

**Comment on the Census Bureau’s Proposal to Adopt a More Restrictive
Disability Measure in the American Community Survey
(Federal Register Doc. 2023–23249)**

We, the undersigned organizations, strongly support efforts to improve the measurement of disability in federal surveys, but have grave concerns about the Census Bureau’s proposal to adopt a restrictive disability measure for use in the American Community Survey (ACS) and Puerto Rico Community Survey (PRCS). The current ACS disability statistics undercount adult disability by more than 20 million people. The proposed changes would *worsen* this undercount, cutting the already too low adult disability rate in the current ACS by roughly 40 percent, or 15 million disabled adults.

If adopted, the change would move the ACS further out of sync with other more accurate and inclusive disability statistics, and further weaken the credibility of the ACS for users, including most importantly, disabled people themselves. Under the Office of Management and Budget’s Statistical Policy Directive No. 1, the Census Bureau and other federal statistical agencies must provide “objective, accurate, and timely information that is relevant to issues of public policy” and “credible with those who use its data and information.”ⁱ Neither the current ACS disability measure nor the proposed more restrictive measure meet these standards.

The Office of Management and Budget (OMB), the Census Bureau, and the National Center for Health Statistics should 1) reject the proposed restrictive measure; 2) engage with the disability community and other stakeholders to develop a more accurate, credible, and inclusive disability measure in the ACS and PRCS, and 3) improve the measurement of disability in other federal surveys, including by establishing a comprehensive National Disability Survey that establishes a “gold standard” for disability measurement.

The Current ACS Undercounts Disabled Americans

In the most recent five-year ACS estimates, about 15 percent of adults—some 38.6 million adults—were classified as disabled.ⁱⁱ By contrast, the original Americans with Disabilities Act of 1990 put the adult disability prevalence rate at over 20 percent.ⁱⁱⁱ In a 2010 Executive Order, President Obama noted there were 54 million Americans with disabilities, a figure likely drawn from the 2005 Survey

on Income and Program Participation (SIPP).^{iv} In 2012, a Census Bureau report using the 2010 SIPP put the adult disability prevalence rate at 22.6 percent.^v Compared to these earlier estimates, which used a more comprehensive set of questions, the ACS undercounts adult disability by 20 million or more people. Because the U.S. population has become older on average over the last few decades, this is likely a conservative estimate of the undercount.

Recent research supports the conclusion that the current ACS undercounts disability by a massive amount. Among people identified as disabled in the National Survey on Health and Disability, about one in five are not classified as disabled using the current ACS measure.^{vi} Notably, a less restrictive definition, which was tested but rejected by the Census Bureau in 2022, performed much better, closing the gap to 4.4 percent.^{vii}

People with chronic illnesses, mental health conditions, and developmental disabilities, among others, are undercounted in the current ACS.^{viii} Long COVID, for example, currently impacts nearly 6 percent of American adults.^{ix} But researchers at the Urban Institute estimate the current ACS disability question set misses 40 percent of non-elderly adults with Long COVID symptoms that significantly limit their ability to carry out day-to-day activities.^x

The More Restrictive Disability Measure Proposed by the Census Bureau Is Unacceptable

Despite the large disability undercount in the ACS and its failure to capture millions of people with disabling chronic illnesses and mental health conditions, the Census Bureau is proposing to adopt an even more restrictive disability definition and is not proposing new questions related to chronic conditions or mental health.^{xi} In the 2022 ACS Content Test, this more restrictive definition classified only 8 percent of people as disabled, compared to 13 percent of people in the control group using the current ACS questions.^{xii} The Census Bureau also tested, but rejected, a less restrictive definition that classified 32 percent of people as disabled.^{xiii}

The more restrictive disability measure proposed by the Census Bureau would produce an adult disability rate in the ACS that is roughly two-thirds lower than the more accurate and inclusive disability statistics cited above. And it would cut the already too low adult disability rate in the current ACS by roughly 40

percent, or 15 million disabled adults. Among people identified as disabled in the National Survey on Health and Disability, over four in ten (43.1 percent) are not classified as disabled based on the restrictive definition proposed by the Census Bureau.^{xiv} As recently documented by the National Partnership for Women & Families, women would be especially impacted by this change as they are the majority of disabled people.^{xv}

The Census Bureau argues that the proposed disability measure “better aligns with the World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF).” This may be the case if disability is understood in narrowly “functional” terms, but the ICF definition is not limited solely to functioning.^{xvi} The proposed measure is also much narrower than the ADA’s definition of disability, especially in light of the 2008 amendments to the Act, and the growing understanding of disability as an identity. Neither the ICF nor the ADA limit disability to a measure of people with current functional limitations.

