during their menstrual periods and after childbirth.
- Although there is no cure for VWD, treatment can control symptoms and help people avoid problems.
- Most people who have VWD are born with it. It is almost always inherited, passed down from either the mother or the father, or both, to the child.

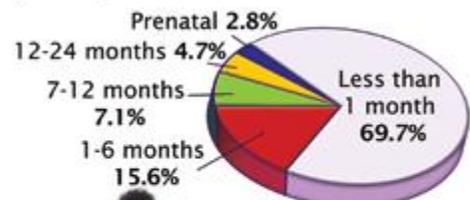
What can we do?

- Continue to support education and outreach activities to prevent secondary conditions in people with bleeding disorders by improving their access to public health programs and implementing effective health promotion and wellness programs.
- Enhance laboratory research capacity in the community by providing collaborating investigators with services such as subject matter expertise, technical support, and laboratory analysis.
- Increase provider and patient education and awareness of the clinical benefit of routine inhibitor screening.
- Increase public health research of bleeding disorders outcomes and risks for complications such as joint disease, and inhibitor development to improve care and prevention of morbidity.
- Begin tracking for inhibitor development and associated morbidity.
- Continue tracking patients with bleeding disorders to better understand bleeding disorders and their complications.
- Assess women's awareness and knowledge of bleeding disorders and assess OB/GYN knowledge and practice related to bleeding disorders.

Accomplishments

- Created and made available for public use on CDC's website, [CHAMP \(CDC Hemophilia A Mutation Project\)](#) a database of more than 2000 unique hemophilia mutations reported worldwide. Knowing the mutation a person with hemophilia has is important for genetic testing of family members and may help in predicting how likely a person is to develop an inhibitor and, in the future, predict what treatments might work better for different mutations.
- Presented information on women and bleeding disorders such as VWD as part of CDC's Expert Video Commentary Series.

Age of Hemophilia Diagnosis
Among Children Less than 2 Years of Age



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- Developed “[Introduction to Hemophilia Care](#)” an online course that promotes a family-centered approach in the diagnosis, assessment and management of hemophilia and addresses potential complications from hemophilia and its treatment. The course is available on our website, is free of charge and provides NCE/CEU credit.
- Developed a dataset of normal joint range of motion (ROM) measurements. The dataset can be used by researchers in comparison studies and to study patterns of joint ROM changes in patient populations with chronic joint disease due to other disorders such as rheumatoid arthritis.
- Working with the Hemophilia Federation of America, highlighting physical activities and dietary meal plans based on age, weight, and medical complications secondary to hemophilia which are components of the [FitFactor: Strength, Flexibility, and Wellness program](#).
- Working with the National Hemophilia Foundation, launched the [Steps for Living Website](#), a one-stop resource for information on bleeding disorders for kids, adolescents, parents and health educators to promote healthy living for the whole family.
- Completed formative research, product development, and message testing to identify materials and messages that will help children and adolescents with hemophilia maintain or improve their health as they become more independent and move toward adulthood. This research resulted in the production of two videos for children with hemophilia focused on disclosure and safe sports.

Did you know?

- For the one-third of babies born with hemophilia in families with no known history of hemophilia, the diagnosis is made when an unusual bleeding event occurs. The most common sites of bleeding are the circumcision site and the head.
- Over 27,000 individuals have participated in our Universal Data Collection (UDC) system, providing information and blood specimens that are used to measure rates of complications of bleeding disorders, identify issues that require further research, and investigate new blood-borne threats.
- Youth with hemophilia are just as likely as youth among the general population to be overweight. However, they are more likely to have decreased joint mobility than those who are not.

Looking to the future

- Increase the focus on preventing and controlling complications resulting from bleeding disorders.
- Conduct pilot tracking projects among patients receiving care outside of the federally funded hemophilia treatment centers to better understand public health needs and gaps of all patients with bleeding disorders.
- Continue analysis of tracking data collected through the Universal Data Collection (UDC) program.

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- Continue to build upon the data that has been collected through the UDC and expand and improve bleeding disorders tracking to include tracking of current and emerging issues such as aging, inhibitor development.
- Conduct an epidemiologic research study to better understand the risks and implications of cardiovascular disease among persons with hemophilia.
- Conduct research to better understand development and prevention of joint disease among persons with hemophilia.
- Host a panel of experts to develop recommendations for screening practices for inhibitor development in people with hemophilia.
- Increase provider and patient awareness of the clinical benefit of routine inhibitor screening.
- Publish findings from the Harris Interactive internet survey that assessed women's level of knowledge about bleeding disorders.
- Publish findings from the formative research and message testing that was conducted to identify transition materials and messages needed by the hemophilia community.



Featured Video

[View "A Look at Hemophilia" Video](#)

Notable 2011 NCBDDD Scientific Publications

- Byams VR, Kouides PA, Kulkarni R, Baker JR, Brown DL, Gill JC, Grant AM, James AH, Konkle BA, Maahs J, Dumas MM, McAlister S, Nance D, Nugent D, Philipp CS, Soucie JM, Stang E; **Haemophilia Treatment Centres Network Investigators. Surveillance of female patients with inherited bleeding disorders in United States haemophilia treatment centres.** Haemophilia 2011;17 Suppl 1:6-13.
- Miller CH, Philipp CS, Stein SF, Kouides PA, Lukes AS, Heit JA, Byams VR, Dowling NF, Kulkarni R. **The spectrum of haemostatic characteristics of women with unexplained menorrhagia.** Haemophilia 17:223-229, 2011.
- Sharathkumar AA, Soucie JM, Trawinski B, Griest A, Shapiro AD. **Prevalence and risk factors cardiovascular disease (CVD) events among patients with haemophilia:**

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experience of a single haemophilia treatment centre in the United States (US).

Haemophilia 2011; 17:597-604.

- Witmer C, Presley R, Kulkarni R, Soucie JM, Manno CS, Raffini L. **Associations between intracranial hemorrhage and prescribed prophylaxis in a large cohort of hemophilia patients in the United States.** Br J Haematol 2011; 152:211-216.

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Human Development and Disability

National Center on Birth Defects and Developmental Disabilities (NCBDDD) prevents disease and promotes equity in health and development of people with or at risk for disabilities. Infants, children, youth and adults should have the opportunity for full participation in life.



