CONSORTIUM FOR CONSTITUENTS WITH DISABILITIES

October 19, 2026

SUBMITTED ELECTRONICALLY

Dr. Erica 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:

The undersigned members and allies of the Consortium for Constituents with Disabilities (CCD) Health Task Force appreciate the opportunity to provide comments on the above referenced data collection, specifically, "Proposed Data Collection Submitted for Public Comment and Recommendations" for the National Health Interview Survey (NHIS).

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.

We are concerned about the proposed changes to the 2028 NHIS. The NHIS is the nation's longest-running household health survey and provides essential information for research and policymaking on our nation's health, including essential health care coverage and access to health care. Since 1957, the survey has collected representative data on sources of coverage, insurance adequacy and continuity, measures of disability and functional status, with behavioral and demographic controls.

NHIS information directly feeds into data that other Executive branch agencies serving people with disabilities rely on, including the Administration for Community Living (ACL), the Department of Veterans Affairs, the Social Security Administration, and the Agency for

Healthcare Research and Quality, among others. As CDC stated in this proposal, the NHIS is the "single most important source of statistics to track progress toward HHS health objectives." Additionally, the survey provides an important check on whether and how people with disabilities actually receive needed services and supports. That in turn helps lawmakers to understand when the allocation of resources intended to meet the needs of specific disabled people need to be adjusted or updated.

Since its inception, the NHIS has only been redesigned three times, which underscores the importance of consistency while collecting information. However, the current proposal would drastically remove and change the scope of many longstanding measures of disability.[1] If revised as proposed, these removals and changes will hinder policy efforts to monitor and improve the health of people with disabilities. We urge the Department to explain its processes in more detail and to reconsider its reliance on a shortened set of questions to measure disability.

I. Retain Disability-Relevant Questions

The prevalence of disability and how disability impacts people's health and wellbeing across the nation is one of the core statistical measures Congress directed NCHS to collect through the NHIS. Section 306 of the Public Health Service Act (42 U.S.C. § 242k) directs the Secretary through the NCHS to collect statistics on "the extent and nature of illness and disability of the population of the United States," including how disability impacts population health.[2] Section 306(h) specifically requires an annual data collection that expressly lists disability among the specific topics that the survey must address.[3]

The 2028 proposal removes many questions that are crucial to understanding the prevalence of specific types of disabilities and their impact on the health of disabled persons. We urge the Department to keep these questions on the Survey:

- **Age of disability onset** - eliminated. Age of disability onset is a marker of how IDD is recognized under the Developmental Disabilities Assistance and Bill of Rights Act.[4] 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 disability researchers, who

[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(b)(1)(A)-(B), 42 U.S.C. § 242k(b)(1)(A)-(B) (as amended through Pub. L. No. 119-75, enacted Feb. 3, 2026).
[3] Public Health Service Act § 306(h)(2), 42 U.S.C. § 242k(h)(2).
[4] Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. §§ 15001–15115.

have said it “matters for “research on early intervention, special education transitions, and lifetime disability trajectories.”[5]

- **Measurements of cognitive and mental health** - eliminated.
    - *“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 one general self-care question that does not capture functional status.
    - *“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?”*

- **Measurements of fatigue** – substituted with sleep-quality items that do not capture the same information.
    - *“In the past 3 months, how often did you feel very tired or exhausted?”*
    - *“Thinking about the last time you felt very tired or exhausted, how long did it last?”*
    - *“Thinking about the last time you felt this way, how would you describe the level of tiredness?”*

- **Caregiver support –** eliminated. This question is particularly important given the extreme caregiver shortage in the U.S..
    - *“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. These questions help

[5] Disability Health Equity Research Network, Comment from on CDC-2026-1387-0018 (Sept. 24, 2026), available at https://www.regulations.gov/comment/CDC-2026-1387-0018.

with planning for the present and future needs of an aging population, including disabled people who are living longer lives:

- *"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?"*

- **Transportation as a barrier to care** - eliminated. Information about transportation as a barrier to care is important because transportation barriers disproportionately impact people with disabilities and access to care.

- **Veteran-specific disability measures** – eliminated. Veteran-specific disability measures are also important to collect because functional limitation status and VA service disability status are not the same. Without this information, the survey will not capture some veterans with disabilities, including mental health disabilities from military service.

CCD recognizes that the disability community as a whole experiences barriers to healthcare and good health, but those barriers cannot be understood or addressed with simplified questions. The approximately 40 or so disability questions in the current NHIS beyond the Washington Group Short Set (WGSS) questions that the Department proposes to eliminate, some of which are listed above, help to close the gap between what the WGSS misses and the actual prevalence of disabled people in the U.S. population.

II. Consistently Measure IDD

It is unclear whether NHIS' proposed new adult questionnaire specifically collects information on IDD diagnoses. We request that the Adult Questionnaire retain diagnostic measures of IDD.

While the child draft questionnaire asks whether a doctor or other health professional has ever told the respondent that the child has an intellectual disability, as well as a measure for autism, the Adult draft questionnaire does not include these measures. It contains only a functional limitation question about "difficulty remembering or concentrating," which is not a diagnostic measure.

Retaining IDD data in NHIS is essential. ACL has been working to better capture IDD data through the NHIS, noting that "although public health surveillance of people with disabilities has improved, the lack of data on the health of people with I/DD persists."[6] ACL has explained that without more comprehensive data, issues and solutions may uniquely leave out people with IDD altogether or certain folks within the population of those with IDD who are disproportionately affected.[7] In fact, as recently as April 2026, ACL said that it is working with CDC to add new questions to the survey, but the proposal does not indicate if this collaboration occurred, whether ACL recommended any of these changes, or justification for their removal. The diagnostic measure of IDD must be retained in the Adult Questionnaire to further research and planning for a chronically underserved and undercounted population.

