

# An Opportunity for the Census Bureau to More Accurately Estimate the Disabled Population in the US

*How the disability measure affects resources for millions of people.*

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## OVERVIEW

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The Census Bureau's official estimate of disabled people in the US comes from [six questions about disability in the American Community Survey](#). These questions likely underestimate the disabled population.

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Policymakers at the federal, state, and local levels use the estimate [to effectively plan, fund, and evaluate programs](#) and [to enforce the Americans with Disabilities Act](#). The estimate affects [resources, supports, and discrimination protections for millions of disabled people](#).

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To ensure the ACS provides an accurate estimate, the Census Bureau should [engage the disability community, explore more comprehensive measures of disability, and evaluate the potential impacts of any proposed change](#).

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The Census Bureau is considering changing how it collects information about disability, which could significantly affect the estimated prevalence of disability in the US. The change would affect the American Community Survey (ACS), one of the most comprehensive sources of demographic and socioeconomic information on the US population. Policymakers, advocates, researchers, and others use ACS data to inform public funding decisions, plan resource and program provision, enforce regulations, and understand the lived experiences of different groups.

The Census Bureau announced a proposal to change the questions about disability in the ACS in October 2023.<sup>1</sup> That proposal was expected to reduce the Census Bureau's official estimate of disabled people from about 14 percent of the US population to about 8 percent (Steinweg et al. 2023), shrinking this estimate by roughly 18 million people. The current set of six disability questions in the ACS (ACS-6) is already considered limited in the types of disabilities it captures, and an additional underestimate of disabled people in the ACS could result in a lack of resources, supports, and discrimination protections for disabled people (Hall et al. 2022). It would also limit the ability of researchers and others to paint a clear picture of the experiences of disabled people in the US.

However, after significant feedback from researchers and the disability community, the Census Bureau announced in February 2024 that it would put that proposal on hold to deliberate further.<sup>2</sup> Now, the Census Bureau has the opportunity to meaningfully engage the disability community as it explores how to more accurately measure disability in the ACS. Given the real-world implications of the Census Bureau's disability measure, the task ahead is to consider ways to more fully capture the prevalence of disability in the US and to avoid exacerbating the current underestimate so that the disabled community can access the critical supports they need.

The proposed change would have replaced the ACS-6 questions (table 1) with a version of the Washington Group Short Set on Functioning (WG-SS) questions and would have replaced the current yes/no responses to these

questions with four scaled response options. The Census Bureau began considering the WG-SS as a possible alternative to the ACS-6 at the request of the National Center for Health Statistics at the Centers for Disease Control and Prevention, which uses the WG-SS in some of its surveys (Steinweg et al. 2023, 7). Both the WG-SS and the ACS-6 ask similar questions about functional limitations in vision, hearing, mobility, cognition, and impediments to activities of daily living such as dressing and bathing. According to the Census Bureau, the WG-SS offered two possible advantages: (1) it is the international standard recommended by the United Nations and might make it easier to compare the prevalence of disability in the US with that of other countries, and (2) it measures disability on a continuum, which may be more in line with current understandings of disability (Steinweg et al. 2023, 85). However, it is essential to weigh the importance of international comparability against domestic policy needs when considering new measures. A 2018 United Nations report acknowledges that national definitions of disability differ in meaning, scope, and severity of disability, and that countries have adopted practical definitions and thresholds for data collection based on their unique policy needs (United Nations Department of Economic and Social Affairs 2018).

**TABLE 1**  
**Six Disability Questions in the American Community Survey**

<b>Functional domain</b>	<b>Question</b>
Vision	Are you blind or do you have serious difficulty seeing even when wearing glasses?
Hearing	Are you deaf or do you have serious difficulty hearing?
Ambulation	Do you have serious difficulty walking or climbing stairs?
Cognition	Because of a physical, mental, or emotional condition do you have serious difficulty concentrating, remembering, or making decisions?
Self-care	Do you have difficulty dressing or bathing?
Independent living	Because of a physical, mental, or emotional condition do you have difficulty doing errands alone, such as visiting a doctor’s office or shopping?

Source: Author’s analysis of the American Community Survey.

