

Recommendations to Improve Collection and Dissemination of Disability Data

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Background

Despite the goals of the Americans with Disabilities Act (ADA), in 2021 people with disabilities continue to struggle with economic advancement and stability. Unfortunately, in a world of “data driven decision-making” and “evidence-based policy-making,” gaps in data can put people with disabilities at a disadvantage in comparison to other at-risk populations for whom survey data and administrative data is readily available. Policy makers and disability advocates rely on data to make the case for investment. When the data exists for some populations but not others, we are put at a policy and advocacy disadvantage. NDI is pleased to see disability included as a key demographic variable in the mission of the Equitable Data Working Group and look forward to supporting the goals of the group in any way possible. This document, developed by researchers at National Disability Institute and the Burton Blatt Institute at Syracuse University provides a starting point for the discussion.

The Six Questions

The Affordable Care Act: *Data Collection, Analysis and Quality* (Sec 3101) required “any federally conducted or supported health care or public health program, activity or survey (including Current Population Surveys and American Community Surveys conducted by the Bureau of Labor Statistics and the Bureau of the Census) to collect and report, to the extent practicable—data on race, ethnicity, sex, primary language, and disability status for applicants, recipients, or participants.”

The Affordable Care Act (ACA) jumpstarted the adoption of a six-question series for identifying disability in national surveys. These questions had been under development for a decade by an interagency workgroup.¹ The task of developing questions to identify the disability population was challenging because there was and continues to be considerable disagreement on how to

¹ <https://www.bls.gov/opub/mlr/2014/article/the-development-of-questions-on-disability-for-the-current-population-survey.htm>

define disability. Additionally, it is challenging to capture a complex concept in a small number of valid and reliable questions.

Six Disability Questions

1. Are you deaf, or do you have serious difficulty hearing?
2. Are you blind, or do you have serious difficulty seeing, even when wearing glasses?
3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)
4. Do you have serious difficulty walking or climbing stairs? (5 years old or older)
5. Do you have difficulty dressing or bathing? (5 years old or older)
6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)

The same six questions are included on multiple surveys and thus allow us to disaggregate data by disability and other characteristics. For example, if the sample is sufficiently large, we can disaggregate by disability and race or disability and gender. However, the surveys yield a range of disability prevalence rates. For example, disability as a percent of the adult population ranges from 11.6% in the Current Population Survey, 12.6% in the American Community Survey to 26% in the Behavioral Risk Factor Surveillance Survey. This disparity is confusing for some advocates and policy makers. However, most of the variation can be explained by different aspects of each survey. More importantly, demographic factors for people with disabilities are consistent across surveys indicating that the questions are capturing a consistent population. As such the six questions represent a critical first step in providing valuable insight into the condition of people with disabilities in the US across the topics covered by multiple surveys such as poverty, housing, employment, health status and others.² Despite their value, the six questions have limitations:

1. Many disability advocacy organizations and providers are interested in data about their own constituencies, but the six questions cannot be used to identify specific groups such as intellectual disability/ developmental disability (ID/DD), wheelchair users, autism spectrum disorder, or other specific conditions.
2. The six questions under-identify those with mental or emotional disabilities.
3. A key driver to many disability-related outcomes is the age of onset and the length of time a person has lived with a disability. However, the questions do not include any indication of whether the disability began at birth, during childhood, during working-age years, or as an older adult.

² Lauer, E. A., & Houtenville, A. J. (2018). Estimates of prevalence, demographic characteristics and social factors among people with disabilities in the USA: a cross-survey comparison. *BMJ open*, 8(2), e017828. <https://doi.org/10.1136/bmjopen-2017-017828>

Availability of Disability Data

National Disability Institute, with our focus on the economic status and financial conditions of people with disabilities has been able to promote policy change, develop programs and generate dialogue because the six questions are included on multiple large national surveys.³ However, data limitations in several areas have impeded our ability to provide the quantitative evidence needed to promote full inclusion.

Surveys that include disability questions:

The **American Community Survey**, with its large sample has allowed us to present disparities in poverty and educational attainment not just between people with and without disabilities but also among people with disabilities based on race and ethnicity. The Census Bureau's small area estimates of the prevalence of disability has been invaluable in identifying the geographic concentration of people with disabilities in order to locate services and show the relationship between disability and low-moderate income neighborhoods.

