



April 24, 2024

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: Agency Information Collection Activities; Submission to the Office of Management and Budget (OMB) for Review and Approval; Comment Request; The American Community Survey (ACS) and Puerto Rico Community Survey (PRCS); FR Doc. 2024-06256

The National Partnership for Women & Families appreciates the opportunity to comment on the Census Bureau's recent Request for a Revision of a Currently Approved Collection. We appreciate the Bureau's decision to forgo any changes to the American Community Survey (ACS) disability questions in 2025. We also sincerely appreciate the Bureau's more recent efforts to more adequately engage with the disabled community and disability researchers. However, we want to ensure that our request for meaningful engagement and collaboration to identify the most inclusive and accurate ways to measure disability is heard and implemented. We also want to ensure that proper consideration of the limitations of the 2022 ACS Content Test are acknowledged.

The National Partnership for Women & Families (the National Partnership) is a nonprofit, nonpartisan advocacy group that has over 50 years of experience in combating barriers to equity and opportunity for women. The National Partnership works for a just and equitable society in which all women and families can live with dignity, respect, and security; every person has the opportunity to achieve their potential; and no person is held back by discrimination or bias. In light of our particular expertise, our comment

focuses in large part on the proposed rule’s impact on disabled¹ women, particularly disabled women of color and multi-marginalized disabled women. Data is critical for our work. Without accurate and inclusive data, it is incredibly difficult to identify the impacts policies have on the populations we advocate on behalf of, as well as advocate for and effect needed change. Thus, we have an interest in the Census Bureau’s data collection practices, priorities and policies.

I. Concerns about the Proposed Change to ACS Disability Questions

The March 25, 2024 Request for Revision of a Currently Approved Collection notes the vast majority of comments it received related to proposed changes to the ACS disability questions discussed the failure to include disabled people in the process. We agree that this lack of engagement was a major concern. However, the Request fails to acknowledge other concerns the National Partnership and many other groups and individuals raise about the proposed questions themselves and the impact of the change on critical services and programming. We want to ensure these shortcomings are also acknowledged.

A. Concerns about the Proposed Questions

While the current ACS disability questions have limitations, using a more limited definition of disability based on the WG-SS would only have further undercounted disabled Americans.² If the recommendations from the Content Test were followed and “Definition 1” was used (in which people with “some difficulty” are not counted as disabled), “the estimated percent of the U.S. population with any disability was about 40 percent lower in [the previously recommended option] than in [the existing data set].”³ National

¹ Overall, the disability community has reclaimed identity-first language (i.e., “disabled”) to acknowledge disability as a critical part of identity in which to take pride. However, not all members of the disability community prefer identity-first language. Others may prefer person-first language (i.e., “person with a disability”). Preferences may also vary by disability. This comment uses identity-first and person-first language interchangeably. However, we will always honor the language a disabled person chooses for themselves.

² 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).

³ Steinweg, A., Young, N., Stern, S., Contard, L., & Spiers, S. 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 12 April 2024, from https://www.census.gov/content/dam/Census/library/working-papers/2023/acs/2023_Steinweg_01.pdf

Partnership research shows that this would erase nearly 10 million disabled women and girls from the official count.⁴ Researchers found that the proposed measure would have undercounted more than half of people with mental health disabilities or chronic illness and 43 percent of disabled people overall⁵ – and it does so at a time we are seeing an increase in the number of disabled people in the wake of the COVID-19 pandemic.⁶ While we recognize that it may not be possible to capture all disabled people in any given survey for reasons outside of Bureau’s control, there are ways to improve the accuracy in the count of disabled people – ways that do not actively cut the number of disabled people counted.

We agree with the Washington Group that disability is a dynamic experience.⁷ However, like the current ACS questions, the proposed questions and their focus more directly adhered to medical, as opposed to social or legal, definitions of disability. In the 2022 ACS Content Test, this was explicitly stated: “[T]hese measures of disability are best understood as measures of functional disability – as opposed to, for example, work disability or self-identification as ‘disabled.’”⁸

This scale may also contribute to inaccurate data. When a “scale” of disability is used, the question then becomes, “How disabled is disabled enough?” However, with the dynamic nature of disability and the range of disabilities that exist, these determinations exclude many disabled people. For example, a disabled person’s ability to climb stairs may vary day to day: some days, someone may answer “not at all,” while another day, they may answer “some difficulty,” leading the person to not be counted as disabled under this proposed definition. A person’s environment can also impact the answers to these questions, thus comparability of disability cross nationally without additional context could be a problematic standard. Additionally, questions

⁴ Ditkowsky, M. & Gallagher Robbins, K. (2023, December 5). New Census proposal would reduce the number of disabled women and girls counted by nearly 10 million [Blog]. Retrieved 12 April 2024 from the National Partnership for Women & Families website: <https://nationalpartnership.org/new-census-proposal-would-reduce-disabled-women-girls-counted-nearly-10-million/>

