

December 6, 2023

Dameka Reese  
Assistant Division Chief of Data Collection  
American Community Survey Office  
U.S. Census Bureau  
4600 Silver Hill Road  
Washington, DC 20233

**Re: American Community Survey and the Puerto Rico Community Survey  
[USBC-2023-0009]**

Dear Assistant Division Chief Reese:

On behalf of the physician and medical student members of the American Medical Association (AMA), I am writing to request that the Census Bureau extend its comment period, thus delaying a decision, on the proposed content related to disability for the 2025 American Community Survey (ACS) and the Puerto Rico Community Survey (PRCS).<sup>1</sup>

The AMA appreciates the focus on disability issues, but we suggest a modified approach to engaging people with disabilities in the process and updating the related content in the ACS and PRCS. Therefore, the AMA recommends:

- Delaying a decision on changes to the disability questions.
- Developing and implementing a replicable inclusion plan for comprehensive input from the disability community and key interested parties.

**1. Delay a decision on changes to the disability questions.**

There has been insufficient information provided about the extent to which development of the proposed changes leveraged the expertise of the disability community in the United States (prior to this comment period) and the extent to which the proposed changes may contribute to an undercount of people with disabilities. We urge a pause in any decisions on proposed changes to the disability questions until further information on these aspects is provided to the public and any deficiencies addressed. As such, we request that the current comment period be extended or that a new comment period be offered.

**2. Develop and implement a replicable inclusion plan for comprehensive input from the disability community and key interested parties.**

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<sup>1</sup> <https://www.federalregister.gov/documents/2023/10/20/2023-23249/agency-information-collection-activities-submission-to-the-office-of-management-and-budget-omb-for>

The World Health Organization's "Global report on health equity for persons with disabilities" advocates for the inclusion of people with disabilities in the decision-making process.<sup>2</sup>

The Executive Order on Advancing Racial Equity and Support for Underserved Communities through the Federal Government,<sup>3</sup> Section 8, states that "agencies shall consult with members of communities that have been historically underrepresented in the Federal Government and underserved by, or subject to discrimination in, Federal policies and programs. The head of each agency shall evaluate opportunities, consistent with applicable law, to increase coordination, communication, and engagement with community-based organizations and civil rights organizations." We note that the Census Bureau's National Advisory Committee includes Marlene Sallo, Executive Director of the National Disability Rights Network.<sup>4</sup> However, the extent of additional proactive engagement with the disability community around these issues is unclear, and the disability community has voiced concerns over being excluded.<sup>5</sup> Intentional and inclusive ways to engage the disability community might include establishing a disability advisory group that intentionally seeks out people with disabilities, Disability Rights advocates, disability researchers, and non-profit organizations providing services and supports.

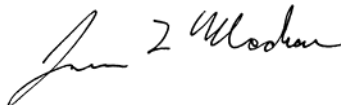
We request that the U.S. Census Bureau provide more information on how they have implemented the Executive Order regarding these proposed changes related to disability. We further suggest the Bureau take this opportunity to develop and implement an inclusive approach to gathering comprehensive input from the disability community and key interested parties and use this as a model for future changes related to disability.

## Conclusion

The AMA appreciates the focus on disability issues; however, additional time is needed for the disability community to adequately respond to the potential changes suggested by the Administration. Accordingly, we request a 1) delay in making a decision on changes to the disability questions and 2) the development and implementation of a replicable inclusion plan for comprehensive input from the disability community and key interested parties.

Thank you for considering the AMA's request for an extension of the comment deadline. If you have any questions, please contact Margaret Garikes, Vice President of Federal Affairs, at 202-789-7409 or [margaret.garikes@ama-assn.org](mailto:margaret.garikes@ama-assn.org).

Sincerely,



James L. Madara, MD

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<sup>2</sup> World Health Organization. Global report on health equity for persons with disabilities [Internet] Accessed 11/16/2023 <https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/global-report-on-health-equity-for-persons-with-disabilities>

<sup>3</sup> <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/20/executive-order-advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government/>

<sup>4</sup> <https://www.census.gov/newsroom/press-releases/2023/national-advisory-committee.html>

<sup>5</sup> <https://www.science.org/content/article/how-many-americans-are-disabled-proposed-census-changes-would-greatly-decrease-count>