The **FDIC Survey of Household Use of Banking and Financial Services**, conducted as a supplement to the Current Population Survey every two years in June, has allowed us to identify large disparities in the use of banks between people with and without disabilities and generate dialogue with the FDIC and multiple banks.

The **Current Population Survey** has allowed us to look at the employment situation of people with disabilities by race over the course of the pandemic.

Surveys that measure critical economic outcomes but do not include disability questions:

The **Annual Business Survey**, the nation's premier survey of businesses conducted annually by the Census Bureau does not include questions to identify the disability status of the business owners. According to the Census website: "Statistics from the ABS will be used by government program officials, industry organization leaders, economic and social analysts, business entrepreneurs, and domestic and foreign researchers in academia, business, and government." Estimates produced on owner demographic data may be used to assess business assistance needs, allocate available program resources, and create a framework for planning, directing, and assessing programs that promote the activities of disadvantaged groups; to assess minority-owned businesses by industry and area and to educate industry associations, corporations, and government entities; to analyze business operations in comparison to similar firms, compute market share, and assess business growth and future prospects.

As governments, financial institutions and non-profits develop programs that "promote the activities of disadvantaged groups," the absence of disability data hinders our ability to advocate for disability inclusion. This is a powerful example of how the absence of data causes people with disabilities to be overlooked.

³ A list of 17 surveys that include the questions is available at:
<https://www.cdc.gov/ncbddd/disabilityandhealth/datasets.html>

The **Consumer Expenditure Survey** captures detailed data on household expenditures across a long list of major product classifications (e.g., clothing, food, recreation, travel, insurance, cars, household durables) and provides estimates of consumer expenditures for these categories. Although it includes demographic characteristics such as race and gender, it does not include the six disability questions.

We recently collaborated with researchers at two Universities to estimate the extra expenditure associated with disability. Using four data sources that provide broad measures of income and standard of living, we estimated people with disabilities need 28% more income to have the same standard of living as a similarly situated household without a disability. However, the absence of disability on the Consumer Expenditure Survey impedes our ability to further explore the types and variation of extra costs.

The **Federal Reserve Board Survey of Household Economics and Decision-making Survey (SHED)** measures the economic well-being of U.S. households and identifies potential risks to their finances. The survey includes modules on a range of topics of current relevance to financial well-being including credit access and behaviors, savings, retirement, economic fragility, and education and student loans. The absence of disability questions on the survey ensures that people with disabilities will be left out of mainstream discussions of financial fragility.

The **Household Pulse survey** was conducted in several phases in 2020 and 2021 by the Census Bureau to provide timely data to help understand the experiences of American households during the coronavirus pandemic. The survey asks questions about how education, employment, food security, health, housing, social security benefits, household spending, consumer spending associated with stimulus payments, intention to receive a COVID-19 vaccination, and transportation have been affected by the ongoing crisis.⁴ Unfortunately, no measure of disability was included on the survey, making it impossible to track the experience of people who were most affected by the health and economic impacts of the pandemic.

Surveys with disability data that may be in jeopardy

The **Survey of Income and Program Participation**, a valuable source of data to look at the experience of people over multiple years has provided us with important information on disparities in net worth between people with and without disabilities, but no data has been released since 2018.

Challenges in Accessing Administrative Data

Administrative data are often hard to access and data-sharing agreements are sometimes difficult to obtain. Although some of these difficulties are justified given the legal, privacy and

⁴ <https://www.census.gov/programs-surveys/household-pulse-survey/technical-documentation.html>

security concerns associated with sharing data collected as part of administering a program, the federal government should explore opportunities to make data available.

Several agencies provide valuable disability data in aggregate. The **National Center for Education Statistics** in the U.S. Department of Education provides aggregate data on students with disability by age, sex, race type of disability and education environments.⁵ This data has been critical to identify the disproportionate number of children of color in special education. The **Social Security Administration** provides data on disability applicants and beneficiaries.⁶ Its ongoing data reporting has, for example, highlighted the underuse of work incentives to facilitate persons with disability's entrance or return to the labor force.

