

Janice Lintz Comment

“All views expressed are my own and do not reflect the position of the Department where I work. The following is based upon information and belief.”

Comprehensive Opposition to Proposed Changes to ACS Disability Washington Group Short Set on Functioning Data Collection Questions

Executive Summary:

I am writing to express my profound opposition to the proposed changes to the American Community Survey's (ACS) Disability Washington Group (WG) Short Set on Functioning Data Collection Questions. The extensive revisions sought by the Census Bureau demand a careful reconsideration, as they raise substantial concerns that, if not addressed, could significantly impact the accuracy, inclusivity, and reliability of data regarding individuals with disabilities.

Previous Census surveys have undercounted people who are hard of hearing dramatically compared to NIH's recent data that shows [72.88](#) million people have some form of hearing loss.

Reasons why the Census Bureau should reject the ACS WG questions:

The proposed alterations to the ACS WG questions regarding disabilities should be vehemently rejected due to the following compelling reasons:

1. Ambiguity Surrounding Auxiliary Aid Usage: A critical concern is the lack of transparency regarding whether the WG is utilizing auxiliary aids to gather data. This raises questions about the validity of the collected information and its potential exclusion of individuals with disabilities who may face challenges in conventional survey responses, such as those who are hard of hearing.

For example, is someone who wears hearing aids using a portable FM system with a neck loop if needed, so he or she can hear the person asking the question and respond correctly?

2. Flaws in Question Design: The inherent problems in the design of these questions may lead to a drastic underreporting of the number of people with disabilities. The subjective nature of the questions poses a risk of biased responses, impacting data-driven decisions and, consequently, the allocation of essential services for individuals with disabilities.

For example, the questions do not eliminate people who use a wheelchair or elevator rather than stairs, but they do eliminate people with hearing loss if hearing aids help them to hear. Further, the question does not consider that a person may use hearing aids or a cochlear implant during the day but removes them at night.

3. Exclusion and Marginalization of Specific Disability Groups: Of particular concern is the omission and marginalization of specific disability groups, such as those with neurological disabilities, intellectual/developmental disabilities, psychiatric disabilities, and chronic illnesses. Such exclusions threaten the survey's ability to provide a comprehensive and accurate representation of the population with disabilities.
4. Inadequate Disability Consultation: The decision-making process must involve comprehensive consultation with representatives from all disability groups, adhering to the fundamental principle of "nothing about us without us." The Census Bureau must disclose the individuals and organizations consulted, and address any concerns raised but dismissed during this crucial phase.
5. Global Applicability Challenges: Attempting to implement the same set of questions on a global scale is a well-intentioned but impractical goal. Variations in access to assistive technology and auxiliary aids worldwide necessitate a nuanced approach, avoiding the risk of inaccurate comparisons and potential misinterpretations of disability prevalence.

For example, in many countries people cannot afford hearing aids, so the number of people who are functionally hard of hearing will be higher. Does that mean the US has a smaller percentage of people who are hard of hearing? Are we counting disabilities or access to auxiliary aids?

Data Collection Background:

Capturing accurate disability data is an inherently complex task, given the multifaceted challenges related to self-identification, stigma, and cultural nuances. The proposed changes must account for these intricacies to prevent the inadvertent undercounting of individuals with disabilities.

In conclusion, I strongly urge the Census Bureau to reassess and ultimately reject the proposed changes, considering the substantial concerns outlined above. Ensuring a fair, inclusive, and accurate representation of the disability community in the collected data is paramount, as the consequences of unreliable data extend far beyond statistical figures.

Thank you for your careful consideration of this matter.

Sincerely,

Janice S. Lintz, Advocate for People Who Are Hard of Hearing
2023 [Presidential Management Fellow](#) Finalist
2023 [MA Senate Docket #923](#) Petitioner Presented by Senator Brownsberger
2022 Congressional Recognition by Congressman Paul Tonko
2022 [NYS Disability Rights Hall of Fame Inductee](#)
2021 Cited in the Proposed [FDA OTC Hearing Aid Regulations](#)' footnotes
2018 Bill and Melinda Goalkeepers Foundations Partnership with TPG Recipient
2016 Aspen Institute Spotlight Health Scholar

2016 Nominated United State of Women Changemaker

2016 Acknowledged in the [National Park Service Accessibility Guidelines](#) (P76)

2008 [People Magazine Hero](#)

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