

National Center on Birth Defects and Developmental Disabilities Annual Report Fiscal Year 2014



Improving the Health of People with Disabilities

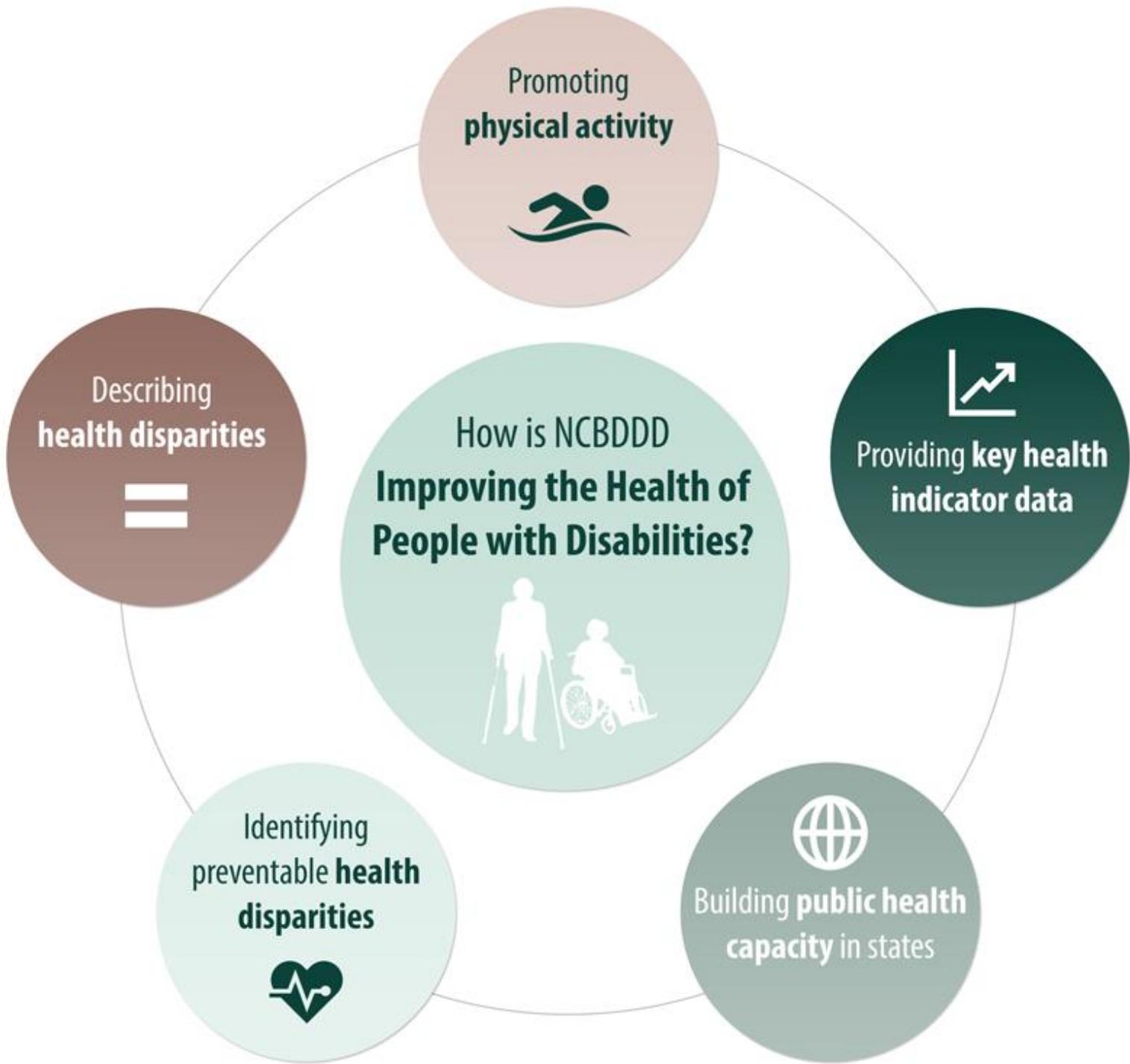
CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) made a difference in the nationwide effort to reduce health disparities among people with disabilities.

In the United States, an estimated 39 million to 57 million people live with a disability. At NCBDDD, we define disability as a long-term or permanent limitation in movement, cognition, vision, or hearing. We work to promote the health of people living with disabilities so they can live, work, and play in their communities. Through public health efforts, such as tracking, research, and health communication and education, we aim to reduce health disparities and the incidence as well as the severity of additional physical or mental health conditions that occur as a result of having a disability.