The uses of the ACS include preparing and responding to disasters, transit service planning, estimating accessible housing needs, determining funding for disability-related services and programs, and enforcing the ADA and other anti-discrimination laws.^{xvii} However well-intentioned, a change that further reduces the number of disabled people counted by the ACS will likely have unintended negative consequences in these and other areas. There is no reason to believe that further reducing the number of disabled people counted in the ACS will reduce the institutional and other barriers disabled people face, and good reason to be concerned that it will make it harder to eliminate or reduce these barriers.

The change will paint a picture of disability as a more limited and exceptional matter, one impacting fewer than one in ten US adults, rather than a more universal public issue directly experienced by more than five of them. Restrictive definitions of disability will only further entrench stereotypes and mistaken assumptions about disability.^{xviii} This is untenable.

Despite the stated goal of making ACS disability statistics more comparable internationally, the change may actually make the ACS even *less comparable* with the headline disability statistics of the vast majority of OECD countries (the most relevant comparison group of countries for US disability policy and research purposes).^{xix} According to the OECD’s most recent disability prevalence

comparison, which uses ACS disability numbers for the US, the US has a very low disability rate compared to other OECD countries, including a rate that is nearly half of the disability rates in the United Kingdom and Canada. However, given the poor showing of the US on life expectancy and related indicators, a disability measure that places the US below most other OECD countries raises questions about credibility and accuracy.^{xx} The proposed disability definition would make it even less comparable within the OECD.

There Are Feasible and More Inclusive Alternatives That the Census Bureau Must Consider

We understand that the ACS is designed to be a relatively short household survey that is typically self-administered and relies heavily on proxy responses, rather than a lengthy, specialized individual survey administered by trained interviewers. As such, it may never provide as accurate and inclusive a count of disabled people as other longer and more specialized surveys. However, it is also clear that there are feasible and more inclusive alternatives to measuring disability on the ACS than the one proposed by the Census Bureau.

For example, in their 2022 paper, Dr. Hall and her colleagues recommended that federal surveys:

... include three additional disability questions, with additional field testing and validation. 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.

Additionally, in his presentation to the Census Bureau National Advisory Committee, Andrew Houtenville, who self-identifies as a disabled person and is the Research Director of the University of New Hampshire Institute on Disability, noted that in addition to the two disability definitions tested by Census, there is another option that uses the same questions, but analyzes the answer responses in a more inclusive way that captures about 25 percent more

disabled people than the current ACS, and about twice as many as the Census proposal.^{xxi} These and other feasible, more inclusive alternatives should be considered by the Census Bureau, in consultation with the disability community and other stakeholders, before it adopts any change to the ACS.

The Federal Government Should Establish a Comprehensive National Disability Survey

The problem of undercounting disabled people is not limited to the ACS. In fact, the undercount is larger in the Current Population Survey (CPS), the primary source of US labor force, income, and poverty statistics, which uses the same questions as the ACS. We understand that the current comment request is limited to the ACS, but we also want to use this opportunity to urge a more comprehensive approach to improving the measurement of disability across federal surveys. This should include the establishment of a comprehensive National Disability Survey that establishes a “gold standard” for disability measurement.