The most significant consideration that the proposed change brought up was the use of scaled responses. The WG-SS questions use graded response categories on a four-point scale (“no difficulty,” “some difficulty,” “a lot of difficulty,” and “cannot do at all”), while the ACS-6 has dichotomous yes/no responses (Steinweg et al. 2023, 7). During the 2022 ACS Content Test, the Census Bureau evaluated two possible new definitions of disability based on the WG-SS. Definition 1 included only respondents who answer “a lot of difficulty” or “cannot do at all” to at least one of the seven WG-SS questions. Definition 2 also included those who respond that they have “some difficulty.” The Census Bureau’s initially recommended using the more restrictive definition 1, because it captures a more homogeneous group with a higher severity of difficulty (Steinweg et al. 2023, 19–20) We explain the significance of using scaled answer choices in box 1.

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## BOX 1

### Understanding Scaled Responses

Scaled responses have the potential to provide researchers, policymakers, and advocates with more information about the severity of limitations and disparities experienced by portions of the disabled population. However, how the Census Bureau uses these responses in its definition of disability can either include or exclude a portion of people experiencing difficulty.

For example, the Census Bureau’s proposed definition 1 disability measure would have only identified a respondent as disabled if they reported “a lot of difficulty” or “cannot do at all”; it considered those who reported “some difficulty” or “no difficulty” to not have a disability. This approach negates the usefulness of including scaled answer options as it takes what could be four data points and collapses them down to two. Research has shown that the proposed definition 1 is significantly more restrictive in who it captures than the current ACS-6 definition, which identifies respondents as disabled based on “yes” or “no” response categories (Landes et al. 2023, Lauer et al. 2019, Weeks et al. 2021, Hanass-Hancock et al. 2023). In addition, disability researchers have argued that emphasizing only “severe” functional disability could deepen hierarchical views of disability and lead to biased resource allocation (Swenor and Landes 2023). Including respondents who report “some difficulty,” as in the Census Bureau’s proposed definition 2, has the potential to capture additional respondents who may not be captured using yes/no answer choices.

Scaled responses will only provide additional granular information about the experiences of disabled people if the response data for all four answer choices are made available to the public. In its previous proposal, the Census Bureau was not yet sure if the new response data would meet its disclosure avoidance or other standards (Steinweg et al. 2023).

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## WHAT GROUPS ARE MOST AT RISK OF BEING MISSED BY THE DISABILITY ESTIMATE?

The current ACS disability measure and the WG-SS primarily focus on functional limitations with activities of daily living. This approach underestimates a significant portion of the disabled community relevant to social policy (Burkhauser et al. 2012, Burkhauser et al. 2014, Hall et al. 2022). Both the ACS-6 and the alternative WG-SS question sets have been shown to perform particularly poorly in capturing neurological disabilities, developmental disabilities, psychiatric disabilities, and chronic illnesses: In one study, the WG-SS failed to identify 43 percent of people with self-identified, enduring disabilities, while the ACS-6 failed to identify to 20 percent (Hall et al. 2022).

To avoid exacerbating this underestimate, the Census Bureau should work to understand ways to more accurately include the groups listed below in its estimates of the prevalence of disability. This should be done with meaningful engagement of these groups to better understand their experiences and how they interact with survey questions. These groups are already underestimated with the current definition and should be given particular consideration going forward.

### *People with Mitigated Disabilities*

Many people with disabilities mitigate the effects of their disability on their activities of daily living through the use of assistive technologies, medications, and the services and supports they receive from public disability programs. As

## BY THE NUMBERS

- According to current ACS estimates, there are more than 44 million disabled people in the US, about 14 percent of the total population.
- Census Bureau estimates are used to allocate more than \$2.8 trillion in federal funds to 353 programs for housing, transportation, and more. Some of these programs may use the ACS disability estimate.
- Failing to count millions of disabled people could significantly affect their access to government programs and services.

a result of these supports, a disabled person may not be captured by questions that focus only on functional limitation, since they may only face “some difficulty” in their activities of daily living on a given day, or limitations they do not feel are severe enough to warrant a “yes” answer. But capturing people with “some difficulty” in disability-prevalence measures is important, especially in the context of resource allocation and policy planning (Hanass-Hancock et al. 2023). Disability researchers have argued that emphasizing only “severe” functional disability could deepen hierarchical views of disability and lead to biased resource allocation (Swenor and Landes 2023).

