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Comment for Docket No. CDC-2026-1387

Centers for Disease Control and Prevention

Information Collection Review Office
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Thank you for the opportunity to provide comments on the proposed redesign of the 2028 National Health Interview Survey (NHIS).

Human Services Research Institute (HSRI) is a nonprofit organization that partners with public agencies to improve social services and public health. For 50 years, we have led collaborative, community-engaged research and evaluation projects to identify best practices, address challenges, and improve systems that change lives. Together with our partners at the state and national level, HSRI has pioneered person-centered data collection efforts with people with intellectual and developmental disabilities, people with physical disabilities, and older adults.

HSRI supports evidence-informed systems change and implementation projects and health care cost and outcomes transparency, often relying on the gold standard data from national sources, such as the NHIS, to provide national context and benchmarks. We understand the stated intent to minimize survey burden and costs, but this should be balanced against the need to collect essential data about the health of the population. The proposed changes to the Adult NHIS raise numerous questions about the implications for data access and quality.

Summary of Recommendations

Retain the three ACL-sponsored questions needed to identify adults with intellectual and developmental disabilities in the annual core. The learning-difficulty, receipt-of-help, and onset-before-age-22 questions capture distinct elements that cannot be reconstructed from the six Washington Group Short Set (WGSS) domains alone. Retaining all three annually is

necessary to evaluate their performance, support multi-year pooling, and produce stable estimates for this relatively small population.

Preserve the minimum disability, functioning, and condition-identification measures needed to distinguish populations and support needs. The National Center for Health Statistics (NCHS) should retain measures of mobility-equipment and personal-assistance use, upper-body and dexterity limitations, memory-specific limitations, dementia, sign-language use, and adult ADHD/ADD, or demonstrate that proposed replacement items measure the same constructs and preserve comparable estimates.

Maintain distinct measures of mental health, fatigue, and related conditions rather than treating brief symptom screeners as substitutes. Two-week symptom screeners, frequency and intensity of functional experience, lifetime professional diagnosis, medication use, and fatigue duration and intensity are scientifically distinct constructs. NCHS should retain the minimum annual-core measures needed for population surveillance and trend continuity, including measures relevant to anxiety, depression, fatigue, and CFS/ME.

Retain healthcare-access and service-use measures that permit linked analyses for people with disabilities. NCHS should reconsider removing measures of home health, rehabilitative therapies, insurance costs and disenrollment, routine care, and prescription, dental, and vision coverage because their value depends on linkage with disability, functioning, chronic-condition, and insurance data that other national sources may not replicate.

Use an accessible, transparent redesign process with bridge and mode-equivalence testing before implementation. NCHS should test online, paper, proxy, and interviewer-assisted response modes with people who have a wide range of disabilities; report response rates, breakoffs, missingness, proxy use, accessibility, and resulting estimates by mode and disability status; preserve interviewer-assisted completion; conduct bridge testing; and provide substantial revisions for further public comment.

HSRI supports modernization that improves administration while preserving the NHIS as a scientifically useful national resource. The proposed removals would affect the ability to identify people with IDD, significant support needs, mobility-support use, upper-body limitations, memory-specific limitations, dementia, anxiety and depressive disorders, fatigue and CFS/ME, ADHD/ADD, and sign-language use. They would also narrow the ability to connect these populations to healthcare access, service use, and outcomes. We respectfully request that NCHS retain questions that are necessary for population identification and continuity, consider the detailed impacts described in this comment, and explain in its response to public comments how the final questionnaire will preserve these capabilities.

HSRI offers the following detailed considerations:

1. Retain questions around disability and functioning

For the last decade, HSRI staff have worked closely with the Administration for Community Living (ACL) on the I/DD Counts Project, which aims to strengthen prevalence and health data on the population that has intellectual and developmental disabilities (IDD). This work stemmed from recognition that US federal agencies currently use data from the 1994-95 NHIS disability supplement to estimate prevalence of IDD.

The I/DD Counts Project worked closely with the National Center for Health Statistics to develop and test questions to better identify the population considered to have a developmental disability.

