

December 19, 2023

via Online Portal (<http://www.regulations.gov/>) and
electronic mail to acso.pra@census.gov

Robert Santos, Director
U.S. Census Bureau
4600 Silver Hill Road
Suitland, MD 20746
United States

**Re: Proposed Revision of the American Community Survey and Puerto Rico
Community Survey, Docket Number USBC–2023–0009**

Dear Director Santos,

Thank you for the opportunity to comment on the Bureau's proposed revisions to the American Community Survey. Disability Rights Education and Defense Fund (DREDF) is a national cross-disability law and policy center that protects and advances the civil and human rights of people with disabilities through legal advocacy, training, education, and development of legislation and public policy. In the more than 40 years that have passed since our founding, we have persistently fought for the right of people with disabilities to be fully integrated within all aspects of community life. DREDF's work is based on the knowledge that people with disabilities of varying ages, racial and ethnic backgrounds, genders, and sexual orientations are fully capable of achieving self-sufficiency and contributing to their communities with access to needed services and supports and the reasonable accommodations and modifications enshrined in U.S. law. Our comments here only address proposed changes to the series of six disability questions in the ACS (ACS-6); our comments equally apply to the Puerto Rico Community Survey (PRCS) but throughout we simply reference the ACS.

People with Disabilities as Subjects, Not Objects

I was first introduced to disability rights by a leading attorney and scholar in international law, Professor Theresia Degener. I provided her with additional legal research while she was a guest lecturer at UC Berkeley's School of Law and co-writing a [paper that detailed a paradigm shift for people with disabilities](#) from being an object of law, to rights-bearing subjects in and under the law.¹ I relay this experience because the work of international disability rights advocates and attorneys such as Professor Degener and Professor Gerard Quinn is central to why and how many in the U.S. disability community, disability researchers, and disability advocates, are reacting so strongly to the Census Bureau's proposed changes to the current set of six disability questions in the American Community Survey (ACS). The recognition of people with disabilities as equal subjects in international law has been akin to the recognition

¹ Gerard Quinn & Theresia Degener, Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability (2002), United Nations, New York and Geneva.

of full personhood and the right to vote for women and for people of color, both within the U.S. and in countries all over the world. Ultimately, Professor Degener's scholarship and advocacy helped seed the ground for the development of the [Convention on the Rights of Persons with Disabilities \(CRPD\)](#)² over a four-year period that culminated in its adoption by the United Nations on December 12, 2006, just over 17 years ago. On its opening day, the CRPD had a record 82 signatories and fully entered into force on May 2008 as the first binding international law that recognizes the human rights of people with disabilities.³

The Bureau has pointed to the improved ability to compare U.S. disability statistics with international disability statistics as a major reason to revise the ACS-6 toward a set of disability questions that incorporates a scaled response with four levels of functional difficulty such as that used in the Washington Group Short Set (WGSS) questions. But surely the larger point of improved disability data is to ensure that *people* with disabilities are provided with tools, programs, and funding for economic, political, and social integration within society, and not merely achieving an improved ability to compare the prevalence of disability across national borders? If the Census Bureau's goal is to recognize international trends regarding disability, the most significant change has been the recognition of people with disabilities as subjects in international law who have the right to maximize their health, well-being, autonomy, and freedom from discrimination rather than objects that take up resources.

The CRPD calls on member countries to provide people with disabilities with "the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them."⁴ To be clear, the U.S. has signed but has not ratified the CRPD. It is not obligated to comply with the CRPD's provisions, just as the Bureau is not obligated to adopt the WGSS within its domestic federal surveillance instruments. But the Bureau appears to have begun considering this change since 2018, and it has done so without involving the disability community, most disability researchers, or disability advocates until very recently, even though counting people with disabilities and funding for government-funded disability programs and activities obviously directly concerns people with disabilities. The Bureau's stated regard for international comparability is conspicuous for its contrast with the Bureau's disregard for disability rights' principle and practice in international law, as exemplified in an international maxim that has been widely associated with people with disabilities in the U.S. as well: "Nothing about us without us."

