JSSAM SPECIAL ISSUE ON DISABILITY MEASUREMENT AND ANALYSIS: PREFACE

Health, like disability, is a multidimensional concept having many different meanings. The physical dimension of health is most often assessed in terms of pathology or problems with body structure and function. But health is not merely the absence of pathology or impairment, as ill health is seen as creating obstacles in undertaking desired activities. Functional status, such as in seeing, hearing, walking, communication, and cognition, is the mechanism through which pathology, or the absence of pathology, can impact all aspects of participation in society such as in education, employment, financial well-being, and civic engagement. The critical role of functioning in attaining full participation is highlighted in the United Nations Convention on the Rights of Persons with Disability (UNCRPD) (United Nations General Assembly 2006), the 2030 Agenda for Sustainable Development Goals (SDGs) (United Nations General Assembly 2015), and the Americans With Disability Act (Americans With Disabilities Act of 1990 1990). Each of these initiatives requires that limitations in functioning or disability be accommodated, often through removing environmental barriers and instituting facilitators, so that those with disability can fully participate in all aspects of society. Reliable, valid, and comparable data are needed to formulate policy to improve the lives of those with disability and to monitor whether full inclusion has been attained. The UNCRPD and the SDGs also specifically include requirements for such data collection and active monitoring.

While the need for information on disability is well established, obtaining that information has been, and continues to be, challenging. One reason for this is the complex nature of the concept itself (Altman 2001). As defined in the International Classification of Functioning, Disability and Health, disability is an umbrella term that involves the interaction of the individual's functional abilities and the environment in which he or she lives (World Health Organization 2001). The nature of the interaction determines whether full participation in society is achieved. Thus, to fully understand disability, data are needed on the multiple component dimensions and the relationships among them. Functional difficulties can exist, for example, across a range of basic activity domains such as sensory, movement, cognition, and communication. Moreover, each of the domains can be characterized by a range of abilities. The environment is similarly broad, including both the physical or built environment as well as the social environment. In addition, while there is interest in the identification of those with disability and the characteristics of this

group, disability and functioning are not inherently dichotomies, but exist along continuums with no external gold standard to help define appropriate cut points on the continuum.

Adding to the data collection challenge is the fact that the very word disability is understood very differently by different groups. For some, the term carries great stigma as the term has been used to perpetuate negative stereotypes. For others, it is limited to a few visible physical characteristics or defined by a small set of conditions. Some see it as an expected characteristic of the "natural" aging process. For many, disability has become increasingly understood as a human rights issue. These multiple, and sometimes inconsistent, definitions are embedded in legislation that provides support and services for those with disability and there is wide variation in the definitions that determine eligibility.

Despite these complexities, data collections often focus on only one aspect of disability, and yet ascribe the label "disability" without fully addressing how the choice of definition affects the interpretation of the findings. Even when looking at the same component of disability, data collections use different operational definitions depending on the need for the data and the sources used. These data collection and reporting practices have led to a lack of consistency across data sets resulting in the inability to produce a coherent picture of disability in the United States and worldwide.

Much methodological work has been undertaken to address disability data collection issues. The improvement of disability statistics has progressed along with the progression of the larger field of survey methodology and includes advances in the evaluation of data collection tools. Well-tested, standard data collection tools have been developed and are being adopted that will lead to more comparable information moving forward (Washington Group on Disability Statistics 2020). There is a greater understanding of the complexities involved in collecting information on disability. The papers in this special edition address selected data collection challenges and add to the body of knowledge that is needed to obtain high-quality information on disability to inform policies and programs.

