MAKE IT COUNT:

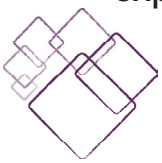
STRENGTHENING DISABILITY DATA THROUGH PARTNERSHIP, PARTICIPATION & REPRESENTATION

»EXECUTIVE SUMMARY

Accurate disability data is essential to ensuring that people with disabilities are fairly represented in federal decision-making and receive the resources, services, and protections they need to thrive. Decennial Census and American Community Survey (ACS) data influence billions of dollars in federal funding, inform policy development, guide enforcement efforts, and shape public understanding of disability in the United States. Yet people with disabilities have long been identified by the Census Bureau as a hard-to-count population, and significant gaps remain in how disability is measured, reported, and understood across federal data systems.

To continue the discussion around the disability ACS questions and prepare for the decennial Census, the National Disability Rights Network (NDRN) convened Protection and Advocacy (P&A) staff, researchers, and federal and state coalition partners to discuss how people with disabilities can be more accurately counted, meaningfully represented, and effectively served through federal data systems. The convening explored barriers to participation in federal surveys, limitations in current disability data collection methods, challenges related to disability question design, and strategies for improving outreach, communications, and advocacy.

Several key themes emerged from the convening. First, participants emphasized that disability data drives funding, policy, and services, making accurate data collection foundational to effective advocacy and equitable resource allocation. Second, participants identified persistent undercounting and data gaps, particularly the lack of intersectional and geographically specific data needed to understand disparities within the disability community. Third, participants highlighted concerns about the accessibility and effectiveness of current disability question design, noting that existing measures do not always reflect how people understand and experience disability in their daily lives. Fourth, participants discussed



barriers to participation, including inaccessible survey formats, government mistrust, fear of discrimination, and broader concerns about how data may be used. Finally, participants emphasized that strong advocacy requires more than data alone; effective storytelling, localized analysis, and increased data literacy are critical to translating data into meaningful policy change.

The convening also reinforced that improving disability data is a shared responsibility. The Census Bureau, researchers, disability advocates, and community organizations all have critical roles to play in strengthening disability data systems before the 2030 Census. Participants identified several priority recommendations discussed later in this report to advance this work.

The discussions captured in this report demonstrate both the urgency and the opportunity facing the disability community. Preparing for the 2030 Census and strengthening disability data systems cannot wait until the next decennial count.

Meaningful progress will require sustained collaboration among federal agencies, researchers, advocates, and disability communities to ensure that disability data accurately reflects lived experiences and supports policies that promote equity, inclusion, and full participation.

»PLAIN LANGUAGE EXECUTIVE SUMMARY

This report outlines the findings from a meeting of disability and Census field experts.

The focus of this group was to discuss barriers and potential improvements to Census and American Community Survey disability data. The participants and presenters made a case for why disability data matters. This data matters because it impacts funding, services, and representation within local, state and federal legislatures. The individuals involved in the meeting

included National Disability Rights Network staff, Protection & Advocacy Network staff, community advocates from other disability organizations, and researchers in the disability data space.

There are several main problems that came to the surface during this meeting:

- People with disabilities are undercounted in federal data systems.
- Current data has gaps and limits.
- The questions within the surveys themselves do not reflect the lived experience of many people with disabilities.
- Some questions on these surveys are inaccessible or hard for people with disabilities to complete.
- Many people are afraid to complete the Census. They do not trust or know what their data may be used for.

These factors contribute to several key impacts for the disability community, including:

- Undercounting leading to less funding.
- Limited data leading to unidentified gaps: it's hard to tell who we're missing, and what voices are being left out.
- A lack of effective outreach leading to some communities being overlooked.

Main insights from the report include the following themes:

- Data drives real world decision-making.
- Data needs to be more detailed, inclusive, and accurate.
- Trust, accessibility and community engagement are important in Census outreach.
- Data is most effective when paired with real human stories.
- Advocates need stronger data skills and resources.