The current ACS undercounts the number of disabled people in the United States and must be improved. But the proposed change, which was developed without input from the disability community, would make the problem worse. We urge the Census Bureau, the National Center on Health Statistics, and OMB to reject the proposed disability measure, and engage with the disability community and other stakeholders to develop a more accurate, credible, and inclusive disability measure in the ACS.^{xxii}

Signed,

Allies for Independence
American Association of People with Disabilities
American Association on Health and Disability
Autistic Self Advocacy Network
Center for Economic and Policy Research
Center for Law and Social Policy (CLASP)
Coalition on Human Needs
Common Cause
Community Living Policy Center, Brandeis University

COVID-19 Longhailer Advocacy Project
Disability & Philanthropy Forum
Disability Rights Education and Defense Fund (DREDF)
Lakeshore Foundation
National Pain Advocacy Center
National Partnership for Women & Families
NC Counts Coalition
New Disabled South
Patient-Led Research Collaborative
PFLAG National
Sjogren's Advocate
The Myalgic Encephalomyelitis Action Network
The New York Women's Foundation
TVS-Transylvania Vocational Services
Tzedek DC
Union of Concerned Scientists

ⁱ Office of Management and Budget, Statistical Policy Directive No. 1: Fundamental Responsibilities of Federal Statistical Agencies and Recognized Statistical Units, accessed December 7, 2023 at: <https://www.govinfo.gov/content/pkg/FR-2014-12-02/pdf/2014-28326.pdf>.

ⁱⁱ Calculated from US Census Bureau, “Disability Characteristics (S1810), 2018–2022 ACS 5-Year Estimates Subject,” accessed December 7, 2023 at: <https://data.census.gov/table/ACSST1Y2022.S1810?q=disability%20United%20States>.

ⁱⁱⁱ See section 2(a)(1) of the Americans with Disabilities Act as enacted in 1990 (“The Congress finds that ... some 43,000,000 Americans have one or more physical or mental disabilities, and this number is increasing as the population as a whole is growing older”). Accessed on December 8, 2023 at: <https://www.eeoc.gov/americans-disabilities-act-1990-original-text>.

^{iv} Executive Order 13548—Increasing Federal Employment of Individuals with Disabilities (July 26, 2010). Accessed on December 12, 2023 at: <https://obamawhitehouse.archives.gov/the-press-office/executive-order-increasing-federal-employment-individuals-with-disabilities>.

^v Brault, Matthew W., “Americans With Disabilities: 2010,” *Current Population Reports*, P70-131, US Census Bureau, Washington, DC, 2012. Last accessed on December 7, 2023 at: <https://www2.census.gov/library/publications/2012/demo/p70-131.pdf>. The disability prevalence rate was even higher in the 2014 SIPP, although the reasons for the increase between 2010 and 2014 are not clear. Taylor, Danielle M., “Americans With Disabilities: 2014,” *Current Population Reports*, P70-131, US Census Bureau, Washington, DC, 2018. Last accessed on December 7, 2023 at: <https://www.census.gov/content/dam/Census/library/publications/2018/demo/p70-152.pdf>.

^{vi} Hall, J., Kurth, N., Ipsen, C., Merys, E., & Goddard, K. (2022, October). Comparing Measures Of Functional Difficulty With Self-Identified Disability: Implications For Health Policy. *Health Affairs* 40(1), last accessed on December 12, 2023 at: <https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00395>.

^{vii} Ibid. For the results of the Census content test, see Steinweg, A., Young, N., Stern, S., Contard, L., & Spiers, S. 2023 American Community Survey Research and Evaluation Report Memorandum, Series ACS23-RER-12. Last accessed on December 12, 2023 at: https://www.census.gov/content/dam/Census/library/working-papers/2023/acs/2023_Steinweg_01.pdf.

^{viii} See, e.g., Ipsen C, Chambless C, Kurth N, McCormick S, Goe R, Hall J. Underrepresentation of Adolescents with Respiratory, Mental Health, and Developmental Disabilities Using American Community Survey (ACS) Questions. *Disabil Health J*. 2018;11(3):447–50, last access at: <https://www.sciencedirect.com/science/article/abs/pii/S1936657417302194>.