The NHIS age of onset question was added in 2020 and has already been used in numerous research projects and publications to parse out the IDD population and better characterize their health outcomes. Subject matter experts recognized that the Washington Group Short Set (WGSS) questions on disability and function may still fail to capture people with IDD who experience different challenges, and so ACL sponsored the development of an additional two questions, which were added to the NHIS beginning in 2026. The three questions sponsored by ACL and necessary to identify the IDD population are:

“Do you have difficulty learning new things, for example, at school, work, or in other places? Would you say no difficulty, some difficulty, a lot of difficulty, or you cannot do this at all?”

“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 [vision | hearing | mobility | cognition | self care | communication]. Did this difficulty begin before age 22?”

The NHIS does not include a single direct identifier for IDD. Researchers must use combinations of indicators to approximate the functional, support-need, and developmental-onset elements of the Developmental Disabilities Assistance and Bill of Rights Act definition. The learning question can identify difficulties not fully represented by “remembering or concentrating.” The receipt-of-help question provides direct evidence of substantial support needs in instrumental activities. The age-of-onset question distinguishes limitations beginning during the developmental period from limitations acquired later in life. None of these elements can be reconstructed reliably from the six WGSS domains alone.

These three questions must be retained in the NHIS to accurately identify people with IDD. Given the modest size of the IDD population, researchers often pool multiple years of NHIS data

to provide robust estimates; hence, these questions must be retained as part of the annual core of the survey. The learning and receipt-of-help questions were first fielded in 2026 and are scheduled for 2027. Removing them in 2028 would leave only two years of data, limiting evaluation of their performance and the ability to pool enough observations for stable estimates.

HSRI respectfully requests that NCHS retain these three questions in the annual core to support meaningful evaluation and multi-year pooling. In responding to this comment, please address the rationale for removing questions about learning difficulty, receipt of help with everyday tasks, and onset before age 22, and explain how the proposed 2028 questionnaire would identify adults with significant functional limitations and adults who may meet the DD Act definition if these items are removed.

The reduction to disability and functioning questions will also impact the ability to identify people with more significant disabilities, including people who require mobility equipment and assistance, people with upper-body functioning limitations, and people with more specific cognitive limitations. The proposed questionnaire retains the broad question, “Do you have difficulty walking or climbing steps?” but does not retain questions that identify whether a person uses equipment or receives help, including:

“Do you use any equipment or receive help for getting around?”

“Do you use any of the following... ..Cane or walker?”

“ Read if necessary: Do you use any of the following? ...Wheelchair or scooter?”*

“ Read if necessary: Do you use any of the following? ...Someone’s assistance?”*

Without these items, researchers may still identify broad mobility difficulty, but they will no longer be able to distinguish people who use different mobility supports or personal assistance. This will weaken analyses of support use, accessibility, community living, and the relationship between mobility assistance and health outcomes.

The proposed redesign also removes detailed upper-body and cognitive questions, including:

*“Do you have difficulty raising a 2-liter bottle of water or soda from waist to eye level? * Read if necessary: Would you say no difficulty, some difficulty, a lot of difficulty, or you cannot do this at all?”*

*“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? *Read if necessary: Would you say no difficulty, some difficulty, a lot of difficulty, or you cannot do this at all?”*

“Is that a difficulty with remembering, concentrating, or both?”

These questions identify limitations that the retained self-care and remembering-or-concentrating questions do not fully capture. Removing them will make it harder to identify people with dexterity or upper-body limitations and to distinguish memory difficulty from concentration difficulty. Those distinctions matter because the populations, etiologies, support needs, and implications for daily life are not interchangeable.

People with age-related functional difficulties and conditions, such as dementia, will also be harder to identify. The redesign does not include a corresponding item for:

“ Read if necessary: Have you EVER been told by a doctor or other health professional that you had ...Dementia, including Alzheimer’s disease?”*

Removing the dementia diagnosis question together with the detailed cognition questions about whether the difficulty involves remembering, concentrating, or both, how often difficulty remembering occurs, and how much a person has difficulty remembering, will make it difficult to produce accurate estimates of age-related conditions and cognitive limitations. **A broad question combining remembering and concentrating cannot determine whether a respondent has memory-specific limitations, and it cannot substitute for a condition-identification question.**

The removal of disability and functioning questions, together with condition-specific removals, also has implications for people with communication disorders and other neurodevelopmental conditions. For example, the proposed questionnaire does not retain “Do you use sign language?” and does not include corresponding adult ADHD/ADD identification questions. These changes will erode the ability to monitor the prevalence and health outcomes of these populations.