Disability is a social phenomenon that encompasses more than functional ability (WHO 2002). The ADA Amendments Act specifies that mitigation does not mean that an individual is not disabled.<sup>3</sup> Disabled people whose functional limitations are mitigated may still face challenges due to their disability, such as impediments to work and discrimination. And as Hall and coauthors note, “even if people with disabilities report no functional limitations because they have adequate services and supports, it is still essential that they be included and their disabilities known so that those services and supports continue to be funded and the disparities continue to be documented” (2022).

### ***People with Psychiatric Disabilities***

According to the Substance Abuse and Mental Health Services Administration, 6 percent of all US adults (15.4 million people) have a serious mental illness (SAMHSA 2023b, 2), defined as a mental health condition “that has resulted in functional impairment, which substantially interferes with or limits one or more major life activities” (SAMHSA 2023a, 94).<sup>4</sup> However, people with psychiatric disabilities are among the groups most likely to be underestimated by the both the current ACS questions and the WG-SS (Hall et al. 2022).

It’s also important to consider how the implementation of scaled answer options could affect the ability to capture people with psychiatric abilities. The results of the 2022 ACS Content Test note that respondents considered how often an impairment was present and the existence of “good day and bad days” when considering the scaled responses (Wilson 2022). For example, one respondent said, “Because of my depression I sometimes let my hygiene go and don’t shower or dress, which is why I said, ‘some difficulty.’” It is possible that omitting individuals who report “some difficulty” to functional questions may not fully capture impairments in functioning that are recurrent or episodic, which is common in many psychiatric disabilities (Ringland et al. 2019).

### ***People with Chronic Illness***

Both the ACS-6 and WG-SS exclude many people with chronic illnesses, such as autoimmune diseases and arthritis, whose symptoms may be intermittent. This issue is particularly salient as the country grapples with an emerging disability, long COVID. In our analysis of the Urban Institute’s Well-Being and Basic Needs Survey, we found that 16.1 percent of adults with long COVID reported their symptoms impacted their day-to-day activities “a lot” (Karpman et al. 2023), but only 61 percent of these respondents reported a disability when answering the ACS-6 questions.<sup>5</sup>

## Population Subgroups

The Census Bureau noted that changes to disability questions could have varying impacts on different population subgroups, such as those with different age, race, ethnicity, or socioeconomic statuses, or even those with different types of disabilities (Steinweg et al. 2023, 87).

This raises important equity considerations about any future changes to the disability questions. Disability researchers have shown that incomplete measures of disability can lead to biased estimates of key social policy measures, such as employment rates, the share of people with disabilities receiving government benefits, and mortality risk, which make it difficult to investigate equity issues for people with disabilities (Burkhauser et al. 2012, Landes et al. 2023). The Census Bureau should conduct analyses of the impact of any forthcoming proposed measures to better understand the possible impacts on population subgroups.

## HOW DISABILITY ESTIMATES AFFECT DISABLED PEOPLE ACROSS THE US

The way that the Census Bureau decides to collect information on disability matters: Its disability measure is used not only by the Census Bureau to capture an accurate picture of the disability community in the US, but also by a wide variety of actors—including federal, state, and local agencies; disability rights advocates; and researchers—to distribute public funding, plan for programs and infrastructure, and monitor compliance with antidiscrimination laws (Steinweg et al. 2023, 84).<sup>6</sup>

Furthermore, a break in question continuity hinders the ability to measure change in prevalence over time, and may “mean that the ACS would not publish 5-year estimates for any period where some respondents were asked the old questions and others the new questions” (Steinweg et al. 2023, 85). This could limit the information that federal, state, local, and tribal entities rely on to decide how to distribute funding and plan for the provision of services. A change should only be made if it leads to more accurate measurement of disabled people. The following policy areas are directly tied to ACS estimates, and could be impacted by any changes to the disabled questions in the ACS.

