



December 19, 2023

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Department
1401 Constitution Avenue NW
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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**

The undersigned 116 organizations 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).

As gender justice and disability justice advocates, we know that data is critical for our work. Without accurate and inclusive data, it is incredibly difficult to advocate for and effect needed change. Thus, we have an interest in the Census Bureau's data collection practices, priorities and policies, especially as they relate to disability. We urge the Census Bureau to not implement a restrictive official definition of disability and to engage extensively with the disability community to ensure any changes to the disability data collection methodology are inclusive and reflect the full range of data needs.

I. Disability Data

Women are more likely than men to have a disability, according to Census Bureau data.¹ Disabled women of color face additional, unique barriers. Indigenous and Black adults are more likely to have a disability: three in 10 American Indian/Alaska Native adults have a disability, while one in four Black adults have a disability.² Members of the LGBT community are also more likely than the general population to have a disability.³ Applying an intersectional lens, we recognize that there is a gendered experience to disability. Accurate and inclusive data on disability is critical for understanding the needs of disabled women and disabled women of color.

The current Census proposal to alter the measurement of disability in the American Community Survey (discussed in detail below) would result in an approximately 40 percent reduction in the number of people counted as disabled,⁴ erasing nearly 10 million disabled women from an already undercounted population.⁵ This change would impact data used in funding decisions for disability programs and by civil rights bodies

¹ U.S. Census Bureau. (2022, September). *American Community Survey 1-Year Estimates (Table S1810: Disability Characteristics)*. Retrieved 7 December 2023, from <https://data.census.gov/table?q=disability&tid=ACSST1Y2021.S1810>

² Centers for Disease Control and Prevention. (n.d.). *Adults with Disabilities: Ethnicity and Race*. Retrieved 7 November 2023, from <https://www.cdc.gov/ncbddd/disabilityandhealth/materials/infographic-disabilities-ethnicity-race.html>

³ Movement Advancement Project. (n.d.). *LGBT People with Disabilities* [Movement Advancement Project, Center for American Progress, National Center for Lesbian Rights and National LGBTQ Task Force publication]. Retrieved 13 December 2023, from <https://www.lgbtmap.org/effective-messaging/lgbt-people-disabilities>

⁴ 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

⁵ 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 7 December 2023 from the National Partnership for Women & Families website: <https://nationalpartnership.org/new-census-proposal-would-reduce-disabled-women-girls-counted-nearly-10-million/>

across the government related to housing, health care, education, employment and more.⁶

We are deeply concerned that these changes were proposed without adequate consultation with the disabled community, including disabled advocates and researchers, and urge the Census Bureau to consult with these experts to develop disability measures that provide a full, inclusive count of disabled people. In fact, the U.S. Department of Commerce National Advisory Committee has recommended not moving forward with changes until the Census consults with disability researchers and advocates.⁷

A. Concerns about the Questions and Method of Collection

We also have specific concerns about the Census proposal to 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. While the current ACS disability questions have limitations (discussed below), using a limited definition of disability based on the WG-SS will only further undercount disabled Americans.⁸ Currently, it is estimated that the ACS disability measures already undercount disabled people by about 20 percent.⁹ If changes are to be made to the ACS questions, we recommend making improvements that will more accurately count disabled people in the United States based on our current conception of disability.

⁶ 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 7 December 2023, from https://www.justiceinaging.org/wp-content/uploads/2015/04/American-Community-Survey-Comment-project_7-16-14-final-2.pdf; 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* (pp. 87-96). Retrieved 7 December 2023, from https://www.census.gov/content/dam/Census/programs-surveys/acs/operations-and-administration/2014-content-review/ACS_Federal_Uses.pdf.

⁷ Bradley, C. & Hafford, C. (2023, November 16). NAC Discussion and Formulation of Recommendations at the National Advisory Committee Fall Meeting.

⁸ 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).

⁹ Ibid.