The attendees also defined what needs to change to improve the Census and its impact on people with disabilities. These changes include:

- Improving disability question design.
- Expanding intersectional and local data collection.
- Making surveys accessible and easier to complete.
- Increasing outreach through trusted community partners.
- Addressing concerns about privacy and misuse.
- Strengthening partnerships between government, researchers, advocacy organizations and community groups.

The report also emphasizes the need to act now in preparation for the 2030 Census. Improving our data and ensuring everyone is a long-term effort. Better disability data results in more equitable policies, funding and representation for people with disabilities.

» INTRODUCTION AND BACKGROUND

For many years, the Census Bureau has consistently identified people with disabilities as a hard-to-count population. Disability cuts across every demographic and geographic segment of society and intersects with a wide range of identities and experiences. According to the Centers for Disease control and Prevention, many people with disabilities also belong to other historically marginalized groups, including people of color, older adults, and women. As a result, the disability community is often considered one of the most diverse and intersectional populations in the United States. Ensuring an accurate count of people with disabilities is critical because Census and ACS data influence how resources, services, and political representation are distributed. Programs and systems that support healthcare, education, transportation, housing, employment, and other community needs rely on federal data to inform funding and policy decisions.

When people with disabilities are inaccurately counted or inadequately represented in federal datasets, communities risk receiving fewer resources and less attention than needed to address existing disparities.

» NDRN'S BACKGROUND IN CENSUS AND DATA ADVOCACY:

Through our engagement in the 2020 Census, the National Disability Rights Network gained a deeper understanding of both the progress and ongoing challenges related to disability data collection. NDRN published a report in 2021 examining disability statistics across the federal government and offering recommendations to federal agencies and the disability community on how to strengthen the collection and use of this critical information. The report was informed by NDRN's work with the Census Bureau and insights from the nationwide Protection and Advocacy (P&A) network. Since November of 2021, NDRN has been, and continues to participate in advocacy around Census funding, as well as pre-planning for the 2030 Census.

» 2023-2024 ACS QUESTION CHANGES

Many disability rights organizations and disability data researchers were surprised when, in October of 2023, the Census Bureau proposed changes to the disability questions used on the ACS. The current ACS disability questions use a binary yes/no format. The Bureau originally proposed moving to a scaled response model developed by the Washington Group on Disability Statistics. Many national and state organizations raised concerns about the Bureau's lack of engagement with the disability community and urged the Bureau to approaches proposed by disability researchers after

the notice was published. In early February 2024, the Census Bureau announced that it would not move forward with the proposed changes to the ACS disability questions until there had been "meaningful engagement" with the disability community.

The Census Bureau, the National Center for Health Statistics, the National Council on Disability, and the Office on Management and Budget partnered with the Leadership Conference Education Fund and the Consortium for Constituents with Disabilities' Health Task Force to convene a meeting on disability data needs, which took place on September 30, 2024. The meeting included panels on defining Disability and Disability Identity; Agency Needs, Procedure, and Communication; A Path Towards Meaningful Engagement with the Disability Community; and Reimaging Disability Data: Disability Researcher Perspective on Gaps, Uses and Promising Practices.

Recognizing that federal efforts extend beyond the ACS, the disability community has continued to consider how it can influence broader disability data issues. NDRN created this convening as a space for candid conversations that could lead to actionable change and build on the 2024 disability and data needs meeting described above.

» ABOUT THE CONVENING

This six-hour convening brought together P&A staff, researchers, and federal and state coalition partners to strategize around a central question: how to ensure people with disabilities are accurately counted, meaningfully represented, and effectively served through federal data systems. Through breakout sessions and larger group discussions, participants explored the importance of Census and ACS data for disability policy, funding, and advocacy efforts, while also discussing barriers that contribute to disability undercounts and persistent gaps in federal data.

Discussions also examined the accessibility and usability of surveys, challenges with disability question design, and opportunities to improve how disability is measured across federal data collection efforts. Participants also identified several strategies to address these obstacles including using trusted community messengers, providing culturally competent outreach, and emphasizing the connection between participation and resource allocation.

