



December 19, 2023

United States Department of Commerce
United States Census Bureau

RE: Docket Number USBC-2023-009, Notice of Proposed Rule Making

To Whom It May Concern:

Able South Carolina (Able SC) is submitting the following comments as a disability-led organization seeking transformational changes in systems, communities, and individuals. Since 1994, we've remained a consumer-controlled, community-based, cross-disability organization that seeks to make South Carolina a national model of equity and inclusion for all people with disabilities. We remain South Carolina's oldest and largest Center for Independent Living, and currently, 80-plus percent of our staff have disabilities, along with nearly 2/3 of our Board of Directors.

In all we do, we practice equity, disability justice and representation, and true inclusion through consumer-driven independence and disability pride. The disparities that exist within the disability community are detrimental, and the proposed rule-making can set the community back and even prevent life-saving funding to communities.

For our purposes, we will not discuss proposed items of Household Roster, Educational Attainment, Health Insurance Coverage, Electric Vehicles, Solar panels, or Sewage Disposals as topic experts from each field will add their unique perspectives. However, it is vital to note that restricting any data sets limits the multitudes and complexities of daily life for individuals with disabilities. As with others, individuals with disabilities do not live in isolation and encounter all other daily aspects as the non-disabled population. Restricting the level of cross-compatibility data limits our understanding of the disability population and their interactions with their communities.

We strongly encourage the Department to enhance the data collection methodologies for people with disabilities. Adding additional questions related to psychosocial, cognitive, intellectual, developmental, health conditions, and speech disabilities strengthens our representation of individuals with disabilities across our communities. We hope this is the first step for including other disabilities in future counts and ensuring equity.

The Americans with Disabilities Act defines disability as a physical or mental impairment that substantially limits one or more major life activities.” This is a legal definition rather than a medical definition. The ADA definition of disability does not apply to disability-related services such as Social Security. As a federal law, it is important that we know and understand the population this law protects and that communities understand the large population they must accommodate.

As an organization, we strongly disagree with the intent of the proposed changes, the impact it would have across communities and the severe lack of involvement from the disability community. As developed, we urge the Department not to adopt the proposed regulations and to further engage with existing disability researchers, the disability community, and organized disability populations to reevaluate future collection methodologies. As presented, these proposals reject persons with disabilities' self-autonomy and embrace an ableist approach determined arbitrarily by an individual's perceived ability to function. Disability is part of society, and we must have appropriate data collection.

With disability rates rising across the country, primarily due to the lasting impact of COVID-19 (Deitz, 2022), data used from the decennial census and the American Community Survey often serve as the foundation of organizational practices and services. These counts frequently act as the primary data source for federal allocations to support Centers for Independent Living – the basis of the Administration for Community Living's (CIL) independent living programs. These organizations “provide the tools, resources, and support for integrating people with disabilities into their communities to promote equal opportunities, self-determination, and respect” (Administration for Community Living, 2023).

Of the nearly 350 disability-led Centers for Independent Living across the country, each is Congressionally mandated to provide core services for (1) Information and Referral, (2) Independent Living skills training, (3) Peer Counseling, (4) Individual and Systems advocacy, and (5) Transition Based services for nursing homes or other institutions. These services are funded through population-based funding allotments determined annually through Congressional discretionary appropriations. The proposed rule-making is set to undercount the disabled population further, resulting in additional strain on existing CILs to maintain compliance with the essential core services as determined by statute. Many of these core services currently serve as unfunded mandates, and organizations must rely upon their own resources to meet these obligations.

Census data is often the first step in determining a community's needs – from housing to transportation, emergency planning, healthcare, education, employment, etc. City planners and elected officials use this data to inform future growth, development, and planning that represents the full mosaic of their city. Undercounting persons with disabilities from an accurate count removes them from the future planning of the city and restricts resources to support their community engagement. More so, the proposed Washington Group methodology creates a scenario where rationing of service allotment to individuals with disabilities is deemed the most “severe.”

The Census Bureau has acknowledged frequent challenges in counting minority populations and has made continued efforts to ensure an accurate representation is included (Census Bureau, 2023). However, as proposed, the changes will lead – as attested to by the Census Bureau itself– to a severe undercount of the disability population. Currently, people with disabilities represent the largest minority population in the country. Yet, this count is even likely an underestimate due to the individuals not attributing their disability to their ability to maintain daily functioning – often with assistive technologies. The instruments proposed by the Washington Group amplify a dangerous thread that removes an individual's identity away from their disability and simply seeks to attest to their daily functioning level.

