October 19, 2026

Jeffrey M. Zirger
Information Collection Review Office
Centers for Disease Control and Prevention
1600 Clifton Road NE, MS H21-8
Atlanta, GA 30329

RE: <u>DRRC Comments in Response to Proposed Redesign of the National Health Interview Survey Process (Docket No. CDC-2026-1387)</u>

Dear Mr. Zirger:

On behalf of the undersigned organizational members of the Disability and Rehabilitation Research Coalition ("DRRC"), we appreciate the opportunity to submit comments regarding the Centers for Disease Control and Prevention's ("CDC") proposed redesign of the National Health Interview Survey ("NHIS") beginning in 2028, including the proposed 2028 Sample Adult and Sample Child questionnaires.[1]

The DRRC is a coalition of national non-profit organizations committed to improving the science of medical rehabilitation, disability, and independent living, including leveraging federal resources in this regard. Our goal is to improve the ability of individuals with disabilities and chronic conditions to function and live as independently as possible.

While we recognize the need for CDC to modernize the NHIS, reduce respondent burden, improve data collection methods, and ensure that the survey remains responsive to emerging public health priorities, the DRRC is deeply concerned that the proposed 2028 redesign would make changes to longstanding measures of disability, functioning, and chronic illness that go well beyond modernization of survey administration. The proposed questionnaire substantially reduces the breadth and specificity of information collected about disability and chronic health conditions. In addition, it also removes important measures that permit researchers to understand disability across the lifespan, therefore creating a significant break in the nation's ability to monitor disability and chronic illness over time.

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[1] Centers for Disease Control and Prevention, National Center for Health Statistics, "Proposed Data Collection Submitted for Public Comment and Recommendations," 91 Fed. Reg. 53869 (Aug. 30, 2026), Docket No. CDC-2026-1387. https://www.federalregister.gov/documents/2026/08/20/2026-17040/proposed-data-collection-submitted-for-public-comment-and-recommendations

For disability and rehabilitation researchers, these concerns are particularly significant. The NHIS provides essential information about the prevalence, characteristics, causes, and consequences of disability and chronic illness across the U.S. population. It is used to examine variation in health care access and utilization, employment and participation, health outcomes, and the interaction between disability and chronic conditions. Changes to the survey therefore have implications well beyond the individual questions being added or removed.

The DRRC supports modernization of the NHIS but urges CDC to ensure that modernization does not come at the expense of the longitudinal, population-level information necessary to continue to try to understand disability and chronic illness. In particular, the DRRC urges CDC to adopt four changes to the proposed redesign:

1. **Retain Age of Disability Onset as a core disability measure;**
2. **Preserve a minimum disability and rehabilitation measurement set beyond the Washington Group Short Set;**
3. **Preserve sufficient chronic-condition detail to permit meaningful analysis of disability, underlying conditions, and comorbidities; and**
4. **Establish a predictable schedule for recurring disability, chronic-condition, rehabilitation, and participation measures.**

I. Overview and History of the NHIS

Since 1957, the NHIS has provided nationally representative information used to monitor the health of the U.S. population. The 2019 redesign specifically established a long-term structure in which certain topics would be collected annually while other topics would rotate on a regular schedule. Disability, functioning, and chronic conditions were among the continuing areas of the survey.

This structure has enabled researchers to examine changes in disability prevalence and health outcomes over time and to analyze disability in conjunction with chronic conditions, health care utilization, socioeconomic characteristics, and other factors. These data are particularly important because disability is not a single health condition. Instead, disability can result from, coexist with, or be affected by numerous physical, sensory, cognitive, developmental, and chronic health conditions.

The proposed 2028 redesign would shorten and simplify the questionnaire and move to a sequential mixed-mode approach beginning with self-administration either online or by paper, followed by in-person follow-up for selected nonresponding households. Further, CDC also proposes substantial changes to the content and its rotation.

The DRRC believes these changes can be accomplished while preserving a core set of disability and chronic-condition measures that researchers and policymakers need to maintain continuity in national disability statistics.

II. CDC Should Retain a Measure of Age of Disability Onset

The DRRC strongly urges CDC to retain a standardized measure of age or period of disability onset in the redesigned NHIS.

The current NHIS includes an age of disability onset component that provides information unavailable from the Washington Group Short Set ("WG-SS"). The current survey structure also permits researchers to distinguish among functional limitations, health conditions, and the timing of disability.[2] This information is indispensable to understanding disability across the lifespan.