We are committed to a life course perspective—by that we mean not only thinking about people of all ages, but also recognizing the importance of earlier experiences in setting the course for later life; and understanding how people live over their lifespan.

Public health has a vital role to play in promoting the health and quality of life for people with, and at risk for, disabilities. There are 54 million people in the United States who have a disability, and many more are at risk for developing or acquiring one in their lifetime through injury, illness or aging. People with disabilities represent a diverse group of children, youth, adults and elders who share the experience of living with limitations in cognition, mobility, hearing, vision, or behavioral/mental health functioning.

Disability-associated health costs are substantial—estimated at almost \$400 billion in 2006, with public resources paying 70% of those costs. Despite these costs, people with disabilities are four times as likely to report fair or poor health compared to people without a disability. We know that many health problems for people with disabilities are preventable through improved access to health care services and health programs.

CDC formally recognized the health of people with disabilities as a significant public health concern in 1988 when it established a program to promote the health of people with disabilities and to prevent health problems that are frequently experienced. This program strives to include people with disabilities in mainstream health programs and services wherever possible, to support the development of cross-disability-specific programs when necessary, and to help build condition-specific programs when essential. The needs of disability populations are addressed through a network of state disability and health programs, public practice and resource centers, and a disability and health data system.

NCBDDD invests in child development, including early hearing detection and intervention programs, since childhood is the ideal time for interventions that promote lifetime health and development. NCBDDD focuses on certain child-onset conditions and infant hearing loss so that children can reach their full potential in life.

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We coordinate with many CDC programs that focus on chronic diseases, injuries, emergency preparedness, environmental health, and minority health. Our collaborative work with other agencies and organizations influences research, programs and policies for the populations we serve. Recognizing that resources are limited now and in the future, NCBDDD will continue to cultivate strategic partnerships, capacity building, and collaborations to obtain maximum effect and positive outcomes.

Our focus includes these key efforts:

- [Disparities in Health Among People with Disabilities](#)
Identify and reduce disparity in key health indicators, including obesity, among children, youth and adults with disabilities.
- [Child Development](#)
Improve developmental outcomes of children.
- [Hearing Loss in Children](#)
Ensure that all newborns are screened and assessed for hearing loss and receive appropriate intervention.
- [Disparities in Health Care Access for People with Disabilities](#)
Reduce disparities in health care access for people with disabilities.
- [Incorporate Disability Status into Surveys, Policies and Practices](#)
Incorporate disability status as a demographic variable into all relevant CDC surveys, policies and practices.

Funded Networks in 2011

NCBDDD funds four types of networks:

- 53 states, territories and DC to collect data on early infant hearing detection.
- A network of 16 state disability and health programs that engage in various data, policy and health promotion efforts to promote the health and wellbeing of people with disabilities in their states.
- Various disability organizations that consist of public health practice and resource centers – currently funding Centers in paralysis, limb loss, physical activity and obesity, Tourette syndrome and ADHD. Depending on budget levels in the future, other topic-specific centers will be added.
- Supporting several condition-specific networks of clinical consortia for muscular dystrophy, spina bifida, and fragile X syndrome.

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Disparities in Health

Identify and Reduce Disparities in Key Health Indicators, including Obesity, among Children, Youth and Adults with Disabilities

What is the Problem?

- Children, youth and adults with disabilities experience disparities in many key health indicators like obesity, smoking, injuries and violence, mental health, and access to health services. Obesity is a particular problem because it:
 - Increases the risk of developing chronic conditions.
 - Is prevalent among people with disabilities.
 - Is linked to many other poor health outcomes.
- Obesity rates for children and adults with disabilities are 38% and 57% higher, respectively, than rates for children and adults without disabilities.
- Annual obesity health care costs related to disability approach \$44 billion/year.
- Adults with disabilities engage in physical activities on a regular basis approximately half as often as adults without disabilities (12% vs. 22%).



What Do We Know?

- Data are needed to document health disparities, identify problems, and identify which groups of people with disabilities are at highest risk for specific problems.
- The growing body of research indicates that people of all ages with disabilities experience a range of disparities in health.
- The standard definition of disability for surveys adopted by the Department of Health and Human Services will provide much more consistency in how disability data are captured.
- Children and adults at greatest risk for obesity have mobility limitations, intellectual/learning disabilities, or both.

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- Whether obesity is the result of disability or a contributing factor to disability, it is important to promote healthy weight for children, youth, and adults with disabilities.
- Standard weight measurements may not be adequate to assess weight for people with some disabilities, such as limb loss or paralysis.
- Reasons for disparities in obesity and healthy weight management include:
 - Lack of accessible environments that promote healthy living, such as sidewalks, parks, and exercise equipment.
 - Lack of healthy food choices for many people with disabilities living in restrictive environments.
 - Use of medications that contribute to changes in weight and appetite.
 - Physical limitations that can reduce a person's ability to exercise.
 - Pain and/or lack of energy.
 - Difficulty with chewing or swallowing food.
 - Lack of resources such as money, transportation, and social support from family, friends, neighbors, and community members.

What Can We Do?

- Integrate disability into national communication and programmatic efforts that address obesity and other health indicators.
- Identify and measure health outcomes for people with disabilities to evaluate effectiveness and monitor change.
- Increase the number of people with disabilities who participate in mainstream health programs for physical activity and good nutrition to improve cardiovascular and muscle fitness, and enhance mental health.
- Document and promote health status and health disparities.
- Increase research on obesity and healthy weight management to build the evidence for effectiveness of related programs for children, youth and adults with disabilities.
- Build effective communication platforms on nutrition and physical activity to improve uptake on messages by people with disabilities, caregivers, and providers.

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- Provide nutrition and physical activity resource guides to residential living facilities, caregivers, and people with disabilities to increase health promotion.
- Collaborate with NCBDDD partners to prioritize and address disparities in other health indicators.

