November 7, 2016

Marcie L. Cynamon  
Director, National Health Interview Statistics Division  
3311 Toledo Road, MS-P08,  
Hyattsville, MD 20782-2064

Docket Number: CDC-2016-0092

Dear Ms. Cynamon:

The Consortium for Citizens with Disabilities (CCD) Health Task Force appreciates the opportunity to continue to participate in the review of the proposed changes to the National Health Interview Survey (NHIS). As we have previously stated, the current set of disability questions in the NHIS is critically important to the disability community.

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. As the population ages and the number of people with disabilities increases, this data will be vital to policymakers and advocates. Decreasing the data currently collected is contrary to the intent of the Affordable Care Act Section 4302’s overall goal of increasing data collection as a means to decrease health disparities.

The CCD Health Task Force had previously recommended that the National Center for Health Statistics (NCHS) include age of onset questions to help identify the adult population with developmental disabilities in light of the decision to stop asking the questions about the specific conditions. As we understand it, without the specific conditions or the age of onset questions, there will be insufficient questions to identify the population of adults with developmental disabilities. We urge the National Center for Health Statistics to develop and test questions to identify adults with developmental disabilities. If this cannot be accomplished, then we urge you to reconsider asking about the specific conditions (intellectual disability, autism, cerebral palsy, epilepsy and others) and the age of onset in order to be able to continue to identify individuals with developmental disabilities.
The CCD Health Task Force is also concerned that the NHIS will include a variation of the six disability questions that are included in the American Community Survey (ACS). It is our understanding that HHS has adopted, at a minimum, the use of the six ACS questions to meet the ACA’s data collection responsibilities. We are concerned that varying the questions may affect the reliability and comparability of the data. We urge the NCHS to continue to include the six ACS disability questions and to specify how often they will be included in the survey.

CCD is the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. The Health Task Force works on a variety of issues related to the health and functional ability of people with disabilities.

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

Sincerely,

ACCSES
American Association on Health and Disability
American Foundation for the Blind
American Network of Community Options and Resources
American Psychological Association
Association of University Centers on Disabilities
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Disability Rights Education and Defense Fund
Easterseals
Epilepsy Foundation
Family Voices
Institute for Educational Leadership
National Alliance on Mental Illness
National Disability Rights Network
National Multiple Sclerosis Society
The Arc of the United States
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