



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

June 30, 2016

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

Marcie L. Cynamon  
Director, DHIS

Sent via email to [healthsurveys@cdc.gov](mailto:healthsurveys@cdc.gov)

Dear Mr. Rothwell and Ms. Cynamon:

The CCD Health Task Force appreciates the opportunity to provide comments on the proposed changes to the National Health Interview Survey (NHIS), and wishes to emphasize the importance of the NHIS' current set of disability questions to the disability community.

The CCD Health Task Force is a coalition of 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.

This current NHIS disability data set provides critical data to policymakers, researchers and advocates 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. The Health Task Force appreciates the depth and breadth of the children's disability questions. We appreciate that the sampled child questionnaire topics have been expanded to include more detail on childhood disability with separate questions about autism, intellectual disability, and other developmental disabilities. We are confident this data will provide key measures for benchmarks and long-term trends and identify priority populations who have an elevated risk of poorer health or receiving inadequate health care. We also value the use of functioning as a framework for measurement of disability and the increased emphasis on social determinants of health.

On the other hand, the CCD Health Task Force remains concerned about aspects of the sample adult questionnaire. We understand that going forward the NHIS will no longer ask for the specific condition that causes the limitations reported by interviewees. While we realize the intent is to keep the length of the NHIS short, the elimination of the condition takes away key public health data that shows causes and effects, needed to find public health solutions. Further, no other survey collects this data in such a large population. The absence of the causal condition inhibits the determination of priority populations at elevated risk of poorer health. If NHIS data can show that certain conditions cause more functional limitations, public health and other interventions may be warranted. Without this data, we cannot meet the needs of the specific population, nor can we project the impact of the social determinants of health on populations with specific conditions. Moreover, causation data can provide critical insights into how disability interacts with other demographic factors such as race, ethnicity, and socio-economic status, and provoke insight into redressing the multiple and compound health barriers that people with disabilities of color likely experience.

Another concern is the plan to eliminate data collection on the date of limitation onset. The date of onset is very important to determine whether a condition is a developmental disability. Elimination of the data is antithetical to the increased emphasis on developmental disabilities, including autism and intellectual disabilities in the sample questionnaire. These conditions do not go away when one becomes an adult. Data is needed to support policy development to meet the needs of adults with autism and adults with intellectual and other developmental disabilities. This information is crucial data that the NHIS must continue to collect.

We appreciate that the NHIS provides richer data and disability data questions than the baseline requirements of Section 4302; however, the information you provided for comment does not specify how often you plan to collect the American Community Survey (ACS) disability data. As we have stated in our previous comment letters, annual data collection supports national policy as established by both the Americans with Disabilities Act and the Affordable Care Act. Because of the demographic role that the disability questions play, it is critical to include them each year in the core of the NHIS. We have heard you are also currently collecting the Washington Group questions annually. These questions closely mirror the NHIS disability questions and we urge you to continue this practice. If the plan is not to continue with the Washington Group questions, we encourage you to collect the NHIS disability questions annually. Collecting this data, either through the Washington Group question or NHIS, is vital and must continue on an annual basis. However, since the ACS questions serve as a

benchmark for all other health and non-health surveys (CPS, Justice) that collect the ACS data, we encourage you to also collect the ACS questions biannually or at the very least every three years.

The Health Task Force also urges the inclusion of demographic questions to identify family caregiver status and information about the caregiving situation (i.e. number of hours of caregiving and relationship). The Behavioral Risk Factor Surveillance System (BRFSS) core survey and optional Caregiving module have previously used questions that could be adopted. There are over 43.7 million family caregivers in the US. Inclusion of these questions will allow researchers and policymakers to better understand the health and wellbeing of this population.

Finally we thank the NCHS for continuing to ask about the use of physical, occupational, and speech therapies as part of the questions about health care utilization. These therapies are critical for attaining, maintaining, and keeping functional abilities for many people with disabilities.

We appreciate the opportunity to provide comments. If you have any questions please contact Julie Ward ([ward@thearc.org](mailto:ward@thearc.org)).

Sincerely,

American Association on Health and Disability

American Association of People with Disabilities

American Foundation for the Blind

American Medical Rehabilitation Providers Association

American Therapeutic Recreation Association

Bazelon Center for Mental Health Law

Christopher & Dana Reeve Foundation

Disability Rights Education and Defense Fund

Easterseals

Epilepsy Foundation

National Alliance on Mental Illness

National Council on Aging

National Disability Rights Network

The Arc of the United States

United Cerebral Palsy

Non-CCD endorser

Lakeshore Foundation