Are We Accurately Counting the Disabled Population in the United States?

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KEY FINDINGS

- The way surveys ask about disability affects the accuracy of the count of disabled people in the United States (U.S.).
- In the National Health Interview Survey (NHIS), more than half of adults who identified a disability using the American Community Survey (ACS) disability questions were undercounted by the Washington Group Short Set (WG-SS) questions.
- The WG-SS questions were more likely to identify people as disabled if they experienced multiple disabilities and undercount those with one disability status.
- Use of the WG-SS questions to measure disability prevents the NHIS from fulfilling its stated objective to monitor the health of the U.S. population.
- Federal agencies conducting national surveys must use measures that provide a more accurate and inclusive count of the disabled population in the U.S.

Disabled people make up a large portion of American society (26.8%), yet health disparities for this subpopulation remain under-addressed. Disabled adults in the United States (U.S.) have a higher prevalence of chronic health conditions, including heart disease, hypertension, diabetes, and cancer. These disparities originate in part from structural ableism, which is observed in an array of socioeconomic disadvantages (e.g., high rate of unemployment) and barriers to accessing healthcare services (e.g., lack of accessible medical environments and disability discrimination in medical settings). Tackling these problems requires effective public health and disability policies that cannot be developed without standardized and accurate disability data.

The National Health Interview Survey (NHIS) is an annual nationally representative cross-sectional survey providing data on health and healthcare outcomes for the non-institutionalized U.S. population, including those with disabilities. The U.S. Centers for Disease Control and Prevention (CDC) states that the primary objective of the NHIS is to provide data for “monitor[ing] the health of the U.S. population.” As such, the NHIS is one of the crucial sources of data for understanding health and healthcare trends among the U.S. population, including among disabled people. Before 2019, the NHIS...
used only the American Community Survey (ACS) disability questions to measure disability. For two years (2011 and 2012), the NHIS included both the ACS questions and the Washington Group Short Set (WG-SS) questions in the survey. In 2019, the NHIS switched to using only the WG-SS questions to measure disability. Question wording and response options for each survey are included in the Data and Methods section at the end of this brief. In short, there are two key differences between the two groups of questions. First, the ACS questions were designed to measure disability and endorsed by the U.S. Department of Health and Human Services (HHS) to do so.7 The WG-SS questions were not.8 Second, the ACS questions use a straightforward yes/no answer format with anyone who answers yes counted as disabled. The WG-SS uses a scaled answer format that can create uncertainty for survey respondents and researchers regarding who will be/should be counted as disabled.9,10,11 It is reasonable to think that the WG-SS may undercount people with disabilities,11,12 preventing the NHIS from accurately tracking health outcomes of the disabled population.

This brief summarizes findings from our recently published study that compared the prevalence of the disabled population estimated in the NHIS by using the WG-SS questions versus the ACS questions. To ensure a direct comparison of the two question sets, we used the 2011-2012 NHIS data because those are the only years when respondents were asked both the ACS and WG–SS questions.


We found that the WG-SS undercounted more than half of adult respondents aged 18 and over who reported being disabled in the ACS questions (8.1% versus 17.0%). On a population scale, this means that using the WG-SS questions artificially reduced the estimated size of the adult disabled population by 21 million (Figure 1). Who were these uncounted disabled people? Among respondents with disability in the ACS questions, 29.13% with one disability status, 54.96% with two disability statuses, and 75.22% with three or more disability statuses were counted as disabled in the WG-SS questions. In other words, WG-SS questions were more likely to undercount those with one disability status.

![Figure 1: Comparative Prevalence of the U.S. Disabled Population Aged 18 and Over Identified by ACS and WG-SS Questions in 2011–2012.](image)

*Data Source:* The estimation of the U.S. adult population aged 18 and over in 2011–2012 is from the USAFacts. The estimation of the disabled population was made based on the data from the National Health Interview Survey, 2011–2012; N=24,694.
These results should not be surprising, as the WG-SS openly states that its questions were not designed to identify all disabled people.\textsuperscript{8,13} Knowingly measuring disability with questions that were not intended to identify all disabled people contradicts the purpose of the NHIS in collecting nationally representative disability data that policymakers can use to tailor effective public health strategies.

**The Federal Government Must Use Measures that Accurately Count the U.S. Disabled Population**

Our findings suggest that the WG-SS questions dramatically reduced NHIS’s estimates of disability and undercounted more than half of the adult disabled people in the U.S. As a result, using the WG-SS prevents the NHIS from fulfilling its primary objective – to monitor the health of the U.S. population – for the disabled population. It is simply impossible to monitor the health of a population that is undercounted by half. A proposed similar switch to WG-SS disability questions in other national surveys, such as the American Community Survey,\textsuperscript{14} is alarming and will impede abilities to accurately count this demographic group. Thus, researchers and policymakers will not be able to develop and evaluate the interventions aimed at ensuring equity for all Americans with disabilities.\textsuperscript{15}

It is concerning that the U.S. Census Bureau, at the recommendation of the National Center for Health Statistics, which houses the Secretariat of the Washington Group, is also considering switching from using the ACS disability questions to using the WG-SS in the American Community Survey.\textsuperscript{14} Any underestimation of the disabled population in these data will have dramatic consequences, such as massive cuts in government spending on health and social welfare programs. This would worsen health disparities among this highly marginalized population, especially during public health crises such as the COVID-19 pandemic.\textsuperscript{15}

Instead of replacing the ACS questions in national data with the inferior WG-SS questions, efforts should be made to improve data collection on disability. Admittedly, neither the ACS or WG-SS include a sufficient set of questions, as both do not count people with psychosocial, intellectual, and developmental disabilities. Yet, instead of changing from one insufficient set of questions (ACS) to a grossly inferior set of questions (WG-SS), similar to what is being done to improve measurement of race-ethnicity in federal statistics,\textsuperscript{16} the federal government should instead focus on actively engaging the U.S. disabled community in efforts to develop new measures that provide a more accurate and inclusive count of the disabled population.

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**Data and Methods**

This study used the 2011 – 2012 National Health Interview Survey (NHIS), a cross-sectional household interview survey on the U.S. civilian noninstitutionalized population. The sample included 24,694 adults ages 18-85. The ACS disability set includes six items: 1) Are you deaf or do you have serious difficulty hearing? 2) Are you blind or do you have serious difficulty seeing, even when wearing glasses? 3) Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older) 4) Do you have serious difficulty walking or climbing stairs? (5 years old or older) 5) Do you have difficulty dressing or bathing? (5 years old or older) 6) Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping? (15 years old or older). Each of these measures uses a
dichotomous scale (Yes/No). The **WG-SS questions** include six items: 1) Do you have difficulty seeing, even if wearing glasses? 2) Do you have difficulty hearing, even if using a hearing aid? 3) Do you have difficulty walking or climbing steps? 4) Do you have difficulty remembering or concentrating? 5) Do you have difficulty (with self-care such as) washing all over or dressing? 6) Using your usual language, do you have difficulty communicating, (for example, understanding or being understood by others)? Each of these measures uses an ordinal scale that includes: no difficulty, some difficulty, a lot of difficulty, and cannot do at all. The results in Figure 1 are based on the estimation of disability prevalence rates using 1) the ACS disability status dichotomous composite measure and 2) the WG-SS disability status dichotomous (0, 1) composite measure. The estimates of prevalence included the five disability statuses (hearing, vision, concentrating/remembering, mobility, selfcare) that are common for the ACS and WG-SS questions. Results can be considered representative of the U.S. population of non-institutionalized adults ages 18-85. Additional methodological details can be found in the published paper.

**References**


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