Accomplishments

- Introduced an online interactive system, the Disability and Health Data System, that helps translate state-level, disability-specific data into valuable public health information. Users can customize how they view disability and health data throughout the country, making it easy to understand health disparity information, identify trends, and help support the development of programs, services and policies that address people with disabilities.
- Collaborated with CDC's nutrition, physical activity and obesity program, national agencies, and international organizations to share research and develop strategies on obesity and healthy weight management among people with disabilities.
- Developed a plan and research agenda to direct our future work on healthy weight management for children and adults with disabilities. This agenda will be used to inform policies, programs, and practices.
- Partnered with the World Health Organization in developing and disseminating the World Report on Disability (2011), the first-ever worldwide report on disability. The World Report provides the most recent scientific data on disability, and makes recommendations for action at the national and international level.
- Collaborated with national organizations to continue development, monitoring, and promotion of the Healthy People 2020 objectives for disability and health. Provided input to child health and development objectives of Healthy People 2020, which provides a blueprint for improving the health of the nation.

Looking to the future

- Increase awareness about obesity and healthy weight management among people with different disabilities through partnerships with a the network of public health practice and resource centers.
- Assess and improve healthy weight of people with mobility limitations in conjunction with limb loss and paralysis organizations.
- Promote healthy weight management among their constituents with disabilities by engaging a network of state disability and health programs.

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- Develop issue briefs to increase public awareness of the risks of obesity for people with disabilities and strategies for healthy weight management.



Feature Videos

[The Spina Bifida Experience: The Importance of Physical Activity](#)

[The Spina Bifida Experience](#)

Notable 2011 NCBDDD Scientific Publications

- Anderson WL, Armour BS, Finkelstein EA, Wiener JM. Estimates of state-level health-care expenditures associated with disability. *Public Health Reports* 2010;125(1):44–51.
- Courtney-Long E, Armour B, Frammartino B, Miller J. Factors associated with self-reported mammography use for women with and women without a disability. *J Women's Health (Larchmt)* 2011;20(9):1279–86.
- Holtzer C, Meaney FJ, Andrews J, Ciafaloni E, Fox DJ, James KA, Lu Z, Miller L, Pandya S, Ouyang L, Cunniff C. Disparities in the diagnostic process of Duchenne and Becker muscular dystrophy. *Genet Med* 2011;10. [Epub ahead of print]
- Krahn GL, Campbell VA. Evolving views of disability and public health: The roles of advocacy and public health. *Disabil Health J* 2011;4(1):12–8.
- Reichard R, Holtus H, Fox MH. Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States. *The Disability and Health Journal* 2011;4(2):59–67.

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Child Development

Improve Developmental Outcomes of Children

What Is the Problem?

- Childhood is the ideal time for interventions that promote lifetime health and development. Unfortunately, poor outcomes are experienced by too many children with diagnoses or conditions such as Attention-Deficit Hyperactivity Disorder (ADHD), Tourette syndrome, spina bifida, fragile X syndrome (FXS) or muscular dystrophy.
- Children who experience poverty are also at risk for poor developmental outcomes, which can be improved through early identification and intervention.
- More than 15 million children in the U.S. are living in poverty, and the number is increasing. Children living in poverty are at significantly higher risk for poor health outcomes and for:
 - Behavior and emotional problems.
 - Lower IQ.
 - Language delays.
- Nearly one in 10 school-aged children in the U.S. (5.4 million children) has been diagnosed with ADHD, and rates have been increasing during the past decade. Children with ADHD are also likely to have emotional and behavioral conditions and may face many challenges such as:
 - Difficulty in establishing peer relationships.
 - More frequent and severe injuries.
 - Difficulty with their emotions (oppositional defiant disorder).
 - Difficulty in learning (learning disorders).
 - Difficulty with their behavior (conduct disorders).
- The annual financial and societal costs of ADHD on the juvenile and criminal justice systems are approximately \$42.5 billion.
- Tourette syndrome (TS) can impact a person's health, education, employment, family and social relationships, and has wide-ranging effects on their physical, mental, and emotional well-being.



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- At least 148,000 children and their families are living with TS in the U.S.
 - Boys are 3 times more likely than girls to have TS.
 - 80% of children with TS have also have a mental, emotional or behavioral condition—including ADHD, anxiety, depression, and developmental delays.
- Fragile X syndrome (FXS) is the most commonly known cause of inherited intellectual disability, but is difficult to diagnose early.
 - Each year, about 1,500 babies are born with spina bifida. Spina bifida may cause physical and mental disabilities that range from mild to severe. In 2009, the lifetime medical cost for a person with spina bifida was estimated to be \$460,923.
 - One of the most common forms of muscular dystrophy in children, Duchenne muscular dystrophy (DMD), is usually fatal in the teens or early 20s, most commonly due to severe respiratory or heart problems, or both.

What Do We Know?

- A positive impact has been reported through *Legacy for Children™*, an evidence-based program whose aim is to improve child outcomes by promoting positive parenting among low-income mothers of infants and young children. Compared with families that did not participate, a stronger mother-child bond was noted, and children performed better on intelligence measures and showed fewer behavior problems.
- Improving the health of people with ADHD could substantially reduce costs to the health care system. It could reduce both the \$31.6 billion spent each year on health care costs, and the costs associated with time lost from work and school among children and adults with ADHD and their family members.
- Mental, emotional and behavioral symptoms can complicate the diagnosis and treatment of TS, and create extra challenges for people with TS, their families, educators, and health professionals.
- For families of a child with FXS, research indicates that about 16 months typically passes between professional confirmation of a developmental delay and the diagnosis of FXS. More than one third of families reported that they had more than 10 visits to the doctor before they received the FXS diagnosis.
- Children with spina bifida can live life to their full potential and become productive members of society. Programs to improve physical and mental health will increase independence and social participation, which will benefit people with spina bifida throughout their lives.

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- Improving screening and diagnosis for muscular dystrophies will improve the services patients and families need across the life course.

What Can We Do?

- Translate research into practice by broadly disseminating Legacy for Children™ through existing programs, such as Early Head Start and measuring the program's impact on child health and development.
- Improve the understanding of risk behaviors and impact of ADHD to develop better prevention and intervention strategies so that the health and long-term outcomes of children with ADHD improves.
- Provide credible health information on recognition, diagnosis, co-occurring conditions, and management of TS for people with TS, their families, health care professionals, teachers, and the public.
- Promote better understanding and earlier identification of FXS and to promote best possible outcomes for children and their families.