In contrast, data from the \$3.7 billion Vocational Rehabilitation (VR) system has not been readily available. Even though State VR agencies collect a wealth of data on the RSA-911 data collection instrument, we were not able to access data on the number who achieved self-employment outcomes. The Rehabilitation Services Administration recently announced an initiative to remedy the situation but it is too soon to tell if it will be effective. Similarly, data from Medicaid Home and Community Based Waiver Services are difficult to access.

Need for a National Disability Survey

In 1994, the National Center for Health Statistics conducted the National Health Interview Survey on Disability (NHIS-D). The survey was a follow-up from the annual NHIS and was designed to collect data that can be used to understand disability and develop public policy. The survey had detailed questions about the nature of the disability. Data from adults with disabilities included questions on housing and long-term care services, transportation, social activity, work history/employment, vocational rehabilitation, assistive devices and technologies, health insurance, assistance with key activities, other services, self-direction, family structure, relationships, living arrangements, conditions and impairments, health opinions and behaviors, community services, and proxy status. Data on children was collected in a separate questionnaire that focused on utilization and need for services, functional assessment, including emotional and behavioral development, and the impact of the child's disability on the family. Because the data was so unique, researchers were still using the survey 20 years after its implementation.⁷

In assessing gaps in disability data in 2011, the Department of Health & Human Services Office of the Assistant Secretary for Planning and Evaluation (ASPE) commissioned a study that reviewed the presence of disability data on 40 national surveys that cover a range of topics likely to be of importance to the policies, programs, and issues that affect the lives of people

⁵ https://nces.ed.gov/programs/coe/indicator_cgg.asp#info

⁶ <https://www.ssa.gov/policy/docs/statcomps/>

⁷ Ward, B. W., Ridolfo, H., Creamer, L., & Gray, C. (2015). The 1994-1995 National Health Interview Survey on Disability (NHIS-D): A Bibliography of 20 Years of Research. *Review of disability studies*, 11(2), 1-22.

with disabilities and identified gaps in data.⁸ At the time, the researchers found gaps in data around program participation and the adequacy of support; supports needed to live in the community and environmental barriers to community participation; supports needed to obtain and maintain employment; disability-related finances and expenditures; and health care access among employed people with disabilities. Their findings led them to recommend a National Disability Survey.

This study was conducted just several years after the ACA directive and to our knowledge has not been updated to reflect any changes in the availability of data but we suspect that, if conducted today, similar findings would emerge and we would still see a need for a National Disability Survey.

Dissemination of Disability Data

As stated earlier, beyond data collection, the ACA (Sec 3101) required the *reporting* of data disaggregated by disability status. This reporting is essential for disability data to be disseminated to stakeholders (e.g., public policy makers, health/education/financial intervention programs, disability advocates, researchers) who need this information to assess the quality of life of persons with disabilities, to identify areas of need, and to uncover when and how having a disability is associated with worse outcomes that are suggestive of discrimination.

This dissemination is critical because, although with ADA, Congress affirmed that disability is a natural part of the human experience and cannot be the basis of discrimination in any aspect of life, data continues to show that persons with disabilities show significantly worse outcomes in health, education, finances and community participation, compared to those without disabilities. As an example, consider this: in 2020 about 8 in 10 persons with disabilities were not in the labor force (i.e., not employed and not actively looking for work), compared with about 3 in 10 of those without disabilities⁹. Whereas this information can be found online, too many disability data points are not reported and remain only accessible to the few in society that have the data analysis skills required to access data sets and conduct statistical analyses.

Reports generated by mandated organizations do not always disaggregate critical data by disability status

Once data is collected and analyzed, mandated organizations (e.g., federally conducted or supported health care or public health program, activity or survey) generate and disseminate reports with key findings. Unfortunately, these reports do not always present key data points

⁸ Livermore, G., Whalen, D. & Stapleton, D.C. (2011). Assessing the Need for a National Disability Survey: Final Report. (Office of Disability, Aging and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation. US Department of Health and Human Services. <https://aspe.hhs.gov/report/assessing-need-national-disability-survey-final-report>.

⁹ <https://www.bls.gov/news.release/disabl.nr0.htm>

disaggregated by disability status, although they do it by other characteristics such as gender, race, ethnicity and age group. There are varying degrees to which different reports present data disaggregated by disability status, as we will exemplify below.

