

October 20, 2026

Submitted electronically to regulations.gov

Dr. Erika Schwartz
Centers for Disease Control and Prevention
Attention: CDC-2026-1387
1600 Clifton Road NE
Atlanta, GA 30329

**Re: Proposed Data Collection Submitted for Public Comment and Recommendations;
CDC 2026-1387**

Dear Dr. Schwartz:

Disability Rights Education and Defense Fund (DREDF) appreciates the opportunity to comment on the above proposed 2028 changes to the questions and collection of the National Health Interview Survey (NHIS). DREDF is a national cross-disability law and policy center that protects and advances the civil and human rights of people with disabilities through legal advocacy, training, education, and development of legislation and public policy. We are committed to increasing accessible and equally effective education, healthcare, transportation, and employment supports and opportunities for people with disabilities so they can lead full, productive lives in the communities of their choice. DREDF has been involved in passing and clarifying federal and state disability rights laws and regulations since our inception in 1979 as an organization that is board-led by people with disabilities and parents of children with disabilities.

We are deeply concerned about the changes that have been proposed to 2028 NHIS. The NHIS has been a critical measure of household and population health since its introduction in 1957. Many researchers and policymakers have relied on the NHIS for current and trending information on US health including data on sources of health insurance coverage, coverage adequacy continuity, the count of people who have functional impairments and other measures of disability such as chronic conditions, mental health and wellbeing and behavioral health. The detailed collection possible under the NHIS allowed law and policymakers to make truly informed decisions on the needs of the US population when it came to issues of essential health benefit coverage, preventive services, and access to healthcare across demographic population groups.

Because the NHIS is the most rigorous and detailed collection of disability information across different types of disability and can be linked to things like Social Security Administration (SSA) benefits history, the medical expenditure panel survey (MEPS), Medicare/Medicaid enrollment, mortality statistics, and so forth. NHIS provides an important “check” on whether and how people with disabilities receive needed services and supports. This reality check in turn helps lawmakers to understand when the allocation of resources intended to meet the needs of specific disabled people groups need to be adjusted or updated. Executive branch agencies that serve people with disabilities such as the Administration for Community Living (ACL), the Department of Veterans Affairs, SSA, and the Agency for Healthcare Research and Quality, all

rely on NHIS data. As CDC stated in its proposal for revision, the NHIS is the “single most important source of statistics to track progress toward HHS health objectives.”

Over almost 70 years, the NHIS has only been redesigned three times emphasizing that the ability to cross-tabulate data over time has tended to overshadow any perceived need to update the NHIS questions. Nonetheless, the current proposal drastically removes and change the scope of many longstanding measures of disability.¹ Not only will this proposal sharply interrupt the ability to track data after the nation’s recovery from COVID and during a period of significant policy change, the proposed changes will directly impede policy efforts to monitor and improve the health of people with disabilities. We urge the Department to provide more transparent justification for its decision to undertake revisions at this time, only a few years after the last revision, and to reconsider relying on such a shortened and demonstrably inadequate measure of curtailed questions to measure disability. Below are DREDF’s comments relating to a few specific questions and issues.

I. Disability-Relevant Questions Must Be Retained

DREDF signed the comments submitted by the Consortium of Constituents with Disabilities and supports those comments and others which speak directly to the integrity and need for the NHIS questions that relate to people with intellectual and developmental disabilities (I/DD). In addition, the proposed NHIS revisions unjustifiably remove many other questions that are important to groups of people with disabilities that are not otherwise captured in the remaining questions. This is the case even though Section 306(h) of the Public Health Service Act (42 U.S.C. § 242k) directs the Secretary through the NCHS to undertake annual data collection that explicitly includes disability among the topics that must be in the survey.² The lost questions greatly contribute to our understanding of the prevalence of specific types of disabilities and their impact on the health and lives of disabled persons.

For example, the question about the age of disability onset is crucial to understanding disability and its prevalence around the country. Age of onset is a marker of how IDD is recognized under the Developmental Disabilities Assistance and Bill of Rights Act.³ This question enables researchers to look closely at what it means to live with a disability from an earlier age and is especially important to “matters for research on early intervention, special education transitions, and lifetime disability trajectories.”⁴ As a practical matter, the needs, expectations, and experiences of people who have I/DD may differ markedly from the support needs, expectations, and experiences of people who acquired a disability as adults, or as older adults.

¹ National Center for Health Statistics, 2028 NHIS Questionnaire Redesign (NHIS “was previously redesigned in 1997 and 2019” and that the 1997 redesign followed the prior major revision in 1982), available at <https://www.cdc.gov/nchs/nhis/about/2028-questionnaire-redesign.html>.

² Public Health Service Act § 306(h)(2), 42 U.S.C. § 242k(h)(2).

³ 42 U.S.C. § 15001 et seq.