The proposal also removes three functional questions (noted above) that are specifically relevant to IDD difficulty learning, help with everyday tasks and age of onset of needing help with everyday tasks:

- *"Do you have difficulty learning new things, for example, at school, work, or in other places?"*
- *"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?"*
- *"You said that you have difficulty with X. Did difficulty begin before age 22?"*

These questions were added just a few years ago. Together, eliminating these questions means researchers and policymakers will lose access to longitudinal data that they had only recently started tracking to understand and fund the critical services that people with disabilities need.

III. Accurately Count Disability

In 2019, the Department substituted ACS-6 disability questions with the Washington Group Short Set (WGSS) on the NHIS Survey. Since then, the Government Accountability Office (GAO) has flagged problems with this change.[8] The proposed redesign would keep this

[6] IDD Counts, Admin. for Cmty. Living, https://acl.gov/iddcounts (last visited October 9, 2026).
[7] *Id.*
[8] U.S. Government Accountability Office. Health Care Accessibility: Further Efforts Needed to Address Barriers for People with Disabilities. GAO-26-107120. Washington, DC: GAO; December 2025, at 22-27 (Table 1 and Recommendation 2).

change. At this time, it's more important than ever to have the scaffolding of the other disability questions in the current NHIS.[9]

However, the graded response used by the WGSS creates a dilemma on how to define disability as a category. Should someone who experiences "some difficulty" in one of these areas count as a person with a disability? What about someone who experiences "some difficulty" across two or more areas? The standard WGSS definition, also recommended by the National Center for Health Statistics (NCHS), says no. It defines disability as anyone answering at least one question with "a lot of difficulty" or "cannot do at all," excluding those who report only "some difficulty" from the count. When using this definition, the WGSS underestimates the population of disabled individuals by more than 50 percent.[10] 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.[11] The WGSS's own materials acknowledge that it captures only about half of people with mental health disabilities.[12]

These flaws suggest that the WGSS, as it now stands, should not become the standard for federal disability questions. The WG-SS's underperformance also underlines the need to keep the NHIS's other current disability-related questions that provide researchers with more nuance on specific types of illness and disability. Eliminating these questions prematurely leaves only a flawed (and restrictive) set of disability questions for future research. We strongly recommend CDC delay this action until 1) a more fulsome and inclusive set of disability-related questions can be developed that resolves the shortcomings of the WGSS (and the ACS-6); and 2) until the NCHS and other relevant stewards have conducted a full evaluation in consultation with stakeholders to determine the effect dropping these questions would have on ongoing and potential new disability research. This analysis is necessary to understand what opportunities might be lost in their removal.

IV. Ensure Accessibility While Testing and Deploying the Survey

We are also concerned about the accessibility of the new survey format. Previously, an interviewer administered the survey. The proposal states that families will now complete the questionnaire themselves, online or on paper, before any interviewer follows up with them. An

[9] 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.
[10] 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.
[11] Landes SD, Swenor BK, Hall JP. Performance of the Washington Group questions in measuring blindness and deafness. Health Affairs Scholar. 2024;2(11):qxae131.
[12] Washington Group on Disability Statistics. An Introduction to the Washington Group on Disability Statistics Question Sets (WG Primer). February 2023.

online design is especially problematic for disabled adults, who are less likely than nondisabled adults to have the needed technology to take the survey.[13]

Secondly, as discussed above and 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 (using a question set that has already been found to undercount people with disabilities).[14] NCHS must ensure that access to the survey is fully accessible.

V. Include People with Disabilities at Every Stage

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. The agency should also audit data for incomplete answers, accessibility problems, and response rates compared to past versions of the survey. NCHS should also make this information public for advocates and other people with disabilities to weigh in.

VI. Conclusion

NCHS should not eliminate these critical measures of disability. In short, the proposed changes marginalize the very population the survey is intended to measure and serve. We respectfully recommend that the NCHS and NHIS:

1) Retain all disability-relevant questions, including diagnostic questions;
2) Ensure consistent measurement of people with IDD;
3) Reconsider use of WGSS with these changes;
4) Test for accessibility; and
5) Include people with disabilities at every stage of testing, revision, and deployment.

Thank you for the opportunity to submit these comments.

Sincerely,

Access Ready, Inc.

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[13] But 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.

[14] 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.

Allies for Independence
American Association of People with Disabilities
American Association on Health and Disability
American Music Therapy Association
American Network of Community Options and Resources (ANCOR)
American Physical Therapy Association
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
Assistive Technology Industry Association (ATIA)
Association of Assistive Technology Act Programs
Association of University Centers on Disabilities
Autism Society of America
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Bazelon Center for Mental Health Law
Caring Across Generations
CommunicationFIRST
Cure SMA
Disability Belongs
Disability Rights Education and Defense Fund (DREDF)
Easterseals, Inc.
Epilepsy Foundation of America
Family Voices NJ
Justice in Aging
Lakeshore Foundation
Muscular Dystrophy Association
National Alliance on Mental Illness (NAMI)
National Alliance to End Homelessness
National Association of Councils on Developmental Disabilities
National Association of County Behavioral Health and Developmental Disability Directors (NACBHDD)
National Association of State Directors of Developmental Disabilities Services
National Disability Institute
National Disability Rights Network (NDRN)
National Down Syndrome Congress (NDSC)
National Health Law Program (NHeLP)
Perkins School for the Blind
SPAN Parent Advocacy Network
TDIforAccess
The Arc of the United States