March 21, 2024

Honorable Robert Santos
Director, U.S. Census Bureau
U.S. Department of Commerce
Washington, DC 20233

Dear Director Santos:

We write to thank you for publicly recognizing the breadth and depth of concern about the proposed revisions to the American Community Survey (ACS) disability questions in your February 6th blog. To fulfill its promise of engaging meaningfully with the disabled community, the Census Bureau must include the disabled community at every step, whether that is issue identification, event planning, research development, or any other elements of decision-making affecting the measurement of disability and participation by disabled individuals in all data collection activities.

As a part of this effort, we write to request a meaningful role in *planning* the convening of disability data stakeholders proposed in the February 6th blog. This convening must occur before any further substantive work and decision-making, including determining the need for any future forums to discuss disability measurement and the development of effective and inclusive engagement policies across the Bureau's work.

As you noted in your blog, comments about the proposed ACS disability question revisions highlighted a need for comprehensive public engagement with affected communities, particularly given the use of ACS data for the enforcement of anti-discrimination and equal opportunity laws, the allocation of government resources, and the provision of support services. The primary themes running through thousands of public comments make it clear that a fundamental re-evaluation of disability measurement is needed to ensure the production of useful, current, and comprehensive data on the disability population. However, comments pointed out that not only would the proposed change to the Washington Group Short Set significantly cut the number of disabled people counted, but also that the disabled community was not adequately consulted or included during the process.

With that challenge in mind, we respectfully ask you to include the disabled community, disability researchers, and disability rights leaders and advocates in the *planning process* for the proposed initial convening and any future gatherings that discuss disability measurement or measurements that impact the disabled community. The Bureau should engage these community members as panelists and presenters. Without this inclusion, the Bureau cannot fulfill its promise of actively and meaningfully engaging the disabled community, nor can it meet Paperwork Reduction Act (PRA) and other requirements for such engagement. The PRA and Office of Management and Budget (OMB) guidance on the PRA require "that agencies go beyond the required publication of notices in the Federal Register…[such as taking] affirmative steps to consult with individuals and groups both internal and external to the Federal Government."[1] Stakeholder engagement must go beyond activities where the disability community is simply a recipient of information; our community should be included in the process from the ground up, helping to determine the timing and format, topics for discussion, and selection of presenters and invitees, as appropriate for each event.

Equally important, soliciting and employing our perspectives on the *accessibility* of events (e.g. meetings, convenings) and how to engage in meaningful and broadly accessible ways with the disabled community is critical. This engagement must include diverse perspectives from the disabled community, including people with many types of disabilities and multiply marginalized disabled people from different racial, ethnic, gender, and other identities. Including stakeholders with diverse lived experiences is key to effective policy-making. This inclusion must begin with the convening you propose to organize with OMB and the National Center on Health Statistics.

We have several recommendations that would ensure such an event (and all future gatherings, including smaller meetings) is as accessible and inclusive as possible. We look forward to highlighting our ideas for you and your staff in a future discussion; for now, we want to elevate the vital importance of communication accessibility. Meaningful engagement and collaboration with the disability community cannot occur without pre-planning to ensure that people with a range of access needs, including those who use augmentative and alternative communication (AAC), use American Sign Language (ASL), or

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[1] Office of Mgmt. & Budget, Executive Office of the President, M-22-10, Memorandum for Heads of Executive Departments and Agencies (2022).

rely on captioning services, can participate fully in events and conversations. We also want to ensure any event on issues impacting the disabled community, at a minimum, has hybrid capabilities.

Finally, we urge you to consider creating a disability task force that advises the Census Bureau on ways to accurately measure, understand, and meaningfully include our community in all of the agency's statistical programs, with the decennial census and American Community Survey being of particular importance. A task force, similar to the task force on the young child population, can help the Bureau build trust and maintain transparency through the development of effective policies in collaboration with the disability community. Such a task force must include people with lived experience. The undersigned organizations and individuals are all ready and willing to provide the Bureau with expertise, feedback, and support in its work. However, the Bureau must take on the responsibility of engaging with the disabled community. The Bureau can neither shift responsibility for its own work on the disabled community, nor ignore the disabled community in the decision-making process.

Again, we very much appreciate the Census Bureau's recognition of the disabled community's concerns, and your willingness to collaborate and engage with us. A convening, planned in partnership with the disability community, is a good first step in this process. We hope that engagement will be broad and include consultation during all phases of research agenda development, testing, and implementation of data collection efforts affecting our community. We look forward to working with you going forward. If you have any questions, 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,

Access Living
Alabama Parent Education Center Inc.
American Association of People with Disabilities
American Association on Health and Disability
American Foundation for the Blind

APNI Inc.
Arkansas Advocates for Children and Families
Association for Special Children and Families
Autism Speaks
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Caring Across Generations
Center for Economic and Social Policy
Center for Family Involvement @ VCU
Center the Science in the Public Interest
Coalition on Human Needs
CommunicationFIRST
Community Parent Resource Center
Connecticut Parent Advocacy Center (CPAC)
Disability & Well-Being In Social Work
Disability EmpowHer Network
Disability Law Center, Inc. (MA)
Disability Rights California
Disability Rights Education and Defense Fund (DREDF)
Disability Rights North Carolina
Disability Rights Washington
Epilepsy Foundation
Families Helping Families of Greater New Orleans
Family Connection of South Carolina
Family Network on Disabilities
Family Resource Center for Disabilities and Special Needs
Family Voices
Family Voices CO
Family Voices NJ
Family Voices of Tennessee
Federation for Children with Special Needs
FIRSTwnc
Hawaii Disability Rights Center
Housing Works
Idaho Parents Unlimited
Illinois-Iowa Center for Independent Living
INCLUDEnyc
Institute for Community Inclusion
Ipas
Lakeshore Foundation

Long Island Advocacy Center, Inc.
Maine Parent Federation
Minnesota Disability Law Center
MomsRising
National Association of Councils on Developmental Disabilities
National Center for Law and Economic Justice
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Council of Asian Pacific Americans (NCAPA)
National Disability Institute
National Employment Law Project
National Family Association for DeafBlind (NFADB)
National Health Law Program
National Partnership for Women & Families
National Women's Law Center
NETWORK Lobby for Catholic Social Justice
NC Counts Coalition
Open Doors for Multicultural Families
Parents Reaching Out
Parent to Parent of Georgia
Patient-Led Research Collaborative
PEAK Parent Center
PEATC (Parent Educational Advocacy Training Center)
Progress Center for Independent Living
Public Advocacy for Kids (PAK)
Rehabilitation Research Training Center (RRTC) on Research and Capacity Building for Minority Entities
Rehabilitation Research and Training Center (RRTC) on Advancing Employment Equity for Multiply Marginalized People with Disabilities
RTC:Rural
South Dakota Parent Connection
SPAN Parent Advocacy Network
The Advocacy Institute
The Arc of the United States
The Parents' Place of MD
TN STEP- Tennessee’s Parent Center
Tzedek DC
United Spinal Association
U.S. Gender and Disability Justice Alliance
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