Accomplishments

- Provided the first outcome results from NCBDDD's Legacy for Children™. The public health approach to positive parenting showed:
 - 16% fewer children exhibited hyperactivity.
 - 9% fewer children with socio-emotional problems.
- Demonstrated that NCBDDD's Legacy for Children™ can be successfully implemented in existing Early Head Start programs, resulting in more efficient use of resources.
- Published findings on the increasing occurrence of ADHD in the Morbidity and Mortality Weekly Report (MMWR).
- Presented preliminary results from a longitudinal study of children with ADHD which showed that children with ADHD:
 - Are more likely to engage in behaviors where they can hurt themselves as compared to children without ADHD.
 - Had below average academic performance in reading and writing skills.

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- Through ongoing collaborative research to better define the impact of TS. Detected challenges in the accurate identification of TS and is investigating ways to tracking through ongoing collaborative research to better define the impact of TS.
- Developed the report, Bridging the Gap Between Tourette Syndrome and Public Health in collaboration with the TS community - including individuals, providers and researchers. This report describes the public health issues around TS, highlighting the health, education, employment, and social outcomes that can be improved by public health research, practice and partnerships.
- Launched the first comprehensive website addressing FXS and fragile X-associated disorders. In conjunction with National Fragile X Awareness Day in July, a web feature on FXS on CDC's homepage received almost 5,200 page views.
- Through NCBDDD, the National Task Force for Early Identification of Childhood Neuromuscular Disorders is shortening the time between first signs of symptoms and diagnosis for a range of neuromuscular disorders in children age 6 months to 5 years. The Task Force has launched an educational website (www.childmuscleweakness.org), which is anchored by point-of-care tools and videos to assist providers in the early identification of childhood muscle weakness. Children who get help sooner have a better chance of having a full and productive life.
- The Spina Bifida Association launched its [Preparations website](#), giving families and individuals living with spina bifida a hands-on tool with specific guidelines to promote a successful, independent adulthood. This partner website is based on CDC's Life Course Model, that considers developmental progress across life stages, and shifts attention from clinical measures to a focus on participation--how one fares in the real world.
- In the past year through funding from NCBDDD, the Tourette Syndrome Association (TSA) improved the knowledge about TS among health care professionals and educators to help them serve children better. Almost 3,000 professionals were reached, with 90% reporting an increase in knowledge of TS. Exhibits reached an additional 2,600 professionals.

Did you know?

Fragile X syndrome (FXS) is the most common known cause of inherited intellectual disability. FXS affects both males and females, however, females often have milder symptoms than males. The exact number of people who have FXS is unknown, but it has been estimated that about 1 in 5,000 males are born with the disorder.



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- In the past year, NCBDDD entirely funded the ADHD National Resource to provide scientifically verified information on ADHD to families, professionals and other by:
 - Responding to 8,237 individual information requests.
 - Serving as a major resource on information about ADHD, with over 850,000 visits to their website.
 - Providing a venue for the general public to interact directly with ADHD experts through a series of monthly Ask the Experts Chats, with an average of 105 attendees each month.
 - Developing a series of five 1-page information sheets, and materials for ADHD and co-occurring conditions to include in the ADHD Toolkit of the American Academy of Pediatrics.

Looking to the Future

- NCBDDD's efforts will expand knowledge, improve practice, and promote optimal health and development of children.
- We are leading the effort to develop the first-ever CDC report on children's mental health. The report will be published in the Morbidity and Mortality Weekly Report (MMWR) and will summarize what is known about the incidence of a number of mental health conditions in children.
- The Project to Learn about ADHD in Youth (PLAY), an ongoing longitudinal study on ADHD, will develop new knowledge on the occurrence of childhood ADHD, secondary conditions, health risk behaviors, treatment, and symptoms experienced over time.
- We will work for implementation of important changes to the recent revised ADHD diagnostic and treatment guidelines, an activity which NCBDDD collaborated with the American Academy of Pediatrics:
 - Expand age range of coverage from 6-12 years to 4-18 years of age.
 - Expand scope that considers behavioral interventions and directly addresses problem-level concerns in children based on the Diagnostic and Statistical Manual for Primary Care (DSM-PC), Child and Adolescent Version.
 - Create a system to guide the clinical care process.
 - Integrate with the Task Force on Mental Health to foster stronger ties to families and mental health clinicians, to intervene early, and to foster good mental health.
- We will continue to work with partners to increase awareness and understanding of Tourette syndrome among health and education professionals and the public. Providing education and outreach activities at both the community and national level will help reduce stigma and improve access to care, aid with timely diagnosis, and ultimately help children with TS lead healthy and productive lives.

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- We are developing and evaluating the implementation of care guidelines for specific muscular dystrophies. The first guidelines for Duchenne muscular dystrophy were developed through an international expert panel process and published in *Lancet Neurology* in 2010. We will evaluate implementation of these guidelines. The Duchenne MD guidelines will inform development of evidence-based guidelines and best practices for four additional forms of muscular dystrophy. In most cases, these will be the first guidelines ever developed for these complex conditions, giving clinicians and families a critical resource.

Stories

Impact of Partnership

My heartfelt thanks go to the CDC and the Tourette Syndrome Association for providing such wonderful educational opportunities to our TS families in Louisiana. Without the Youth Ambassador program, my son's life would likely be on a very different track right now. The training gave him the confidence and the boost in self-esteem at a time when he desperately needed it, and he has continued to "pay it forward" with his presentations in schools and youth groups. –Mother of a son with TS

Angela and *Legacy for Children*[™]

Angela was one of the 600 mothers enrolled in the first study of *Legacy for Children*[™]. Watching the other children in the *Legacy for Children*[™] program helped Angela understand what to expect of her daughter, Lara. Helping other parents practice new parenting skills reinforced her own skills and helped define her career track. "It never would have crossed my mind to want to help others [as a profession] – I never realized what an influence I was to other people." Sharing parenting experiences with the other mothers created a community that supported Angela's desire for the best possible life for her children and persisted beyond the three years of the *Legacy for Children*[™] program.

