

9/23/2026

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

RE: Docket No. CDC-2026-1387 — National Health Interview Survey (NHIS) Proposed 2028 Redesign

Dear Mr. Zirger,

The Collective for Racial & Disability Justice (CRDJ) at UCLA School of Law is an interdisciplinary research initiative focused on how law, public systems, and data shape the rights, health, and opportunities of disabled people and other communities. Our work brings together research, policy analysis, and community knowledge to improve the quality of public decision-making and strengthen the ability of communities, researchers, and policymakers to understand how government programs and policies are working in practice.

CRDJ submits these comments in response to [Docket No. CDC-2026-1387](#) concerning the National Center for Health Statistics' proposed redesign of the *National Health Interview Survey* (NHIS) beginning in 2028. NHIS is one of the federal government's most important sources of population-level information about health, disability, health care access, and health outcomes. NCHS proposes to both shorten and revise the questionnaires and to shift from an interviewer-administered model to a sequential mixed-mode design beginning with online or paper self-response. NCHS has specifically invited comment on proposed additions and removals, data quality and usability, trend measurement, and the effects of the new collection method.

We are particularly concerned about the proposed changes affecting the federal government's ability to identify and understand people with intellectual and developmental disabilities (I/DD). This concern extends beyond the loss of individual survey questions. Federal agencies have recently invested in improving national data about people with I/DD, including through questions designed to better identify adults whose age of onset, functional limitations, learning difficulties, and support needs are consistent with the population contemplated by the *Developmental Disabilities Assistance and Bill of Rights Act of 2000* ("DD Act"), [Pub. L. 106-402](#), 114 Stat. 1677 (2000). The proposed 2028 questionnaire would remove several of those measures before the newest questions have generated enough years of data to fully evaluate or use them.



These changes also do not occur in isolation. They are being proposed during a period of substantial change to the federal disability infrastructure, including the restructuring of HHS and repeated proposals to eliminate or reduce programs and research capacity associated with the DD Act. That context does not establish the purpose or motive behind the NHIS redesign. It does, however, make it especially important to understand what data capacity would be lost, what would replace it, and whether HHS has considered the cumulative effect of these changes on its ability to identify need, measure disparities, evaluate programs, enforce rights, and remain accountable to people with developmental disabilities.

CRDJ therefore urges NCHS to consider the proposed redesign through four related concerns:

- **Reversing Hard-Won Progress:** The proposed redesign would undo recent federal efforts to make people with I/DD more visible in national health data, removing newly developed measures before they have had sufficient time to establish a meaningful evidence base.
- **Weakening the Disability Evidence Infrastructure:** The loss of developmental-disability data cannot be evaluated separately from broader changes to the federal disability infrastructure, including repeated proposals to eliminate or reduce programs responsible for research, data, rights protection, systems change, and accountability.
- **Compounding Inequities in Who Gets Counted:** Reducing disability and functioning data will not affect everyone equally. The redesign risks further obscuring the experiences of people who live at the intersections of disability, race, poverty, language, geography, and other forms of marginalization.
- **Accountability Before Redesign:** NCHS has not yet provided the evidence, testing, or transparency necessary to demonstrate that the proposed redesign will preserve continuity, representation, and accountability for people with developmental disabilities, nor explained what will replace the federal data capacity it proposes to remove.

BACKGROUND

The DD Act established a national framework intended to support the independence, self-determination, inclusion, and protection of the rights of people with developmental disabilities. That framework includes State Councils on Developmental Disabilities, state Protection and Advocacy systems (P&As), University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs), and Projects of National Significance (PNS). Congress also expressly included among the purposes of the Act funding for national initiatives to collect necessary data on issues directly or indirectly relevant to the lives of people with developmental disabilities. PNS similarly is statutorily authorized to support national and state policy development through, among other activities, “data collection and analysis.”

The need for stronger population-level data on people with I/DD has been recognized within HHS for years. Since 2015, the Administration for Community Living (ACL) has led [I/DD Counts](#), a cross-agency initiative to improve estimates of I/DD prevalence and strengthen the collection, analysis, and interpretation of health data concerning people with I/DD. Improving identification of people with I/DD in NHIS became a specific component of that work, with ACL and CDC/NCHS collaborating to develop questions for use in the national survey.

