

National Center on Birth Defects and Developmental Disabilities Annual Report Fiscal Year 2015



IMPROVING THE HEALTH OF PEOPLE WITH DISABILITIES

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) promotes optimal health outcomes for people with disabilities.

At any point in life, people can live with a disability. Functional disabilities can be acquired at birth or through illness, injury or aging, and may include difficulty with walking or climbing stairs, making decisions, seeing or hearing, taking care of oneself, or living independently. An estimated 37 million¹ to 57 million² people are living with a disability in the United States.



Accomplishments

- Elevated awareness about adults with disabilities during the 25th anniversary of the Americans with Disabilities Act (ADA) with a Morbidity and Mortality Weekly Report (MMWR) entitled, "Prevalence of Disability and Disability Type Among Adults — United States, 2013". This report described the percentage of adults living with selected functional disabilities in each state. This information can be used to better understand and address the needs of people with disabilities in the United States. The findings achieved awareness through national news outlets such as The Washington Post, USA Today, and U.S. News and World Report.
- Promoted ways in which disability can be included more routinely in public health activities by launching a new CDC disability inclusion website, which features information that is used by public health practitioners, healthcare providers, and people interested in the health and wellbeing of people with disabilities. It describes barriers that people with disabilities usually experience in communities, and offers strategies to create inclusive public health programs and activities.
- Increased public health knowledge of spina bifida by publishing data from the National Spina Bifida Patient Registry. This large, multi-site clinic study found relationships between patient characteristics and health outcomes, such as patients with spina bifida who were male, non-Hispanic blacks, or who did not have private health insurance had less favorable outcomes. This study can lead to efforts to improve clinical care in ways that improve the health of people living with spina bifida.
- Increased awareness of mental health issues among men with Duchenne or Becker muscular dystrophy by releasing a report summarizing newly published data from the Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet). Nearly half of men with Duchenne or Becker muscular dystrophy have mental health problems related to behavioral issues, such as depressed mood or attention-deficit/hyperactivity disorder. This study can help health professionals monitor treatment for boys and men living with these types of muscular dystrophy.
- Identified barriers to early identification and connection to evidence-based treatments by supporting the first national study of diagnostic and treatment histories of children and youth with Tourette syndrome. These data help stakeholders better understand the public health needs of people living with Tourette syndrome.

1. U.S. Census Bureau; American Community Survey, 2011 American Community Survey 1-Year Estimates, Table S1810; generated by Michael H. Fox, using [American FactFinder](#); (16 July 2013).
2. Brault MW. Americans with disabilities: 2010. Washington, DC: US Census Bureau; 2012.

Looking to the Future

NCBDDD conducts critical work to help foster a healthy lifestyle and an improved quality of life for people with disabilities. We do this by monitoring public health data to identify opportunities for impact, answering research questions to reduce health disparities between people with and without disabilities, helping shape inclusive health programs that encourage full participation of people with disabilities, and supporting state and national programs to deliver targeted prevention messages and interventions. We will continue to build state-based and national disability and health programs for adults with disabilities, with a focus on support for those with mobility and cognitive limitations.

Notable Scientific Publications

Bandini L, et al. Obesity in children with developmental and/or physical disabilities. *Disabil Health J* 2015;8(3):309-16.

Correa-de-Araujo R, et al. Persons with disabilities as an unrecognized health disparity population. *Am J Public Health* 2015;105(2):198-206.

Courtney-Long EA, et al. Prevalence of disability and disability type among adults — United States, 2013. *MMWR Morb Mortal Wkly Rep* 2015;64(29):777-83.

Cyrus A, et al. Tools for improving clinical preventive services receipt among women with disabilities of childbearing ages and beyond. *Matrn Child Health J* 2015;19(6):1189-1201.

Forman-Hoffman VL, et al. Disability status, mortality, and leading causes of death in the United States community population. *Med Care* 2015;53(4):346-54.

Ouyang, L. et al. Characteristics and survival of patients with end stage renal disease and spina bifida in the United States renal data system. *J Urol* 2015;193(2):558-64.

Romitti PA, et al. Prevalence of Duchenne and Becker muscular dystrophies in the United States. *Pediatrics* 2015;135(3):936-44.

Sawin, KJ et al. The National Spina Bifida Patient Registry: profile of a large cohort of participants from the first 10 clinics. *J Pediatr* 2015;166(2):444-50.



Spotlight on: American Association on Health and Disability

This Spotlight was contributed by Roberta Carlin, MA, MS, JD, who is Executive Director of the American Association on Health and Disability.

I have been involved in the disability field since the late 1970's and have witnessed the evolution of the disability and health field to the place where this important work has a home – the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC. On a personal and professional level, it is gratifying to have had the opportunities to work with NCBDDD as the Chair of the Friends of NCBDDD as well as through my role as Executive Director of the American Association on Health and Disability (AAHD). AAHD shares the vision of NCBDDD, and our organization could not be successful in our work in the area of health promotion and wellness for people with disabilities without the tremendous leadership and support we receive from NCBDDD.

AAHD is proud to play a leadership role in the Friends of NCBDDD "Improving Health of People with Disabilities" Workgroup. The workgroup strives to improve health care access to providers and facilities for children and adults with disabilities. Collecting disability data is also a priority for the workgroup and AAHD and our members.

A priority of AAHD is to expand the Disability Research and Dissemination Center, www.disabilityresearchcenter.com, funded by NCBDDD, and grow its capacity to identify and fund the best research in the field of birth defects and disabilities. Through NCBDDD's commitment to integrating disability into the public health agenda and improve the health of children and adults with disabilities, the quality of lives of children and adults with disabilities has been greatly enhanced. As a professional involved for nearly four decades in the disability field, I am thankful that current and future generations of children and adults with disabilities will continue to have improved health status, increased accessibility and be able to look to NCBDDD as the leader in public health and disability.

To view the annual report online, please visit:
www.cdc.gov/ncbddd/aboutus/annualreport2015

For more information, please visit:
www.cdc.gov/ncbddd or www.friendsofncbddd.org