Accomplishments

- Launched a nationwide report on adults with disabilities and physical activity. CDC's Vital Signs™ : “Adults with Disabilities – Physical Activity is for Everybody” presented data showing that 1 in 2 adults (18-64 years of age) with a disability get no aerobic physical activity and that people with disabilities who had a recommendation from a doctor or health professional were more likely to be physically active. Materials and messages, including a website dedicated to resources for doctors and health professionals, were delivered to over 140 partner organizations and reached an estimated 138 million people.
- Updated Disability and Health Data System (DHDS) to include the latest data from the 2012 Behavioral Risk Factor Surveillance System on key health indicators and provide new ways to see data. DHDS continues to be the only state-level disability and health data system that helps national and state organizations identify opportunities to improve the health of people with disabilities by using data to build partnerships with programs.
- Increased public health capacity in 18 states using the Disability and Health Network to plan, prepare and include people with disabilities in health-protecting programs and services. The majority of these states have identified policy needs within their state; worked to increase the number of facilities providing preventive healthcare screenings; and assessed state emergency plans – all to better include, provide access to, and ultimately improve the health of, people with disabilities.
- Published an important scientific article, which documented for the first time that adults with specific types of disabilities are more likely to have measured high blood pressure compared with adults without disabilities. A key findings web page was developed and was promoted to thousands of people and organizations in conjunction with the Million Hearts Program.



Looking to the Future

Disability is part of the typical human experience and is often perceived as poor health. Our work, with sustained support, can change that perception. NCBDDD is committed to protecting the health of people with disabilities across their lifespan by integrating CDC's public health science with national and state disability and health programs.

We will continue to help reduce health disparities of people with disabilities by including them in public health surveys, public health programs, emergency preparedness and planning efforts, and accessible healthcare services. We will continue to support state-based programs, which promote healthy lifestyles and improve the quality of life for people with disabilities. Our collaboration with national partners will continue to improve the health of people with disabilities by increasing access to health care services and implementing programs, while also providing health education to promote health, wellness, and the adoption of healthy behaviors for people with disabilities.

Notable 2014 Scientific Publications

Anderson WL, et al. Obesity and people with disabilities: The implications for health care expenditures. *Obesity*. 21: E798–E804. doi: 10.1002/oby.20531.

Bayliss EA, et al. Understanding the context of health for persons with multiple chronic conditions: moving from what is the matter to what matters. *American Family Medicine*. 2014;May-Jun;12(3):260-269.

Carroll DD, et al. Vital signs: disability and physical activity - United States, 2009-2012. *MMWR Morb Mortal Wkly Rep*. May 9 2014;63(18):407-413.

Courtney-Long E, et al. Disparities in current cigarette smoking prevalence by type of disability, 2009-2011. *Public Health Rep*. 2014 May;129(3):252-60.

Kim S, et al. Metabolic risk factors in U.S. youth with low relative muscle mass. *Obesity Research & Clinical Practice*. Published online: June 17, 2014

Krahn G, et al. Health Disparities of Adults with Intellectual Disabilities: What Do We Know? What Do We Do? *Journal of Applied Research in Intellectual Disabilities*. 2014;Sep; 27(5):431-446.

Ouyang L, et al. Characteristics and survival of end stage renal disease (ESRD) patients with spina bifida in the United States Renal Data System (USRDS). *The Journal of Urology*. 2014 Aug 25. doi: 10.1016/j.juro.2014.08.092.

Ouyang L, et al. A comparison of family financial and employment impacts of fragile X syndrome, autism spectrum disorders, and intellectual disability *Research in Developmental Disabilities*. 2014;Jul;35(7):1518-1527.

Stevens A, et al. Hypertension Among US Adults by Disability Status and Type, National Health and Nutrition Examination Survey, 2001–2010. *Prev Chronic Dis*. 2014;11:140162.

Visser SN, et al. Trends in the Parent-Report of Health Care Provider-Diagnosed and Medicated Attention-Deficit/Hyperactivity Disorder: United States, 2003–2011. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2014;53(1):34-46.e32.



Spotlight On: Spina Bifida Association

The Spina Bifida Association (SBA) is the only national organization in the United States that works on prevention of spina bifida while supporting those people affected by the birth defect and its complicated conditions. SBA has partnered with NCBDDD for a decade to improve the health of people with spina bifida. In fact, no other organization or governmental entity is working on improving the health of people with spina bifida—both young and old!

In conjunction with NCBDDD, we are working to create a Spina Bifida Collaborative Care Network (SBCCN). When the SBCCN is fully functioning it will identify and facilitate the provision of expert clinical care and necessary educational resources for people living with spina bifida in order to improve their health, function, and participation in their healthcare.

Some activities of the SBCCN will be to:

- Monitor, track and evaluate care provided in spina bifida clinics,
- Provide input into research priorities for the National Spina Bifida Patient Registry (NSBPR), and
- Monitor and track the implementation of those practices that have had the greatest positive impact on the health of people with spina bifida.

Over the years, SBA has partnered with NCBDDD to create a Spina Bifida National Resource Center. Each year, SBA connects with over 1000 families to answer their questions about spina bifida. Sometimes, the question may be from a mother who has just found out that her child is going to be born with spina bifida while others are from adults with spina bifida looking to find a physician who can treat them. Other questions are from caregivers looking for funds to buy catheters for their children or from adults with very serious health conditions with no physicians to treat them. NCBDDD has helped SBA to find answers to these questions and on some occasions those answers have saved a person's life.

- Sara Struwe

To view the annual report online, please visit:

<http://www.cdc.gov/ncbddd/aboutus/annualreport2014>

For more information, please visit:

<http://www.cdc.gov/ncbddd>