Angela developed a strong connection to the idea of "parents are the child's first teachers" and consequently changed her interactions with her children, including her discipline decisions. She learned to be an advocate for Lara's academic success. As a result, at the age of five, Lara was enrolled in a magnet school a year ahead of her peers. In general, Angela reported that *Legacy for Children*[™] helped her to think more about her influence on her children. Mothers quickly develop a deep connection to their *Legacy for Children*[™] group, and participation rates have stayed high since the first group session. "*Legacy for Children*[™] opened my eyes to thinking through the long-term effects of what I do, rather than just at that moment." — Angela, a *Legacy for Children*[™] mother

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Legacy for Children™ moms being with their children in a typical program seen above.

Building a Better Roadmap: The Spina Bifida Multi-Site Study

Nancy went for her five-month ultrasound to find out whether she was expecting a boy or a girl. “They kept repeating the ultrasound over and over. I knew from a mother’s instinct, and from being a nurse, that something was wrong. The doctor walked in and said your son’s going to have spina bifida. I had briefly studied spina bifida in nursing school, only hearing about the worst-case scenarios, so immediately I thought that’s what my child would be facing.”

Nancy was referred to a high risk obstetrician and the spina bifida clinic at Children’s Hospital of Alabama in Birmingham. At her prenatal consultation in the clinic she went with questions about her son’s prognosis. “The pediatric neurosurgeon told me to put away all my questions and said I don’t know, I don’t know.” Nancy and her husband were very scared and shaken.

Nancy shares that the staff at Children’s Hospital were wonderful, “...but the lack of research when Clark was born meant there were so many ‘don’t knows.’ It would have been so helpful to have a better roadmap based on research. More spina bifida research would give parents definite steps to take at each milestone to ensure the best results for their child. It would also help manage the secondary conditions. Every issue is just as important as the next. Some families might deal more with neurological symptoms, while others struggle daily with bowel and bladder concerns. Nutrition and physical activity are also important when it comes to living with the condition. Clark is ambulatory and goes to the gym but it’s still very difficult for him to get his heart rate up. I’m constantly watching his weight. For us, the closest accessible sports are an hour and fifteen minutes away. There are not enough resources available.”

Clark is now twelve years old. He walks with braces. He takes piano lessons and will start guitar lessons soon. He loves watching college football and he’s the assistant coach of his younger brother’s soccer team. He likes to hang out with his friends. Although spina bifida impacts his life every day, Clark does not let it define who he is. Nancy continues, “Clark had a shunt put in at two weeks and then a revision at two years, but since then no shunt malfunctions.” She crosses her

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fingers and knocks on wood when she talks about how lucky they've been because shunt problems are common with spina bifida.

"We want there to be more knowledge of all aspects of spina bifida and the best way to manage it. Everything is so intertwined," Nancy says. "Any time there is an opportunity that is non-invasive for Clark to be involved in the research, we do it because we know that in the long run the research will help us and all the other families affected by spina bifida, as well as those to come. Clark is proud to be part of the research. I know for some families the research they'd like to have is on the neurological side because they're dealing with frequent shunt revisions or their child has symptoms from tethered cord syndrome. Also every parent I've spoken with who has a child that's a little bit older says their child seems to show other neurological symptoms like an increased emotional response, like wearing their emotions on their sleeve or a lack of motivation. Without more research in this area, it's difficult to say if these behaviors are related to puberty, depression, or perhaps the effects of hydrocephalus."

Each year, about 1500 babies are born with spina bifida. Health issues and treatments for people with spina bifida will be different for each person. Some health issues and treatments related to spina bifida include hydrocephalus, tethered cord, limited mobility and physical activity, incontinence, skin sores, and latex allergy. The 2009 estimate of medical costs for the first year of life for a child with spina bifida was \$52,415 and the lifetime medical cost was estimated to be \$460,923.

NCBDDD began funding data collection from Children's Hospital of Alabama as part of the Multi-Site Study in 2008. Today there are 17 spina bifida clinics across the country sending their de-identified patient data to NCBDDD for analysis. The clinics use an electronic medical record (EMR) specially designed for spina bifida and developed by NCBDDD and its partner the Spina Bifida Association, to collect information about patients' clinical experiences. This information includes the type of spina bifida diagnosis, mobility, surgeries, pressure sores, education and employment, and insurance coverage, as well as other clinical information. Using the EMR also guarantees that all clinics in the study provide registry information in the same way, ensuring that NCBDDD has standardized and reliable data for research.

As part of the Nurse First program she's launched, Nancy gives presentations on spina bifida to nursing students. As both a nurse and a mother of a child with spina bifida she says, "If I talked about spina bifida in depth, and covered all the topics, it would take me six months of continuous talking. So if NCBDDD did research on spina bifida nonstop for the next twenty-five years, there would still be more to know."

NCBDDD is the only organization in the United States designing the infrastructure and conducting the clinical research to build a better road map for living with spina bifida.

In collaboration with our partners, we are learning which health care services may be most beneficial, with the goals of health and condition self-management, success in developing relationships, and success in learning so that participation in society throughout life can be relevant and meaningful.

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The first findings from this study will be shared with health care providers and families beginning in 2012.

Featured Videos

[The Spina Bifida Experience: Developing Independence](#)

[The Spina Bifida Experience: Managing Your Own Medical Care](#)



Notable 2011 ncbddd scientific publications

- Bitsko RH, Cortese MM, Dayan GH, Rota PA, Lowe L, Iversen SC, Bellini WJ. **Detection of RNA of mumps virus during an outbreak in a population with high two-dose measles-, mumps-, and rubella vaccine coverage.** J Clin Microbiol 2008;46(30): 1101–3.
- Fairman AD, Thibadeau JK, Dicianno BE, Parmanto B. **Implementing a specialty electronic medical record to document a life-course developmental model and facilitate clinical interventions in spina bifida clinics (a review).** Pediatr Clin North Am 2010;57(4):959–71.
- Kronk R, Bishop EE, Raspa M, Bickel JO, Mandel DA, Bailey DB Jr. **Prevalence, nature, and correlates of sleep problems among children with fragile X syndrome based on a large scale parent survey.** Sleep 2010; Swanson ME, Sandler AD eds. Spina bifida: health and development across the life course. An Issue of Pediatric Clinics (The Clinics: Internal Medicine). Maryland Heights (MO): Elsevier, 2010.
- Swanson ME, Sandler AD. Preface. **The natural history of spina bifida.** Pediatr Clin North Am. 2010;57(4):xv–xvi
- Swanson ME. **Need for the life course model for spina bifida (A Review).** Pediatr Clin North Am. 2010;57(4):893–901.
- Visser SN, Bitsko RH, Danielson ML, Perou R, Blumberg SJ. **Increasing prevalence of parent-reported attention-deficit/hyperactivity disorder among children — United States, 2003 and 2007.** Morbidity and Mortality Weekly Report. 2010;59(44):1439–43

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Hearing Loss in Children

Ensure that all Newborns are Screened and Assessed for Hearing Loss and Receive Appropriate Intervention

What Is the Problem?