That work produced several measures relevant to identifying adults whose disabilities are consistent with important elements of the DD Act's functional definition. An age-of-onset measure, first fielded in 2020, asks whether an identified functional difficulty began before age 22. Two additional ACL-sponsored measures first fielded in 2026 ask about difficulty learning new things and receipt of help with everyday tasks. These measures are not diagnostic questions and do not identify every person with I/DD. Rather, together with information about functioning, they provide information about developmental onset, learning, and support needs that cannot be derived from the Washington Group Short Set (WGSS)¹. The proposed 2028 adult questionnaire does not retain any of these three measures.

Yet, the proposed redesign is broader than these individual omissions. NCHS proposes to shorten and simplify the adult and child questionnaires and replace the current interviewer-administered approach with a sequential mixed-mode design in which households would first be asked to respond online or by paper, followed by in-person outreach to some nonresponding households. NCHS identifies rising survey costs, increasing difficulty reaching households, respondent burden, and the need for greater flexibility as reasons for the redesign. The agency acknowledges that the change raises questions about data quality, usability, and trends over time and has specifically requested public input on those issues and on proposed additions and removals from the questionnaires.

The redesign also comes during a period of significant change to the federal disability infrastructure. In March 2025, [HHS announced a department-wide reorganization](#) under which programs previously housed within ACL would be divided among other HHS components, including the Administration for Children and Families (ACF), ASPE, and CMS. The administration's [FY2026 budget](#) subsequently proposed eliminating discretionary funding for UCEDDs and DD Projects of National Significance. In the end, Congress maintained both programs in FY2026, providing \$43.119 million for UCEDDs and \$12.25 million for PNS, but the FY2027 budget proposes their elimination again. HHS's own [FY2027 budget](#) documents identify both programs among those proposed for elimination in both consecutive President's budgets.

These proposals are relevant to the data environment surrounding NHIS because federal DD programs themselves contribute to the nation's evidence infrastructure. The DD Act assigns distinct but complementary roles across the network: UCEDDs conduct research, training, and policy analysis; P&As protect and advocate for the rights of people with developmental disabilities; DD Councils support systems change and community-based planning; and Projects of National Significance support data collection, research, and national initiatives addressing

emerging needs. Through PNS, ACL currently supports three long-running national data projects—the *Residential Information Systems Project* (RISP), *StateData* from ThinkWork!, and *State of the States in I/DD*, which track services and supports, employment outcomes, and public spending. ACL has described these projects as collecting information “found nowhere else.”

Against this background, the proposed 2028 NHIS redesign is not simply a question of whether one set of survey items should replace another. It changes a population-level data source at the same time that other components of the federal infrastructure for producing, analyzing, and using information about people with I/DD are undergoing substantial restructuring or repeated proposals for elimination. The sections that follow address the implications of those changes for visibility, evidence, representation, and federal accountability.

REVERSING HARD-WON PROGRESS

For years, the federal government has recognized that people with I/DD are difficult to identify consistently in national health data. ACL launched *I/DD Counts* in 2015 as a cross-agency initiative involving CDC, CMS, NIH, ASPE, researchers, advocates, and people with lived experience. The initiative seeks to establish more accurate estimates of the prevalence of I/DD and strengthen the collection, analysis, and interpretation of health data concerning people with I/DD. In 2020, *I/DD Counts* developed a ten-year roadmap for strengthening the national I/DD data system, with NHIS identified as a specific part of that work. As recently as April 2026, ACL described its collaboration with CDC to add new NHIS questions as the first national survey effort since 1994–1995 specifically aimed at improving the collection of I/DD data.

The proposed 2028 redesign would reverse that progress almost as soon as it has begun. The current NHIS includes an age-of-onset question asking whether a reported functional difficulty began before age 22, as well as two ACL-sponsored questions first fielded in 2026 addressing difficulty learning new things and receipt of help with everyday tasks. Together with existing functioning measures, these questions provide information relevant to identifying adults whose disabilities are consistent with key elements of the DD Act definition. While the proposed 2028 questionnaire retains the WGSS¹, it eliminates all three of these measures.

