



December 13, 2023

U.S. Census Bureau
Department of Commerce
4600 Silver Hill Road
Washington, DC 20233

[Submitted electronically]

Re: Census Bureau Proposed Changes to the 2025 American Community Survey Questions, Docket Number USBC-2023-0009

To whom it may concern:

The undersigned members of the Consortium for Constituents with Disabilities (CCD) Rights and Health Task Forces and friends appreciate the opportunity to provide comments on the Census Bureau's proposed changes to the 2025 American Community Survey questions.

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 free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance.

We are particularly concerned with the proposed changes related to defining disability for the purposes of the survey. While we agree that the current questions miss a substantial fraction of people with disabilities and need to be improved, we have deep concerns about both the process and the substance of the proposed changes. We urge you to pause the proposed changes and engage our communities in a more inclusive public process that is founded on two key principles:

1. **Do no harm** – Ensure that any changes to the census process carefully weigh potential consequences for people with disabilities in the areas of data collection and research and resource allocation, with the intent to minimize any potential negative outcomes; and

2. **Nothing about us, without us** – Develop a participatory and transparent public process that encourages input from people with disabilities, disability researchers, and disability advocates to build consensus around a gold standard for disability data collection going forward.

The proposed changes will not resolve existing problems with disability questions on the American Community Survey, and might make them worse

While the 6 question set used on the American Community Survey (ACS) since 2008 has become the standard for many national surveys, it has numerous well-known limitations. For example, the questions significantly undercount people with disabilities, particularly people who have mental or psychiatric conditions and/or chronic conditions as their primary disability. One recent study based on survey responses from over 2100 individuals who reported having a disability found that one in five (19.5%) would have answered no to all six ACS questions.¹ Individuals who identified their primary disability as a mental or psychiatric condition (22.7%) or as a chronic illness or disease (31.6%) were even more likely to be missed.² Another study found widespread undercounting by the ACS among youth with psychiatric and intellectual and developmental disabilities.³

We have also previously recommended that the ACS add questions for people with speech-related or other communication disabilities who cannot rely on speech to be understood, as the current questions do not effectively capture this category of disabilities. The current ACS questions also do not distinguish between people with enduring versus temporary functional difficulties,⁴ and researchers have identified differences in responses based on who in the household responds to the survey (answers for themselves or for another household member).⁵

¹ Jean P. Hall et al., *Comparing Measures of Functional Difficulty with Self-Identified Disability: Implications for Health Policy*, 41 HEALTH AFFAIRS 1433 (2022).

² *Id.*

³ Catherine Ipsen et al., *Underrepresentation of Adolescents with Respiratory, Mental Health, and Developmental Disabilities Using American Community Survey (ACS) Questions*, 11 DISABILITY & HEALTH J. 447 (2018).

⁴ Bryce Ward et al., *Health Status Changes with Transitory Disability Over Time*, 107 AM. J. PUB. HEALTH 706 (2017).

⁵ Kristen Miller, J. Brent Vickers & Paul Scanlon, Collaborating Ctr. for Questionnaire Design and Evaluation Research (CCQDER), National Ctr. for Health Statistics, *Comparison of American Community Survey and Washington Group Disability Questions* (Oct. 2022), https://wwwn.cdc.gov/qbank/report/Miller_2020_NCHS_ACS.pdf.

We recognize that the ACS questions were never intended to identify all persons with disabilities, but the uneven sensitivity to certain types of disability, in addition to the systematic undercounting of disability prevalence, skews the data landscape that informs government policies and resource distribution. Millions of people with disabilities struggle with unmet health and long-term care needs every year. Systematically undercounting people with disabilities can understate the extent of those needs, while overstating the mortality risk of disability.⁶ Those with disabilities more likely to be missed by the survey questions might find it even more difficult to secure needed resources. We thus fully agree that the Census Bureau should seek to improve the ACS disability questions.

Our concern is that the proposed switch to the Washington Group Short Set (WGSS) would not resolve many of the current limitations of the ACS-6, and may actually make some of them worse. Like the ACS-6, the WGSS performs poorly in identifying people with mental or psychiatric conditions, as well as many people with chronic conditions, such as auto-immune diseases. It also fails to measure the duration or onset of disabilities and does not resolve the limitations around proxy responses (from a different household respondent.) It does include a question related to communication challenges, which would address an ACS limitation, but another feature of the WGSS format could lead to substantially worse undercounting of people with disabilities.

