

December 19, 2023

Robert L. Santos
Director, U.S. Census Bureau
Department of Commerce
4600 Silver Hill Road
Washington, DC 20233

**Re: Census Bureau Proposed Changes to the 2025 American Community Survey Questions, Docket
Number USBC-2023-0009**

Dear Director Santos,

I am writing on behalf of United Spinal Association in response to the U.S. Census Bureau has published a notice of information about changing data collection questions in the [American Community Survey \(ACS-6\)](#) regarding the size of the disability population to be replaced with the [Washington Group Short Set \(WGSS\)](#) questions on physical functioning (mobility, vision, hearing etc.) as well as the removal of the independent living question (running errands, managing personal finances).

United Spinal Association, founded by paralyzed veterans in 1946, is dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D), paralysis, neurological conditions and other mobility disabilities, including veterans, and providing support and information to loved ones, care providers and professionals. United Spinal represents 5.5 million wheelchair users across the country, has over 61,000 members, 47 chapters, 120 support groups and 115 rehabilitation facilities and hospital partners nationwide. Additionally, we work collaboratively with Spinal Cord Injury Model (SCI) System Centers and the Model Systems Knowledge Translation Center that provide innovative research and support in the field of SCI. United Spinal Association is also a VA-accredited veterans service organization (VSO).

The ACS survey asks for a yes/no response and the WGSS survey asks for a graded response like this: “no difficulty”, “some difficulty”, “a lot of difficulty” or cannot do at all regarding doing daily tasks. Asking for a graded response instead of a yes/no response has the effect of reducing the number of people with disabilities by roughly 50% (from 14% to 8% of the population) since only people who answer “a lot” or “cannot do at all” are counted as being disabled.

Federal and state governments use the census’s disability prevalence estimates to identify vulnerable populations that are more likely to experience worse health outcomes, determine the United States’ disability community housing needs, plans for emergencies and disasters, transit services, document discrimination in education and employment, and allocation of state resources and programs.

United Spinal supports forming 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 roadmap 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 and accessible. Similar task forces have been

developed out of the White House Office of Science and Technology Policy (OSTP) and this strategy is supported by recommendations from the National Science and Technology Council Equitable Data Working Group.

Our concern is that the proposed switch to the Washington Group Short Set (WGSS) would not resolve many of the current limitations of the ACS-6 and may actually make some of them worse. Like the ACS-6, the WGSS performs poorly in identifying people with mental or psychiatric conditions, as well as many people with chronic conditions, such as auto-immune diseases. It also fails to measure the duration or onset of disabilities and does not resolve the limitations around proxy responses (from a different household respondent.) It does include a question related to communication challenges, which would address an ACS limitation, but another feature of the WGSS format could lead to substantially worse undercounting of people with disabilities.

The current ACS-6 standard questions are used on more than a dozen other national disability surveys (such as the American Housing Survey, National Crime Victimization Survey, the Behavioral Risk Factor Surveillance Survey (BRFSS), and Current Population Survey). The BRFSS is a cornerstone to CDC's disability data collection, analysis, and public sharing efforts. Any shift in the ACS questions should include a detailed analysis of how the changes would affect data produced by these other surveys, as well as longitudinal data or data compiled across a number of years.

We echo the [concerns](#) of the Census National Advisory Council shared at the November public meeting that the disability community was not appropriately involved in the question change process. Stakeholder input is essential throughout the question development process to ensure the ACS is accurately capturing the large and diverse disability population.

The Census Bureau should actively engage with representatives of the disability community, disability researchers, and other key stakeholders to consider more accurate alternatives to the proposed changes that better address the limitations in the current standards. We urge the Census Bureau to pause the work you have done to reform the ACS questions, to seek feedback broadly from the community of researchers and people with disabilities, and to use that process to develop a set of changes that both improves the accuracy of the collected data on disability and carefully lays out how the changes might impact future policymaking, including recommendations to mitigate potentially negative outcomes. Such an impact analysis would help anticipate unintended consequences and develop trust and support for the changes among the disability community and the public at large and is consistent with efforts across the federal government to implement President Biden's [Executive Order on Advancing Racial Equity and Support for Underserved Communities](#).

We believe our recommendations will create a more effective, more accurate, and more actionable final product that has broad support within the community most affected by the changes. We also must adhere to United States' civil rights protections, as fundamental as the U.S. Americans with Disabilities Act, that align better with a broader definition of disability and would more usefully inform U.S. related policy decisions. Thank you for considering our comments. Please do not hesitate to contact me, Alexandra Bennewith at abennewith@unitedspinal.org or (800) 404.2898 with any questions.

Sincerely,

Alexandra Bennewith

Alexandra Bennewith, MPA
Vice President, Government Relations