

Charles J. Rothwell MS, MBA
Director, National Center for Health Statistics (NCHS)

Marcie L. Cynamon
Director DHIS

October 30, 2015

Sent via email to healthsurveys@cdc.gov

Dear Mr. Rothwell and Ms. Cynamon,

The Friends of NCBDDD together with the Consortium for Citizens with Disabilities (CCD) Health Task Force, the Partnership to Improve Patient Care (PIPC), the undersigned organizations, and researchers submit this letter in response to the Office of the Director of the Division of Health Interview Statistics' request for comments on the NHIS redesign. We appreciate the opportunity to provide comments on the value and use of the National Health Interview Survey (NHIS), and the NHIS' current set of disability questions to the disability community, disability advocates, and disability researchers. Friends of NCBDDD, CCD, PIPC, and the undersigned disability-related organizations and researchers recognize the critical need for annual disability data.

The Friends of NCBDDD is a coalition of government and private sector participants who work together to enhance the mission and activities of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) in identifying the causes of birth defects and developmental disabilities; helping children to develop and reach their full potential; and promoting health and well-being among people of all ages with disabilities, including blood disorders.

The CCD Health task force is a coalition national disability organizations working together to advocate for national public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

The mission of the PIPC is to advance the principles of patient-centeredness throughout the healthcare system. We strive to raise awareness about the value of well-designed comparative clinical effectiveness research, the important role of continued medical innovation as part of the solution to cost and quality challenges in health care, and the importance of shared decision-making between patients and providers that empowers patients to play a more active role in their own healthcare decisions.

We write to urge you to maintain the extensive indicators you use to *annually* document the broad continuum of disability that supports "disability" as a demographic. The extensive indicators in the NHIS identify individuals at risk with respect to poverty, unemployment, emergency planning, health, and other areas of disparities, and individuals who represent the group specified in the Americans with Disabilities Act. The extended questions in the NHIS

provide information used collectively for many purposes. The extended questions help to distinguish and follow trends experienced by people with disabilities. They also help to formulate federal policy, and to appropriately allocate funding in distinct subject areas, as demonstrated by the use of the Basic Action Difficulty measure (BAD) highlighted in the Disability and Health Chartbook published by the National Center on Health Statistics (NCHS).

The NHIS provides a valuable resource to all of us as disability-related organizations and researchers through its inclusions of a broad range of measures of disability. The data represented in NCHS chartbooks, such as the *Disability and Health in the United States, 2001-2005* is critical information about the health and well-being of the population of people with disabilities. Many articles about different aspects of health for the population of people with disabilities published annually in the *American Journal of Public Health*, *Disability and Health Journal*, *Social Science and Medicine*, *The Journals of Gerontology*, and many more rely on this data to provide information essential to the health and well-being of the population of people with disabilities. This data is vital to organizations serving young and old, rich and poor, those of multiple ethnicities and races, and those with various types of functional limitations. It is valuable to disability researchers who seek to improve the health and well-being of people with disabilities

While the new American Community Survey provides an important short set of questions to identify the most seriously, functionally limited population, both in a census and survey contexts, it represents only the most severely impaired part of the disabled population. However, disability is really a continuum associated with a wide range of functional limitations. The questions used in the NHIS allow identification of that broader continuum by combining the use of questions about all the major areas of functional limitations, including mental health associated limitations, and thus allows for a truer measure of the disability population to which the Americans with Disabilities Act (ADA) applies.

Since the passage of the ADA, disability has become a demographic with which to level the playing field for employment, health, and other issues that affect all populations that face disparities. The basic action measures defined in the *Disability and Health* chartbook allow for measurement of disability as a demographic, similar to gender, age and race. This ability to compare people with disabilities to other demographic groups allows for and contributes to implementation of the ADA.

The nature of the *Disability and Health* chartbook questions about physical, sensory and mental health limitations also allows for a scaling of severity of the problems people with disabilities have and thus provide a representation of the range of functional outcomes associated with different levels of impairment. The use of a severity scale in the *Disability and Health* chartbook demonstrates for example the difference in access to health insurance for different levels of physical limitations (See Chartbook Figure 28), or the differences in access to preventive care such as pap smears or mammograms for women with disabilities (See Chartbook Figure 33).

