

Federal surveys missing as many as 43% of individuals with disabilities, study finds

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To better understand the prevalence of disability in America and to address health disparities, the Affordable Care Act mandated that federal health surveys collect data to identify people with disabilities.

But new research from the University of Kansas has found that the two most common sets of disability questions used in federal surveys are missing as many as 43% of individuals who should be counted, especially those with psychiatric disabilities or chronic health conditions.

KU researchers conduct the National Survey on Health and Disability, known as the NSHD, which collects a broad range of information on disability, health, employment and other factors. When they compared the results from that survey with responses to disability questions from the American Community Survey, or ACS-6, and the Washington Group Short Set, known as WG-SS—the two most common disability question sets—they discovered gaps in how many people are missed as having a disability through the question sets compared to those same people who self-reported a disability.

These gaps indicate that the amount of funds, services and health care resources allotted for certain types of disability are likely not consistent with need and that such surveys and counts should be improved, the researchers said.

The study was written by Jean Hall, director of KU's Institute for Health & Disability Policy Studies in the Life Span Institute; Noelle Kurth and Kelsey Goddard, research associates at the institute; and Catherine Ipsen and Andrew Myers of the University of Montana; and was published in the journal *Health Affairs*.

It was known prior to the study that some people with mental health disabilities and [chronic conditions](#) were overlooked by the ACS-6 and WG-SS. The extent was not clear, however. When the research team compared results from the 2020 NSHD, they found that the two measures failed to identify 20% and 43%, respectively, of respondents who reported a disability on other NSHD questions.

The NSHD includes the ACS-6 and WG-SS questions but also asks individuals if they identify as having any physical or mental condition, impairment or disability that affects [daily activities](#) and/or requires the use of special equipment or devices, and also how they classify their own disability.

"The ACS-6 is widely used in this country by federal and state agencies. What we know about disability in America largely comes from these questions," Hall said. "The WG-SS is used more internationally but is still widely used in the U.S. We were able to categorize how people self-identify and categorize their own disability and how those results compared with the other commonly used measures."

The ACS-6 asks yes or no questions about difficulty with certain functions or activities, while the WG-SS asks people the level of difficulty they experience in certain daily life activities due to their conditions. Neither question set is comprehensive to include all functions or activities that someone may have difficulty with, and neither question set asks about specific conditions experienced.

The measures produce both full and partial false negatives. Some individuals may be partially counted as having a disability—but not one that reflects their self-reported condition. Others are missed by the measures, noted as a full false negative.

"We argue that you're identifying people as disabled but not categorizing them correctly with the type of disabilities they report, and because of that, probably not getting people the supports and services they need," Hall said.

Further complicating matters is the COVID-19 pandemic, which has resulted in a sharp increase in the number of people with mental health disabilities across the country. Individuals also have experienced

complications from long COVID-19, which can both exacerbate existing disabilities or present new ones. The study found that the two standard measures miss people with these conditions in the greatest numbers, further leading to undercounting.

Because the American disability population is large and growing, it is essential to have accurate numbers to improve policy, address risk, understand disability prevalence and reduce adverse outcomes, the authors wrote. That can be addressed by including additional questions in federal surveys that ask:

- Whether the person has a mental or [physical condition](#), impairment or disability that affects daily activities and/or requires use of equipment or technology.
- What the condition or conditions are and which is the primary condition.
- Age of onset, duration or expected duration of the condition.

"People with [disabilities](#) are the best at defining their own conditions," Kurth said. "There is a rising tide of disability pride in the U.S. in the last 10 years as well, so obtaining the most accurate counts of disability is something worth talking about."

More information: Jean P. Hall et al, Comparing Measures Of Functional Difficulty With Self-Identified Disability: Implications For Health Policy, *Health Affairs* (2022). [DOI: 10.1377/hlthaff.2022.00395](https://doi.org/10.1377/hlthaff.2022.00395)

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