⁵ See note 2

⁶ Roberts, L., Ives-Ruble, M., & Khattar, R. (2022, February 9). COVID-19 Likely Resulted in 1.2 Million More Disabled People by the End of 2021—Workplaces and Policy Will Need to Adapt. Retrieved 12 April 2024 from the Center for American Progress website: <https://www.americanprogress.org/article/covid-19-likely-resulted-in-1-2-million-more-disabled-people-by-the-end-of-2021-workplaces-and-policy-will-need-to-adapt/>

⁷ Washington Group on Disability Statistics. (n.d.). *WG Short Set on Functioning (WG-SS)*. Retrieved 12 April 2024, <https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>

⁸ See note 3, pp. 11-12

with categories as opposed to yes or no responses may be more difficult to fill out for those with intellectual/developmental disabilities.

We and over 100 other commenters, including the ACLU and the Arc of the United States,⁹ were also concerned that WG-SS (in addition to current ACS questions) excluded many disabilities that are explicitly covered following the passage of the ADA Amendments Act (ADAAA), especially as several agencies cite using these specific questions to assess ADA compliance.¹⁰ WG-SS was developed to be used internationally, not specifically for the U.S. context and needs;¹¹ thus, it excludes many people who qualify as disabled under the Americans with Disabilities Act (ADA). Congress explicitly expanded the definition of disability in the ADAAA to include “major bodily functions,” such as gastrointestinal, immunological, endocrine and other functions.¹² Disabled people with conditions such as Crohn’s Disease, diabetes, chronic pain or endometriosis, for example – which are covered under the ADAAA – may not have been counted based on the WG-SS questions.

The question on hearing on the typical WG-SS would also likely have excluded many disabled people who are Deaf/Hard of Hearing (HoH). The ADAAA defines as disabled anyone with “a physical or mental impairment that substantially limits one or more major life activities,”¹³ “without regard to the ameliorative effects of mitigating measures,”¹⁴ like hearing aids. The language, “[Do/Does] [you/he/she] have difficulty hearing, even if using a hearing aid(s)?” is not reflective of the ADAAA conception of disability. If an individual uses a hearing aid and is HoH, they may be considered disabled regardless of whether a hearing aid improves hearing. This is unlike the use of ordinary glasses or contact lenses under the ADAAA, in which case a person is not necessarily considered disabled. Thus, the question, “[Do/Does] [you/he/she] have difficulty seeing, even if wearing glasses?” does accurately

⁹ National Partnership for Women & Families 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, 88 Fed. Reg. 72,424 (proposed October 20, 2023).

¹⁰ U.S. Census Bureau, U.S. Department of Commerce, American Community Survey Office. (2014, October). American Community Survey: Handbook of Questions and Current Federal Uses (p. 91). Retrieved 12 April 2024, from https://www.census.gov/content/dam/Census/programs-surveys/acs/operations-and-administration/2014-content-review/ACS_Federal_Uses.pdf

¹¹ See note 7

¹² 42 U.S.C. §12102(2)(B) (2022).

¹³ Ibid.

¹⁴ Ibid.

represent American legal and societal definitions of disability, whereas the hearing question does not.

We supported the Bureau’s proposal to add questions more directly related to mental health and communication-related disabilities. However, the question the Bureau recommended adding to the current ACS questions, “Using his or her usual language, does this person have difficulty communicating, for example understanding or being understood?,”¹⁵ still does not fully capture the range of communication-related disabilities (including those who use augmentative and alternative communication, those who use American Sign Language (ASL) as an alternative, those with speech and language disorders, etc.) Simply keeping the current ACS question, “Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor’s office or shopping?,”¹⁶ also fails to address the majority of psychosocial disabilities or cognitive disabilities.

B. Concerns about the Impact of Changing these Questions

If we further undercount the disability community, disabled people in the United States are likely to face an even more dire struggle to obtain needed resources and supports. Certain health care and housing assessments for the disabled community are even required to use the ACS.¹⁷ Some examples of critical services, programs and supports that use ACS data include the following:

- Administration for Community Living (ACL) funding for state councils on developmental disabilities;¹⁸
- U.S. Department of Housing & Urban Development funding assessments for accessible housing;¹⁹
- Disaster preparedness and response;²⁰

¹⁵ Hill, J. (2023, November). 2022 American Community Survey Content Test Results. Presented at the Census National Advisory Committee Meetings, Washington, DC. (p. 11) <https://www2.census.gov/about/partners/cac/nac/meetings/2023-11/presentation-2022-acsc-content-test-results.pdf>

¹⁶ Ibid.