In using the Census Bureau Report “Income and Poverty in the United States: 2019”¹⁰ (based on information collected through the Current Population Survey Annual Social and Economic Supplements) we found both data on median household income and poverty rate disaggregated by variables like race/ethnicity, age, and nativity (i.e., native- or foreign- born). However, when it comes to disability status we only found disaggregated data for poverty rate but not for median household income.

The report “How America Banks: Household Use of Banking and Financial Services, 2019 FDIC Survey”¹¹ (data collected through a Supplement to the Current Population Survey) does report all main variables disaggregated by disability status (e.g., unbanked rate, bank account ownership, use of bank and non-bank credit). Within each of these main variables, other data are reported that aim to help understand the findings. For instance, within the area of unbanked rate, the report then present results regarding the reasons respondents reported for not having a bank account, information that can help the design of programs aiming to increase banked rates. These additional data points are not reported disaggregated by disability status. To be fair, this may be the result of having to keep the report of a size that is manageable for its intended audience. Still, this does not negate the fact that data points that can help explain unbanked rates and other negative financial outcomes need to also be disaggregated by disability status in order to inform policy and intervention tailored to persons with disabilities. In the past, NDI has managed to secure private funding to analyze, report, and disseminate FDIC data disaggregated by disability status. However, this is dependent on private funding which is not always available.

[Access to data disaggregated by the intersection of disability status and race/ethnicity requires significant research skills](#)

At last, mainstream society is acknowledging what communities of colors have known and experienced for centuries: systemic racial discrimination. Persons with disabilities who are also members of communities of color face discrimination arising from both disability and race/ethnicity. Research by NDI has analyzed publicly available data including the American Community Survey and demonstrated that within persons with disabilities those who are Black or Hispanic have worse financial outcomes than persons with disabilities who are White.¹² In one of the most striking findings, we found that the household net worth of Black households with disability was a mere \$1,282, compared to \$27,100 in White households with disability.

¹⁰ <https://www.census.gov/library/publications/2020/demo/p60-270.html>

¹¹ <https://www.fdic.gov/analysis/household-survey/2019report.pdf>

¹² <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/08/race-ethnicity-and-disability-financial-impact.pdf>

Findings like this demonstrate that policy and intervention must be guided by data that explores the unique barriers faced by persons with disabilities depending on their race/ethnicity. However, to our knowledge this type of data is not included in reports by mandated organizations and must be accessed by conducting data analyses of publically available data sets, a capability not available to all stakeholders.

Reports created by mandated institutions are a main way through which stakeholders who are not skilled in research can access data disaggregated by disability status. Although the Census Bureau makes available data sets that researchers can analyze to generate disability data not include in the above mentioned reports, we would argue that the majority of stakeholders do not have the research expertise necessary to utilize these data sets. The federal government funds several organizations to report disaggregated data that is responsive to the needs of the disability community, most notably the National Institute on Disability, Independent Living, and Rehabilitation Research funded the Rehabilitation Research and Training Center on Disability Statistics. Nonetheless, there are still gaps in data analysis and dissemination. Thus, there is a need for continued and expanded federal funding that can consistently fund additional data analyses and reports that fulfill the goal of providing stakeholders with all relevant disability data, including on its intersectionality with race/ethnicity.

In sum, critical information on disability remains unknown to those who could utilize it to design and implement policies and programs necessary to provide persons with disabilities with full human rights. At a larger societal level, these barriers to the dissemination of disability data help to maintain persons with disabilities as a group that is rarely intentionally included in policies and programs that purport to promote diversity and inclusion.

Conclusion

The targeting of federal resources to promote equity continues a historical pattern of ignorance, discrimination and neglect of persons with disabilities. As new opportunities are now being created in the public and or in combination with private sector resources to accelerate economic opportunity for at-risk groups, gaps in data collection, dissemination and analysis will continue the exclusion of people with disabilities.

As we frame equitable solutions, we must recognize past unequal treatment of people with disabilities and be intentional about raising visibility and focus of this population and especially those individuals at the intersection of disability, race, ethnicity and gender. We cannot underestimate the power of data in making the invisible visible.

Whether these solutions come in the form of reparations, government programs, targeted below market lending for home ownership, small business startup and development, or affirmative action and prioritization in workforce development, apprenticeship, and hiring, relevant data, dissemination and analysis will ensure that decision-makers do not continue to ignore economic status and challenges among people with disabilities.