The Choice is Not Limited to the Current ACS-6 Versus WGSS

DREDF has signed on to three coalition comment letters that have been submitted to the Census Bureau in response to its Federal Register Notice on the ACS revisions. The Consortium for Constituents with Disabilities (CCD), the National Partnership on Women and

² United Nations, Human Rights, Office of the High Commission, *Convention on the Rights of Persons with Disabilities*.

³ See United Nations, Department of Economic and Social Affairs, *Convention on the Rights of Persons with Disabilities (CRPD)*, available at <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-Persons-with-disabilities.html>.

⁴ Provision (o) of the Preamble.

Families, and a large group of disability researchers and organizations have all provided the Bureau with well-supported points, studies, and recent research on how much the ACS-6 currently undercounts people with disabilities in the US, and how the WGSS would worsen the undercount by potentially lowering the estimated number of people with disabilities in the U.S. by 15 million, or roughly 15% to 9% of the U.S. general population. We will not be reiterating those reference materials unless directly relevant to an issue that we raise in this letter.

Both the ACS-6 and the WGSS have shortcomings. Over the years, many disability advocates including DREDF have pointed out how particular segments of people with disabilities such as those with mental health disabilities, some people with developmental disabilities, persons with communication disabilities, and people with chronic or episodic conditions are simply not adequately encompassed by the ACS-6. Recognizable sub-populations of people with disabilities are therefore not counted by the Bureau under the current set of questions. The WGSS very likely exacerbates that undercount of respondents who are disabled by further forcing them to distinguish between whether they experience “a lot of difficulty” or “some difficulty” when assessing the impact of a functional limitation in their own life, as opposed to the ACS-6 which more simply asks respondents to answer “yes” or “no” to having “serious difficulty.” All of these descriptive options are arbitrary. There are people with varying disabilities, from multiple sclerosis to depression, who do not experience functional limitations consistently from day to day, and people who have some difficulty in two or more areas of functional limitation who will face different levels of overall activity limitation over time. Moreover, people who have a lot of difficulty being understood in their usual language are functionally distinct and need distinct accommodations, policies, and program from people who have a lot of difficulty understanding, but the WGSS communication question which is proposed for adoption conflates this difference.

It is no answer to assert that WGSS estimates of disability prevalence can be tailored for varying purposes depending on where one draws the cut-off point in the severity levels because many of those estimates have broader purposes. Employers, public accommodations, and healthcare facilities do not discriminate only against people who experience what they consider “a lot of difficulty.” Persons with Long Covid who have less trouble in the single dimension of concentrating than others with the same condition are not necessarily in less need of healthcare services and supports to recover. And politicians and policy-makers who wish to impose work conditions on Medicaid eligibility are unlikely to tailor the imposition of such barriers to healthcare depending on the level of functional limitation given that every proposal for work requirements that I have ever seen also involves cutting funding and personnel for administering Medicaid in the state.

The Census Bureau and disability advocates should not engage in an unproductive debate over the respective merits of the ACS-6 or the WGSS because those two options do not comprise the universe of possible improvement. DREDF strongly recommends against the Bureau’s proposal to revise the ACS disability questions toward a model that hews toward the WGSS, but not because we inherently favor the current ACS-6, rather we recognize that any wholesale change along the lines proposed by the Bureau will be harmful *in and of itself*. Changing the ACS disability questions will be a major disruption to the availability of local area data for at least five years following the change and also forestall the accuracy of trend data.

Both local area and trend data are important for policy analyses at the national, state, and municipal level. During these coming years of increased climate/weather extremes, natural disasters, forest fires, and the ongoing potential for epidemics/pandemics, the absence of such timely and accurate data at local levels will have serious consequences for the inclusion of disabled people living in the community and in institutions in all disaster responses.