### Federal Funding Formulas

It can be difficult to quantify the exact impact on program funding for each person who is not included in the Census Bureau’s disability estimate, but we know that population estimates from the Census Bureau are used to inform federal funding decisions. According to a Census Bureau analysis, data from the Decennial Census, the ACS, and annual population estimates were used to distribute more than \$2.8 trillion in funds, in whole or in part, through 353 federal programs in fiscal year 2021 (Villa Ross 2023, 2). This includes programs for housing, transportation, healthcare, and education. While these programs likely use a variety of data points to make funding decisions, some of them, particularly those designed to provide services to people with disabilities, may use the ACS disability estimates to assess how to distribute funding to meet the needs of disabled people across states and communities. For example, the US Department of Transportation’s Enhanced Mobility of Seniors and Individuals with Disabilities (Section 5310) program distributes funds “based on the number of older adults and people with disabilities in each state according to the latest available US Census data.”<sup>7</sup> This program is designed to meet the transportation needs

## POTENTIAL EFFECTS OF PROPOSED CHANGES

An underestimate of disabled people in the US could make it more difficult for:

- **federal programs** to adequately distribute funds for housing, transportation, and other programs to communities across the US;
- **federal agencies** to enforce the Americans with Disabilities Act;
- **state and local governments** to identify their residents’ unmet housing and financial needs;
- **researchers** to capture the lived experiences of people with disabilities; and
- **localities** to plan for climate disasters.

of older adults and people with disabilities. Formula fund recipients from the Community Development Block Grant Program, HOME Investment Partnerships Program, and other programs may use ACS data to meet requirements for reporting the housing needs of disabled persons in their communities. The Low-Income Home Energy Assistance Program uses ACS data on disability, among other demographic characteristics, to achieve program goals (US Census Bureau 2014, US Census Bureau 2021).

### ***Local Planning***

State and local governments look to the ACS for up-to-date information on their jurisdictions to guide planning, program evaluation, and resource allocation. For example, the City of Nashville’s annual “Community Needs Evaluation” and “Know Your Community Report” rely heavily on ACS estimates to identify needs and offer insights on resident’s socioeconomic well-being. In addition, the Nashville government used census and ACS data on the number of senior and disabled homeowners in Davidson County who qualified for property tax relief and tax freeze programs to determine that a considerable number of eligible homeowners were not applying for the programs. They then used that information to develop an informational campaign to increase program participation.<sup>8</sup> The town of Wenham, Massachusetts, used ACS disability data, among other information, to help prioritize and address housing needs (US Census Bureau 2020). Similar policymaking plays out in localities across the country, making it difficult to fully quantify the impact that a change in the disability questions—especially one that may result in a drop in the estimated prevalence of disability—will have on programs serving and protecting disabled people.

### ***Emergency Preparedness***

Emergency planning, preparedness, and response programs across multiple federal, state, and local agencies rely on disability data from the ACS to ensure appropriate assistance for people with disabilities. For example, the Centers for Disease Control and Prevention’s Office of Public Health Preparedness notes that it uses disability data to estimate the size and nature of the populations that may be affected (US Census Bureau). The ACS disability estimate is also one of 20 indicators for community resilience identified by the Federal Emergency Management Agency to help in resource distribution and planning (Federal Emergency Management Agency 2022). Particularly after Hurricane Katrina, it became clear that people with disabilities face vastly different experiences in evacuation, shelter, and recovery than people without disabilities (Consortium for Citizens with Disabilities 2014). As climate change continues to exacerbate environmental emergencies, preparedness will only continue to be more essential.

### ***Employment Statistics***

The US Department of Labor uses the ACS and Current Population Survey (which uses the same disability questions as the ACS) to determine the unemployment rate and other workforce statistics for the disabled population.<sup>9</sup> Other producers of widely used disability statistics, such as the federally funded Institute on Disability, also use ACS estimates to illustrate dimensions of the disabled experience.<sup>10</sup> By underestimating number of disabled people, the Census Bureau’s proposed disability measure could make it difficult for these organizations to capture a full picture of the employment landscape for disabled people or adequately plan for necessary supports or resources.