¹⁷ United States Census Bureau, U.S. Department of Commerce. (n.d.). *Why We Ask: Disability*. Retrieved 12 April 2024, from <https://www2.census.gov/programs-surveys/acs/about/qbyqfact/Disability.pdf>

¹⁸ See note 10, p. 88

¹⁹ Economics & Statistics Information, Office of the Chief Economist. (2015, April). *The Value of the American Community Survey* (p. 23). Retrieved 12 April 2024, from <https://www.commerce.gov/sites/default/files/migrated/reports/the-value-of-the-acs.pdf>

²⁰ See note 10, p. 87

- Determining emergency allocations for and effective provision of the Low Income Home Energy Assistance Program (LIHEAP); and²¹
- Navigator funding and enrollment efforts for Marketplace, Medicaid, and Children’s Health Insurance Program (CHIP).²²

If this data does not appropriately capture the prevalence and range of disabilities covered under federal law, it will also inhibit enforcement of civil rights laws by agencies such as the U.S. Department of Justice (DOJ), the U.S. Department of Health & Human Services,²³ the U.S. Department of Transportation²⁴ and the U.S. Equal Employment Opportunity Commission (EEOC),²⁵ for example. The DOJ, Office of Civil Rights, uses this information for ADA enforcement and regulatory changes,²⁶ while the EEOC uses this information to monitor federal employment opportunities for disabled people under the Civil Rights Act of 1964 (amended).²⁷ Civil rights enforcement bodies rely on these data to help identify discriminatory patterns and practices impacting groups of individuals.²⁸

This list addresses only a fraction of the vital uses for ACS data on disability. We appreciate the Bureau recognizing that the National Center for Health Statistics (NCHS) is not the only agency for which disability data holds practical utility.²⁹ Indeed, at least 25 departments, agencies and offices have cited using these specific questions for a range of reasons,³⁰ as well as numerous state agencies. We hope that the Bureau continues to engage all relevant agencies, including through the newly created Disability Data Interagency Working Group.

²¹ Ibid (p. 88).

²² Ibid (p. 91).

²³ Ibid (p. 91).

²⁴ Ibid (p. 93).

²⁵ Ibid (p. 95).

²⁶ Ibid (p. 92).

²⁷ Ibid (p. 95).

²⁸ See various examples regarding civil rights enforcement efforts using these data. Ibid (pp. 87-96).

²⁹ Agency Information Collection Activities; Submission to the Office of Management and Budget (OMB) for Review and Approval; Comment Request; The American Community Survey (ACS) and Puerto Rico Community Survey (PRCS), 89 Fed. Reg. 20,630 (March 25, 2024).

³⁰ See note 10, pp. 87-96

II. The 2022 ACS Content Test and the Bureau’s Plan Moving Forward

In the March 25, 2024 Request for Revision of a Currently Approved Collection, the Census Bureau writes, “The Census Bureau and National Center for Health Statistics (NCHS) stand behind the statistical validity of the 2022 ACS Content Test results and the practical utility of the proposed disability change. However, we recognize that statistical validity and practical utility for NCHS should be only two components of the decision about whether to change questions on the ACS—we must also consider the needs of other data users inside and outside of government.”³¹ Our concerns about this comment are two-fold:

- A) We maintain that our concerns about the Content Test’s scope and decision criteria have not been addressed,
- B) It is unclear what other components will be part of any decision to change ACS disability questions or how such components will be developed, and
- C) We are concerned about the path forward, as these statements indicate the Census Bureau may not be sufficiently open to entertaining new proposals from disability researchers and the disabled community.

A. The Statistical Validity of the 2022 ACS Content Test

The Census Bureau’s comment regarding the statistical validity of the Content Test is confusing and concerning. The National Partnership has not claimed, nor are we aware that others have claimed, that the results of the Content Test are not accurate. We have deep respect for the skills and expertise of the methodologists at the Bureau and believe they have fully shared the results accurately. Indeed, it is because we believe these results are accurate that we are so deeply concerned and we are disappointed the Bureau has not addressed these concerns, including the scope of the Content Test and the Decision Criteria (and application of results to those criteria).

Scope of the Content Test

Just because the results are accurate does not mean that they have addressed all the relevant research questions. For example, we have shared concerns about the scope of the Content Test, highlighting that the test as

³¹ See note 29.

currently constructed does not address changes in responses across different populations – only by disability type. The impacts of disability are intersectional, and understanding how responses to any proposed changes differ by race, gender and gender identity, age, national origin, veteran status and more is essential. We are also concerned that the Content Test did not include people living in group quarters.³² Disabled people are dramatically overrepresented in institutional group quarters such as mental health facilities and correctional institutions.³³ Failure to include this population in the Content Test means we lack a clear understanding of how these measurement changes will affect this population.