If the recommendations from the ACS Survey Research and Evaluation Report (hereinafter “Content Test”) are followed and “Definition 1” is used (in which people with “some difficulty” are not coded as disabled), “the estimated percent of the U.S. population with any disability...[will be] about 40 percent lower in [new recommended option] than in [the existing data set]”.¹⁰ Researchers find that the proposed new measure undercounts more than half of people with mental health disabilities or chronic illness and 43 percent of disabled people overall¹¹ – 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.¹² We estimate that this change would result in the erasure of 18.6 million people in the United States who are currently counted as disabled in the ACS.¹³ We estimate this change would erase approximately 9.6 million women and girls from this count, including more than 3.5 million women and girls of color.¹⁴

We agree that disability is a dynamic experience.¹⁵ However, these questions and their focus more directly adhere to medical, as opposed to social or legal, definitions of disability. In the Content Test, this is made clear: “[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.’”¹⁶ The answer categories further enforce this limited medical model. When a “scale” of disability is used, the question then becomes, “How disabled is disabled enough?” The Census proposal only counts individuals as disabled who mark that they have “a lot of difficulty” completing a task or “cannot do at all.”¹⁷ However,

¹⁰ See note 4, p. 9.

¹¹ See note 8.

¹² Roberts, L., Ives-Rublee, 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 7 December 2023 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/>

¹³ National Partnership for Women & Families analysis of American Community Survey 2021 one-year data.

¹⁴ See note 5.

¹⁵ Washington Group on Disability Statistics. (n.d.). *WG Short Set on Functioning (WG-SS)*. Retrieved 7 December 2023, <https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>

¹⁶ See note 4, pp. 11-12.

¹⁷ *Ibid*, p. 8.

with the dynamic nature of disability and the diversity of disabilities that exist, these determinations exclude disabled people. A person's environment can also impact a respondent's answers, thus comparability of a functional definition of disability cross nationally could be a difficult standard to assess. Additionally, questions with categories, as opposed to yes or no responses, may be more difficult to fill out for those with intellectual/developmental disabilities.

We are also concerned that the WG-SS measures (as well as current ACS questions) exclude many disabilities that are explicitly covered following the passage of the ADA Amendments Act (ADAAA). While the WG-SS is often used internationally, it excludes those who would actually qualify as disabled under the Americans with Disabilities Act (ADA). The ADAAA explicitly expanded the definition of "disability" to include "major bodily functions," such as gastrointestinal, immunological, endocrine, and other functions. Disabled people with conditions such as Crohn's Disease, diabetes, or endometriosis, for example, may not be counted based on the limitations of these questions.

Disabled women may be particularly undercounted. Women are more likely than men to have chronic illnesses and mental health disabilities, both of which are more likely to be undercounted by both the WG-SS and the ACS questions.¹⁸ For example, endometriosis, which occurs when endometrial tissue grows outside the uterus, is estimated to affect up to 10 percent of women between the ages of 25 and 40.¹⁹ Women are at four times the risk for autoimmune disease.²⁰ Women are also more likely to experience gastrointestinal disorders than men.²¹ For example, Irritable Bowel Syndrome (IBS) is between two and six times more

¹⁸ See note 8.

¹⁹ John Hopkins Medicine. (n.d.). *Endometriosis*. Retrieved 7 December 2023, from <https://www.hopkinsmedicine.org/health/conditions-and-diseases/endometriosis>

²⁰ Kronzer, V., Bridges, S., & Davis, J. (2020, December 1). Why women have more autoimmune diseases than men: An evolutionary perspective. *Evolutionary Applications* 14(3).

²¹ American Physiological Society. (2015, March 30). Why gastrointestinal disorders afflict women more often. *Science Daily*. Retrieved 7 December 2023, from <https://www.sciencedaily.com/releases/2015/03/150330134409.htm#:~:text=Summary%3A,are%20more%20sluggish%20in%20women>

likely to affect women than men.²² Inflammatory Bowel Disease (IBD), which includes conditions such as Crohn’s and Ulcerative Colitis, is more frequent in women than men at a ratio of 2:1.²³ Chronic pain or chronic conditions covered under the ADAAA are also often not captured by these data questions. Women are more likely to experience chronic pain.²⁴

B. ACS Data’s Critical Role in Funding and Civil Rights Enforcement

The Content Test explicitly noted that the prevalence of disability in making these changes was not considered.²⁵ However, 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.²⁶ If we further undercount the disability community, disabled people in the United States may 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.²⁷ 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;²⁸

²² American College of Gastroenterology. (n.d.). *Common Gastrointestinal Problems in Women*. Retrieved 7 December 2023, from <https://gi.org/topics/common-gi-problems-in-women/>

²³ Ibid.