These measures are not perfect, nor do they identify every person with I/DD. That is not a reason to discard them. It is a reason to continue evaluating and improving them. The learning and receipt-of-help questions will have been fielded for only two years before the proposed redesign. For a relatively small and heterogeneous population, multiple years of consistent data are often necessary to evaluate measures, pool samples, produce stable estimates, and examine differences within the population. NCHS itself has emphasized that the NHIS design allows researchers to combine multiple years of data to produce reliable estimates for population

¹ Colleagues (Forber-Pratt, Hall, Myers, Landes & Swenor) have extensively critiqued the use of the WGSS for population-level statistics. These concerns are being addressed in a separate letter as it pertains to the NHIS proposed 2028 redesign.

subgroups. The proposed redesign would interrupt that process before the newest I/DD measures have had a meaningful opportunity to establish an evidence base.

The loss is therefore greater than three survey questions. It is a loss of capacity. Without information about developmental onset, learning, and support needs, researchers and policymakers have fewer tools to identify people with I/DD in a population-level health survey and to examine their health, health care access, and outcomes over time. A population does not disappear because a federal dataset can no longer identify it. Rather, their needs and disparities become harder to document, their experiences harder to distinguish, and the consequences of public policy harder to measure.

This reversal is particularly difficult to reconcile with the federal government's own recent work. In April 2026, ACL was still presenting improved NHIS identification of people with I/DD as an accomplishment within a decade-long federal data strategy. Only months later, NCHS proposed an instrument that would remove the newly developed questions supporting that work. The public materials do not adequately explain why this investment is being abandoned, what evidence supports that decision, or what data source will replace the capacity being lost.

NCHS should retain the age-of-onset, learning, and receipt-of-help measures as stable annual content long enough to evaluate their performance and establish a meaningful longitudinal evidence base. At minimum, it should not eliminate them without first publicly explaining how the redesigned NHIS will continue to identify adults with I/DD, how continuity with the *I/DD Counts* strategy will be maintained, and what alternative will provide comparable population-level information if these measures are removed.

WEAKENING THE DISABILITY EVIDENCE INFRASTRUCTURE

The federal disability evidence infrastructure has historically drawn on multiple, complementary sources—population surveys, longitudinal studies, community-based research, administrative records, and program data. Together, these sources make it possible to identify people who may never appear in disability service systems, document unmet needs, follow changes in services and public spending, examine outcomes over time, and evaluate government policy from perspectives not contained within administrative records alone.

Several of the sources now under pressure perform precisely those functions. PNS supports three national longitudinal studies that have tracked I/DD residential supports, employment, and public spending for nearly four decades and ACL states that they produce data “found nowhere else.” UCEDDs provide a national research infrastructure spanning states and territories. The FY2027 budget proposes eliminating dedicated funding for both PNS and UCEDDs, after proposing their elimination the previous year, and reducing NIDILRR funding by \$19 million.

At the same time, HHS continues to invest in other forms of I/DD data, particularly administrative and claims-based approaches. In May 2026, ASPE published work to improve

identification of people with I/DD using Medicare and Medicaid claims, and another federal project is linking Medicaid claims with state-level sources such as the National Core Indicators (NCI) and Supports Intensity Scale (SIS). HHS's own research acknowledges the limitations of these investments: claims-based definitions depend on diagnostic and billing codes, existing federal condition flags omit potentially relevant diagnoses, and estimates vary considerably depending on the definition and data source used. Administrative data can tell us about people who are already legible to an administrative system, whereas population and community-based data can help reveal who is not.

The FY2027 budget proposes redirecting funding from programs, including UCEDDs and PNS, toward Independent Living and argues that states could use that additional flexibility to continue previously supported activities. However, this shift in funding does not, by itself, preserve the national disability evidence infrastructure. When choosing whether or not to fund projects, states cannot independently preserve decades-long national longitudinal data series, maintain consistent measures across jurisdictions, or recreate the institutional knowledge and comparability produced through sustained national investment. Once a longitudinal dataset is interrupted, later funding cannot reconstruct the missing years.

This is a matter of accountability. Data do more than describe government programs. They provide an independent basis for assessing them. Population surveys can reveal people programs fail to reach. Longitudinal studies can show what changes after funding, eligibility, or service systems change. Community-connected research can identify outcomes that administrative systems were not designed to measure. If the sources capable of revealing those gaps are weakened while evidence becomes increasingly dependent on the administrative systems being evaluated, the government may lose its capacity to detect its own blind spots.