Decision Making Criteria in the Content Test and Application of Results

Additionally, we have also shared concerns about the decision-criteria used in the Content Test, specifically the failure to consider prevalence.³⁴ Once again, we believe that the results published in the Content Test regarding the reduction in prevalence are accurate – this is precisely why we are so concerned about the decision to disregard prevalence in the ultimate decision regarding which measure to use. Given the role the ACS data play in federal funding distribution and civil rights enforcement, discounting the prevalence of disability fails to consider the serious implications of the proposed change on the lives of disabled people.³⁵

Additionally, we remain concerned that even when applying the two key criteria utilized in the Content Test, the results reported fail to clearly indicate the need to shift to the WG-SS questions. Specifically, one of the “[t]wo key decision criteria...[was] the item missing data rates for the Disability measure in the Test treatment versus Control.”³⁶ Yet the report of

³² See note 3, p. 39

³³ Brault, M. (2008, February). Disability Status and the Characteristics of People in Group Quarters:

A Brief Analysis of Disability Prevalence Among the Civilian Noninstitutionalized and Total Populations in the American Community Survey. Retrieved 12 December 2023, from <https://www.census.gov/content/dam/Census/library/working-papers/2008/demo/gq-disability.pdf>

³⁴ “While we did compare estimates of Disability prevalence, both overall and by Disability type, between the Test and Control treatments (see Section 2.4.2.3), this was for informational purposes and was not part of the decision criteria.” See note 3, p. 30

³⁵ Consortium for Citizens with Disabilities. (2014, July 18). Comment on the American Community Survey - Six Disability Status Questions [Letter written July 18, 2014 to Honorable Penny S. Pritzker]. Retrieved 12 April 2024, from https://www.justiceinaging.org/wp-content/uploads/2015/04/American-Community-Survey-Comment-project_7-16-14-final-2.pdf; See note 10, pp. 87-96

³⁶ See note 3, p. 85

the Content Test notes, “[I]n summary, the percentage of respondents who were missing data on all Disability questions was significantly higher in the Test treatment, relative to the Control treatment, when all modes (and proxy vs. self-report responses) were combined.”³⁷ Though this difference was substantively small, the evidence from the Content Test demonstrates that the proposed measures did not offer a clear improvement over the existing measures. Similarly, for the second decision criteria, which was “the response reliability of the Disability measure in the Test treatment (modified WG-SS), relative to the Control (ACS-6),” the proposed change also did not offer a clear improvement. Researchers found that “[o]verall, when all response reliability results are considered together, they present a mixed picture of the response reliability of the Test treatment.”³⁸ In short, even considering the two key criteria for the Content Test, limited though those criteria are, the proposed changes did not offer clear improvements over the existing set of questions.

B. Lack of Clarity in Decision-Making Metrics or Factors Moving Forward

While the Bureau acknowledges in this Request for a Revision of a Currently Approved Collection that additional components must be considered in this disability collection moving forward, there is no clear specificity regarding what those components might be, how they will be developed or how they will be considered. For example, we believe that additional components of the decision to change the ACS questions should include disability prevalence, the impact of the change of measurement on programs and funding, inclusivity of the measurements of different types of disabilities, utility of the measurements for various other agencies and programs, inclusivity of the process in generating the measurements, and more. While we appreciate the Bureau acknowledging “the needs of other data users inside and outside of government” in making this decision, the importance of these data go well beyond the needs of just data users, just as the importance of the ACS and the Bureau’s work reaches well beyond just creating estimates.

C. The Bureau’s Intentions for Collaboration and Engagement

By doubling down on the “statistical validity” of the 2022 ACS Content Test and the “practical utility” of the changes for NCHS, we worry that the

³⁷ Ibid (p. 53).

³⁸ Ibid (pp. 86).

Bureau is not open to new proposals for more inclusive disability measurement and data collection practices that more accurately address the range of practical needs and applications for the ACS disability questions. We want to ensure that engagement with the disabled community and disability researchers is more than just a formality, but rather a true effort to collaborate and re-imagine existing proposals.

As the Bureau moves forward, we appreciate the opportunity to engage on next steps and look forward to working together to develop additional testing strategies based on new proposals created in collaboration with the disabled community and disability researchers. For example, we would recommend conducting a National Academies of Sciences, Engineering, and Medicine (NASEM) study to further determine best practices and needs for disability data collection. We hope that the renewed commitment to engagement with the disabled community and disability researchers can lead to fruitful partnerships and inclusive ways of thinking about the ways we collect disability data.

* * *

We look forward to further collaboration with the Bureau, the agencies that rely on these data and other stakeholders to reimagine the way we collect disability data.

If you have any questions about this comment, please feel free to contact Marissa Ditkowsky (mditkowsky@nationalpartnership.org), Disability Economic Justice Counsel at the National Partnership for Women & Families, or Katherine Gallagher Robbins, PhD (kgallagherrobbins@nationalpartnership.org), Senior Fellow at the National Partnership for Women & Families.

Sincerely,

The National Partnership for Women & Families