The proposed questionnaire retains the existing WG-SS functional domains, including seeing, hearing, mobility, cognition, self-care, and communication. While these measures provide valuable information about functional difficulty; they do not, however, provide information about when a disability began in a person's life. Without an age of onset measure, researchers will have substantially greater difficulty distinguishing, for example:

- Disabilities present from childhood or early adulthood from disabilities acquired later in life;
- Disabilities associated with developmental or congenital conditions from those acquired through injury or disease;
- Longstanding disabilities from newly acquired disabilities;
- Disability trajectories associated with chronic and progressive conditions; and
- Differences in health care utilization, employment, education, income, and other outcomes associated with different disability trajectories.

Age of onset is also essential to disability and rehabilitation research. For instance, a person who acquires a disabling condition at age 10 may have fundamentally different educational, employment, health care, and social experiences from a person who acquires the same functional limitation at age 60. Those differences cannot be reconstructed reliably from a cross-sectional functional status measure.

The DRRC, therefore, strongly recommends that CDC retain a standardized measure of age of disability onset in the redesigned NHIS. At a minimum, CDC should retain a measure that permits researchers to identify whether disability or functional limitation was present during childhood, began during adolescence or early adulthood, or was acquired later in life. Ideally, the measure should maintain sufficient comparability with the existing NHIS age-of-onset variable to permit longitudinal analyses across the redesign.

III. Preserve a Minimum Disability and Rehabilitation Measure Set

The WG-SS was developed as a concise set of questions addressing selected functional domains. It is not designed to capture every dimension of disability, including the full range of activity limitations, participation restrictions, environmental barriers, need for assistance, or the

[2] Centers for Disease Control and Prevention, National Center for Health Statistics, 2025 National Health Interview Survey Description and NHIS questionnaire materials (September 29, 2026). https://www.cdc.gov/nchs/nhis/documentation/2026-nhis.html

relationship between impairment and functioning. As such, while the DRRC believes that the WG-SS is an important component of disability measurement; it should not become the sole foundation for understanding disability in the NHIS.

The proposed questionnaire appropriately retains the six core WG-SS domains and includes additional questions concerning activities such as errands, social participation, and work. The DRRC encourages CDC to build upon, rather than narrow, this foundation.

At a minimum, the redesigned NHIS should preserve measures sufficient to:

- Identify disability across major functional domains;
- Distinguish disability from general health status and individual medical diagnoses;
- Assess limitations in activities and participation;
- Identify important differences in disability across age groups and demographic populations;
- Measure disability onset;
- Examine the relationship between disability and chronic conditions;
- Assess the role of assistance and accommodations where appropriate; and
- Support analysis of employment, community participation, and other outcomes relevant to independence living and quality of life.

We believe that maintaining this minimum measurement framework would allow CDC to reduce respondent burden while preserving the NHIS's unique value to disability and rehabilitation researchers.

IV. Preserve Chronic Condition Data

The DRRC stresses to CDC that disability cannot be adequately understood without information about the health conditions that cause, contribute to, or coexist with disability. The NHIS has historically provided an important source of nationally representative information on chronic conditions, allowing researchers to examine the relationship between specific health conditions, functional limitations, disability, health care utilization, and community participation.

The proposed redesign would substantially reduce this information. Although the proposed 2028 questionnaire retains a core set of chronic conditions, including cardiovascular conditions, asthma, cancer, diabetes, arthritis, kidney disease, and other conditions, many of the more detailed condition-specific questions collected during the 2019-2027 period are not included in the proposed questionnaire. This represents more than a reduction in questionnaire length. It will limit researchers' ability to examine the specific conditions underlying disability, the interaction among multiple chronic conditions, and differences in disability associated with particular diagnoses or health conditions.

This information is particularly important for rehabilitation research. Individuals with disabilities frequently experience multiple chronic conditions and comorbidities, and the relationship between an underlying condition and functional limitation is not always straightforward. Researchers need to be able to examine whether disability is associated with a

particular condition, multiple comorbid conditions, the severity or duration of a condition, or combinations of physical, sensory, cognitive, and mental health conditions. Without sufficient condition-specific information, researchers will have greater difficulty studying these relationships and identifying populations with unmet rehabilitation, health care, and support needs.

The loss of detailed chronic condition data would also make it more difficult to evaluate changes in disability and variations in health status among different subpopulations over time. For example, changes in the prevalence of a functional limitation may reflect changes in the prevalence, diagnosis, treatment, or management of an underlying chronic condition rather than a change in disability itself. Maintaining information about both functional status and underlying health conditions is therefore essential to interpreting trends accurately.

The DRRC recognizes that CDC cannot retain every historical question in a redesigned, streamlined NHIS. Nevertheless, the redesigned survey should preserve a minimum set of condition-specific, chronic-illness measures sufficient to support meaningful analysis of disability, underlying conditions, and comorbidities from one set of data to the next. CDC should specifically consider the needs of disability and rehabilitation researchers when determining which chronic condition measures are retained as core or recurring content.

