



December 19, 2023

Ms. Sheleen Dumas  
Department PRA Clearance Officer  
Office of the Under Secretary for Economic Affairs  
U.S. Department of Commerce  
1401 Constitution Ave., NW  
Washington, DC 20230

Submitted via <http://www.regulations.gov>

**Re: Public comment in response to U.S. Census Bureau submission to OMB for review and approval of revisions to the American Community Survey and Puerto Rico Community Survey (Docket No. 2023-23249)**

Dear Ms. Dumas:

On behalf of The Leadership Conference on Civil and Human Rights, a coalition charged by its diverse membership of more than 240 national organizations to promote and protect the civil and human rights of all persons in the United States, and its Census Task Force co-chairs, Asian Americans Advancing Justice | AAJC and NALEO Educational Fund, we appreciate this opportunity to provide comments on the proposed revisions to the questions on disability, in response to the Census Bureau's request for review and approval of revisions to the American Community Survey (ACS) and Puerto Rico Community Survey (PRCS) beginning in 2025. For the reasons discussed below, we strongly urge the Census Bureau to pause its plan to revise the ACS disability questions as proposed in the Federal Register Notice, until it has engaged in meaningful consultation with disability rights advocates and the disability community directly and has demonstrated that any revised questions produce accurate, useful data for all applicable statutory and policy purposes.

The Leadership Conference is the nation's oldest, largest, and most diverse civil and human rights coalition and provides a powerful unified voice for the many constituencies we represent. Our coalition views the collection of useful, objective data about our nation's people, housing, economy, and communities to be among the most important civil rights issues of our day. Our longstanding role as a Census Information Center has allowed us to lift up within our broad civil rights coalition the fundamental importance of comprehensive, high-quality data about our population, communities, and economy.

The proposed revisions to the questions on disability are significant, consequential, and will have lasting implications for how our nation views and supports persons with disabilities. That is why we are deeply troubled by the proposed changes both to the questions on disability and the way disability is defined. We are particularly concerned about an apparent lack of meaningful consultation with the disability community throughout the revision

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Maya Wiley

process, as well as with the full range of federal agencies that use ACS disability data to enforce civil rights laws, implement federal programs, and allocate resources to meet the needs of individuals with a wide range of disabilities.

Instead of moving forward at this time with the proposed revisions, the Census Bureau should consult with the disability community and disability rights advocates and experts, as well as all agencies that use the data to administer federal laws, to ensure that any revisions to the ACS disability questions accurately capture physical, medical, developmental, and mental health challenges that describe the full needs of the community. The Census Bureau also should consult with relevant congressional committees to ensure that data produced from any revised disability questions will meet the needs of policymakers into the foreseeable future.

Data are an essential tool for promoting opportunity and access, and advancing equity, for all — a goal of the Biden administration under Executive Order 13985.<sup>1</sup> That is why it is essential that all population subgroups are fully seen in the portraits of Americans and U.S. communities our federal statistical system creates. The ACS is the nation’s largest household survey, adding richness and currency through vital annual socio-economic and demographic characteristics to the foundational data collected in the decennial census.

In fact, the ACS is the nation’s only source of consistent, small-area data on individuals with disabilities for every community. The annually-updated estimates provide recognition for a significant population group — one whose members are often overlooked, underserved, or marginalized. Equally important, data on the disability population are necessary to identify and quantify inequities in access, opportunities, incidence, and outcomes across social and economic institutions, and to pursue policies to remedy those inequities.

We commend the Census Bureau for recognizing that the current set of ACS questions on disability, adopted in 2008, may not be sufficient to yield a comprehensive, useful measure of disability in today’s changing world. Useful data must effectively guide policymaking and resource allocation across economic sectors and social institutions where the presence of a disability can prevent individuals from pursuing opportunities, achieving their full potential, and exercising the rights to which they are entitled by law and under the U.S. Constitution.