The proposed NHIS changes cannot be assessed only in terms of whether enough questions remain to produce a disability prevalence estimate. The question is whether the federal government is preserving a sufficiently independent, appropriate, and complementary evidence system to identify need, test whether policies are working, document harms, and determine who has been left out. Weakening population-level I/DD data in NHIS while other national disability research and longitudinal-data infrastructure faces elimination or reduction compounds that risk.

Before removing these measures, NCHS and HHS should therefore assess the redesign as part of the cumulative federal disability evidence infrastructure. They should identify which existing sources can replace the functions being lost (not merely whether another source contains disability data) and explain how HHS will preserve population-level identification, longitudinal continuity, information about people outside formal service systems, and independent evaluation of policy outcomes. The central question is not whether the federal government will continue collecting data about people with disabilities. It is whether it will retain the kinds of data necessary to see who government systems are missing and to hold those systems accountable.

COMPOUNDING INEQUITIES IN WHO GETS COUNTED

The consequences of reducing disability data will not be evenly distributed. People with I/DD are not a homogeneous population and aggregate estimates can conceal substantial disparities when it comes to health, access to care, services, and outcomes. Race, ethnicity, income, language, geography, gender, and other characteristics shape how people encounter health and disability systems and whether their needs are recognized within them. A federal data system capable of identifying people with I/DD but unable to examine meaningful differences within that population is insufficient for understanding where inequities occur or whom public systems are failing.

HHS has already recognized this problem. ACL's *I/DD Counts* initiative specifically identifies the lack of demographic information in I/DD data as a major limitation. ACL explains that inadequate data make it more difficult both to identify issues that disproportionately affect people with I/DD and to identify groups within the I/DD population who are disproportionately affected. The *2025 Federal Evidence Agenda on Disability* similarly recognized disability as a demographic characteristic that should be analyzed alongside race, ethnicity, socioeconomic status, and other characteristics so that disparities within the disability population can be identified rather than obscured.

NHIS is essential for this purpose because it combines disability and health information with demographic and socioeconomic data in a nationally representative survey. NCHS currently allows users to examine NHIS estimates by characteristics including race, ethnicity, geography, and family income, and the 2019 survey design explicitly contemplated pooling multiple years of data to produce reliable estimates for population subgroups. The value of that infrastructure, however, depends on having sufficiently consistent and detailed measures to identify the population being analyzed.

This problem becomes more consequential as the population of interest becomes smaller. Analyses at the intersection of I/DD and other demographic characteristics frequently require pooling multiple years of data to produce stable estimates. Removing recently introduced I/DD measures before a meaningful longitudinal series has been established does more than reduce overall prevalence information. It narrows the ability to ask which people with I/DD are experiencing particular disparities, where those disparities are occurring, and whether they are changing over time. The people most likely to disappear analytically are often those least represented in existing datasets.

The proposed shift in how NHIS is administered creates an additional representation concern. A self-administered survey may work well for many respondents, but disability access goes beyond whether a website technically meets accessibility standards. Some people may require plain language, communication assistance, accessible paper formats, assistive technology, help entering responses, or interviewer support. The disability-focused public-comment guidance similarly recommends testing response rates, incomplete surveys, missing answers, proxy use,

and accessibility across disability groups and response modes rather than assuming the new design will affect everyone equally. NCHS itself acknowledges that the move to mixed-mode collection may affect data quality, usability, and trends over time.

These concerns should be examined intersectionally. Access to technology, reliable internet, language assistance, literacy supports, and trusted help completing government forms varies across communities. NCHS should therefore test not only whether disabled and nondisabled respondents participate differently under the new design, but whether response rates, missing data, proxy use, and completion differ across combinations of disability, race and ethnicity, language, income, age, and geography. Without that analysis, superficially neutral changes in survey administration could systematically alter which people with disabilities are represented in the resulting data.

Data determine which disparities can be demonstrated. When federal data cannot reliably distinguish the experiences of multiply marginalized people with disabilities, disparities can appear smaller, become statistically unusable, or disappear from analysis altogether—not because the inequity has been resolved, but because the evidence needed to document it has been weakened. That in turn limits the ability of communities, researchers, P&As, DD Councils, policymakers, and others to identify systemic problems and demand a response.