### ***ADA Compliance***

The US Department of Justice Civil Rights Division uses ACS disability data to enforce the Americans with Disabilities Act by evaluating the effects of proposed new regulatory changes or discriminatory policies and practices, including discrimination in housing (US Census Bureau 2014). The US Department of Housing and Urban Development has stated that compliance reviews for public housing agencies use ACS data to assess the need for accessible units in specific communities (Pratt 2011).

## Research

Limitations in available data on disability affect what can be determined about the disability population through research and analysis. In our previous work, we ran into challenges capturing the experiences of the disabled community because of the limited nature of census data.<sup>11</sup> Any future change should look to strengthen the available data by making it a more complete estimate of the disabled community.

Because of all these critical uses of ACS disability data, the Census Bureau should look to quantify the impacts of any change to its disability measures, especially with regards to how it may alter the estimated prevalence of disability in the US.

## RECOMMENDATIONS

The Census Bureau's official measure of disability has real-world implications for disabled people. Therefore, any change to the disability questions in the American Community Survey should capture a more complete view of people with disabilities rather than further underestimate the number of people with a disability. To ensure disabled people can access the critical supports they need, we recommend Census Bureau take the following steps:

- **Consult with disabled researchers and advocates when evaluating disability measurements.** Any future new measure should be undertaken only with deep and meaningful engagement with the disability community. In the wake of the Census Bureau's previous proposal, the disability community expressed significant concerns that the Census Bureau did not make a good faith effort to listen to and fully consider the experiences of a diverse group of disabled people in the decisionmaking process (Consortium for Citizens with Disabilities 2023). Disability researchers have raised similar concerns about whether the National Center for Health Statistics engaged the disability community prior to recommending the new measure.<sup>12</sup> In its announcement of the pause, Robert Santos, the director of the Census Bureau, acknowledged these concerns and committed to more fully engaging with the disability community as it considers changes to its measures going forward.<sup>13</sup> We encourage the Census Bureau to continue to find new ways to more thoroughly engage the disability community, particularly people from historically underrepresented groups. The Census Bureau should particularly consider ways to make engagement opportunities more accessible for people with a wide variety of disability types by ensuring appropriate accommodations, such as ASL or CART interpreters, are available.<sup>14</sup> For engagement on proposed changes to be truly meaningful, disabled individuals should have the opportunity to fully participate in a dialogue around any proposed measures.
- **Explore alternative survey questions that would more accurately and fully capture the disabled population.** The current and proposed set of disability questions do not reflect the entire disability community, but still are used as a primary tool in developing policy and research about disabled people. While measuring impairments in activities of daily living represents an improvement over past frameworks of disability that were more focused on specific medical diagnoses, focusing only on functional disability is not comprehensive and will lead to an artificial underestimate.<sup>15</sup> Any future change to the ACS disability questions should seek to capture a more complete picture of disabled people, either by adding questions to the existing set of functional disability measures or considering other approaches. It may also be beneficial to measure disability in a way that is more in line with the ADA's discrimination protections, to further investigate the nature and duration of a disability, and to gather additional information about the lived experiences of disabled people.
- **Evaluate the potential impacts of any future proposed change in disability questions.** The Census Bureau has the opportunity to evaluate how any future change will impact the lives of disabled people. Because ACS estimates are used as inputs for critical activities such as distributing public funding, planning for programs and infrastructure, and monitoring compliance with antidiscrimination laws, the Census Bureau and Office of Management and Budget, which is charged with approving any proposed changes, should consider how a

change in its questions may impact these activities and the ability of disabled people to receive the supports and protections they need. It should also explore how changes may affect specific disability types, state-level disabled population estimates, and specific sociodemographic groups (e.g. race, ethnic, gender, or age groups), and consider the potential equity implications of any change.