In a consequential change, the WGSS would alter the response format of the ACS disability questions from a binary yes/no to graded responses (no difficulty, some difficulty, a lot of difficulty; or cannot do at all.) On the one hand, this change produces more nuanced data on the severity of functional disabilities that could help inform disability research and policy. However, the graded response also 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.⁷ It defines disability as anyone answering at least one question with “a lot of difficulty” or “cannot do at all.” Comparisons between the ACS-6 and the WGSS

⁶ Scott D. Landes, Bonnielin K. Swenor & Nastassia Vaitiakhovich, *Disability Documentation in the National Health Interview Survey and Its Consequence: Comparing the American Community Survey to the Washington Group Disability Measures* (2023), <https://www.medrxiv.org/content/10.1101/2023.10.16.23297081v1.full.pdf>.

⁷ Amy Steinweg et al., The U.S. Census Bureau, *2022 American Community Survey Content Test Evaluation Report: Disability Final Report*, 7 (Nov. 13, 2023), https://www.census.gov/content/dam/Census/library/working-papers/2023/acs/2023_Steinweg_01.pdf.

using this definition have found that the WGSS consistently identifies substantially fewer people with disabilities than the ACS-6.⁸ One study found that disability prevalence declined from 16.3% of respondents using ACS-6 to just 9.2% for respondents to the WGSS.⁹ The ACS content test from 2022 similarly found a 40% reduction in the prevalence of disability for the WGSS Test group (8.1%) when compared to the ACS-6 Control (13.9%).¹⁰ Adopting this stricter definition of disability would dramatically worsen one of the major limitations of the current ACS -- the undercounting of people with disabilities. This would further reduce the accuracy of ACS disability data and the ripple effects on resource allocation across the disability community could be profound.

We strongly oppose the use of this more restrictive definition of disability.

The Census Bureau should consider more inclusive alternative approaches

No survey will ever be able to definitively capture every aspect of disability. We recognize the term is bounded by different legal, administrative, cultural, and physiological factors, and the scope of different disabilities is too broad to capture in the limited questions that are possible on a national survey. However, we believe that reasonable steps can be taken to address shortcomings in the current ACS questions, including the undercounting, without creating an unwieldy survey tool.

The Census has considered defining disability by including individuals who respond, “some difficulty.” The ACS content test found a prevalence of 31.7% using this definition,¹¹ with other studies using similar definitions finding prevalence as high as 39.4%.¹² These two definitions based on the same underlying questions produce dramatically different pictures of the scope of disability in this nation. The final report on the ACS content test found slightly lower consistency in responses using the broader

⁸ Eric A. Lauer, Megan Henly & Rachel Coleman, *Comparing Estimates of Disability Prevalence Using Federal and International Disability Measures in National Surveillance*, 12 DISABILITY AND HEALTH JOURNAL 195 (2019); Scott D. Landes, Bonnielin K. Swenor & Nastassia Vaitiakhovich, *Disability Documentation in the National Health Interview Survey and Its Consequence: Comparing the American Community Survey to the Washington Group Disability Measures* (2023), <https://www.medrxiv.org/content/10.1101/2023.10.16.23297081v1.full.pdf>; Jean P. Hall et al., *Comparing Measures of Functional Difficulty with Self-Identified Disability: Implications for Health Policy*, 41 HEALTH AFFAIRS 1433 (2022).

⁹ Eric A. Lauer et al., *supra* note 8.

¹⁰ Note that the ACS-6 control omitted answers related to independent living, since that question is not included in the WGSS. Amy Steinweg et al., *supra* note 7, at 9.

¹¹ *Id.* at 57.

¹² Eric A. Lauer et al., *supra* note 8.

definition,¹³ but other research suggests that the broader standard performed much better in identifying a sample of people with disabilities, missing only 4.4% of sample respondents versus the stricter WGSS missing 43.1%.¹⁴ There may be certain policies, such as civil rights protections, that align better with this broader definition of disability and would more usefully inform related policy decisions.

Other potential alternatives seem not to have been deeply considered, even though they would directly address some of the known limitations and inaccuracies of both the WGSS and the current ACS questions. For example, Jean Hall and colleagues recommend testing 3 additional questions for the ACS:

The first question should simply ask whether the respondent has a mental or physical condition, impairment, or disability that affects daily activities or requires use of equipment or technology. The second should ask what the condition or conditions are and which is the main or primary condition (via either open-ended or self-categorization questions). The third should ask either age of onset, duration, or expected duration of the condition to address concerns about enduring versus transitory disability.¹⁵

Other approaches could include expanding the use of other national disability surveys, expanding the use of an extended set of WGSS disability questions, or even developing a disability-specific national survey. Before making such consequential changes that will influence decades of disability research and profoundly affect the lives of people with disabilities, these alternatives should be carefully vetted for their statistical validity, practical viability, and potential usefulness in guiding disability policy for the full range of people with disabilities in the United States. And that evaluation should be driven by people with disabilities and disability researchers in conjunction with the experts at the Census Bureau.