²⁴ International Association for the Study of Pain. (n.d.). *Pain in Women*. Retrieved 7 December 2023, from <https://www.iasp-pain.org/advocacy/global-year/pain-in-women/#:~:text=Chronic%20pain%20affects%20a%20higher,longer%20lasting%20pain%20than%20men>

²⁵ See note 4, p. 30. “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.”

²⁶ See note 6.

²⁷ United States Census Bureau, U.S. Department of Commerce. (n.d.). *Why We Ask: Disability*. Retrieved 7 December 2023, from <https://www2.census.gov/programs-surveys/acs/about/qbyqfact/Disability.pdf>

²⁸ See note 6, U.S. Census Bureau, p. 88.

- U.S. Department of Housing & Urban Development funding assessments for setting aside accessible housing;²⁹
- Disaster preparedness and response;³⁰
- Determining emergency allocations for and effective provision of the Low Income Home Energy Assistance Program (LIHEAP);³¹
- Navigator funding and enrollment efforts for Marketplace, Medicaid, and Children’s Health Insurance Program (CHIP), which are critical programs for disabled women and their families;³²
- Measuring the criminal victimization of individuals with developmental disabilities in conjunction with Bureau of Justice Statistics’ National Crime Victimization Survey;^{33 34} and
- Providing information on the “women, minorities, group members and disabled people in the science and engineering workforce.”³⁵

This list addresses only a fraction of the vital uses for ACS data on disability.

If this data does not appropriately capture the range of disabilities covered under federal law, it will also inhibit enforcement of civil rights laws by agencies such as the Department of Justice, the U.S. Department of Health & Human Services,³⁶ the U.S. Department of

²⁹ Economics & Statistics Information, Office of the Chief Economist. (2015, April). *The Value of the American Community Survey* (p. 23). Retrieved 7 December 2023, from <https://www.commerce.gov/sites/default/files/migrated/reports/the-value-of-the-ac-s.pdf>

³⁰ See note 6, U.S. Census Bureau, p. 87.

³¹ See note 6, U.S. Census Bureau, p. 88.

³² See note 6, U.S. Census Bureau, p. 91.

³³ See note 6, U.S. Census Bureau, p. 92.

³⁴ Disabled women are more likely to experience violent crime, and more than 80 percent of disabled women have experienced sexual assault. YWCA (2017, September). *Survivors with Disabilities Facts*. Retrieved 7 December 2023, from <https://www.ywca.org/wp-content/uploads/Survivors-w-Disabilities-Fact-Sheet.pdf>; Smith, N., Harrell, S., & Judy, A. (2017, April). *How Safe are Americans with Disabilities? The facts about violent crime and their implications*. Retrieved 7 December 2023 from the Vera Institute website: <https://www.vera.org/downloads/publications/How-safe-are-americans-with-disabilities-web.pdf>

³⁵ See note 6, U.S. Census Bureau, p. 95.

³⁶ See note 6, U.S. Census Bureau, p. 91.

Transportation³⁷ and the U.S. Equal Employment Opportunity Commission,³⁸ for example. The U.S. Department of Justice, Office of Civil Rights uses this information for ADA enforcement and regulatory changes,³⁹ while the EEOC uses this information to monitor federal employment opportunities for disabled people under the Civil Rights Act of 1964 (amended).⁴⁰ Civil rights enforcement bodies rely on these data to help identify discriminatory patterns and practices impacting groups of individuals.

* * *

For these reasons, we recommend that the Census not implement any changes until they have properly consulted with disability experts and researchers, including disabled people themselves, to develop full, inclusive measures of disability that address the range of uses of the ACS data in the federal government. We also recommend that the Census not implement this extremely narrow and limited definition of disability that will further harm disabled people.

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
A Better Balance

³⁷ U.S. Department of Transportation, Federal Highway Administration. (n.d.). *Data Collection and Analysis*. Retrieved 7 December 2023, from https://www.fhwa.dot.gov/civilrights/programs/title_vi/data_collection_analysis.cfm

³⁸ As an example, the Equal Employment Opportunity Tabulation is based on American Community Survey data. U.S. Census Bureau. (n.d.). Equal Employment Opportunity Data. Retrieved 7 December 2023, from <https://www.census.gov/acs/www/data/eeo-data/>

³⁹ See note 6, U.S. Census Bureau, p. 92.

