Evaluating Survey Questions Used to Identify Disability: An Application of the International Classification of Functioning, Disability and Health(ICF)

Short Abstract. This paper uses a conceptual model of disability derived from the World Health Organization's International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) to assess and categorize survey questions. The first part presents the ICF concepts and shows how current survey questions on disability map to ICF concepts. The second part uses the ICF framework to examine the estimates of the population with a disability across national surveys. The national surveys we use include the American Community Survey (ACS), the decennial Census long form, the CPS, the National Health Interview Survey (NHIS), and the Survey of Income and Program Participation (SIPP). The final part of the paper uses the conceptual model to assess several current efforts underway to develop new survey questions—including the Bureau of Labor Statistics disability questions to be tested in the February 2006 CPS and new questions being developed for the 2008 ACS.

Andrew Houtenville Cornell University

S. Antonio Ruiz-Quintanilla Cornell University

Robert Weathers Cornell University

Abstract

National surveys are the primary source of data to track the size and the characteristics of the population with disabilities. However, the questions used to identify the population with disabilities vary substantially across surveys and have been criticized as insufficient to track the population covered under the New Freedom Initiative, Healthy People 2010 and the Americans with Disabilities Act of 1990. Recent efforts to develop new survey questions have proven to be difficult. For example, Executive Order 13078, signed in 1998, initiated an effort within the U.S. Bureau of Labor Statistics (BLS) to develop and implement new survey questions in the Current Population Survey (CPS) for the purposes of establishing "a statistically reliable and accurate method to measure the employment of people with disabilities." As of 2005, while some progress has been made on the development of survey questions, the questions have not been integrated into the CPS. A common problem with the development of survey questions is that, in many cases, the development does not begin with a sound conceptual model of disability. Rather, the development of questions usually starts with a pool of questions derived from other surveys and research instruments, and the application of various methods to reduce the large set of questions to a small set of questions that identify persons with a disability (see, for example Adler et al, 2000; Hale, 2002; Kruse and Hale, 2003). The problem with this approach is that the survey questions used as a starting point for the instrument may or may not be capturing a concept of disability that is informative to the policies that are relevant to the population

1

with disabilities and the methods used to reach a final set of questions are not carefully described or open to assessment by the scientific community.

In this paper, we lay out an approach that begins with the conceptual model of disability described in the World Health Organization's International Classification of Functioning Disability and Health (ICF) (WHO, 2001) to assess and categorize survey questions. The ICF provides a conceptual model of disability that recognizes that disability is not solely a function of a person's health condition, but is the result of an interaction between the physical and social environment, personal characteristics and a health condition. In the first part of the paper, we present the ICF concepts and show how current survey questions on disability map to ICF concepts. The survey instruments that we use include the American Community Survey (ACS), the decennial Census long form, the CPS, the National Health Interview Survey (NHIS), and the Survey of Income and Program Participation (SIPP). We then use the ICF conceptualization to identify areas that are missing from national survey instruments, and that identify important aspects of disability. Finally, we discuss survey questions that are commonly used to define disability in surveys but that may not fit within the ICF conceptualization of disability.

In the second part of the paper, we use the ICF framework to compare the estimates of the population with a disability from the ACS, CPS, SIPP, and NHIS. Because these datasets use several survey questions to estimate the size of the population, we first examine responses to each single questions used to estimate disability. We then apply the ICF framework by categorizing the survey question from each of the datasets into the ICF domains identified in the first part of the paper. In doing so, we compare

2

how estimates from different surveys and analogues ICF domains, such as the estimates of work limitations from the different surveys, result in differences in the estimates of a particular domain. The ICF framework is used to provide insight into possible reasons for the observed differences. We also show how estimates of the various domains contribute to the overall concept of disability defined by the survey questions. This information is used to assess the degree to which each of the surveys over or under estimates the population with disabilities based upon the ICF conceptual framework.

The final part of the paper describes several current efforts underway to develop new survey questions—including the Bureau of Labor Statistics disability questions that will be tested in the February 2006 CPS and the questions being developed for the 2008 ACS. We use the lessons learned from this paper to assess the content of these newly developed questions and we make recommendations for the development of future survey questions used to estimate the size of the population with disabilities.