The potential downstream implications of changes to the ACS disability questions must be clearly and thoughtfully explored BEFORE making any changes.

The proposed changes to the ACS do not clearly explain the potential policy impacts of a dramatic reduction in disability prevalence due to the proposed shift to WGSS. The supporting statements that accompany the information request suggest only that the

¹³ Steinweg et al., *supra* note 7, at 86.

¹⁴ Hall et al., *supra* note 1.

¹⁵ *Id.* at 1440.

definition would reduce the ACS prevalence for disabilities, and might increase the comparability of U.S. Census data on disability with other nations that use the WGSS standard. They do not explain whether different definitions of disability would be used for different domestic policy purposes, or how a dramatic reduction in disability prevalence might also reduce funding for critical policies like enforcing civil rights protections, creating more affordable housing for people with disabilities to remain in their communities instead of institutions, or addressing the shortage in direct care workers who provide needed home and community-based services.

We also know that the current ACS-6 standard questions are used on more than a dozen other national disability surveys (such as the American Housing Survey, National Crime Victimization Survey, the Behavioral Risk Factor Surveillance Survey (BRFSS), and Current Population Survey). The BRFSS is a cornerstone to CDC's disability data collection, analysis, and public sharing efforts. Any shift in the ACS questions should include a detailed analysis of how the changes would affect data produced by these other surveys, as well as longitudinal data or data compiled across a number of years.

We cannot support the proposed changes – or any other alternatives – without a clearer investigation of how these definitions would be applied to policy decisions and what effects that might have on resource allocation and on ongoing disability research. The ACS questions are used to “Monitor against discrimination, and to distribute funds, provide services, and develop programs for people with disabilities.”¹⁶ This includes identifying vulnerable populations with limited health care access, quantifying the housing needs of disabled persons, allocating funds for the Low Income Home Energy Assistance Program, preparing and responding to disasters and public emergencies, planning public transit and para-transit services, enforcing against discrimination in education and public housing, and more.¹⁷ In short, major changes to the ACS data collection could have dramatic effects on people with disabilities' access to critical government supports. Any change will also disrupt longitudinal disability research due to discontinuities in data collection methodologies. It is critically important to get these changes right the first time.

¹⁶ U.S. Census Bureau, *American Community Survey: Handbook of Questions and Current Federal Uses*, 87 (Oct. 2014), https://www.census.gov/content/dam/Census/programs-surveys/acs/operations-and-administration/2014-content-review/ACS_Federal_Uses.pdf.

¹⁷ *Id.*

The Census Bureau should actively engage with representatives of the disability community, disability researchers, and other key stakeholders to consider more accurate alternatives to the proposed changes that better address the limitations in the current standards.

We urge the Census Bureau to pause the work you have done to reform the ACS questions, to seek feedback broadly from the community of researchers and people with disabilities, and to use that process to develop a set of changes that both improves the accuracy of the collected data on disability and carefully lays out how the changes might impact future policy-making, including recommendations to mitigate potentially negative outcomes. Such an impact analysis would help anticipate unintended consequences and develop trust and support for the changes among the disability community and the public at large.

We represent one of the largest coalitions of disability organizations in the nation, and yet virtually none of our members knew of these proposed changes before this fall. We appreciate that some disability groups and researchers have participated on the Census National Advisory Committee, but such consequential decisions as these proposed changes should proceed only with the robust involvement of those most likely to be directly affected by the changes. Equally important is the development of an ongoing conversation with disability groups and researchers through establishing a sub-group of disability subject matter experts as part of the Census Bureau's work.

This process should build on the work the Census Bureau has already done to evaluate the WGSS questions, including the use of graded responses and the addition of a question on communication disabilities, as well as the better capture of people with intellectual and developmental disabilities, mental health conditions, and other episodic disabilities. It should aim to identify a consensus, inclusive, statistically valid standard for the ACS that, at a minimum:

- Reduces systemic undercounting, particularly the disproportionate undercounting of certain types of disabilities;
- minimizes but clearly acknowledges its inevitable limitations,
- identifies alternative data sources researchers and policy-makers can use to address those limitations; and
- attends to how the questions align with key legal and policy definitions for disability – including the ADA definition of disability, the Social Security disability criteria, and the standard for Veterans Affairs disability compensation benefits.
- Provides clear guidance to downstream federal, state, and local public health entities on how ACS disability can be used, with explanations concerning the data's reach, limitations, and potential adaptation for related disability surveys.

We believe such a process will create a more effective, more accurate, and more actionable final product that has broad support within the community most affected by the changes.

If you have any questions or need any further information, please contact David Machledt (machledt@healthlaw.org), CCD Health Task Force co-chair.

Sincerely,

National Health Law Program