The proposed 2028 questionnaire changes, rather than simply shortens, the mental health content. Mental health conditions can be episodic, raising the question of whether a two-week period used in the GAD-2 and PHQ-2 is sufficient for population identification. These tools were developed as brief clinical screeners to identify people who may require further diagnostic evaluation. They do not measure the same constructs as lifetime diagnosis questions or the Washington Group frequency-and-intensity functioning questions.

The current questions proposed for removal include:

“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 these feelings?”

“How often do you feel depressed?”

“Thinking about the last time you felt depressed, how depressed did you feel?”

The redesign also does not retain the annual-core diagnosis questions:

“ Read if necessary: Have you EVER been told by a doctor or other health professional that you had ...Any type of anxiety disorder? * Read if necessary: Some common types of anxiety disorders include generalized anxiety disorder, social anxiety disorder, panic disorder, post-traumatic stress disorder, obsessive-compulsive disorder, and phobias.”*

“ Read if necessary: Have you EVER been told by a doctor or other health professional that you had ...Any type of depression? * Read if necessary: Some common types of depression include major depression (or major depressive disorder), bipolar depression, dysthymia, post-partum depression, and seasonal affective disorder.”*

Symptoms during a two-week period, frequency and intensity of functional experience, lifetime diagnosis, and medication use are related but scientifically distinct constructs. A negative brief screener does not establish that a person has never had an anxiety or depressive disorder, and medication questions cannot identify people who are untreated or not currently taking medication.

A 2025 Cochrane review found that using the recommended cut-off for GAD-2 resulted in a summary sensitivity of 0.53 for detecting any anxiety disorder, meaning that 47% of people with an anxiety disorder would not be identified properly using the GAD-2 alone. Likewise, the PHQ-2 misses 42% of patients with a new depression diagnosis. By removing the condition identification questions related to diagnosis of anxiety and depression, the NHIS revisions will make it difficult to produce accurate estimates of population experiences with anxiety and depression. Removing both the functioning measures and diagnosis measures will impede replication of earlier NHIS analyses, interrupt trends, and make estimates increasingly dependent on the properties of a short screening window.

The removal of the fatigue sequence will also eliminate information used in recent NCHS analyses of frequency, duration, and intensity of fatigue across groups with functional limitations. The omitted items ask how often a person felt very tired or exhausted during the past three months, how long the most recent fatigue lasted, and its intensity. These measures can identify activity-limiting experiences across diagnoses and are not replaced by the retained general pain questions. The proposed draft also has no corresponding item identifying Chronic Fatigue Syndrome (CFS) or Myalgic Encephalomyelitis (ME). Notably, the removals impact analyses that NCHS is currently producing, such as the National Health Statistics Reports No. 221 which looked at the frequency, duration, and intensity of fatigue overall and across groups with various functional limitations.

HSRI respectfully requests that NCHS consider these measurement distinctions and population-identification consequences before removing the mental health, dementia, fatigue, CFS/ME, ADHD/ADD, sign-language-use, mobility-support, upper-body, and detailed cognition items. In responding, please explain how the redesigned NHIS will identify each of these populations, preserve relevant trend analyses, and support federal surveillance and research now relying on the omitted questions. Where NCHS believes a proposed item is an adequate replacement, please address whether it measures the same construct and whether estimates will remain comparable.

2. Retain questions around access to care

Beyond the important role of the NHIS in identifying populations, the NHIS is a vital tool for researchers, policymakers, and community members to monitor health and health care access of different groups, including those with and without disabilities. The proposed revisions remove questions on receipt of care at home from a nurse or other health professional and use of physical therapy, speech therapy, occupational therapy, or other rehabilitative therapies. People with disabilities often use these services to support community living, and these measures provide important context for understanding functional outcomes and service use.

Removing questions related to health insurance premiums, reasons for disenrollment, routine care utilization, and insurance coverage of prescriptions, dental care, and vision care would also limit the ability to assess whether coverage provides access to needed services. Because NHIS allows access measures to be linked to disability, functioning, chronic conditions, and insurance, the loss is not limited to individual utilization measures. It also removes the ability to investigate whether identified populations receive the supports and health care services associated with better outcomes. Many of these linked analyses cannot be recreated from administrative claims or surveys that do not contain comparable functioning measures.