- Each year, more than 12,000 babies are born with hearing loss; most have two hearing parents. If hearing loss is not identified until two or three years of age, and appropriate intervention services are not initiated, the child may experience delays in language development and in cognitive and social skills and not reach their full potential.
- When an infant has a hearing loss, it is cause for immediate attention. That is because language and communication skills develop most rapidly in early childhood, especially before the age of 3. When hearing loss goes undetected, children are delayed in developing language and communication skills. Early intervention is an effective way to help infants and children develop communication skills as soon as possible in their lives.
- Universal screening is only the first step—the next steps are confirming hearing loss and then receiving intervention services.
- In 2009, 45% of newborns not passing their hearing screening could not be documented as receiving the follow-up testing needed to make a diagnosis, or being enrolled in early hearing loss services. Adequate data systems and tracking procedures are needed so that families, health care providers, and programs can follow the progress of children identified with possible hearing loss.



What Do We Know?

- Hearing loss can vary greatly among children and can be caused by many things. In the United States, 1 to 3 children per 1,000 are born with hearing loss each year. The hearing loss can range from a mild loss (they do not hear as well as you do) to a profound loss (where they may not hear anything).

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- Genetic factors are the cause of hearing loss in about 50% of babies – some of these babies might have family members who are deaf. Illnesses, injuries, certain medicines, and loud noise levels can also cause children and adults to lose hearing.
- Early intervention is one of the best ways to help children with hearing loss. The earlier children with hearing loss are diagnosed and start getting services, the more likely they are to reach their full potential. Families are able to choose from a full range of hearing loss options and receive support to succeed. States have developed strong programs for screening infants for hearing loss.
- Over 95% of all newborns in the U.S. are now screened, so there is a tremendous success there. The next challenge is in ensuring that those newborns who do not pass the screening receive recommended follow-up service.
- Awards and technical assistance from NCBDDD's Early Hearing Detection and Intervention (EHDI) program have supported state efforts to:
 - Share information across jurisdictions to match information about children born in one state but living in another.
 - Develop comprehensive reporting systems to improve the amount, quality, and timeliness of data from clinicians and other health care professionals to follow children.
 - Integrate EHDI data collection with other child health data systems to help account for all children.

What Can We Do?

- Support the national EHDI 1-3-6 benchmarks, which include hearing screening no later than age 1 month, diagnostic audiologic evaluation no later than age 3 months (for those infants not passing the screening), and enrollment in early intervention no later than age 6 months (for those identified with a hearing loss).
- Continue development and implementation of EHDI tracking systems in 53 states and territories. Provide technical assistance and health education all states.
- Look for potential causes and risk factors for hearing loss, and identify causes and solutions for those infants not following-up with the testing needed to make a diagnosis, or being enrolled in early hearing loss services.
- Improve information systems to help states:
 - Generate timely statistics.

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- Improve their service delivery.
- Measure changes related to policy and program changes.
- Address other issues that are important to state, local, and national policymakers.
- Develop and implement standards for interoperability for electronic health records (EHRs) on infant hearing loss identification and services.

Accomplishments

- With over 95% of newborns in reporting jurisdictions now screened for early hearing loss, the EHDI program is focusing on what happens to infants who did not pass the hearing screening—the loss of infants to documented follow-up.
- Four selected states are taking part in a pilot project to improve quality and timeliness of EHDI data.
- Started a sentinel surveillance model in select states to provide more consistent and timely information on loss to documented follow-up and identify areas for continued improvement.
- Awarded competitive grants to 53 states and territories for EDHI tracking systems that allow tracking of services for infants.

Looking to the Future

- Enhance state and territorial EHDI tracking systems so programs are better able to take advantage of electronic health records and national data reporting and coding standards, as well as gather a limited set of individual level data from states.
- Accurately assess the number of infants who receive appropriate, timely follow-up services.
- Document improvements in infant/family outcomes after follow-up services for hearing loss.
- Investigate early hearing loss intervention service gaps within and among different socioeconomic, race/ethnicity, and gender groups.
- Test implementation tools for clinical - public health systems interoperability with Electronic Health Records (EHR). Development of standards internationally will facilitate future surveillance through EHRs. Data will provide better understanding of health disparities (e.g., race, geographic) on follow-up for audiologic evaluation and referral for intervention services.

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Notable 2011 NCBDDD Scientific Publications

- Abhyankar S, Lloyd-Puryear MA, Goodwin R, Copeland S, Eichwald J, Therrell BL, Zuckerman A, Downing G, McDonald CJ. **Standardizing newborn screening results for health information exchange.** AMIA Annu Symp Proc 2010; 1–5.
- Biernath KR, Montero DP, Mehl A, Toomey KE. **Universal newborn hearing screening and beyond.** Am Fam Physician 2010;81(2):124.
- Gaffney, M. Eichwald J, Grosse SD, Mason, CA. **Identifying Infants with Hearing Loss — United States, 1999—2007.** Morbidity and Mortality Weekly Report; 2010; 59(08):220–3.
- White KR, Forsman I, Eichwald J, Munoz K. **The evolution of early hearing detection and intervention programs in the United States.** Seminars in Perinatology 2010;34(2):170–9

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Health Care Access

Reduce Disparities in Health Care Access for People with Disabilities

What Is the Problem?

