

Defining Disability: A Comparison of Disability Prevalence Estimates Produced by BRFSS and Other Data Sources

Introduction

Defining and measuring disability presents major challenges for public health surveillance programs. There is no consensus about what “disability” means or how to measure it. As a result, there are wide differences in the estimated prevalence of disability. Any prevalence estimate is dependent both on the definition and on the intended purpose for collecting disability statistics. To make the best use of data, users of disability data sources must carefully consider the specific definition of disability used in a data source, understand how it is measured, and compare it to other data sources to assess which ones are most useful for meeting their goals.

Objective

The purpose of this report is to describe the definition of disability used by the Behavioral Risk Factor Surveillance System (BRFSS) and how the BRFSS definition compares to a limited number of other major sources of disability data for non-institutionalized U.S. adults. The intent of this report is to help clarify the reasons for differences in prevalence estimates.

Background

There are three basic theoretical models used to define disability – a medical model, a functional model, and a social model.¹ The medical model focuses on physical or cognitive pathologies or impairments.^{2,3} During the last 30 years, people with disabilities began organizing for better services, more human and legal rights, and full participation in social and economic development.^{4,5} This approach included a shift from focusing on what people could not do, to what they could do.^{6,7} Today, disability is generally recognized as a dynamic relationship between individuals with some degree of impairment and their social and physical environment.⁸⁻¹⁰ A central challenge in disability research continues to be a lack of widely agreed upon definitions that capture social, functional, and medical aspects of disability in a consistent way that is useful for a variety of applications.^{11,12}

In addition to changing definitions of disability, several specific issues complicate the measurement of disability. No clear

threshold exists that defines when a person becomes “disabled.” People may be born with disabilities, others get sick or sustain injuries that result in disabilities, and still others develop disabilities as they age. People with a given impairment vary in their response when asked if they see themselves as “disabled.”¹³ Finally, some impairments are episodic in nature and vary in severity. The comparability of disability estimates also is affected by the instruments used to measure it. There are more than 40 disability surveys in the US, ranging from short and general to long and very detailed and focusing on varied reference periods.^{14,15}

Methods

Three disability data sources were selected for comparison to BRFSS data because they measure disability among non-institutionalized adults living in the U.S. and they each represent a unique approach to defining disability: the U.S. Census Bureau’s American Community Survey (ACS), the Survey of Income and Program Participation (SIPP), and administrative data from the Social Security Administration (SSA). These data sources were compared to BRFSS based on both the conceptual definition for disability used and age-specific disability prevalence estimates produced for the entire U.S. and for Montana alone where available (Table 1).

Behavioral Risk Factor Surveillance System (BRFSS)

BRFSS is a state-based, random-digit-dialed telephone survey of adults in all 50 states, Washington DC, and three territories. Beginning in 2001 and continuing through 2012, except the 2002 survey year, respondents were asked about activity limitation with the question,

- 1) *Are you limited in any way in any activities because of physical, mental, or emotional problems? (Y/N).*

Respondents were then asked about the need for assistive devices with the question,

- 2) *Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone? (Y/N). The response includes occasional use or use in certain circumstances.*

Respondents who answered “No” to both questions were classified as having no disability; those who answered “Yes” to either question were classified as having a disability. BRFSS questions, based on the functional model, focus only on activity limitation and assistive devices and do not measure the severity, duration, or permanence of disability, nor do they assess any underlying medical conditions.¹⁶

States can add questions to the basic survey that meet their data needs.¹⁷ Montana has occasionally added several questions about the nature of the respondent’s major impairment, how long activities have been limited by it, whether help is needed for daily activities, and whether the caregiving is adequate. Questions have also addressed self-identification of disability, use of special assistive equipment, difficulty walking, hearing, remembering or cognition, accessibility, and transportation issues.¹⁸

American Community Survey (ACS)

The ACS, sponsored by the US Census Bureau, sends mailed surveys to a sample of households throughout the United States each year.¹⁹ All members of selected households are surveyed, with the assistance of proxy respondents as needed. Starting in 2008, ACS has classified an individual as having a disability if the respondent answered “Yes” to any of the following questions about specific conditions.²⁰