The primary challenge with the modification as proposed by the Washington Group is that measuring someone's disability level discounts the individual's identity as someone with a disability. An individual will only be counted as disabled if they indicate "a lot of difficulty" or "unable or cannot do at all." This, simply by the process, will restrict the number of individuals who will be classified as disabled. A rating system of this sort will unnecessarily exclude many people. This measure fails to account for individuals with multiple disabilities, or that types of disabilities whose impact may fluctuate on a daily or weekly basis. This single point-in-time count fails to reflect the fluctuation of an individual's disability or their use of assistive technologies for support.

In essence, by attributing a point-based value system to determine whether an individual has a disability, the proposed rule removes individual autonomy away from the person, allowing them to claim their disability and shift to another, outside entity to determine if their disability is valid enough.

The Washington Group acknowledged that the questions would limit the ability for coherent, uniform disability statistics. They further note that "a more comprehensive evaluation would be possible in other forms of data collection or in administrative data. The population captured by the short set will not represent the total population with limitations, nor will it necessarily represent the 'true' population with disability, which would require measuring limitations in all domains and a much more extensive set of questions" (United Nations, 2007). Comparisons of the American Community Survey and the Washington Group (Hall, 2022), (Lauer, 2019) indicate that the Washington Group will cut disability prevalence roughly in half.

The Washington Group survey's multiple-choice options prompt people with more functional capacity to reveal a disability status that is somehow less than that of people with "more severe" functional limitations, which risks diverting funding and resources away from them. Its removal of the independent living question also risks excluding people who can see, hear, think, speak, bathe, and dress without difficulty but who have trouble with instrumental activities of daily living like running errands or managing personal finances.

Policymakers and governmental agencies who are unaware that people like Able SC, our staff, and the 3,000 plus we serve annually even exist will not know to account for their needs.

Investments in people with disabilities must not be optional. Everyone with at least one disability, whether their conditions are static, fluctuating, mild, or severe, deserves programming, funding, and appropriate policies that allow for inclusion and equitable access to society.

We should have a national disability data count that is robust and builds upon an established methodology that demonstrates trends over time. The Washington Group survey would discount 17 national surveys that have established the framework for disability census. We strongly urge the review body to reject the proposed recommendations and to build on the existing body of data methodology to allow for a complete and comprehensive count of all individuals.

Thank you for allowing us to provide comment, and we genuinely hope the Department will listen to these concerns and not further the marginalization of disabled people and allow for ongoing discrimination to occur against Americans with disabilities.

Respectfully Submitted,

A handwritten signature in black ink that reads "Kimberly A. Tissot". The signature is written in a cursive, flowing style.

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Sources Cited:

Administration for Community Living (2023). Centers for Independent Living. Available online at: <https://acl.gov/programs/aging-and-disability-networks/centers-independent-living>

Deitz, R. (2022). Long Covid Appears to Have Led to a Surge of the Disabled in the Workplace. Federal Reserve Bank of New York. Available at: <https://libertystreeteconomics.newyorkfed.org/2022/10/long-covid-appears-to-have-led-to-a-surge-of-the-disabled-in-the-workplace/>

Hall, J.P., Kurth, N.K., Ipsen, C., Myers, A. & Goddard, K. (2022). Comparing Measures of Functional Difficulty with Self-Identified Disability: Implications for Health Policy. *Health Affairs*. Vol. 41, Issue 10. Available at: <https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00395>

Landes, S.D., Swenor, B., Vaitiakhovich, N. (2023). Counting disability in the National Health Interview Survey and its consequence: Comparing the American Community Survey to the Washington Group disability measures. *Disability and Health Journal*. Available at: <https://www.sciencedirect.com/science/article/pii/S1936657423001358>

Lauer, E., Henley, M., & Coleman, R. (2019). Comparing estimates of disability prevalence using federal and international disability measures in national surveillance. *Disability and Health Journal*, Volume 12, Issue 2, 2019, Pages 195-202. <https://www.sciencedirect.com/science/article/abs/pii/S1936657418301833>

United Nations Economic and Social Council (2007). Report of the Washington Group on Disability Statistics. Available at: <https://unstats.un.org/unsd/statcom/38th-session/documents/2007-4-disability-E.pdf>

United States Census Bureau (2023). Counting Every Voice: Understanding Hard to Count and Historically Undercounted Populations. Available at: <https://www.census.gov/newsroom/blogs/random-samplings/2023/10/understanding-undercounted-populations.html#:~:text=The%20PES%20and%20Demographic%20Analysis,that%20a%20E2%80%9Cnet%20undercount.%E2%80%9D>