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Proposed Census Changes Would Drastically Undercount Disabled Americans

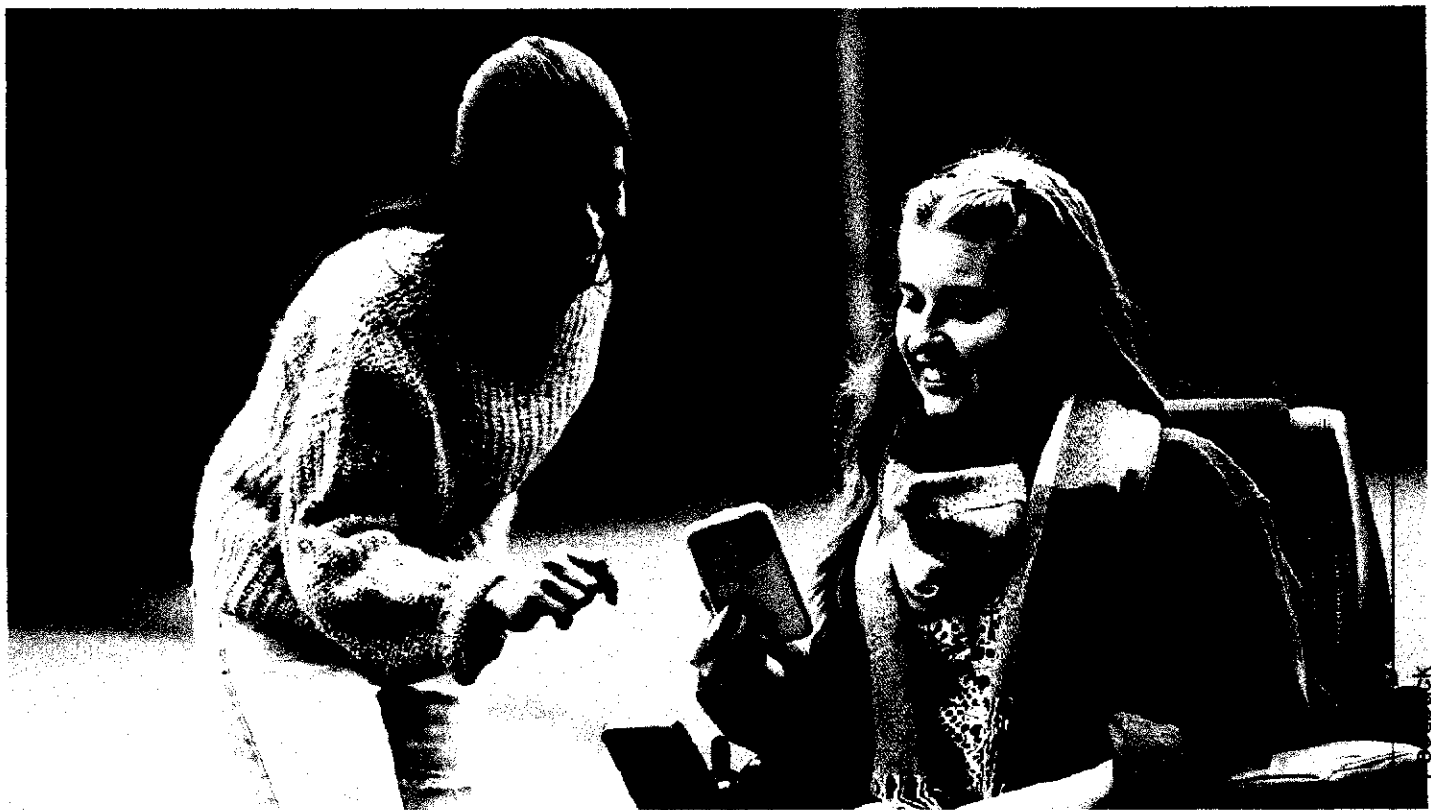
Feedback

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November 28, 2023



An earlier version of this blog post stated the Census Bureau had postponed its proposed changes. We have updated the post to clarify that the National Advisory Committee has recommended the bureau consider postponing the changes (corrected 11/29/2023).



(Dougal Waters/Getty Images)

Each year, the US Census Bureau undercounts the number of disabled people in the US. A proposed change to the census's survey methods would further reduce the number of people counted, effectively halving its current estimates.

