



American Association on Health & Disability

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AAHD - *Dedicated to better health for people with disabilities through health promotion and wellness*



LAKESHORE

January 6, 2025

Sheleen Dumas
Departmental PRA Clearance Officer
Office of the Under Secretary for Economic Affairs
U.S. Department of Commerce
Washington, DC 20230
Submitted via email to acso.pra@census.gov

Dear Ms. Dumas:

The American Association on Health and Disability and the Lakeshore Foundation appreciate the opportunity to provide comments in response to the U.S. Census Bureau's request for an extension of the American Community Survey (ACS) and Puerto Rico Community Survey (PRCS), published in the *Federal Register* on November 5, 2024 (the "notice") (Docket Number USBC-2024-0029).

The American Association on Health & Disability is a national cross-disability organization that conducts research, engages the community, and facilitates the development and implementation of programs to advance public health and healthcare policy for the health and wellness of people with disabilities. Through these actions, AAHD is committed to eliminating systemic barriers to healthcare and drive health equity for people across all disabilities, valuing the diverse and intersecting identities within the disability community. AAHD connects people with disabilities, disability advocates, health practitioners, researchers, and policy makers to accessible cross-disability health data and resources—creating a more inclusive society where data-driven healthcare leads to more equitable health outcomes.

The Lakeshore Foundation (www.lakeshore.org) mission is to enable people with physical disability and chronic health conditions to lead healthy, active, and independent lifestyles through physical activity, sport, recreation and research. Lakeshore is a U.S. Olympic and Paralympic Training Site; the UAB/Lakeshore Research Collaborative is a world-class research program in physical activity, health promotion and disability linking Lakeshore's programs with the University of Alabama, Birmingham's research expertise.

Data helps us understand how many people across the United States might benefit from a multitude of programs. At AAHD, we are particularly interested in preserving the disability questions that are administered within the ACS. The number of people with disabilities has a direct impact on resource allocation to meet many different community needs, from housing to health services. ACS is one of the very few nationally representative data sources that includes and collects disability data. Not only does our organization rely on using ACS data for our own work and research, we also use ACS data to ensure that our primary community, the disability community has an understanding of important national trends, gaps and needs. We use these data to educate about the impact of potential policy changes or issues and what portion or subset of the disability community would be most affected and use these data to educate about the estimated population size of that subsample. When we're talking about health equity, we need data equity too. From a public health perspective, better data will help us to address health disparities across the disability community. This will only be possible with the continuation of the ACS.

We urge the Office of Management and Budget (OMB) to approve the ACS extension request as presented by the Census Bureau in a timely manner, to ensure the continued availability of irreplaceable data that are vital to the informed functioning of virtually every economic sector and social institution in the U.S. and allow for longitudinal trend analyses.

We also understand that currently, response to the ACS is required by law. Congress has historically set penalties for failure to complete the census, of which the ACS is a part. The rationale for mandatory response is clear. A 2003 Census Bureau test (conducted at the request of Congress) showed that people are far more likely to participate in the census and ACS when the law requires their response, and that making response voluntary would significantly decrease the reliability of the data.

The burden of completing the ACS does not outweigh the value of its data. A specific U.S. address will receive the survey only once every five years, and most households will never receive the survey. The Paperwork Reduction Act ensures that the burden on ACS respondents is minimal.¹ If the ACS becomes voluntary, AAHD has real concerns that people with disabilities will be undercounted or potentially erased in resulting data not because they don't exist.

Underserved communities often get undercounted in voluntary surveys due to a variety of systemic, logistical, and social barriers. At AAHD, we are particularly concerned that people with disabilities would be undercounted in the event of this change. More specifically, people with disabilities may prioritize meeting basic needs over participating in voluntary activities like this ACS survey, particularly if they are working multiple jobs or managing other stresses. Many individuals from the disability community may mistrust government or official organizations due to historical discrimination, fear of surveillance, or potential misuse of information. This can lead to hesitancy in participating in surveys, especially voluntary ones. Members of the disability community might not know about the ACS survey or understand its importance, leading to lower participation rates, especially if it becomes voluntary.

¹ https://www.census.gov/content/dam/Census/library/publications/2020/acs/acs_general_handbook_2020.pdf

When communities have been underrepresented in the past, as the disability community has been, there may be a sense of futility or skepticism about whether their participation will make a difference. This is a tremendous risk that jeopardizes having high quality national population data about the disability community.

For these reasons, OMB must approve an extension of the ACS and PRCS programs and maintain mandatory responses.

The Census Bureau must also continue to research and implement improvements to the ACS and PRCS to collect accurate, inclusive data on historically under-represented population groups, people with disabilities.

Thank you for considering our views. Please direct any questions about these comments to Anjali Forber-Pratt at aforberpratt@aahd.us

Sincerely,



Anjali J. Forber-Pratt, Ph.D.

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