DRRC
Disability & Rehabilitation Research Coalition

VIA ELECTRONIC TRANSMITTION

December 19, 2023

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

RE: Proposed Changes to Disability Questions in the 2025 American Community Survey

Dear Director Santos:

On behalf of the undersigned organizations of the Disability & Rehabilitation Research Coalition (DRRC), we write to share our concerns with the proposed changes to the American Community Survey (ACS) questions measuring disability. We request that the U.S. Census Bureau halts implementation of the proposed changes so that the disability community can be fully engaged in understanding the implications of this new data collection approach and assist in the development of a stakeholder-informed process for future disability data collection efforts.

The DRRC includes 25 national research, clinical, and consumer non-profit organizations committed to improving the science of rehabilitation, disability, and independent living. We seek to maximize the return on the federal research investment to improve the ability of Americans with disabilities to live and function as independently as possible following an injury, illness, disability, or chronic condition. As a coalition advocating for investment in and focus on disability research, we are alarmed by the potential scientific and public policy repercussions of changing the disability questions and by the lack of disability stakeholder involvement in the process through which these changes are being made.

The DRRC strongly supports the Census Bureau's mission "to serve as the nation's leading provider of quality data about its people and economy" and is particularly invested in its data for equity commitment to "depict an accurate portrait of America, including its underserved communities." Unfortunately, the largest and most diverse underserved community in the U.S., people with disabilities, has not been accurately represented by the Census Bureau or its partners at the Centers for Disease Control and Prevention. Studies show that current national surveys consistently undercount important disabled subpopulations, including people with psychiatric conditions and those with chronic illnesses. The proposed changes to the ACS, therefore, could potentially represent a step in the wrong direction.

It appears that the proposed changes to the ACS will further undercount the population of people living with disabilities – reducing national disability prevalence estimates by 41% (from 13.9% to 8.1%). The public policy consequences of this false drop in disability prevalence are potentially severe, because the ACS provides comprehensive statistical information about local, state, and regional communities, measuring critical demographic information to inform decision-making for governments and private sector organizations.

The Census Bureau cites specific examples of how federal, state, local, and tribal governments use ACS disability data to make informed decisions on the allocation of resources, planning and responding to natural disasters, and enforcing civil rights laws prohibiting discrimination. Private Sector businesses and nonprofits also use ACS data for a wide variety of organizational decisions including planning locations for new workplaces and tracking program success.

Considering its importance, it is critical that the ACS's estimates accurately represent the population of people with disabilities to appropriately plan, fund, and track trends over time. ***In light of this, we request that the Census Bureau issue an impact statement that would detail the consequences of undercounting the disability population for government and private sector programs and funding.***

DRRC is also deeply troubled that essential disability stakeholders were not involved in the process of changing the ACS questions. 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.

Fundamentally, we are unaware of any compelling scientific or public policy rationale for switching the current (ACS6) questions with those used in the National Health Interview Survey (the Washington Group short set). Researchers and policymakers can use that survey if they need data on disability on a scaled score. Instead of replacing one imperfect set of questions with another, DRRC recommends collaboration with disability researchers and those with lived experience to develop an inclusive plan for enhancing federal disability data collection. This 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 request that the Census Bureau halt the proposed changes to the ACS and engage with the disability community to develop a stakeholder-informed approach. Thank you for considering our comments. We appreciate your impactful work to improve the lives of people with disabilities.

Sincerely,

The Undersigned Members of DRRC

American Academy of Orthotists & Prosthetists
American Academy of Physical Medicine and Rehabilitation
American Association on Health & Disability
American Congress of Rehabilitation Medicine
American Music Therapy Association
American Occupational Therapy Association*

American Physical Therapy Association*
American Therapeutic Recreation Association
Amputee Coalition
Association of Academic Physiatrists
Association of University Centers on Disabilities
Brain Injury Association of America*
Christopher & Dana Reeve Foundation
National Association for the Advancement Orthotics & Prosthetics
National Association of Rehabilitation Research and Training Centers*
Rehabilitation Engineering and Assistive Technology Society of North America
Spina Bifida Association
United Spinal Association

Indicates DRRC Coalition Steering Committee Member*