⁴

CCD recognizes that the disability community as a whole experiences barriers to healthcare and good health, but those barriers cannot be understood or addressed on some generic high level. Specificity matters for both identification of the affected population and the needs of that population. The Washington Group Short Set (WGSS) of six questions does not adequately capture various populations of disabled people, including people with IDD, people with mental health disabilities, and people with communication disabilities that are not linked to functional hearing limitations. The approximately 40 or so disability questions in the current NHIS beyond the WGSS, some of which are listed below, help to close the gap between what the WGSS misses and the actual prevalence and lives of people living with a wide range of disabilities in the US population.

Moreover, questions such as the one addressing specialized equipment and assistive devices help with planning for the present and future needs of an aging population, including disabled people who are living longer lives. If anything, the question should expand to include the use of augmentative and assistive communication devices by people with disabilities, which would help to capture the prevalence of people who have communication disabilities without hearing or intellectual disabilities. The same rationale applies to retaining questions about cognition, upper body and manual function, and caregiving, which are particularly important for understanding the needs of disabled persons that require personal care assistance. The data derived from these questions is especially important now given the extensive caregiver shortage in the US as well as current charges that such needs are inherently linked to fraud, waste, and abuse. The accusations should not be made and linked to policy changes and legal restrictions unless there is real population data to back it up, rather than politically motivated anecdotes. Questions that are not in the list below but which are equally important include references to chronic conditions and a question about immunosuppression which provide data that is vital for accurate information on how current HHS priorities are impacting the well-being, community participation, and preventive care needs of people with disabilities.

For ease of reference in reading this comment letter, the questions that we comment on above are reproduced below with comments from the Disability Health Equity Research Network (DHERN), which compared the current Adult Questionnaire against the proposed draft questionnaire and found several measures missing.

- **Age of disability onset**
- **Measurements of cognitive and mental health**
 - *“Is that [difficulty remembering or concentrating] a difficulty with remembering, concentrating, or both?”*
 - *“How often do you have difficulty remembering?”*
 - *“Do you have difficulty remembering a few things, a lot of things, or almost everything?”*
 - *How often do you feel worried, nervous or anxious?”*
 - *“Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of those feelings?”*
 - *“How often do you feel depressed?”*
 - *“Thinking about the last time you felt depressed, how depressed did you feel?”*

- *“Do you have difficulty learning new things, for example, at school, work, or in other places?”*
- **Measurements of upper-body and manual function** – substituted for a general self-care question.
 - *“Do you have difficulty raising a 2 liter bottle of water or soda from waist to eye level?”*
 - *“Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?”*
- **Caregiver support** –
 - *“Because of a physical, mental or emotional condition, does someone help you with everyday tasks such as grocery shopping, paying bills or visiting the doctor’s office?”*
- **Use of specific, specialized equipment and assistive devices**, including whether specific equipment address functional limitations – substituted with one, equipment-agnostic question for vision, hearing, and mobility:
 - *“Do you wear glasses or contact lenses?”*
 - *“Do you use a hearing aid?”*
 - *“How often do you use your hearing aid(s)?”*
 - *“Do you have difficulty hearing what is said in a conversation with one other person in a quiet room... even when using your hearing aid(s)?”*
 - *“Do you have difficulty hearing what is said in a conversation with one other person in a noisier room... even when using your hearing aid(s)?”*
 - *“Do you use any equipment or receive help for getting around?”*
 - *“Do you have difficulty” walking 100 yards; 1/3 of a mile*
 - *“Do you have difficulty walking up or down 12 steps?”*
 - *“Do you use... a cane or a walker?”*
 - *“Do you use... a wheelchair or scooter?”*
 - *“Do you use someone’s assistance?”*
 - *“Without the use of your aid, do you have difficulty” walking 100 yards; 1/3 of a mile; up or down 12 steps?*
 - *“When using your aid, do you have difficulty” walking 100 yards; 1/3 of a mile; up or down 12 steps?*
- **Other missing measurements:**
 - **Transportation as a barrier to care** – transportation is a gateway service and the absence of these questions disproportionately affects people with disabilities, and particularly when transportation networks and autonomous vehicles continue to delay providing equitable accessible service to disabled riders;
 - **Veteran-specific disability measures** – functional limitation status and VA service disability status are not the same and this measure manages to capture

captures veterans with mental health disabilities resulting from military service, with implications for support and housing services as a consequence.

II. The Washington Group Short Set of Questions In Inadequate as the Primary Measure of Disability Used in the NHIS

The Washington Group Short Set (WGSS) does not adequately measure the disability population.⁵ According to researchers, compared to the six questions in the American Community Survey (ACS) (which still failed to capture 20 percent of self-reported disabled respondents), the WGSS underestimates the population of disabled individuals by more than 50 percent.⁶ Another study found that the WGSS did not classify 1 in 3 blind adults and 2 in 5 adults who are deaf as having any disability.⁷ In fact, WGSS's own materials acknowledge that it captures only about half of people with mental health disabilities.⁸ The use of a question set which requires some kind of consensus cut-off among a range of disability severity will undercount people with disabilities, particularly compared with the ACS-6. This cannot be the basis for federal statistics on the health and health care access of people with disabilities, nor can it serve as a basis for allocation of resources across the disability community.

