



Research Paper

An evaluation of the American Community Survey indicators of disability

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ABSTRACT

Background: Collection of data in the Census for implementing disability legislation has been continuous since 1970 although the questions used have changed several times. Concerns have been raised about the ability of the newest question set developed for the American Community Survey (ACS) to adequately represent the population with disabilities because it does not capture all those eligible for certain benefit programs.

Objective: Using national data, we examine how the addition of questions on the receipt of SSI/SSDI changes the composition of the population identified by the ACS measures. In ancillary materials we also examine the addition of a work limitation question to the population identified by ACS measures.

Methods: Using descriptive secondary analysis of 2011 NHIS data we compare the characteristics of those identified by the ACS questions to those identified by the ACS questions and receipt of SSI/SSDI and those only receiving SSI/SSDI. The comparison is based on conditions, specific functional limitations and severity of limitation.

Results: The results provide evidence ACS questions identify a population representing persons at risk for participation difficulties including those who receive SSI/SSDI. The ACS population has higher proportions with mental health and development disabilities than comparison population. The ancillary data demonstrates the work limitation question does not make a significant difference in identifying recipients of SSI/SSDI.

Conclusion: The analysis demonstrates that the disability measures developed for the ACS produce an unbiased picture of the population with disabilities by including persons with all conditions, more severe disability or selected types of functional limitations.

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The collection of information about the nation's population with disabilities began with the 1830 Census asking questions about blindness and deafness. Disability was included in the Census until 1890 after which the questions were dropped. It was 1970 when questions on disability returned to the long form, a major change to the Census adopted in 1940 allowing statistical techniques of sampling to provide added questions for 5% of the persons enumerated¹ The disability questions in the recent version of the American Community Survey (ACS) (the replacement for the long form) were developed by an interagency workgroup led by the National Center for Health Statistics (NCHS) with membership from

federal agencies with legislative or programmatic need for information on disability for small geographic areas.² The workgroup reviewed agency mandates and determined that information on disability was necessary for at least two major reasons: 1) to monitor whether persons with disabilities are being prevented from full participation in society as outlined in the 1990 Americans with Disabilities Act³ and 2) to estimate the number of persons eligible for service programs offered by state and federal governments. The workgroup used the Institute of Medicine Model of Disability and the International Classification of Functioning, Disability and Health (ICF) as conceptual guides for identifying disability domains.^{4,5} The workgroup defined disability at the person level conceptualizing limitations or difficulties as possible risk factors associated with restrictions to full participation in society.⁶

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The ACS provides population estimates for small geographic areas and includes measures of key indicators of social participation such as employment, education and income. The addition of questions on disability allows comparison between those with and those without disabilities on these social participation indicators to determine if differences exist. However, the ACS format is not suited for the collection of complete information on all aspects of disability. There are considerable limitations on the number and length (including answer categories) of questions that can be asked in a census format. The questions must also be appropriate for the various modes of data collection used for the ACS.

The goal of the ACS disability question set was not to capture **all** aspects of disability or to identify **all** persons with disabilities (unpublished notes of ACS Subcommittee, February 13, 2004), as this would be impossible,⁷ but rather to identify the majority of persons with disabilities using questions that provide valid and reliable information about those with more serious levels of limitation. Extensive development work went into crafting the questions which then underwent extensive cognitive and field testing.^{8,9} Using available information from the National Health Interview Survey (NHIS), the workgroup identified the most prevalent functional domains that were associated with disability and questions were crafted to capture these domains. Based on legislative mandates of several of the agencies involved in the workgroup, two additional questions were developed to monitor aspects of independent living (a listing of the questions can be found in [Appendix A](#)).