The Bureau has not counter-acted these certain negative impacts with any evidence or even discussion of probable benefits that a change to the WGSS questions will have for people with disabilities as a whole, or even to particular groups of disabled people. The Federal Register notice about the provisions does not address the impact that the changed questions would have on how people with disabilities answer the question, including people with limited English proficiency and immigrant populations who may already be receiving incorrect information about how the presence of disability or the use of public benefits could impact on their eligibility for citizenship or permanent residence. The Notice does not even clearly include a comparison of the ACS-6 questions and the WGSS questions under consideration, and there is also no indication of where the Bureau would draw the “cut line” for defining disability under a revised ACS question set. It is hard to understand how the Federal Register Notice adequately and fully communicates the ACS revisions and the consequences of those revisions to people with disabilities who need plain language, or who may have limited subject matter expertise in surveillance tools and disability data but who absolutely can explain to the Bureau why it is important for them to be counted as a person with disabilities. DREDF does not doubt that the Bureau welcomes comments from people with disabilities, but we question that the Bureau has done the work needed to achieve equally effective outreach and solicitation of comments from people with a wide range of disabilities.

The Move Toward Community Outreach and Cooperative Work

Both the current ACS questions and the WGSS questions are loosely based on the conceptualization of disability in the International Classification of Functioning, Disability, and Health. Some set of disability questions has been in the ACS for over two decades, though there has been a move away from an initial focus on work-related disability. In all this time, neither set of questions was developed systematically following a rigorous research process involving and led by disabled stakeholders. This omission of involvement from people with disabilities was already problematic in 2008 when the current ACS-6 was adopted. It is nothing short of anachronistic today.

In the past couple of years alone, we have seen appropriate and welcome communication and cooperative work between federal agencies and subject matter experts who are also part of the communities for whom they advocate. The federal Office of Management and Budget (OMB), at the beginning of 2023, proposed new standards for the collection of race and ethnicity data.⁵ The new proposal would update standards that have not been revised since 1997, and it recognizes a distinct non-white Middle Eastern and North African (MENA) racial

⁵ OMB, Initial Proposals for Updating OMB’s Race and Ethnicity Statistical Standards, available at <https://www.federalregister.gov/documents/2023/01/27/2023-01635/initial-proposals-for-updating-ombs-race-and-ethnicity-statistical-standards>.

category that MENA advocates have long sought. If a group is not counted, it does not exist for purposes of data and research, funding, government services, or protection from discrimination. We have similarly seen appropriate efforts at the National Academies of Science Engineering, and Medicine (NASEM) to include stakeholder expertise among the LGBTQ+ community on how to word and ask sexual orientation and gender identity (SOGI) questions.⁶ In 2023, the National Institutes of Health was responsive to responses and advocacy from the disability community and decided to designate people with disabilities as a health disparity population despite an initial recommendation to delay the designation made by an Advisory Committee of National Institutes on Minority Health and Health Disparities that lacked disability representation.

The Census Bureau's own work over several years to improve its outreach to and recognition of American Indians within the census, including specific meetings with federally recognized Indian tribes, is another good example of the kind of cooperative stakeholder work that leads to concrete recommendations and, eventually, improved outcomes.⁷ The Bureau's reporting of its work with native tribes proves that the agency recognizes the limits of its own technical expertise and experience in general population and topical surveillance. It isn't enough for the Census Bureau to know how to count if the Bureau doesn't know the people it is trying to count and those people don't trust the Bureau. The disability community is a highly heterogeneous community that encompasses multiple racial, ethnic, cultural, gender, age, and LGBTQI+ characteristics. It is a community that includes people with congenital disabilities, people who acquire disabilities at different life stages, and people who have a range of functional and activity limitations, but it is nonetheless a community and an identity that holds much in common from experiencing ableism to facing inaccessibility barriers, from being held back by paternalism to having diminished access to education and employment. The Bureau has lost much trust among the disability community, but it is not too late to mitigate the damage and reorient its approach to improving its disability questions.

Moving Forward

The key to moving forward at this point is to build an ongoing long-term relationship with disability researchers, advocates, and community members. This means that the Bureau must reach out to ensure that people with disabilities, and not only other federal agencies, are included before the Bureau makes recommendations on changing the ACS-6. Its interactions with federal agencies must include entities such as the Administration for Community Living and the Office for Civil Rights at the Department of Health and Human Services. The Bureau must not only include "disability issues" such as communication accessibility when it speaks with other under-represented groups, but also seek out diverse people with disabilities. If we look at the intersection of disability with just a single additional characteristic such as Native

⁶ See *Measuring Sex, Gender Identity, and Sexual Orientation* (2022), <https://www.nationalacademies.org/our-work/measuring-sex-gender-identity-and-sexual-orientation-for-the-national-institutes-of-health>.

