

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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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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