## NOTES

- <sup>1</sup> “Agency Information Collection Activities; Submission to the Office of Management and Budget (OMB) for Review and Approval; Comment Request American Community Survey and Puerto Rico Community Survey,” US Census Bureau, accessed February 8, 2024, <https://www.federalregister.gov/documents/2023/10/20/2023-23249/agency-information-collection-activities-submission-to-the-office-of-management-and-budget-omb-for>.
- <sup>2</sup> Robert Santos, “Next Steps on the American Community Survey Disability Questions,” accessed February 6, 2024, <https://www.census.gov/newsroom/blogs/director/2024/02/next-steps-on-acs-disability-questions.html>.
- <sup>3</sup> ADA Amendments Act, 42 U.S.C. § 12102.
- <sup>4</sup> The functional impairments counted by the National Survey on Drug Use and Health include essential components of psychiatric disability beyond those included in the ACS-6 and WG-SS. The *2022 National Survey on Drug Use and Health: Methodological Summary and Definitions* states “Functional impairment is defined as difficulties that substantially interfere with or limit role functioning in one or more major life activities including basic daily living skills (e.g., eating, bathing, dressing); instrumental living skills (e.g., maintaining a household, managing money, getting around the community, taking prescribed medication); and functioning in social, family, and vocational/educational contexts,” (SAMHSA, 2023a, 94).
- <sup>5</sup> This analysis was limited by a small sample size (178 respondents). Susan J. Popkin and Sarah Morriss, “Proposed Census Changes Would Drastically Undercount Disabled Americans,” *Urban Wire* (blog), Urban Institute, November 28, 2023, <https://www.urban.org/urban-wire/proposed-census-changes-would-dramatically-undercount-disabled-americans>.
- <sup>6</sup> “Why We Ask Questions About ... Disability,” US Census Bureau, accessed January 19, 2024, <https://www.census.gov/acs/www/about/why-we-ask-each-question/disability/>.
- <sup>7</sup> “Enhanced Mobility of Seniors & Individuals with Disabilities - Section 5310,” US Department of Transportation, accessed January 19, 2024, <https://www.transit.dot.gov/funding/grants/enhanced-mobility-seniors-individuals-disabilities-section-5310>.
- <sup>8</sup> “Metropolitan Social Services Uses ACS Data to Understand and Support Older Residents in Need,” US Census Bureau, accessed January 19, 2024, <https://www.census.gov/programs-surveys/acs/about/acs-data-stories/mss-nashville.html>.
- <sup>9</sup> “Employment-Population Ratio Map,” US Department of Labor, accessed January 19, 2024, <https://www.dol.gov/agencies/odep/research-evaluation/EPRmap>.
- <sup>10</sup> “Disability Statistics and Demographics Rehabilitation Research and Training Center (StatsRRTC),” University of New Hampshire, accessed January 19, 2024, <https://iod.unh.edu/disability-statistics-demographics-rehabilitation-research-training-center-statsrtc>.
- <sup>11</sup> Amanda Hermans, “How Can Research Better Represent People with Disabilities?” *Urban Wire* (blog), Urban Institute, January 3, 2023, <https://www.urban.org/urban-wire/how-can-research-better-represent-people-disabilities>.
- <sup>12</sup> Bonnielin Swenor, Jean Hall, and Scott Landes, “No Evidence to Proceed: Justification to Stop the Implementation of the Washington Group Short Set (WG-SS) Questions to Measure Disability in the American Community Survey (ACS),” (self-pub., Google Docs, 2024), [https://drive.google.com/file/d/1LGLHZX9KBg\\_am51EBowbwGKs6K5jorrJ/view](https://drive.google.com/file/d/1LGLHZX9KBg_am51EBowbwGKs6K5jorrJ/view).
- <sup>13</sup> Robert Santos, “Next Steps on the American Community Survey Disability Questions,” accessed February 6, 2024, <https://www.census.gov/newsroom/blogs/director/2024/02/next-steps-on-acs-disability-questions.html>.
- <sup>14</sup> Lauren Farrell and Susan J. Popkin, “‘Nothing about Us without Us’: How Community Engagement Can Help Create Disability-Forward Research,” *Urban Wire* (blog), Urban Institute, February 2, 2023, <https://www.urban.org/urban-wire/nothing-about-us-without-us-how-community-engagement-can-help-create-disability-forward>.
- <sup>15</sup> Amanda Hermans, “How Can Research Better Represent People with Disabilities?” *Urban Wire* (blog), Urban Institute, January 3, 2023, <https://www.urban.org/urban-wire/how-can-research-better-represent-people-disabilities>.

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