As noted above, disability is not inherently a dichotomy. Rather, individuals experience functioning along a continuum from no difficulty to complete inability. The identification of the group "with disability" and the resulting prevalence of disability depend on the selection of cut points along the functioning continuums. For some objectives, such as to support universal design where the objective is to make environments more broadly accessible and used to the fullest by all people, the cut point could be more inclusive identifying those with less severe levels of functional limitation as having disability. For many policy needs, however, the population with more severe limitations is of interest. This population is small enough that large samples are needed to accurately describe its characteristics, especially if there is interest in cross-classifying disability status with other characteristics such as age, sex, race and ethnicity,

urbanicity, socioeconomic status, or geography. Using internet surveys to obtain information on disability is an attractive option given the lower cost of this mode of data collection. The paper by Houtenville, Phillips, and Sundar entitled "Usefulness of Internet Surveys to Identify People with Disabilities: A Cautionary Tale" in this issue investigates the use of internet surveys and finds that such methods can introduce bias if the target population lacks access to or the ability to use the necessary technology.

Several of the papers in this issue deal with variations in how disability is conceptualized and measured. The paper by Pettinicchio and Maroto looks at the impact of using different data collection instruments by using IPUMS International Census microdata since 2000 to examine disability measurement across sixty-five countries. Analyzing these data with the Total Survey Error framework in mind, they find that definitions, translation, measurement, and instructions to both respondents and enumerators matter for understanding disability prevalence cross-nationally. The authors recommend that researchers take great care when using compiled cross-national census data to study disability and always consider how disability is defined and measured within surveys.

The paper "Collecting objective measures of visual and auditory function in a national in-home survey of older adults" by Hu, Freedman, Ehrlich, Reed, Billington, and Kasper presents the results of a pilot study to address the feasibility of incorporating objective data collection methods and compared the results obtained from objective and subjective measures of vision and hearing. The authors found that respondents were highly likely to participate with low rates of missingness and that test results were significantly associated with age and self-reported measures of hearing and vision limitations. They conclude that objective visual and auditory functioning can be successfully incorporated into an interviewer-administered home-based protocol.

Differences resulting from obtaining information directly from the subject as opposed to from a proxy are investigated in the paper by Elkasabi entitled "Differences in proxy-reported and self-reported disability in the Demographic and Health Surveys." Based on data from Uganda, South Africa, and Mali, propensity score-weighted multivariate logistic regression models are used to balance the weighted distributions of the covariates between self and proxy reports. Disabilities that have an immediate effect on the interaction with others or that require one-to-one help are likely to be under-reported by self-reports, especially among the elderly age 60 and above, whereas disabilities that are not observable might be under-reported by proxies.

The paper by Flaherty and Shono, "Parsimonious restricted latent class models for improved measurements of activities of daily living" presents a restricted latent class approach to summarize the multidimensional aspects of disability as measured by ten binary questions on activities of daily living. The authors suggest a restricted fourteen-class model to better capture heterogeneous manifestations of disability. Despite the larger number of classes, this

model contains fewer parameters and has smaller measurement error than the unrestricted four-class latent class model. The suggested constrained latent class specification may be useful for practitioners interested to conduct sub-group analyses aimed at, for example, studying treatment responses.

Finally, the relationship between the functional status and the environment is addressed in the paper, "Who is at risk of workforce exit due to disability? State differences in 2003–2016" by Ben-Shalom, Martinez, and Finucane. The large increase in the number of disabled workers receiving Social Security Disability Insurance (SSDI) from 1980 to 2017 was much larger than what would be expected on the basis of demographics alone. This paper investigates trends in workforce exit due to disability and how these trends vary across states and subgroups using national survey data and Bayesian multilevel modeling techniques. The authors find that age, education, race, and gender are important factors for the at-risk rate but that differences across states may be due to differences in their industrial composition, job opportunities, and safety net structure. Identifying these factors, especially those that may vary by place, can help target timely interventions toward the most at-risk populations with the goal of helping them stay in the labor force rather than enter SSDI.

The need for disability data remains and is likely to increase in the future. Additional methodological work to improve data collection and analysis meth-ods is needed to assure that appropriate high-quality data will be available to meet policy and program needs.

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