Another set of very useful questions in the NHIS - especially for the upcoming period as our aging population increases substantially - are the questions about the need for and use of help

with ADLs and IADLs. A reasonable addition to those questions should look at who those helpers are, and whether they live with the person, or receive payment to come into the home. Caregiving is going to be an

increasingly significant issue over the next 20 years and beyond, and the inclusion of those questions will be essential to policy planning activities.

As mentioned above, the ADA has already established disability as a demographic in the United States. Internationally, the Convention on the Rights of Persons with Disabilities, enacted by the United Nations, also treats disabilities as a demographic with the goal to improve the lives of people with disabilities around the globe, as with other demographic groups that face higher rates of poverty, unemployment, and marginalization. The Affordable Care Act (ACA) further affirmed disability as a demographic with the inclusion of disability in Section 4302, a section aimed at eliminating health disparities in America among all demographic groups that experience health disparities.

The NHIS provides much richer data than the baseline requirements of Section 4302. The NHIS currently provides that disability data *annually* – some of which is not collected anywhere else and certainly not annually. This current NHIS disability data provide critical data to policymakers, researchers and others to represent the complete population of people with disabilities as a demographic, and to inform policymakers and those of us who work to decrease disability health disparities. Decreasing the data currently collected is patently antithetical to the spirit and intent of Section 4302's overall goal of increasing data collection as a means to decrease health disparities. Eliminating some of the disability data collected in the NHIS can only serve to threaten our efforts to decrease health disparities in the population of people with disabilities as our efforts rely on this critical data. We know that the NHIS includes, among other data topics:

- The six disability questions from the American Community Survey;
- Questions about ADLs and IADLS
- Very specific mobility data;
- Social participation questions;
- Questions regarding work limitations and ability to work;
- A six question scale about mental health;
- Memory and concentration questions;
- Questions about difficulty seeing or blindness;
- Questions about hearing or deafness; and
- Questions about the specific condition that may cause the problem areas reported, as well as when the conditions began.

Only annual data collection can support national policy, well established by both the ADA and ACA, of disability as a demographic group. Because of the demographic role that the disability questions play, it is critical to include them each year in the core of the NHIS. One would not collect age, gender or race on alternate years, so it is imperative to ask the disability questions each year as well. Support for people with disabilities as a demographic requires the annual collection of the detailed data that the NHIS currently collects. Elimination of any of this

comprehensive annual data will threaten disability as a demographic group. As a country, as organizations, as researchers, we need the ability to compare people with disabilities to people without disabilities in health, employment, poverty, and social determinants of health. We urge CDC not to eliminate any disability related questions from the NHIS and certainly not the annual data collection that would threaten disability as a demographic and threaten our collective efforts to eliminate disability health disparities.

We thank you for the opportunity to have input into this process. The undersigned **organizations and researchers stand ready to serve as resources, should you have any questions or require any assistance.**

Organizations

American Academy of Developmental Medicine and Dentistry
American Association on Health and Disability
Access Living
ADAPT Montana
American Foundation for the Blind
American Network of Community Options and Resources
Association of Maternal & Child Health Programs
Association of University Centers on Disabilities
Center for Inclusive Design and Environmental Access
Center for Leadership in Disability
Christopher & Dana Reeve Foundation
Coalition for Disability Health Equity
Disability Policy Consortium
Disability Rights Education and Defense Fund
Easter Seals
Epilepsy Foundation
Family Voices
Federal Employees with Disabilities
Hemophilia Council of California
Hepatitis Foundation International
Friends of NCBDDD
Independent Living Resource Center
Lakeshore Foundation

Mid-Atlantic Lyceum
National Multiple Sclerosis Society
National Alliance on Mental Illness
National Association of Hispanic Nurses
National Center for Environmental Health Strategies
National Council on Aging
National Council on Independent Living
National Fibromyalgia and Chronic Pain Association
National Organization of Nurses with Disabilities
Not Dead Yet
Oregon Public Health Association
Pacific ADA Center
Partnership to Improve Patient Care
Pineda Foundation / World Enabled
Placer Independent Resource Services
Seattle Quality of Life Group
Service Center for Independent Life
Spina Bifida Association
The Amputee Coalition
The Arc of the United States
Tri-County Independent Living
Tuberous Sclerosis Alliance
Western States Regional Hemophilia Network

Researchers, Individuals and Universities

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<p>Rebecca Sheffield, Ph.D., Senior Policy Researcher, American Foundation for the Blind</p>

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