Nevertheless, we believe that the Census Bureau has missed an important opportunity to evaluate broadly and deeply the needs of policymakers across the Executive Branch and in Congress for data on persons with disabilities, as well as to better understand their views on what conditions constitute a disability for programmatic purposes. These issues are complex, sometimes fluid, and often sensitive, which is why representatives of the disability community must be at the table every step of the way.

Regrettably, the process for developing and testing a new set of disability questions was too narrow, focused — as it was — primarily on health-related goals of the National Center for Health Statistics and

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<sup>1</sup> Exec. Order 13985. “Advancing Racial Equity and Support for Underserved Communities Through the Federal Government.” 86 Fed. Reg. 7009. Jan. 20, 2021. <https://www.federalregister.gov/d/2021-01753/page-7009>.

other HHS agencies. It appears that the Census Bureau failed to consult fully with the Departments of Education, Housing and Urban Development, Labor, Transportation, and other federal agencies tasked with administering programs that support persons with disabilities and enforcing anti-discrimination laws. Relevant federal initiatives include the Community Development Block Grants (CBDG) Program, Individuals with Disabilities Education Act (IDEA), Low Income Home Energy Assistance Program (LIHEAP), and the Bureau of Justice Statistics-administered National Crime Victimization Survey, to name but a few.

As a result, the proposed new set of questions, based on the Washington Group on Disability Statistics' Short Set on Functioning (WG-SS), may exclude many disabilities that are covered under the Americans with Disabilities Act Amendments (ADAA) Act of 2008. It also is not clear that the new questions will produce useful data for implementing all of the statutes that rely on ACS disability measurement. At a minimum, results from the 2022 ACS Content Test, showing that the percent of the population estimated to be disabled would be reduced by 40 percent (to 8.1 percent from 13.9 percent) when comparing the current questions to the WG-SS questions, and after applying Definition 1 to those results, are themselves a red flag that warrant further examination with respect to the many uses of disability data across the federal government.

OMB and Census Bureau policy appropriately require all questions on the nation's largest survey to collect data mandated by federal law or that are required for implementation or enforcement of a federal statute(s) or federal court order(s), in order to limit respondent burden. Each decade, the Census Bureau asks all federal agencies to confirm existing needs for data at the smallest levels of geography the ACS produces (census tracts and block groups) or to justify requests for new data sets, in order to implement, monitor, and/or enforce federal programs and policies tied to statutes. Therefore, once NCHS requested a shift to the WG-SS disability measurement questions, the Census Bureau should have conducted broad outreach to and consultation with all other federal agencies that are required to use the data for statutory purposes, and to members of the disability community, whose identities are defined, *in part*, by their ability to participate in society as fully as possible. While we recognize that the comparability and cohesion of statistical measurements (in this case, of disability) internationally is a desirable interest, these considerations cannot drive and, ultimately overwhelm, the decision-making process with respect to ACS content. To the extent those considerations were primary here, the process was flawed.

Our coalition includes groups with significant knowledge of issues related to defining and measuring the disability population in ways that will advance effective economic and social policies and the fair distribution of public resources. Those advocates include the National Disability Rights Network, American Association of People with Disabilities, Disability Rights Education and Defense Fund, and Association of University Centers on Disabilities, as well as many advocates who work to advance equitable and fair treatment for people with physical, developmental, medical, and mental health challenges in education, housing, the workforce, and other sectors. Many of these organizations will submit their own comments in response to the Notice, addressing in greater detail concerns about the proposed approach, specific questions, and definitions for measuring the disability population. We urge the Census Bureau to fully consider those comments and recommendations as well, as it considers when and how to move forward with revisions to the ACS disability questions.

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We urge the Census Bureau not to move forward at this time with its proposed revisions. Thank you for your consideration of our concerns and views. Please direct any questions about these comments to Meeta Anand, senior program director, Census and Data Equity at The Leadership Conference ([anand@civilrights.org](mailto:anand@civilrights.org)).

Sincerely,

The Leadership Conference on Civil and Human Rights

Asian Americans Advancing Justice | AAJC

NALEO Education Fund