The convening further focused on messaging, communications, and outreach strategies to better engage disability communities and increase participation in federal surveys. Participants shared promising practices for national, state, and local organizations and identified potential pathways to strengthen partnerships with trusted community messengers.

Through collaborative discussion, attendees highlighted key challenges, emerging priorities, and recommendations for improving disability data collection as disability rights organizations, coalitions, researchers, and advocates begin preparing for the 2030 Census and continue evaluating disability questions used in the ACS. These conversations ultimately informed the themes and recommendations presented in this report.

» KEY FINDINGS

Data System Limitations

1. Data Drives Funding, Policy and Services

Accurate census and federal data are foundational to disability advocacy. They determine how resources are allocated, shape public policy, and justify investments in programs. Undercounting people with disabilities leads directly to underfunding and long-term systemic gaps in areas like housing, healthcare, and transportation.

2. Persistent Undercounting, Data Gaps and Intersectionality

Current data systems do not adequately capture the disability community. Major challenges include underreporting due to stigma and self-identification barriers and limited detail on types of disabilities, access needs, and living situations; insufficient sample sizes, particularly in the American Community Survey (ACS); and gaps in rural and smaller populations. As a result, existing data often reflects only a partial picture of the community. According to convening participants, another major gap is the lack of data reflecting overlapping identities, i.e., race, gender, income, immigration status, and so on. The disability community very much intersects with all communities listed above. Without this, disparities within the disability community remain hidden, limiting the ability to advocate for targeted, equitable solutions.

3. Limitations in Current Disability Question Design

Current census and ACS disability questions do not fully reflect how people understand disability, nor the disability community's lived experiences. Convening Participants identified the need for more nuanced and flexible question design to better capture functional needs and living situations. Along with that comes the importance of balancing simplicity to increase response rates with detail to improve usefulness when it comes to disability data.

Participation Barriers

1. Obstacles to Census and Survey Participation

Barriers to census participation include inaccessible formats, lack of plain language materials, complex and lengthy questionnaires, outdated addresses, especially for institutionalized populations. Participants also noted that traditional messaging does not reflect community realities.

2. Trust, Fear and Barriers to Participation

Mistrust of government and fear of harm significantly affect participation in data collection. Concerns include discrimination, institutionalization, and data misuse—particularly among immigrant communities and people with mental health disabilities. Cultural differences in how individuals define and identify disability further contribute to underreporting. Data collection is occurring in a climate of heightened skepticism and political tension. Concerns about data misuse, "fraud" narratives, and potential policy rollbacks are influencing both participation and trust, raising the stakes for accurate and inclusive data collection.

Advocacy Capacity Needs

1. Importance of Localized Data

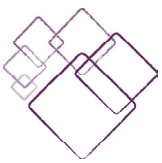
State and local data can be more persuasive than national data, particularly with policymakers. Tailoring data to specific communities increases its impact and relevance in advocacy efforts.

2. Data Must Be Paired With Storytelling

Data alone is not enough to drive change. Effective advocacy requires translating data into clear, relatable narratives; pairing statistics with lived experiences; and framing issues in ways that resonate locally.

3. Capacity and Data Literacy Gaps

Advocates face challenges accessing and using data effectively. There is a critical need for greater data literacy and training, improved access to cross-sectional datasets, and stronger partnerships with researchers and data experts, as well as national, state and local coalitions.



» RECOMMENDATIONS

The following recommendations reflect the themes raised during the convening and identify practical steps that the Census Bureau, researchers, advocates, and federal policymakers can take to improve disability data systems and collection before the 2030 Census.

Census Bureau

Modernize Disability Question Design

The Census Bureau should revise disability questions in consultation with disability communities to better reflect real-world experiences, functional needs, and living situations. This would address limitations in current question design and improve the accuracy and usefulness of disability data.