- 1) *Is this person deaf or does he/she have serious difficulty hearing?*
- 2) *Is this person blind or does he/she have serious difficulty seeing, even when wearing glasses?*
- 3) *Because of a physical, mental or emotional condition does this person have serious difficulty concentrating, remembering, or making decisions?*
- 4) *Does this person have serious difficulty walking or climbing stairs?*
- 5) *Does this person have difficulty dressing or bathing?*
- 6) *Because of a physical, mental, or emotional condition does this person have difficulty doing errands alone such as visiting a doctor’s office or shopping?*

Using these six questions, respondents may be classified as having sensory impairments (hearing and vision), and also functional limitations in cognition, physical activity, self-care or activities of daily living, and community participation or independent living. The ACS questions have changed over time, so trend analysis is difficult.

Table 1. Prevalence of Disability Among Adults by Data Source & Age Group

	National		Montana	
	Percent (95% CI)	Population Estimate	Percent (95% CI)	Population Estimate
BRFSS				
All Adults	22.8 (22.6-23.0)	53,117,000	26.0 (24.3-27.7)	196,300
18-44 yrs	13.9 (13.6-14.3)	15,365,000	16.5 (13.5-19.9)	54,800
45-64 yrs	27.3 (26.9-27.7)	21,855,000	29.8 (27.7-31.9)	83,100
65+ yrs	37.8 (37.4-38.2)	15,604,000	40.7 (38.3-43.1)	58,500
ACS*				
All Adults	12.5 (± 0.1) [^]	38,367,400	13.7 (± 0.5)	134,590
18-44 yrs	6.5 (± 0.1)	7,356,500	7.4 (± 0.6)	24,525
45-64 yrs	15.6 (± 0.1)	12,489,000	15.6 (± 0.6)	44,600
65+ yrs	39.2 (± 0.1)	15,522,500	38.6 (± 1.7)	56,000
SIPP**				
All Adults	21.8 (21.3-22.3) [^]	47,501,000	Not Available	
18-44 yrs	11.0 (10.5-11.5)	12,094,000		
45-64 yrs	23.9 (23.1-24.7)	17,274,000		
65+ yrs	51.8 (50.4-53.2)	18,133,000		
SSA[‡]				
18-64 yrs	6.2	11,988,072	7.4	45,793

* U. S. Census Bureau, American Community Survey 3-Year Estimates, 2008-2010 Analyzed using PUMS DataFerret . Accessed on March 30, 2012 at: www.dataferrett.census.gov.

[^] 90% confidence intervals

** Survey of Income and Program Participation. Accessed on March 30, 2011, at: <http://quarterhorse.dsd.census.gov/TheDataWeb/launchBetaDFA.html>.

[‡] U.S. Social Security Administration, Office of Retirement and Disability Policy, SSI Annual Statistical Report, 2010, Table 15. Accessed on Dec 7, 2011 at:

http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2010/sect03.html, includes adults 18 years of age or older who received either SSI (as recipients) or SSDI (as beneficiaries) in 2010.

Survey of Income and Program Participation (SIPP)

SIPP, also sponsored by the US Census Bureau, is a longitudinal study of a nationally representative sample of households. All household members age 15 years and older are interviewed face-to-face. Proxy respondents are allowed when household members are unable to respond for themselves. Respondents may be classified as having a disability due to any number of conditions or limitations in specific activity categories.²¹ The broad categories of activities used are functional activities, activities of daily living, instrumental activities of daily living, use of assistive devices, and employment limitations. Each category includes a varying number of questions depending upon the survey wave.

- 1) Limitations in functional activities include difficulty seeing, hearing, speaking, lifting, carrying, using stairs, or walking.
- 2) Limitations in activities of daily living include not being able to get around inside the home, get in or out of a bed or chair, bathe, dress, eat, or toilet without the help of others.
- 3) Limitations in instrumental activities of daily living include not being able to go outside the home, keep track of money or bills, prepare meals, do light housework, take prescription medication, or use the telephone without the help of others.

- 4) Use of an assistive device includes needing a wheel chair, crutches, cane, or walker.
- 5) Employment limitations include difficulties finding a job or remaining employed due to a health-related condition.