As disabled researchers, this issue hits close to home: under both the current and proposed definitions of disability, we are among the millions of Americans not counted. An accurate estimate of disabled people is critical to ensuring programs that support people with disabilities—including income supports (e.g., Supplemental Security Income), educational programs, and programs that support independent living—are allocated the federal funding they need. It also affects funding for research on disability, including emerging disabilities like Long COVID.

To develop inclusive policies and plans, policymakers need accurate information about how many people are disabled.

Current census survey methods fail to accurately count the disabled population

Currently, the Census Bureau uses a set of six questions from the American Community Survey—known as the ACS-6—to measure disability. These questions ask whether

respondents experience functional limitations in hearing, vision, cognition, or walking, or difficulty with daily living activities (e.g., dressing, bathing, doing errands).

Many conditions are not captured by these functional definitions, including neurological disabilities like ADHD and autism, intellectual or developmental disabilities, psychiatric disabilities, and chronic illness like autoimmune diseases. Though some conditions have intermittent effects on people's ability to function, this reality is not captured in the ACS language. Researchers have estimated that the current ACS-6 framework fails to identify almost 20 percent of people who identify as having a disability.

Other factors make it difficult to obtain an accurate count of the disabled population. There is still stigma associated with being disabled, and respondents may be hesitant to identify themselves as having a disability. Moreover, disability is an evolving concept. For example, Long COVID is an emerging type of disability; how it affects people and the number of people affected are only now becoming clear.

In our own research, we have used the Urban Institute's Well-Being and Basic Needs Survey (WBNS) to assess how well the ACS-6 works. We found that among adults under age 65 who self-identified as being severely affected by Long COVID on the WBNS—that is, their symptoms significantly reduced their ability to carry out day-to-day activities—only 60 percent reported a disability when answering the ACS-6 questions. Given that Long COVID affects millions of Americans, this discrepancy has important policy implications; policymakers rely on the bureau's estimates to plan and adequately fund programs that address the needs of this and other disabled populations.

The undercounting of disability in federal surveys has made it difficult to investigate policies that affect people with disabilities in our research. We've used the Current Population Survey (CPS) to try to measure the barriers disabled people face in finding affordable housing. We found approximately 18 million disabled people are eligible for housing assistance but do not receive it. However, the CPS uses the ACS-6 to identify people with disabilities. The CPS also excludes people living in institutions, as well as people who are incarcerated or unhoused, many of whom are disabled. Because of the limitations of the ACS-6, we know our analysis of housing barriers did not provide a complete picture.

Proposed census changes would capture even fewer disabled people

Recently proposed changes to the Census Bureau's survey methods will make it even more difficult to accurately count disabled Americans. The bureau has recommended switching from the ACS-6 to the Washington Group Short Set on Functioning questions (WG-SS) while keeping a modified version of the ACS question that asks about a respondent's ability to run errands. The WG-SS represents an attempt to improve the measurement of disability across cultures and has been adopted by the World Health Organization. However, these questions have the same limitations as the ACS-6, focusing on limitations in functioning and specific activities of daily living that ultimately exclude many types of disability. In addition, these new questions ask respondents to rate the level of difficulty they experience in each area on a scale from "no difficulty" to "cannot do at all." According to this new proposal, the census would only count a respondent as disabled if they select "a lot of difficulty" or "cannot do at all" on a given question, thereby excluding those who experience "some difficulty."

Research has shown that this restrictive definition fails to capture 43 percent of people who self-identify as having a disability and ultimately identifies fewer people than the original ACS-6. Furthermore, the bureau's own analysis shows this change will drastically undercount people with disabilities, cutting the estimated percentage of disabled people in the US from 14 percent to 8 percent. Failing to count tens of millions of disabled people could significantly affect their access to government programs and services and impede efforts to advance equity.

On November 16, Susan Popkin presented at the National Advisory Committee's Fall Meeting about other approaches to measuring disability the bureau could explore. Using Urban's WBNS, we are currently investigating how adding a broader disability question to the ACS-6, or a question about whether children in a household are covered by Individual Education Plans or have Section 504 accommodations, could result in a more accurate count of disabled people. Other researchers are looking at alternatives to the ACS-6 that would capture a broader range of disabilities.

Following that meeting and pushback from many in the disability community, the National Advisory Committee has recommended that the Census Bureau postpone the proposed changes to its disability survey methods and "engage with disability advocacy organizations and communities to improve future Census Bureau engagements." As the bureau considers this decision, we hope they will take this time to consult with researchers and advocates in the disability community and continue to explore alternative survey methods that more accurately reflect the realities of disability in the US.

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