Expand Intersectional and Cross-Sectional Data Collection

The Census Bureau should prioritize collecting and publishing disability data that can be disaggregated by race, ethnicity, gender, income, geography, age, and immigration status. This level of detail can help identify disparities within the disability community that are often hidden in broader datasets. It also supports a more complete understanding of disability across communities and can help address persistent gaps in representation and resource allocation.

Continue to Improve Outreach Through Trusted Community Partnerships

The Census Bureau should invest in long-term partnerships with national, state, and local disability organizations, advocates, and community-based groups to improve participation in Census surveys. Trusted community or

partners are often best positioned to reach people who may be hesitant to participate due to concerns about discrimination, government mistrust, or inaccessible information. Strengthening these relationships can improve participation among historically undercounted communities, including the disability community.

Increase Accessibility Across All Census Operations

The Census Bureau should ensure that Census and ACS materials are fully accessible, available in plain language, and designed to meet a wide range of accessibility and communication needs. These efforts must go beyond Section 508 compliance and include accessibility testing throughout the design and development processes Accessible surveys and outreach materials help reduce participation barriers and allow more people to complete Census activities independently, supporting a more fair and accurate count of the disability population.

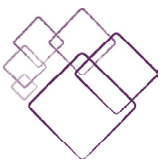
Expand Small-Area and Rural Disability Data Collection

The Census Bureau should strengthen sampling methods and invest in disability data collection for rural communities and smaller population groups. Often, federal data alone does not provide the information advocates and policymakers need to address local community challenges. More geographically specific data would help communities identify unmet needs, target resources, and support effective policy decisions.

Researchers

Prioritize Community-Engaged Disability Research

Researchers should collaborate directly with disability communities and advocacy organizations when designing studies, interpreting findings, and sharing results. Research informed by lived experience is more likely to produce accurate findings and meaningful policy solutions. Community engagement also helps build trust and improve understanding of how different communities experience disability.



Produce More Actionable Local and State-Level Analysis

Researchers should work directly with advocates to translate national datasets into state, county, and local analyses that advocates and policymakers can use in their communities. Local data is often more persuasive and actionable than national statistics alone. Providing localized insights can help identify regional disparities and support more targeted advocacy efforts.

Expand Research on Disability Intersectionality

Researchers should invest in studies that examine how disability intersects with race, gender, poverty, immigration status, age, and geography. Understanding how disability overlaps with other demographic factors helps reveal disparities that may otherwise remain hidden. This information can support more equitable policies and improve how resources are targeted to communities with the greatest needs.

Translate Data Into Public-Facing Narratives

Researchers should communicate findings in clear, accessible language and pair statistics with stories and real-world examples. Data is often most effective when people can connect it to lived experiences and how those experiences impact community needs. Moreover, making research more accessible can strengthen public understanding and increase its impact on policy discussions for all.

Build Data Literacy Partnerships with Advocates

Researchers and universities should partner with disability organizations to provide training on data interpretation, research methods, and federal datasets. Many advocates have limited access to technical training despite regularly using data to support policy goals. Stronger partnerships can build capacity and improve the effective use of disability data in advocacy efforts.

Advocates

Pair Data With Personal Narratives

Advocates should combine quantitative data with lived experiences and community stories when communicating with policymakers and the public. Personal stories help demonstrate the real-world impact behind statistics and make complex issues more relatable. Combining evidence with lived experience can strengthen advocacy campaigns and encourage action.

Build Localized Advocacy and Communications Strategies

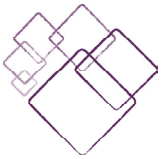
Disability advocates should tailor messaging and data use to state and local priorities whenever possible. Policymakers are often most responsive to information that reflects the needs of their own communities. Using localized data and examples can make advocacy efforts more relevant and persuasive.

Invest in Data Literacy and Technical Capacity

In collaboration with disability data researchers and universities, advocacy organizations should prioritize staff training on Census data, ACS tools, cross-sectional datasets, and data interpretation strategies. Strong data skills help advocates identify disparities, support policy recommendations with evidence, and respond effectively to misinformation.