- Access to quality and timely health care is critical for everyone. For people with disabilities who may have complex health conditions it is even more important.
- Health care access encompasses much more than insurance coverage for health care services. Access includes physical access to buildings and medical appointments, attitudes of providers, and accessible transportation, health promotion programs and health information.
- In 2010, 29% of people with disabilities report unmet health care needs compared to 12% of people without disabilities.
- Health care access problems differ depending on type of disability.



What Do We Know?

- The health of people with disabilities is affected not only by their disability, but also from many preventable factors. Proportionately, they experience more secondary conditions (like depression and pressure ulcers) and chronic conditions (like diabetes and stroke) than people without disabilities. Good health care is essential to achieving and maintaining good health.
- To achieve national health goals set for the general population, health care access issues need to address the needs of the disability community. For instance, general health communication messages may need to be modified in format for people with vision or hearing loss, and may need to be simplified for people with intellectual disabilities.
- For people with disabilities, health care access means:
 - Physically accessible facilities.
 - Accessible messages and communication services.
 - Accessible medical equipment.

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- Providers with disability knowledge, respectful attitudes, and expectations of good health for people with disabilities.
- Programs that plan for accommodation for clinical, preventive, and health promotion services.
- Adequate insurance coverage.
- Available and accessible transportation.
- Health promotion programs that are effective with people with disabilities.

What Can We Do?

- Improve data to understand the health care access problem and enhance state-based practice.
- Initiate implementation of public health research, programs, and policies to reduce the disparity in health care access.
- Reduce disparities by applying data to improve practice at the state and local levels and increase disability inclusion in mainstream health care where possible, develop cross-disability programs when necessary, and build condition-specific programs when essential.
- Improve access to health care services, including health programs and prevention services, to reduce disparities in health for people with disabilities.

Accomplishments

- Demonstrated major disparities in health status and health care access for people with disabilities using population-based data in CDC reports that included Vital Signs, Morbidity and Mortality Weekly Report (MMWR) QuickStats and CDC Health Disparities and Inequalities Report.
- Documented disparities in reporting a mammogram in the past two years, with 72% of women with a disability having received a mammogram compared to 78% for women without a disability.
- Improved communication and care of patients with disabilities, by partnering with medical schools and other health training programs to reach students in medicine, nursing, public health and other health professions.
- The disability and health state network promote breast health screenings for women with disabilities. States have developed:
 - Training programs for technicians, women with disabilities and care providers.

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- Methods to assess the accessibility of mammogram facilities for women with physical disabilities in particular.
- Resource materials to help women know where to go for facilities that are accessible.
- Demonstrated that among children with special health care needs, children with reported muscular dystrophy were more likely to have family members who reported financial problems, reduced or gave up employment, and spent more than 10 hours weekly providing or coordinating care.
- Launched the Pilot Longitudinal Data Collection to Inform Public Health for Fragile X Syndrome. From this study, NBCDDD will learn the challenges and needs of those impacted by fragile X as they navigate from delayed diagnosis, to treatments and services, to the transition to adulthood and adult health care providers.

Looking to the Future

- NBCDDD is working with disability and health programs to strengthen the linkages between state health agencies and women's health and chronic disease programs. A toolbox of health care resources for women with disabilities will be developed for use by state and county health entities, local and non-government organizations, providers and researchers.
- NBCDDD is using an expert panel process to define core competencies for public health staff who work in disabilities, and a curriculum that would provide necessary training.
- Through our state disability and health network, we are specifically funding states to assess and address health care access in facilities and equipment.

Did you know?

- Adults with disabilities are 2 ½ times more likely to experience unmet health care needs than people without disabilities.
- If urinary tract infections could be reduced by 50% for people with spina bifida, health care savings of \$4.4 million per 1000 persons could be realized.
- New standards on accessibility of medical equipment have recently been released by the Access Board. They provide an important basis for assessing and assuring the accessibility of medical equipment like mammography equipment and examination tables.

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Featured Video

[Mark's Story](#)

Notable 2011 ncbddd scientific publications

- Brustrom J, Thibadeau J, John L, Liesmann J, Rose S. **Care Coordination in the Spina Bifida Clinic Setting: Current Practice and Future Directions.** J Pediatr Health Care. 2012 Jan;26(1):16-26. Epub 2010 Jul 10.
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- Kemper AR, Ouyang L, Grosse SD. **Discontinuation of thyroid hormone treatment for US children with congenital hypothyroidism: Findings from health insurance claims data.** BMC Pediatrics 2010;10(9):1–6.
- Ouyang L, Grosse SD, Raspa M, Bailey DB. **Employment impact and financial burden for families of children with fragile X syndrome: findings from the national fragile X survey.** Journal of Intellectual Disability Research 2010;54:918–28.
- Ouyang L, Grosse SD, Swanson M, Thibadeau J, Campbell V. **Outpatient medical conditions among children and adults with spina bifida in the United States: Frequency and expenditures.** Journal of Pediatric Rehabilitation Medicine 2010; 3(3):177–185.
- Swanson ME, Dicianno BE. **Physiatrists and developmental pediatricians working together to improve outcomes in children with spina bifida.** Pediatrics Clin North Am 2010;57(4):973–81.
- Thibadeau JK, Alriksson-Schmidt AI, Zabel TA. **The national spina bifida program transition initiative: the people, the plan, and the process.** Pediatrics Clin North Am 2010;57(4):903

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Disability Status

Incorporate Disability Status as a Demographic Variable into all Relevant CDC Surveys, Programs, and Policies

What Is the Problem?

- Promoting health and preventing secondary conditions in people with disabilities is a relatively new development in public health. There have been few data sets and few public health programs that explicitly addressed inclusion of people with disabilities.
- Until 2003, disability status was not captured in the Behavioral Risk Factor Surveillance System (BRFSS), which meant that there were no data for state and local health departments concerning how many people were living with a disability or the health status of those with disability. In the 2011 [CDC Health Disparities and Health Inequalities Report](#),  disability status was included in only 17 of the 33 descriptive demographic tables.
- Many different definitions of disability exist across national data sources, which make it difficult to describe the population of people with disabilities in the same way populations are described based on gender, age or race/ethnicity.
- Health promotion programs like smoking cessation, weight management, and diabetes management do not typically make accommodations for people with physical, mental, cognitive or intellectual disabilities.
- Health education materials are usually not developed in alternative formats that make communications accessible to people with disabilities.