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- ^{ix} National Center for Health Statistics. US Census Bureau, Household Pulse Survey, 2022–2023. Long COVID. Generated interactively: from <https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>.
- ^x Popkin, S.J. & Morriss, S. (2023, November 28). Proposed Census Changes Would Drastically Undercount Disabled Americans. Urban Institute. Last accessed on December 8, 2023 at: <https://www.urban.org/urban-wire/proposed-census-changes-would-drastically-undercount-disabled-americans>.
- ^{xi} The Census Bureau is proposing a new question on communication difficulties, which is helpful, but far from sufficient to address the ACS disability undercount.
- ^{xii} Steinweg and others (2023). See also the similar findings in Scott D. Landes, Bonnielin K. Swenor, Nastassia Vaitiakhovich, Counting Disability in the National Health Interview Survey and Its Consequence: Comparing the American Community Survey to the Washington Group Disability Measures, *Disability and Health Journal*, last accessed on December 12, 2023 at <https://doi.org/10.1016/j.dhjo.2023.101553>.
- ^{xiii} Steinweg and others (2023). The less restrictive classification counted people as disabled if they responded that they had “some” or a higher level of difficulty in at least one of the functional areas; the more restrictive classification dropped people who only reported “some” difficulty in one or more functional areas.
- ^{xiv} Hall and others (2023), For the NSHD questions, see their Supplemental Appendix A, last accessed on December 12, 2023 at: https://www.healthaffairs.org/doi/suppl/10.1377/hlthaff.2022.00395/suppl_file/2022-00395_suppl_appendix.pdf. For a spreadsheet comparing questions in the current ACS, proposed ACS, NSHD and other surveys, see https://docs.google.com/spreadsheets/d/1PDSdTG0w_Klx5ceCvTIqhYB3qqiEh_4Lds1L4qiPRZ0/edit?usp=sharing.
- ^{xv} Ditkowsky, M. & Gallagher Robbins, K. (2023, December 5). New Census proposal would reduce the number of disabled women and girls counted by nearly 10 million [Blog]. Last accessed on December 5, 2023 at: <https://nationalpartnership.org/new-census-proposal-would-reduce-disabled-women-girls-counted-nearly-10-million>.
- ^{xvi} See, e.g., Rachel Hurst, “The International Disability Rights Movement and the ICF,” *Disability and Rehabilitation*, Vol. 25, No. 11-12, 572-576 (2003).
- ^{xvii} US Census Bureau, US Department of Commerce, American Community Survey Office. (2014, October). *American Community Survey: Handbook of Questions and Current Federal Uses* (p. 88). Retrieved 1 December 2023, from https://www.census.gov/content/dam/Census/programs-surveys/acs/operations-and-administration/2014-content-review/ACS_Federal_Uses.pdf.
- ^{xviii} See, e.g., Katie Eyer, Claiming Disability, *Boston University Law Review*, 101(2) (2021), last accessed on December 8, 2023 at: <https://scholarship.libraries.rutgers.edu/esploro/outputs/journalArticle/Claiming-disability/991031686466104646>.
- ^{xix} See Fig. 2.1 in OECD, *Disability, Work, and Inclusion* (October 2022), accessed on December 8, 2023 at: <https://www.oecd.org/employment/disability-work-and-inclusion-1eaa5e9c-en.htm>.
- ^{xx} See, e.g., The Commonwealth Fund, *Mirror, Mirror 2021: Reflecting Poorly—Health Care in the U.S. Compared to Other High-Income Countries* (August 2021), accessed on December 11, 2023 at: <https://www.commonwealthfund.org/publications/fund-reports/2021/aug/mirror-mirror-2021-reflecting-poorly>
- ^{xxi} Andrew Houtonville, Identifying the Population of People with Disabilities in Surveys, Presentation to the Census Bureau Advisory Committee, November 16, 2023, last accessed at: <https://www2.census.gov/about/partners/cac/nac/meetings/2023-11/identifying-the-populations-of-people-with-disabilities-in-surveys.pdf>. In his remarks, Houtonville noted that this more inclusive definition would classify 19 percent of adults as disabled.
- ^{xxii} The Census Bureau’s National Advisory Committee has also called on the Census Bureau to not adopt any changes to the current ACS disability measure until it has consulted with a “representative cross-section of diverse members of the disability community.” See <https://www.youtube.com/watch?v=2N9YoP9o5ec>.