

**Honorable Tony Coelho**  
**Disability Advocate**

December 19, 2023

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

Re: Docket Number USBC–2023–0009

Dear Director Santos:

I am writing to express my concern and disappointment with the Census Bureau’s proposed changes to the 2025 American Community Survey (ACS) questions. After serving as a Member of Congress and leading the introduction of the Americans with Disabilities Act, I had the great privilege of serving as a co-chair of the former Census Monitoring Board under President Bill Clinton. What I had hoped to leave behind was a process for meaningful engagement of people with disabilities as the ACS questions are developed and updated. Today, I must conclude that the Census process is inherently flawed.

I strongly support calls for a more inclusive public process to improve the current questions. To be clear, the proposed changes to the disability questions do not represent an improvement. The proposed changes represent what happens when the perspectives of people with disabilities, disability researchers, and disability advocates are absent from the decision-making process. It is my hope that the proposal on which the disability community is providing comment does not reflect the final product. Instead, I urge this be the start of an engaged and transparent process of communication and engagement.

Almost ten years ago, some in the disability community urged the Census, in the spirit of “do no harm,” to allow the ACS questions to remain unchanged for fear of them being made weaker, thereby undercounting people with disabilities. Since then, there has been substantial work among the community to develop recommendations for improving the questions. If the Census wanted to consider changes to the questions, it is not unreasonable to expect that people with disabilities, disability researchers and disability advocates would have been consulted much earlier. Instead, the proposal on which the community is commenting represents changes that the community broadly opposes and fails to include changes the community supports.

The impact of the proposed changes is substantial. Government funding for an array of programs depends on Census data. If people with disabilities are undercounted, the risk to funding for programs that support them could prove dire for their access to benefits supporting their livelihood and survival. I am also concerned that the proposed changes do not consider

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longitudinal disability research if data collection methodologies are modified. The proposal in the Federal Register did not address any potential unintended consequences. It will be too late to address them when the questions are made final.

Therefore, I strongly urge the Census Bureau to work with experts in the disability community to fully consider their proposed changes to improve the questions and to understand how the questions as proposed by the Census will change the count of people with disabilities, impact funding levels for programs that rely on this data, and the consequences for longitudinal disability research.

The lack of engagement with the disability community in relation to the proposed ACS questions is surprising due to the administration's otherwise consistent recognition of the health disparities faced by people with disabilities and efforts to address them. For example, HHS recently advanced a proposed rulemaking on Section 504 of the Rehabilitation Act of 1973 that includes explicit recognition of recommendations from the National Council on Disability, the Disability Rights Education and Defense Fund and others. The proposed rule calls out the health disparities experienced by people with disabilities as a key priority for updating the regulations. The National Institutes of Health also recently designated people with disabilities as a population experiencing disparities, opening up opportunities for funding of disability-focused research and advancement of researchers with disabilities, and is working to amend its mission statement to address ableist language. In July 2022, the Office for the National Coordinator for Health Information Technology released Version 3 of their interoperability standards, including documentation of patients' disability status, recognizing the need for collecting data on people with disabilities.

Additionally, Executive Order 13985 on Advancing Racial Equity and Support for Underserved Communities also highlights the importance of community engagement and how the Equitable Data Working Group must "support agencies in implementing actions, consistent with applicable law and privacy interests, that expand and refine the data available to the Federal Government to measure equity and capture the diversity of the American people." The manner in which the proposed questions were determined appears to be in stark contrast to this goal. I would urge the Census Bureau to review the recent report from the Office of Science and Technology Policy to ensure the Census Bureau is following its recommendations.<sup>1</sup> It is my hope that, in the future, the Equitable Data Working Group itself will also prioritize disability data.

Finally, the Affordable Care Act (ACA) strongly recognizes disability as a health disparity factor and included Section 4302 on health disparities and data collection. The law called for federally conducted or supported health care and public health programs, activities or surveys – explicitly including the ACS – to collect and report data on "disability status for applicants,

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<sup>1</sup> <https://www.whitehouse.gov/ostp/news-updates/2023/03/24/fact-sheet-white-house-office-of-science-and-technology-policy-announces-progress-on-advancing-equitable-data/>

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recipients, or participants.” Knowing that Congress added a provision in the ACA to amplify the need for disability data collection from the ACS, a robust process of engagement between ACS and the disability community related to the questions was our expectation.

As a next step, I urge the Census Bureau to outline a robust process for engagement and communication between experts in the disability community and Census staff to address the shortcomings of the proposed questions and to ensure full consideration is given to the recommendations from people with disabilities, disability researchers and disability advocates, including the Consortium of Citizens with Disabilities. A robust process for engagement will also require the following steps to demonstrate an internal commitment to the engagement process:

- The Census Bureau will need a team of subject matter experts on disability to engage with experts in the disability community;
- The Census Bureau must include people with disabilities in their efforts to identify those most hard to count or historically undercounted populations. I was pleased to see that this is a priority for the Census Bureau in its November 7, 2023 blog.<sup>2</sup>
- The Census Bureau should add disability experts to the Census Scientific Advisory Committee. As stated in its charter, “...where possible Census will also consider the ethnic, racial, and gender diversity and various abilities of the United States population. Individuals will be selected based on their expertise in specific areas as needed by the Census Bureau and specified in the Federal Register Notice call for nominations.” Clearly, disability expertise is needed.<sup>3</sup>

I have spent most of my adult life working to ensure that people with disabilities count and are counted. The most fundamental thing we do as a country to ensure that is our census. Therefore, I urge you to consider my suggestions for a process moving forward to assure the disability community’s hard work to develop its own recommendations for the ACS questions are given full consideration.

Sincerely,



Tony Coelho

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<sup>2</sup> <https://www.census.gov/newsroom/blogs/random-samplings/2023/10/understanding-undercounted-populations.html>

<sup>3</sup> <https://www.census.gov/about/cac/sac.html>