HSRI respectfully requests that NCHS reconsider the removal of the home-health, rehabilitative-therapy, insurance-cost, disenrollment, routine-care, prescription, dental, and vision measures. In responding, please address the loss of linked analyses for people with disabilities and identify any nationally representative source that would provide comparable information if these questions were removed.

3. Concerns about methodological changes

HSRI has extensive expertise in collecting survey data from people with disabilities and older adults through the National Core Indicators program. Surveys of people accessing state-funded long-term services and supports rely on interviews conducted by trained surveyors. This permits appropriate adaptations, including rewording questions to use more familiar terms for individuals, language interpretation/translation, and use of a proxy response.

A shift in methodology to online or paper responses may not work equally well for people with disabilities. Some respondents may require a screen reader or large print, assistance because of dexterity limitations, or may need help understanding questions. If people with disabilities are less likely to complete the surveys on their own, estimates may be affected by differential non-response, proxy use, missing data, or surveys not completed. The redesigned survey could introduce differential selection and nonresponse bias by disability status.

These concerns related to survey modality can and should be tested. Cognitive, usability, and field testing should intentionally include people with intellectual, cognitive, communication, sensory, physical, and mental health disabilities. The draft 2028 questionnaire does not explain how skip logic and loop elements (e.g., writing down years for each type of cancer) would be built out in a paper survey. It is not clear from the current materials whether indicators from the current iteration of the NHIS were removed due to constraints with the updated data collection methods and what alternatives have been considered to minimize loss of data.

An emerging concern related to web-based data collection is the increase in bot responses. The default approach to minimizing bot responses is to use CAPTCHA methods; however, some of these methods can create barriers for people with disabilities, and particularly those who use assistive technology to communicate. As part of the testing phase, the NCHS should closely evaluate how to uphold the integrity of web-based responses while minimizing barriers for legitimate survey respondents.

HSRI respectfully requests that NCHS publish results from testing online, paper, proxy, and interviewer-assisted responses with people who have a wide range of disabilities. The results should address response rates, proxy use, missing data, breakoffs, accessibility, and resulting disability estimates by response mode and disability status. Please explain which questions, if any, were removed because of paper-mode or skip-logic constraints, preserve interviewer-assisted options for people who cannot use self-administered modes, and describe how web-verification safeguards will avoid blocking legitimate respondents who use assistive technology or assistance.

4. Concerns about the development of the redesign

Public records about the last NHIS redesign in 2019 show a robust and extended timeline for gathering input from experts and community members, as well as iterative stages of testing across four years. In addition, the 2019 redesign process included a bridge sample that fielded the old instrument and the 2019 redesign simultaneously, allowing for direct comparisons of the old and new instruments. The 2028 proposal makes substantial changes to both questionnaire content and data-collection methods, yet comparatively little information has been shared publicly about expert review, involvement of the public in testing, including people with disabilities or a bridge design. The timeline for gathering public comment, testing revisions, and implementing the updated instrument appears to be compressed in comparison to the prior revisions of the NHIS.

Such significant changes to national survey efforts can have substantial impacts on who is represented in the data and whether data can be compared year over year. Because the redesign changes both the content of the questionnaire and the methods for gathering data simultaneously, these concerns are compounded. There are especially consequential considerations related to continuity of smaller disability population identification and health outcome trend measurement that are magnified by the need to pool multiple years of NHIS data to obtain stable estimates for many measures.

HSRI respectfully requests that NCHS take the scientific and population-identification impacts documented in this comment into account before finalizing the redesign and respond specifically to them. Please describe the participation of people with disabilities and external subject-matter experts; the criteria used to retain or remove items; the cognitive, usability, field, and bridge testing planned; and how NCHS will distinguish actual changes in health from changes caused by questionnaire content or response mode. Testing results should be reported by disability status, and substantial revisions should be made available for further public comment before implementation.

In conclusion, we sincerely hope NCHS carefully considers the input from subject matter experts and people with lived experience of disability, and considers the retention of many disability and functioning items that are essential to the identification of people with disabilities and monitoring their health outcomes. For too many years, people with disabilities have been misidentified or missing from health surveillance efforts, and we made great progress recently in rectifying these omissions; we must continue to build on this momentum by retaining these valid and reliable measures. Thank you for considering these comments.