Lead or Collaborate on Community Trust-Building Efforts

Advocates should continue serving as trusted messengers who educate communities about the importance of Census participation and the role data plays in funding and services. Community organizations often have established relationships that can help address concerns about discrimination, privacy, and government mistrust.



Building trust is critical for increasing participation and improving the accuracy of disability data.

Advocate Directly for More Inclusive Federal Data Systems

Disability organizations should push federal agencies to improve disability data collection methods, increase transparency, and expand intersectional reporting. Federal data systems shape how disability is measured and understood across the country. Continued advocacy can help ensure these systems better reflect the experiences of disabled people and produce more accurate, representative data.

Develop a National Disability Count Campaign for 2030

A coordinated national campaign led by disability organizations should begin well before the 2030 Census to increase disability self-identification, educate communities about the importance of federal data, and build trust in Census participation. This recommendation directly addresses participation barriers, mistrust, and the need for stronger community engagement identified throughout the convening.

While advocates, researchers, and the Census Bureau each have important responsibilities, participants also emphasized that many challenges identified during the convening require broader federal policy action. The following recommendations outline opportunities for Congress, OMB, the Census Bureau, and federal agencies to strengthen disability data systems before the 2030 Census.

Policy Recommendations for Federal Departments and agencies, members of Congress, and the broader administration

Create a Federal Disability Data Modernization Initiative:

Congress and the Administration should establish a government-wide initiative to improve disability data collection, coordination, and reporting across federal agencies.

Require Meaningful Disability Community Engagement in Federal Data Development:

Federal agencies should be required to engage disability stakeholders before making substantial changes to disability data collection instruments.

Invest in Community-Based Census and Survey Infrastructure:

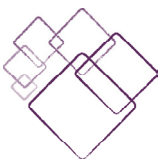
Congress should provide dedicated funding for disability community outreach and engagement before the 2030 Census.

Establish Disability Data Equity Reporting Requirements:

Federal agencies should be required to publish disability data disaggregated by race, ethnicity, gender, age, geography, and income whenever statistically valid.

Protect Privacy and Build Trust Through Stronger Data Safeguards:

The Census Bureau and other federal agencies should strengthen public communication regarding privacy protections and limitations on data sharing.



Fund State and Local Disability Data Capacity:

Congress should support grants that enable disability organizations to analyze and use Census and ACS data.

» CONCLUSION

The discussions captured in this report reinforce a simple but important reality: disability data matters. It shapes how resources are allocated, how policies are developed, how programs are evaluated, and ultimately how disabled people are represented in decisions that affect their daily lives. Yet the themes identified throughout this convening demonstrate that significant challenges remain. Persistent undercounting, limitations in current data collection methods, barriers to participation, and gaps in data literacy continue to hinder efforts to fully understand and address the needs of the disability community.

At the same time, the convening highlighted a shared commitment among advocates, researchers, and coalition partners to improve disability data systems and ensure that people with disabilities are accurately counted, meaningfully represented, and effectively served. While discussions surrounding the future of the ACS disability questions have brought renewed attention to disability data, participants emphasized that improving federal data systems requires more than changes to a single survey instrument. It requires sustained investment in accessibility, community engagement, research, storytelling, and collaboration across sectors.

Preparing for the 2030 Census must begin now. The recommendations outlined in this report reflect the understanding that the responsibility for improving disability data does not rest solely with the Census Bureau. Researchers, advocates, community organizations, and federal agencies all have a role to play in strengthening data collection, increasing public trust,

building data literacy, and ensuring that disability data reflects the full diversity of the disability community and our collective, lived experiences.

The disability community cannot afford to wait until the next decennial Census to address these challenges. By acting now and working together, stakeholders can help create federal data systems that more accurately capture disability, support equitable policymaking, and ensure that people with disabilities are fully included in the decisions, programs, and resources that shape their lives.

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