III. The Survey Must Be Accessible to People with Disabilities

We are also concerned about the accessibility of the new survey format. Previously, a trained interviewer administered the survey. The proposal states that families will complete the questionnaire themselves, online or on paper, before any interviewer follows up with them. An online design is especially problematic for disabled adults, who are less likely than nondisabled adults to have the needed technology to take the survey.⁹

Secondly, and even more importantly, as well as related to concerns about the WGSS questions, a study found that missed responses dramatically increased among people with disabilities when the WGSS survey is self-administered. The study found self-administration of the WGSS potentially undercounts the prevalence of disability by roughly 20 percent. This change in method of administration while the WGSS is retain will further exacerbate the undercount of people with disabilities.¹⁰

⁵ Landes SD, Swenor BK, Hall JP, Forber-Pratt A. In Measuring Disability, Do Not Abandon Established US Standards. *Health Affairs Forefront*. June 25, 2025. <https://doi.org/10.1377/forefront.20250623.803072>.

⁶ Landes SD, Swenor BK, Vaitsiakhovich N. Counting disability in the National Health Interview Survey and its consequence: Comparing the American Community Survey to the Washington Group disability measures. *Disability and Health Journal*. 2024;17(2):101553.

⁷ Landes SD, Swenor BK, Hall JP. Performance of the Washington Group questions in measuring blindness and deafness. *Health Affairs Scholar*. 2024;2(11):qxae131.

⁸ Washington Group on Disability Statistics. An Introduction to the Washington Group on Disability Statistics Question Sets (WG Primer). February 2023.

⁹ The accessibility implications of an online-first design for disabled respondents specifically do not appear to have been addressed in the materials released with this docket, and we ask NCHS to do so before finalizing the 2028 instrument.

¹⁰ Saito T, Imahashi K. Characteristics of the Washington Group Short Set in Assessing Functional Difficulty Among People With Physical Disability Certificates of Vision, Hearing, and Lower-Limb Impairments in Japan. *Cureus*. 2025;17(11):e96999.

IV. Testing and Deployment of the Survey Must Include People with Disabilities

As NCHS refines and deploys the NHIS, the agency must consult members of the disability community. The agency should include people with a wide range of disabilities in the testing process, and should include families where a disabled adult taking the survey on behalf of households that have other disabled family members. The agency should also audit data for incomplete answers, accessibility problems, and response rates compared to past version of the survey. NCHS should also make this information public for advocates and other people with disabilities to weigh in.

V. Conclusion

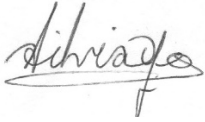
DREDF strongly opposes NCHS's elimination of important disability measures currently included in the NHIS. These changes would take place during a period of curtailed public health dollars and surveillance as states struggle to adjust to large cuts to Medicaid and health insurance exchange funding, proposed changes to preventive care coverage, and proposals to alter other major data collection surveillance tools such as the Census. The global impact of these significant changes to the nation's healthcare infrastructure and data collection happening at the same time means that data on the impact of those changes is likely to be both limited and potentially unreliable. Many sub-populations, including people with disabilities, who experience communication barriers, cognitive disabilities, and education gaps due to insufficient educational services and supports, will fall through the gaps. Law and policy makers, private healthcare entities, and the public cannot be expected to make good decisions about resource distribution or develop fair healthcare policies that benefit everyone in the country when they lack accurate data and counts of people with disabilities. This is especially true as the nation ages and because of the fundamental human tendency to resort to stereotype and ableism to justify healthcare policy when facts are not available.

We urge the NCHS and NHIS to:

- Commit to obtaining the most accurate count of disabled people in the country by retaining disability-relevant questions that are currently slated for removal, including diagnostic questions;
- Improve consistent measurement of identifiable groups of people with disabilities such as people with I/DD, people with mental health disabilities, and people with communication disabilities, which groups could benefit from the use of the ACS questions rather than the WGSS, as well as to the specialized equipment/assistive devices question as outlined above;
- Ensure that all proposed collection methods are tested to ensure that people across a wide range of disability can participate in the NHIS;
- Fully integrate disabled people in question development, field testing, survey revision, deployment, and obtaining feedback of the survey.

Thank you again for the opportunity to submit comments. Please feel free to contact me at syee@dredf.org or 510-644-2555 x5234 if you have any questions about the above.

Sincerely,

A handwritten signature in black ink, appearing to read "Silvia Yee", with a horizontal line underneath.

Silvia Yee
Policy Director, DREDF