



December 19, 2023

Sheleen Dumas, Department PRA Clearance Officer  
Office of the Under Secretary for Economic Affairs, Commerce Department  
1401 Constitution Avenue NW  
Washington, DC 20230

*Submitted via regulations.gov*

**Re: Comment on Agency Information Collection Activities;  
Submission to the Office of Management and Budget (OMB) for  
Review and Approval; Comment Request American Community  
Survey and Puerto Rico Community Survey; FR Doc. 2023-23249**

On behalf of the National Association of Councils on Developmental Disabilities (NACDD) and the 41 undersigned state councils on developmental disabilities, we write to express serious concerns about the proposed changes to data collection on disability and questions related to the household roster for the American Community Survey (ACS) and Puerto Rico Community Survey (PRCS). If adopted, the current Census proposal would severely undercount the disability population and undermine the diligent efforts of disability rights activists and federal agencies who have worked collaboratively to address flawed data on disability prevalence in our country.

NACDD is the national association for the 56 Councils on Developmental Disabilities (DD Councils) across the United States and its territories. DD Councils work within state and territorial systems to promote community living free from discrimination for people with intellectual and developmental disabilities (I/DD) and their families.

Data are critical for our work. We use data to inform national and state policy makers about the number of people with disabilities and the disparities among groups. DD Councils also use data to identify gaps in public systems where people with I/DD are disproportionately disadvantaged and underserved. The proposed change would impact the way data are used

in funding decisions for disability programs and by civil rights bodies across the government related to all aspects of community living including health care, employment, education, transportation, civil rights, and more. A few examples emerging public policy issues that need accurate data include:

- Tracking and understanding upward trends in Autism Spectrum Disorder (ASD) prevalence are important public health objectives. Policy makers need to monitor and understand the reasons for this trend which may reflect improved screening, awareness, and access to services among historically underserved groups. In fact, between 2018 and 2020, autism prevalence rose more than twice as fast among Asian, Black and Hispanic children than it did among White children.
- The aging demographic profile of the country will increase the number of people who acquire disabilities as they age. It is important to be able to project the population of people who may become non-drivers, need accessibility or accommodations, and require supports, services, and care workers to stay in their homes.
- People with I/DD now have lifespans equivalent to people without disabilities. However, their support needs change over time as this population acquires additional disabilities as they age.
- People with I/DD disproportionately rely on unpaid family caregivers, many of whom are aging themselves and will not be able to provide the same level of support in perpetuity. As these unpaid caregivers acquire disabilities and need care, the people who rely on them will need support and systems must anticipate these care needs.
- Instances of Alzheimer's, Dementia, Parkinson's, and other adult-onset conditions that cause cognitive impairment or other neurological limitations are increasing. An accurate count that is as inclusive as possible is necessary. People can have similar challenges, even if the causes differ.

While we agree that the current ACS methodology needs improvement to accurately reflect the disability population, any changes to the definition of disability cannot exclude more people with disabilities from data collection. For years, advocates have raised concerns about data collection by federal agencies that overwhelmingly undercounts people with disabilities, including

those with I/DD. We applauded interagency efforts, which included, extensive stakeholder input, to provide more accurate data for I/DD prevalence, such as the efforts by the Administration for Community Living's (ACL) “IDD Counts” and “The Surveillance and Health Status of People with I/DD Project.”<sup>1</sup> These efforts promise to address the data concerns mentioned in this comment and provide policy makers with more accurate information so they can achieve an informed and more equitable distribution of valuable public resources for the disability community.

In contrast, experts agree that the Census's proposed alternative measurement of disability in the ACS is problematic. Currently, it is estimated that the ACS disability measures already undercount disabled people by about 20 percent.<sup>2</sup> Another study found undercounting of people with developmental disabilities in the current methodology.<sup>3</sup> The Census proposes a change to use a limited definition of disability based on the Washington Group Short Set on Functioning (WG-SS) as opposed to the current ACS questions and the process for this change. But this proposed method does not address undercounting. It makes it worse. By using a limited definition of disability based on the WG-SS will only further undercount disabled Americans. The proposed methodology would result in an approximately 40 percent reduction in the number of people counted as disabled.<sup>4</sup> Instead, a broader definition, based on years of advocacy and policymaking should be used.