V. Establish a Predictable Schedule for Disability and Chronic Condition Measures

The DRRC is also concerned about the proposed departure from the established NHIS content-rotation structure. The 2019 redesign deliberately established a long-term structure under which annual core topics and rotating topics would recur on a regular schedule. CDC now proposes a more flexible approach and has indicated that the redesigned NHIS will not have a detailed schedule of rotating content established years in advance.

The absence of a predictable schedule creates substantial challenges for researchers who depend on recurring national data to evaluate trends, identify disparities, conduct longitudinal analyses, and assess the effects of federal and state policies.

The DRRC, therefore, urges CDC to establish a predictable recurring schedule for detailed disability, chronic condition, rehabilitation, and community participation measures. CDC should identify these subjects as priority recurring content rather than treating them solely as emerging topics that may be added or removed based on short-term priorities.

A predictable schedule would allow researchers to plan studies, maintain consistent analytic frameworks, identify changes in disability prevalence and outcomes, and evaluate whether disparities are improving or worsening over time.

VI. Bridge Testing Must be Conducted Before Establishing New Disability Trends

CDC is appropriately seeking public input on how these proposed changes may affect data quality, usability, and trends over time. The scope of the proposed redesign makes it critical to distinguish actual changes in population health from changes caused by the survey itself.

Because the proposed 2028 NHIS will change both its mode of administration and the content of the questionnaire, CDC should carefully evaluate how these changes affect data quality, comparability, and the ability to measure trends over time.

As part of that evaluation, the DRRC recommends that CDC conduct rigorous bridge testing of existing and proposed disability and chronic condition measures before discontinuing longstanding measures. Where feasible, existing and redesigned questions should be administered concurrently or in overlapping samples to determine whether observed differences reflect actual changes in the population or differences in question wording, survey mode, response behavior, or measurement methodology. Additionally, CDC should make the results of this testing publicly available and clearly identify where 2028 estimates cannot be directly compared with prior NHIS estimates.

This is particularly important for the integrity of disability prevalence data. A break in the historical series of data collection could otherwise be mistaken for a change in the prevalence or severity of disability when it may instead reflect a change in how disability is measured.

VII. Conclusion

The DRRC supports CDC's efforts to modernize the NHIS and recognizes the legitimate need to reduce respondent burden, improve survey methods, and address emerging health priorities. The NHIS, however, is more than a general health survey. It is a critical source of national data on disability, functioning, chronic illness, and health disparities. As such, the DRRC respectfully restates its priorities below and urges CDC to:

1. Retain age of disability onset as a core disability measure;
2. Preserve a minimum disability and rehabilitation measurement set beyond the WG-SS;
3. Preserve sufficient chronic condition detail to analyze disability, underlying conditions, and comorbidities; and
4. Establish a predictable recurring schedule for disability, chronic-condition, rehabilitation, and participation measures.

We further urge CDC to conduct and publicly report bridge testing before discontinuing longstanding measures or establishing new trend lines.

The disability and rehabilitation research community depends on the NHIS to answer fundamental questions about who experiences disability, when disability begins, what conditions contribute to it, how disability affects participation and health care access, and how these outcomes change over time. Those questions should remain answerable under the redesigned NHIS.

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Thank you for your consideration of these concerns and for your continued commitment to advancing disability and rehabilitation research. If you have any questions or if the DRRC can assist you or your colleagues, please do not hesitate to contact Peter Thomas or Michael Barnett, DRRC Co-Coordinators, at Peter.Thomas@PowersLaw.com or Michael.Barnett@PowersLaw.com, or by calling 202-349-4251.

Sincerely,

The Undersigned DRRC Members:

Alliance for NIDILRR Grantees (ANG)*
American Academy of Orthotists & Prosthetists (AAOP)
American Academy of Physical Medicine & Rehabilitation (AAPM&R)
American Association on Health and Disability (AAHD)*
American Congress of Rehabilitation Medicine (ACRM)
American Medical Rehabilitation Providers Association (AMRPA)
American Music Therapy Association
American Occupational Therapy Association (AOTA)*
American Orthotic and Prosthetic Association (AOPA)
American Physical Therapy Association (APTA)*
American Therapeutic Recreation Association (ATRA)
Association of Academic Physiatrists*
Brain Injury Association of America*
National Neurotrauma Society
Paralyzed Veterans of America
RESNA
Spina Bifida Association
United Spinal Association
VisionServe Alliance

****Indicates DRRC Steering Committee Member***