NCHS should therefore evaluate the proposed redesign not merely for overall disability prevalence or overall response rates, but for its ability to support disaggregated and intersectional analysis. Before finalizing the redesign, NCHS should demonstrate that the revised questionnaire and mixed-mode methodology will preserve the ability to identify disparities within the I/DD population, produce reliable estimates for smaller subgroups over time, and detect differential participation or missingness among populations already underrepresented in federal data.

ACCOUNTABILITY BEFORE REDESIGN

A redesign that changes both what NHIS measures and how people are asked to participate should not move forward on the assumption that any resulting loss of data can be addressed later. Once a longitudinal series is broken, a population becomes more difficult to identify, or a change in survey mode alters who responds, the missing information cannot be recreated. Before implementing the 2028 redesign, NCHS should therefore demonstrate with evidence that the revised survey will preserve the capacity necessary to identify people with I/DD, analyze disparities within that population, and measure change over time.

NCHS has previously treated this kind of transition with considerably greater caution. During the 2019 NHIS redesign, NCHS sought public input in 2015, 2016, and 2017, convened technical expert panels, conducted field testing, and ran the redesigned and existing questionnaires alongside one another in a national bridge sample before implementation. That bridge made it possible to compare response rates, respondent burden, and substantive estimates across the

old and new instruments. Further, NCHS cautions that changes associated with the 2019 redesign mean estimates before and after 2019 may not be comparable.

The 2028 proposal changes questionnaire content and mode of administration at the same time. NCHS states that the mixed-mode design will undergo cognitive, usability, and field testing, but the current Federal Register notice also acknowledges that important details of the 2028 and 2029 designs have not yet been finalized and that revised questionnaires and additional details will be submitted to OMB in 2027. This should be treated as an opportunity to test and correct the redesign before decisions that affect longitudinal continuity and population representation become difficult to reverse.

There is also an unresolved question about how the I/DD-related changes were made. In April 2026, ACL was still publicly describing its work with CDC to add NHIS questions as part of the *I/DD Counts* roadmap and as the first national survey effort since 1994–1995 specifically intended to improve I/DD data collection. Four months later, the proposed 2028 questionnaire omitted several measures supporting that work. NCHS's public materials do not explain what evidence led to that change, whether ACL's Administration on Disabilities (AoD) or the *I/DD Counts* initiative was consulted, how people with I/DD and the DD network were involved, or what alternative source is expected to provide the population-level information those measures were designed to produce. The absence of that explanation is particularly significant given that the federal government has spent more than a decade identifying the lack of reliable I/DD data as a policy problem.

Nor should NCHS assess these decisions solely within the boundaries of the NHIS. As discussed above, other parts of the federal disability evidence infrastructure are simultaneously being restructured, reduced, or proposed for elimination. NCHS may not control those decisions, but HHS is responsible for understanding their cumulative consequences. It is not enough to point to another dataset containing information about disability. HHS should determine whether alternative sources can perform the same functions: identifying people outside formal service systems, capturing developmental onset and support needs, permitting disaggregated population analysis, preserving longitudinal continuity, and providing evidence independent of the administrative systems being evaluated.

Before finalizing the redesign, NCHS and HHS should therefore:

Explain the decision: Publish the evidence and criteria supporting removal of the I/DD-related measures and explain how that decision is consistent with, or represents a change from, the *I/DD Counts* roadmap.

Disclose who was consulted: Identify how ACL, the AoD, people with I/DD, researchers, DD Act programs, and other relevant federal agencies were involved in developing and reviewing the proposed changes.

Test before breaking continuity: Conduct a sufficiently robust bridge or parallel study comparing the current and redesigned instruments and the different response modes before implementation, including their effects on I/DD identification, missing data, proxy response, subgroup estimates, and longitudinal comparability.

Test representation, not merely overall response: Report whether participation and data quality differ across disability, race and ethnicity, language, income, age, geography, and other relevant characteristics.

Identify genuine replacements: For each significant capacity being removed, identify whether another federal source provides comparable information.