⁷ See, for example, <https://www.census.gov/newsroom/blogs/director/2023/11/native-american-heritage-month.html> and <https://www.census.gov/library/publications/2017/dec/2020-federally-recognized-tribes.html>.

Indian racial identity, we find multiple connections that can all affect how disabled American Indian and Alaskan Natives (AI/AN) are counted. We know there is a higher incidence of disability among AI/AN persons.⁸ How is that known fact influenced by how tribal cultures think and talk about disability, the extent to which people with disabilities of different ages are included within tribal activities, how geography and location in urban centers or on rural reserves influence activity limitation outcomes, and how communication and accommodation capacities among tribes affect the way that census questions about race and disability are answered by disabled AI/AN persons? Is it possible that a particular contextual interaction between race and disability could require greater attention preventive services and access to social determinants of health to people who have “some difficulty” with functional activities, as an investment that will avoid or delay the rapid acquisition of “a lot of difficulty” or the complete inability to engage in functional activities?

We are at a moment when we need more information about people with disabilities, not less, in the aftermath of a pandemic where we still do not fully understand the impact of COVID-19 on people with disabilities who live in the community, where hundreds of thousands continue to experience the impact of Long COVID, and in a country gripped by both an addiction crisis and a mental health crisis that is especially affecting our youth. Longstanding disability advocacy is on the cusp of getting states to follow the lead of Oregon and Washington and require some healthcare institutions to include demographic disability data questions in state level healthcare surveillance tools that will help uncover health disparities. In doing so, states will naturally look to the ACS-6 as a set of base questions. The challenges of discovering and rooting out racial and disability bias in automated decision-making tools and artificial intelligence while protecting consumer privacy are imminent. And the U.S. population is aging, which will bring with it a greater incidence of disability and increased demand for disability and home and community-based services that will allow people to appropriately age in place. This is a moment that requires accurate and detailed assessments of disability prevalence, and greater depth of knowledge about the needs of people with disabilities.

DREDF agrees with many of our colleagues that the current ACS-6, as imperfect as it is, be retained while the Census Bureau works to establish a strong, ongoing internal working group that is dedicated to disability subject matter expertise and inclusively staffed by disability-led researchers that maintain strong ties with diverse disability advocates and community members. This working group can refine a broad framework for the Bureau’s future work on disability, focusing on the disability’s long-expressed need to be more inclusive of people with mental health, developmental, and communication disabilities as well as people with chronic or episodic conditions. Moreover, this working group should not be constrained by an artificial choice between the ACS-6 and the WGSS. Rather, the group should be free to consider how and when to consider including disability among the decennial census or otherwise obtaining a far fuller picture of how people with disabilities live, how their disabilities impact not only their activities of daily living and their instrumental activities of daily living, but also their actual decisions with regard to engagement in economic, social, and community activities. The

⁸ Centers for Medicare and Medicaid Services, AI/AN Age and Disability (last modified 9/6/23), available at <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/ai-an-age-and-disability>.

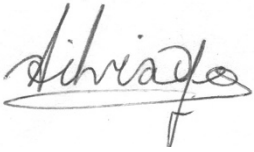
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working group's considerations should also consider how disability interacts with other characteristics such as race, ethnicity, LGBTQ+ status, gender, and age. Even as the Bureau considers the incorporation of the WGSS, the international community has moved on to consider other disability surveys that would allow for greater in-depth knowledge about living with disability.⁹

Thank you again for this opportunity to comment on the Bureau's proposed revisions to the ACS. Please do not hesitate to contact me at syee@dredf.org or 510-644-2555 if you have any questions concerning the above comment, or any of our reference materials which we would like to be added to the Bureau's official record of public comment.

Yours Truly,

A handwritten signature in black ink, appearing to read "Silvia Yee", with a horizontal line underneath the name.

Silvia Yee
Senior Staff Attorney

⁹ Nora Ellen Groce, Which One to Use?: The Washington Group Questions or The Model Disability Survey, available at <https://www.ucl.ac.uk/epidemiology-health-care/which-one-use-washington-group-questions-or-model-disability-survey>.