

12/18/2023

Robert L. Santos  
Director, U.S. Census Bureau  
U.S. Department of Commerce

Dear Director Santos,

I am writing on behalf of the Academy of Spinal Cord Injury Professionals with concerns regarding the proposed changes to the questions assessing disability status within the U.S. Census.

The Academy of Spinal Cord Injury Professionals is a multidisciplinary group of rehabilitation professionals that work closely with the disability community. The proposed change from the American Community Survey (ACS) to the Washington Group Short Set (WG-SS) is an unacceptable reversal of course to measure disability in the population by the U.S. Census.

One reason for our opposition is that the disability community, key stakeholders, and those with lived experience did not have input into the policy change and proposed switch to the WG-SS. It is our belief and the belief of other government agencies that policy changes should always involve key stakeholders. For example, the Interagency Committee on Disability Research holds Stakeholder Meetings for the Inclusion of People with Disabilities for shared decision-making. This model of inclusivity was not utilized when making the change to the WG-SS. In addition, prior to the call for comments, organizations that represent people with disabilities were not invited to discuss the change from ACS to WG-SS and were not provided the opportunity to evaluate and discuss the impact that this change may have on the lives of people living with disabilities. For example, United Spinal Association, the largest membership organization representing individuals with spinal cord injuries and all wheelchair users, was not given the opportunity to provide input. We find this approach to engagement and change unacceptable.

A second concern about changing from the ACS to the WG-SS is that the number of people with disability will be underrepresented. Utilizing the WG-SS, it is feared that using the "Disability 3" definition of disability would decrease the number of people as counted by the census with disability by 25% to 50%. Our organization believes the variance in the number of those counted with disabilities is not the number of people with disabilities but rather the way they are being counted. In a recent study by Hall et al., the WG-SS was found to miss up to 43% of individuals with disability. The underrepresentation of people with disabilities by the Census Bureau data could have a catastrophic effect on the funding allotted for people with disabilities. The data obtained from the ACS

is used for allocating funding both at the state and federal levels. “This same data is used to evaluate whether disabled people are being given equal opportunities when it comes to things like housing, education, and healthcare.”

This marginalized and underfunded community could be devastated by funding cuts based on an underrepresented census.

In closing, the Academy of Spinal Cord Injury Professionals advocates pausing using the WG-SS to count disability. The organization recommends the forming of a national task force to develop a plan for improving and expanding disability data collection across the federal government. This task force should include content experts with lived experience and intersecting identities, disability community members, and federal policymakers. The goals of this task force should be to: (1) support the development of a national plan to improve disability data collection grounded in the perspectives of the disability community; (2) create a road map to roll out a comprehensive and integrated plan to collect disability data as a core demographic component across the federal government, including the U.S. Census Bureau; and (3) outline a comprehensive strategy for using this data to advance equity for disabled people, including making these data publicly available.

Thank you for your consideration and attention to this matter. We are grateful for your leadership and focus on making the U.S. Census more equitable and inclusive.

*Joe Fangman, PT*

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President, Academy of Spinal Cord Injury Professionals

Amilon, A., Hansen, K. M., Kjær, A. A., & Steffensen, T. (2021). Estimating disability prevalence and disability-related inequalities: Does the choice of measure matter?. *Social Science & Medicine*, 272, 113740.