Assess cumulative effects: Examine how the NHIS changes interact with concurrent restructuring, proposed program eliminations, and reductions elsewhere in the federal disability research and data infrastructure.

Preserve the measures while that work occurs: Maintain the recently developed I/DD measures until NCHS has completed the necessary testing, publicly reported the results, and provided an opportunity to review substantial revisions to the proposed redesign.

The burden should not fall on people with I/DD and their communities to demonstrate after implementation that a federal redesign made them harder to count, made disparities harder to document, or broke data needed to evaluate public policy. NCHS has the opportunity now to determine whether those harms can be avoided. Modernizing NHIS and reducing respondent burden are legitimate goals, but neither should be achieved by weakening the evidence necessary to understand whom government systems serve, whom they miss, and what consequences federal policy has for their lives.

CONCLUSION

The proposed 2028 NHIS redesign raises a fundamental question about whether the federal government will preserve the capacity to identify people with I/DD, understand differences within that population, measure unmet need, evaluate public policy, and hold the systems affecting their lives accountable.

For more than a decade, federal agencies invested in addressing longstanding gaps in I/DD data. NHIS became part of that effort because population-level data provide something administrative and service-system records cannot: the ability to identify and study people whether or not they are already known to Medicaid, disability programs, health systems, or other government institutions. As recently as April 2026, ACL described its collaboration with CDC on new NHIS questions as the first national survey effort since 1994–1995 specifically designed to improve I/DD data collection. The proposed redesign would begin dismantling that newly developed capacity almost immediately.

The consequences are especially concerning in the present federal context. As detailed above, this proposed loss of population-level I/DD data is occurring while other components of the disability research and evidence infrastructure face restructuring, reductions, or repeated proposals for elimination. HHS's reorganization dispersed functions previously housed within ACL across other components of the Department, while successive administration budgets have sought significant changes to the DD infrastructure. These actions need not share a common motive to produce a cumulative effect. When multiple independent and complementary sources of evidence are weakened at the same time, the result can be a government that knows less about the people most affected by its decisions precisely when that knowledge is most needed.

That harm will not be evenly distributed. People who are already poorly represented in administrative records and national datasets have the most to lose when federal data become less capable of identifying small populations and documenting differences within them. This includes people with I/DD who are disconnected from formal services and people whose experiences sit at the intersections of disability, race, poverty, language, geography, and other forms of marginalization. When those experiences cannot be reliably measured, disparities do not disappear. The evidence of them does.

Before proceeding, NCHS and HHS should be able to answer basic questions that remain unresolved: What changed between ACL's April 2026 description of the new NHIS questions as an important federal I/DD data initiative and their omission from the proposed 2028 instrument? Was ACL's Administration on Disabilities and the I/DD Counts initiative consulted, and what did they recommend? What nationally representative source will replace the capacity these questions were designed to provide? Has HHS assessed the cumulative effects of the NHIS redesign alongside changes to UCEDDs, PNS, NIDILRR, and other parts of the disability evidence infrastructure? How will long-running national datasets and population-level measures remain comparable over time? And how will HHS ensure that the people already least well represented in federal data are not further excluded from the evidence used to make decisions about their lives?

These questions deserve public answers before the redesign is finalized. CRDJ therefore urges NCHS to retain the recently developed I/DD measures while it conducts rigorous bridge and mixed-mode testing, publicly explain the evidence and consultation underlying any proposed removals, evaluate the cumulative effects on the federal disability evidence infrastructure, and provide a meaningful opportunity for public review before implementing substantial changes in 2028.

Modernizing a national survey, reducing respondent burden, and controlling costs are legitimate goals, but efficiency cannot be measured only by the number of questions removed or the cost of collecting a response. It must also account for what the government loses when information is no longer collected and who bears that loss. A federal health survey should not become more efficient by becoming less capable of identifying need, documenting inequity, and evaluating

the consequences of federal policy. The I/DD community have spent decades fighting to be counted in the systems and data that shape their lives. The federal government should build on that progress, not make their experiences easier to overlook.

If you have any questions, please feel free to contact Dr. Kate Caldwell at caldwell@law.ucla.edu.

Sincerely,

Kate Caldwell, PhD

Director of Research & Policy

Collective for Racial and Disability Justice

UCLA School of Law