Concerns have been raised as to whether the question set fails to identify an important, programmatically relevant group – those who are unable to work. Two forms of benefits for those who can't work include support through the Supplemental Security Income (SSI) and Social Security Disability Income (SSDI) programs. Both programs require medical verification of disabling conditions from physicians and SSDI also requires that the individual has worked 40 quarters to be eligible. As evidence, Burkhauser et al. note that the six questions failed to identify all persons receiving income support.^{10,11} Because of this concern, Burkhauser, et al.¹⁰ proposed that a work limitation question be added to the ACS battery to prevent understating the population. They assert the absence of a work limitation question fails to capture a substantial portion of the population relevant to key disability policies and programs creating “systematically biased estimates of employment, program participation and economic well being”.¹⁰

It should be noted that a work limitation question was tested in the development of the ACS questions but not included based on the results of cognitive and field testing.^{8,9} While cognitive testing found the question identified some persons with functional limitation who were also limited in their ability to work, it also identified persons who would not be considered to have functional limitations but were limited in work for other reasons, such as caring for persons with illness or disabilities. The observation that the ACS questions do not identify all persons receiving benefits could be a function of how those programs are administered and how eligibility is determined. Benefit programs (e.g. SSI, SSDI), particularly those that provide financial benefits, consider a range of characteristics and program eligibility criteria other than the functioning or independence itself when making eligibility determinations. While the definition of disability for SSI or SSDI differs from the ADA definition used for the ACS, it is a worthwhile exercise to examine whether the ACS questions also capture those receiving benefits to assure the benefits population is represented as well as the general population with disabilities defined by the ADA.

Since the NHIS includes both the six ACS questions and questions on the receipt of SSI or SSDI benefits, disability status as defined by the ACS questions can be compared to reported receipt of benefits to investigate whether the six questions represent those

receiving SSI/SSDI. Though it is possible that respondents misreport SSI/SSDI benefits, this analysis addresses the extent to which those reporting SSI/SSDI benefits are identified by the six ACS questions and the impact of including those reporting only SSI/SSDI benefit receipt on the prevalence and characteristics of the population with disabilities. The analysis also describes the disease and functional characteristics of those reporting SSI/SSDI benefits who are and are not identified by the ACS questions in order to determine if the population defined by the ACS questions is in any way biased.

While the critiques of the ACS questions state that approximately 25% of those who receive SSI/SSDI benefits are not identified by the ACS questions, no one has analyzed the combined ACS and SSI/SSDI data nor has anyone examined the differences between the groups captured by the ACS, the ACS plus those reporting receipt of SSI/SSDI and those only reporting the receipt of SSI/SSDI.¹⁰ Examination of expanded information on the disease and functional limitations of those identified by each question set and the combined question sets will determine if a bias is introduced in the population identified by the ACS questions alone. Ancillary material also demonstrates the effects of adding a work limitation question to the ACS set.

Methodology/analysis

NHIS data from 2011 were used for this analysis. NHIS collects information about the health and health care of the civilian noninstitutionalized population of the United States from a representative sample of households across the country, and is conducted continuously throughout the year by NCHS. Persons excluded from the NHIS include patients in long-term care institutions, correctional facilities and U.S. nationals living in foreign countries. Interviews are conducted in the respondents' households, but follow-ups may be conducted over the telephone in order to complete interviews.¹²

The data used are from the sample adult file and are based on self-report unless the sample adult could not respond due to a health condition, in which case a proxy respondent was used. The analysis is limited to persons aged 18 to 64. The ACS questions were asked of a random half sample of the 32,014 sample persons. A special weight was developed for use with the half sample. The conditional response rate for the Sample Adult file was 81.6% of persons identified as Sample Adults. Final response rate was calculated as (Family response rate) (Sample Adult response rate) or $(81.3\%) (81.6\%) = 66.3\%$.

Measures used

Disability - Several measures of disability were included in the analysis. For the measure based on the six ACS questions a ‘yes’ response to any of the six questions classifies a respondent as a person with an ACS disability. Answers of refused or don't know on any of the ACS questions were assumed to indicate non-disability on that particular function.

Two additional measures were constructed based on basic action difficulties and complex activity limitations as previously defined from questions not included in the ACS set.¹³ A report of any difficulty in mobility, sensory functioning, selected elements of emotional functioning, and important elements of cognitive functioning are classified as basic action difficulties. Any difficulty in walking, standing, sitting, climbing stairs, reaching overhead, lifting and carrying and using fingers to pick up small items is classified as mobility difficulty. Emotional difficulty is defined by the Kessler six questions (KG) with a score of 13 or higher used as the cut off point for identifying emotional difficulties.¹⁴ Vision difficulty is defined by either trouble seeing even when wearing glasses or contact lenses or

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