What Do We Know?

- It is difficult to determine the effectiveness of mainstream programs that include people with disabilities due to a lack of disability status in health surveys.
- The absence of disability status make it difficult to appropriately address health disparities of people with disabilities compared to people without disabilities; the absence of data also makes it difficult to determine the need to develop disability-specific health programs.
- Overall national health goals cannot be achieved if health prevention and promotion needs of people with disabilities are not met.

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- Health education materials are usually not developed in alternative formats that make communications accessible to people with disabilities.

What Can We Do?

- Incorporate disability status as a demographic variable into CDC surveys and evaluation strategies to improve data on issues including chronic conditions, injuries, and emergency preparedness to improve the lives of people with disabilities.
- Influence and implement policies to incorporate people with disabilities into CDC research, programs, and activities.
- Leverage key partnerships to expand the inclusion of people with disabilities in mainstream public health activities.
- Identify best practices to improve the effectiveness of CDC programs for people with disabilities; develop disability-specific programs, when necessary.
- Establish training for the CDC workforce and its partners on disability issues and their importance in improving the nation's health.

Accomplishments

- Collaborated to develop data standards for HHS policy on inclusion of disability identifiers in HHS supported surveys.
- Completed the Healthy People 2020 (HP2020) disability and health objectives that built on the preceding decade of work in which people with disabilities were fully recognized as a population in the Healthy People plan. HP 2020 advances the way the nation will engage in health promotion systems, programs and practices.
- Led first-ever CDC cross-agency Disability and Health Work Group to develop a disability inclusion policy to be used by all CDC programs.
- Included people with disabilities in the first-ever CDC Health Disparities and Inequalities Report, Morbidity and Mortality Weekly Report (MMWR), January 14, 2011. This report marked the first time that disability status was included as a major demographic category in a NCBDDD published report. This report illustrated that health disparities exist for the disability population, but also highlighted the current limitations of existing data sources to reliably and consistently measure disability status. (Report available at <http://www.cdc.gov/mmwr/pdf/other/su6001.pdf> )
- NCBDDD provided fact sheets that communicated state-specific health disparity data for people with and without disabilities in support of including disability in the Community Transformation Grant Funding Opportunity Announcement. States and disability interest groups now have the information necessary to demonstrate the need for disability to be included in applications for funding under other relevant funding opportunity announcements.

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- NCBDDD funded states to include people with disabilities in emergency planning. These states have developed public awareness campaigns, training programs for first responders and people with disabilities, emergency preparedness kits and checklists, and have generally raised awareness of the importance of disability inclusion in emergency preparedness.
- Hosted a disability and health partners meeting in Chicago June 2011 to share cutting edge science and exchange program and policy recommendations.

Looking to the Future

- Collaborate with offices and centers across CDC to facilitate the integration of people with disabilities into public health efforts.
- Train the CDC workforce and its partners on disability issues and their importance in improving the nation's health.
- Promote a policy that would require the specific inclusion of disabilities where relevant in CDC reports. Data would be analyzed with disability as a demographic to determine whether there are specific effects for disability.

Mike's Story

I became a below-knee amputee on January 12, 2007. I was a 400-pound diabetic who had undergone several toe amputations prior to that. I was floored by the doctors telling me it would have to be done, but I survived it quite well.

I found a local support group through the Amputee Coalition and started going to meetings. After two years on total disability, I had gastric bypass surgery and lost 150 pounds. I lost enough weight to get back in a truck and drive again.

It's been a year, and I'm working full-time, and off of disability altogether. I couldn't have done it without the help of the Amputee Coalition. —Mike C.

People with limb loss are more likely to be at high risk of complications related to diabetes, including additional limb loss, heart disease and renal failure. CDC is improving diabetes education among people with limb loss so that they have a greater likelihood to live healthy and productive lives.

Notable 2011 ncbddd scientific publications

- Hall T, Krahn GL, Horner-Johnson W, Lamb G. **Rehabilitation Research and Training Center Expert Panel on Health Measurement. Examining functional content in widely used health-related quality of life scales.** Rehabil Psychol 2011;56(2):94–9.
- Krahn GL. **W.H.O. world report on disability: A review.** Disabil Health J 2011;4(3):141–2.
- Krahn, GL. **Reflections on the debate on disability and aid in dying.** Disability and Health. 2010; 3(1):51–5.

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NCBDDD 10 Years of Service

We celebrated 10 Years of Service in 2011, and honored that decade of progress by showcasing the exceptional work of our partners' and the National Center on Birth Defects and Developmental Disabilities (NCBDDD). Partners worked with us to offer a series of events and activities throughout the year and to highlight our collective successes. We gained valuable insights on the future strategic direction of the Center through focused, meaningful discussions with our partners and are so grateful for their presence, support, and their hand in making the past a success and the future a land of possibilities.

Many of NCBDDD's advancements and innovations in public health programs are due to the contributions of groundbreaking experts in the field, who have paved the way to more promising public health prevention and intervention programs. The year-long celebration was an opportunity to honor the pioneering spirit of the health professionals and advocates who support the Center's mission and to empower today's generation to continue efforts toward potential for full and productive living for our most vulnerable populations.

[To view more about the 10 Years of Service >>](#)



Healthy Beginnings: *"We've made tremendous progress in the last 10 years and that is due in large part to NCBDDD & their partners."* – Rep. Lucille Roybal-Allard (D-CA)

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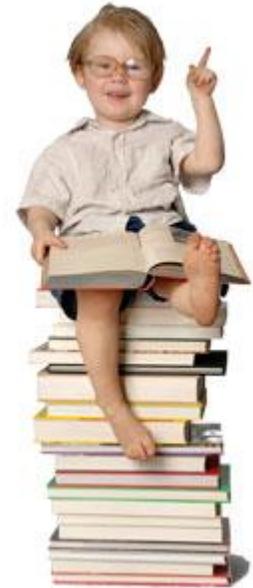
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