

IS THE 2010 AFFORDABLE CARE ACT MINIMUM STANDARD TO IDENTIFY DISABILITY IN ALL NATIONAL DATASETS GOOD ENOUGH FOR POLICY PURPOSES?

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Introduction

The Americans with Disabilities Act of 1990 was the culmination of a decades-long effort to afford people with disabilities the same protections against discrimination that the Civil Rights Act of 1964 or subsequent civil rights legislation provided those facing discrimination based on race, national origin, sex, and age. Unlike these other protected classes, whose characteristics are immutable or relatively easy to determine, disability is not an immutable characteristic. Hence, it is a more difficult characteristic to conceptualize and operationalize for purposes of affording civil rights protection and, more generally, for statistical purposes including the monitoring of the health, employment, and economic well-being of this protected class.

To provide the information for evidence-based public policymaking, it is necessary for researchers both inside and outside government agencies to have sufficient data to capture the effect of current and future policies on citizens who, based on past discrimination or current circumstances, require targeted government actions. This has led to efforts by government statistical agencies to develop a minimum set of questions that could, within national datasets, identify the population with disabilities in a manner similar to the questions used to identify people by race, ethnicity, gender, and age.

ACA Mandated Standard

In what is considered a milestone in the effort to determine a minimum standard for the set of questions required to identify disability in all national datasets, Section 4302 of the Affordable Care Act (ACA) of 2010 mandates the establishment of standards for the collection and dissemination of health statistics for five specific demographic sub-populations: race, ethnicity, gender, primary language, and disability status.

As part of its response to this mandate, in October 2011, the U.S. Department of Health and Human Services (HHS) deemed the six-question sequence on disability (6QS) introduced in the American Community Survey and currently used in the Current Population Survey (CPS) the new minimum “data standard for survey questions on disability” (HHS, 2011, p. 7). The first four questions of the 6QS are function-based, focusing on hearing, vision, cognition (concentrating,

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remembering, or making decisions), and mobility (physical matters like walking and climbing stairs). The last two are activity-based, relating to activities of daily living (dressing or bathing) and instrumental activities of daily living (doing errands alone, such as visiting a doctor's office or shopping).

However, none of these six questions directly relates to work-activity limitations. We examine the consensus view as expressed in HHS (2011) that the 6QS is an adequate minimum "data standard for survey questions on disability". In doing so, we provide evidence that the lack of a work-activity question in the 6QS results in its inability to capture a substantial portion of the population with disabilities relevant to key U.S. disability policies and programs.

Using linked 2009 CPS/Social Security Administration (SSA) records data, we find that this 6QS captures only 66.3 percent of those actually receiving Social Security benefits based on their disability (a group that presumably should be captured as a subpopulation of any more general disability population). Furthermore, substantial portions of Social Security beneficiaries within diagnostic groups are not captured by the 6QS.

Proposed Seven-Question Sequence

When we add a work-activity question to the 6QS, we capture 23.1 percentage points more of this population of Social Security disability beneficiaries, or a total of 89.3 percent. Hence a seven-question-sequence (7QS) would capture a larger share of a subpopulation that should be in any general population with disabilities—Social Security Disability Insurance (SSDI) and Supplemental Security Income-Disabled Adult beneficiaries.

Importantly, we also provide evidence that the added disability benefit population is very similar with respect to its distribution of diagnoses to the disability benefit population that is captured by the 6QS, or even to the subset of that population who positively respond to one of the questions in the 6QS but who also report that they do not have a work limitation—i.e., the 6QS-only population. Hence, using a 7QS, which includes those who positively respond to either a question on the 6QS or to the work limitation question, does not change the distribution of diagnoses.

This similarity with respect to the distribution of diagnoses is in sharp contrast to major differences in labor force participation, employment, and poverty rates that we find when we compare the overall 6QS-based, 6QS-only-based, work activity-based, work-activity-only-based and 7QS-based disability populations. As discussed in Table 6 of our working paper on which this brief is based (see MRRC Working Paper 2014-267), a short-term way to adjust for Type 2 errors could be reweighting the disability samples based on how well they capture SSDI/SSI-Disabled Adult recipients. These reweighting exercises provide a first approximation of the degree that current CPS statistics based on the 6QS or on the work-activity question overstate the labor force participation and employment rates and understate the poverty rates of working-age people with disabilities. But, in the long term, we argue that some form of work activity question must be a part of any minimum "data standard for survey questions on disability."

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