Social Security Administration (SSA)

Eligibility for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) provide non-survey data on the number of disabled claimants. However, the SSA uses a very narrow functional definition of disability that only considers an individual's ability to maintain gainful employment to determine eligibility for SSDI or SSI.²² They must meet all three of the following criteria:

- 1) The individual cannot do work that they did before they filed their claim,
- 2) The individual cannot adjust to other work because of their medical condition(s), and,
- 3) The disability has lasted or is expected to last for at least one year or to result in death.

The criteria used to assess benefit entitlements do not include everyone who may be classified disabled as measured by the other surveys described above. Also, some people who consider themselves disabled may not claim SSA disability benefits or may not be eligible for them.²³

Discussion

Different surveys rely upon different definitions of disability, which in turn lead to different prevalence estimates. There are several challenges to using information derived from different sources. Surveys that use a broader conception of disability yield higher estimates. For example, the 2010 SIPP, which includes a number of questions to identify individuals of all ages with disabilities living in the household, estimated that 22% of all adults, or more than 47 million people nationally, have a disability. The BRFSS, which includes two broad items based on functional limitations to identify the adult community-based (non-institutionalized) population with disabilities, yielded similar estimates (23% or about 53 million adults). However, the SSA defines eligibility based solely on the ability to support oneself, and yields much lower numbers.

Future Directions

The Affordable Care Act requires new standards to improve the data collection and reporting of health care information based on race, ethnicity, sex, primary language, and disability. The US Department of Health and Human Services (DHHS) released guidance in October 2011, requiring uniform data collection standards for inclusion in surveys conducted or sponsored by

DHHS.²⁴ A six-item set of questions was developed by a federal interagency committee.²⁵ The questions define disability using a functional model. These new data standards will be implemented in BRFSS in 2013. Several other surveys sponsored by the federal government have already adopted these changes.

US DHHS Data Standard for Disability Status

1. *Are you deaf or do you have serious difficulty hearing?*
a. Yes
b. No
2. *Are you blind or do you have serious difficulty seeing, even when wearing glasses?*
a. Yes
b. No
3. *Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)*
a. Yes
b. No
4. *Do you have serious difficulty walking or climbing stairs? (5 years old or older)*
a. Yes
b. No
5. *Do you have difficulty dressing or bathing? (5 years old or older)*
a. Yes
b. No
6. *Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)*
a. Yes
b. No

The data collection requirement for all health surveys sponsored by DHHS is expected to help better measure and track health disparities, including persons with disabilities, but the proposed set of questions is not without its problems and limitations.²⁶ The questions were cognitively tested for face-to face interviews and at least one of the questions, the question about deafness or difficulty hearing, represents a problem for telephone interviewing, which is the main mode of data collection for BRFSS. In addition, people who are deaf and without special telecommunication equipment or those who have moderate to severe cognitive limitations, would most likely be screened out of the selection process early in the interview due to "physical or mental impairment." Therefore, the CDC Behavioral Surveillance Division is currently working with other DHHS staff regarding appropriate wording of the questions for telephone interviewing.

Endnotes

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Background:

The Montana Behavioral Risk Factor Surveillance System (BRFSS) has been collecting and reporting state-specific, population-based estimates of health-related data since 1984. The purpose of this statewide telephone survey of Montana residents aged 18 and older is to gather information regarding personal health risk behaviors, selected medical conditions, and the prevalence of preventive health care practices among Montana adults. A full set of Montana yearly questionnaires and health indicators can be found on the Department of Public Health and Human Services (DPHHS) BRFSS database query system website at: www.brfss.mt.gov. The CDC website also provides national, state, and some local area prevalence estimates of health indicators, as well as access to downloadable datasets for further analyses at: www.cdc.gov/brfss.

Survey Limitations:

The BRFSS relies on self-reported data. This type of survey has certain limitations: many times, respondents have the tendency to underreport some behaviors that may be considered socially unacceptable (e.g., smoking, heavy alcohol use); conversely, respondents may over report behaviors that are desirable (e.g., physical activity, nutrition). Cross-sectional design makes causal conclusions impossible. In addition, the sample sizes used to calculate the estimates in this report vary as respondents who indicated, “don’t know,” “not sure,” or “refused” were excluded from most of the calculation of prevalence estimates. BRFSS data collected through 2008 excludes households without landline telephones.

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