Finally, the lack of consultation with the disability community, including disabled advocates and Administration for Community Living grantees, cannot be overlooked. The Census Bureau must consult with these experts to develop disability measures that provide a full, inclusive count of disabled

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<sup>1</sup> “I/DD Counts | ACL Administration for Community Living.” Acl.gov, acl.gov/iddcounts.

<sup>2</sup> Hall, J., Kurth, N., Ipsen, C., Merys, E., & Goddard, K. (2022, October). Comparing Measures of Functional Difficulty with Self-Identified Disability: Implications for Health Policy. *Health Affairs* 40(1).

<sup>3</sup> Catherine Ipsen et al., Underrepresentation of Adolescents with Respiratory, Mental Health, and Developmental Disabilities Using American Community Survey (ACS) Questions, *11 Disability & Health J.* 447 (2018).

<sup>4</sup> Steinweg, A., Young, N., Stern, S., Contard, L., & Spiers, S. (2023, November 13) 2023 American Community Survey Research and Evaluation Report Memorandum, Series ACS23-RER-12 (p. 9) [Memorandum to Donna Daily Chief, American Community Survey Office]. Retrieved 7 December 2023, from

[https://www.census.gov/content/dam/Census/library/working-papers/2023/acs/2023\\_Steinweg\\_01.pdf](https://www.census.gov/content/dam/Census/library/working-papers/2023/acs/2023_Steinweg_01.pdf)



people. "Nothing about us without us" remains the unifying motto for the disability community. It is concerning that this agency would consider a proposal which would quite literally erase thousands of people with disabilities from the ACS data collection without their input.

We recommend that the Census Bureau reject the proposed changes to the collection of disability data and instead engage extensively with the disability community, ACL, and other federal agencies working on accurate data for the disability population, to ensure any changes to the disability data collection methodology are inclusive and reflect the full range of data needs.

For more information, please contact Erin Prangley, Director, Policy, National Association of Councils on Developmental Disabilities at [eprangley@nacdd.org](mailto:eprangley@nacdd.org) or (202) 506-5813.

Sincerely,

National Association of Councils on Developmental Disabilities

Alabama Council on Developmental Disabilities  
Alaska Council on Developmental Disabilities and Special Education  
Arizona Developmental Disabilities Planning Council  
California State Council on Developmental Disabilities  
CNMI Council on Developmental Disabilities  
Commonwealth Council on Developmental Disabilities (Kentucky)  
District of Columbia Developmental Disabilities Council  
Delaware Developmental Disabilities Council  
Developmental Disabilities Council of Oklahoma  
Georgia Council on Developmental Disabilities  
Hawaii State Council on Developmental Disabilities  
Idaho Council on Developmental Disabilities  
Illinois Council on Developmental Disabilities  
Indiana Governor's Council for People with Disabilities  
Iowa Developmental Disabilities Council  
Kansas Council on Developmental Disabilities



Louisiana Developmental Disabilities Council  
Maryland Developmental Disabilities Council  
Massachusetts Developmental Disabilities Council  
Michigan Developmental Disabilities Council  
Minnesota Governor's Council on Developmental Disabilities  
Missouri Developmental Disabilities Council  
Nebraska Council on Developmental Disabilities  
Nevada Governor's Council on Developmental Disabilities  
New Hampshire Council on Developmental Disabilities  
New Jersey Council on Developmental Disabilities  
New Mexico Developmental Disabilities Council  
North Carolina Council on Developmental Disabilities  
North Dakota State Council on Developmental Disabilities  
Oregon Council on Developmental Disabilities  
Pennsylvania Developmental Disabilities Council  
Puerto Rico Council on Developmental Disabilities  
South Carolina Developmental Disabilities Council  
South Dakota Council on Developmental Disabilities  
Tennessee Council on Developmental Disabilities  
Texas Council for Developmental Disabilities  
Virginia Board for People with Disabilities  
Washington State Developmental Disabilities Council  
West Virginia Developmental Disabilities Council  
Wisconsin Board for People with Developmental Disabilities  
Wyoming Governor's Council on Developmental Disabilities