⁴⁰ See note 6, U.S. Census Bureau, p. 95.

ACA Consumer Advocacy
Alabama Disabilities Advocacy Program
American Association of People with Disabilities
American Association on Health and Disability
American Civil Liberties Union
American Psychological Association Services
API Equality-LA
Arizona Center for Disability Law
Arkansas Advocates for Children and Families
Asset Building Strategies
Autistic Self Advocacy Network (ASAN)
Autistic Women & Nonbinary Network
Bazelon Center for Mental Health Law
CA LGBTQ Health and Human Services Network
California State Council on Developmental Disabilities
Caring Across Generations
Center for American Progress
Center for Law and Social Policy (CLASP)
Center for Science in the Public Interest
Center for WorkLife Law, UC Law SF
Central Coast Coalition for Inclusive Schools
Coalition on Human Needs
Colorado Consumer Health Initiative
Congregation of Our Lady of Charity of the Good Shepherd, U.S.
Provinces
Disability & Philanthropy Forum
Disability & Well-Being In Social Work
Disability EmpowHer Network
Disability Law Center (MA)
Disability Law Center of Utah
Disability Resource Center
Disability Rights Education and Defense Fund (DREDF)
Disability Rights Iowa
Disability Rights Maine
Disability Rights Maryland
Disability Rights New Jersey
Disability Rights North Carolina
Disability Rights Tennessee

Disability Rights Vermont
Disability Rights Washington
Disability Rights of West Virginia
Economic Opportunity Institute
Epilepsy Foundation
Every Texan
Family Values @ Work
FL National Organization for Women (NOW)
Florida Institute for Community Studies (FICS)
Gender Justice LA
Georgia Budget and Policy Institute
Greater Orlando National Organization for Women (NOW)
Hawaii Disability Rights Center
Housing Works
Illinois-Iowa Center for Independent Living
Institute for Work & the Economy
Iowa Developmental Disabilities Council
Ipas
JFCS East Bay
Justice in Aging
Justice for Migrant Women
Lakeshore Foundation
Legal Aid at Work
Long Beach Alliance for Clean Energy
Minnesota Disability Law Center at MMLA
MomsRising
Movement Advancement Project
National Advocacy Center of the Sisters of the Good Shepherd
National Association of Councils on Developmental Disabilities
National Black Justice Coalition
National Center for Lesbian Rights (NCLR)
National Community Action Partnership
National Council of Asian Pacific Americans (NCAPA)
National Disability Institute
National Disability Rights Network (NDRN)
National Education Association
National Employment Law Project
National LGBT Cancer Network

National Network for Arab American Communities
National Network to End Domestic Violence
National Organization for Women
National Women's Law Center
Native American Disability Law Center
Native American Health Center, Inc.
NC Counts Coalition
NETWORK Lobby for Catholic Social Justice
Nevada Disability Advocacy and Law Center
Nevada Governor's Council on Developmental Disabilities
New Disabled South
Oklahoma Policy Institute
Patient-Led Research Collaborative
Planned Parenthood Federation of America
Progress Center for Independent Living
Public Advocacy for Kids (PAK)
Reproductive Freedom for All (formerly NARAL Pro-Choice America)
Reproductive Health Impact: The Collaborative for Equity and Justice
SAGE
San Joaquin Pride Center
Southeast Asia Resource Action Center (SEARAC)
SSD Lawyers PA
Stone-Hayes Center for Independent Living
The Arc of the United States
The Arc Wisconsin
The Center for Research and Education on Accessible Technology and Experiences
The Disability Economic Justice Collaborative
The Myalgic Encephalomyelitis Action Network
The National Domestic Violence Hotline
The Source LGBT+ Center
The Statewide Independent Living Council of Illinois
Transgender Law Center
Tzedek DC
U.S. Gender and Disability Justice Alliance
Whitman-Walker Institute
Wisconsin Board for People with Developmental Disabilities
Women Enabled International

Working Partnerships USA
YWCA USA