

Reliability and Validity of Disability Questions for US Census 2000

ABSTRACT

Objectives. We investigated the validity and proxy reliability of 7 new disability questions from the 2000 US census ("Census 2000").

Methods. A total of 131 people with disabilities and their proxies from St Louis, Mo, and Massachusetts were interviewed, and responses were compared for concordance. Responses also were compared with responses to questions from the Behavioral Risk Factor Surveillance System (BRFSS) and the Activities of Daily Living (ADL) instrument.

Results. Overall, proxies reported more impairment than did people with disabilities, and agreement was low ($\kappa=0.24-0.55$). Concordance was moderate between the census questions and their BRFSS and ADL counterparts.

Conclusions. The Census 2000 questions may not provide an accurate profile of disability in America. (*Am J Public Health.* 2000;90:1297-1299)

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The 2000 US census ("Census 2000") contains 7 questions (see Table 1) that measure the prevalence of disability among Americans. These differ from the disability questions used in the 1990 census¹ and also from other disability surveillance questions—for example, those used by the Centers for Disease Control and Prevention (CDC).

The present study of people with known disabilities posed the following questions: (1) Since the census queries one respondent per household, do index and proxy respondents agree (reliability)? (2) Do these questions reproduce other disability definitions (validity)?

Methods

People with disabilities and proxies were recruited from 2 cohort studies. A Missouri cohort included residents of 2 nursing homes and 5 assisted living centers and clients of provider/service organizations for persons with spinal cord injury, multiple sclerosis, Parkinson's disease, and traumatic brain injury.^{2,3} A Massachusetts cohort was recruited from independent living centers and medical practices as part of the Massachusetts Survey of Secondary Conditions. The study's goals were to determine the epidemiology of secondary conditions, the factors that influence their incidence and severity, and the ability of clinical and public health interventions, in the broadest sense, to promote health and to reduce or eliminate secondary conditions. Residents of the 6 independent living centers were from Boston, smaller cities and towns, suburbs, and rural regions. Proxies were family members, health care providers, and friends and were interviewed about 1 week later.

All respondents consented to interviews, which followed an oral and written protocol approved by our institutional review boards. For analyses combining proxies, we selected 1 proxy per subject, by order of preference as follows: (1) spouses, (2) relatives, (3) friends, (4) health care workers. All proxies contributed to comparisons of individual proxy types. When needed (e.g., in nursing homes), computer-assisted⁴ interviews were conducted in person; otherwise, they were carried out by telephone. Interviews averaged 45 minutes in length and included questions from the CDC's Behavioral Risk Factor Surveillance System (BRFSS) disability surveillance⁵ and Activities of Daily Living (ADL) instrument.⁶ The

BRFSS classified respondents as having disabilities if they reported being "limited in any way" or met at least 1 of the following criteria: had work or cognitive limitations or used some form of physical assistance (e.g., walker, service animal).

Kappa statistics were computed to measure agreement beyond chance between index subjects and proxies.⁷ Kappa values above 0.75 demonstrate excellent agreement; below 0.40, they demonstrate poor agreement.⁸ Because all index subjects reported some impairment, census questions had high proportions of yes responses. Consequently, the kappa values penalized relatively small discordance. We also report index-proxy agreement, the direction and level of discordance, and percentage of positive index and proxy responses.^{9,10}

Results

We completed 131 index-proxy sets (144 proxies overall). The proxies' mean age of 53.8 years (SD=18.2) was similar to that of the subjects with disabilities (55.1 years; SD=15.3). Most proxies (77.1%) were women, whereas 48.9% of subjects with disabilities were women. About a third (32.8%) of proxies were spouses, 26.0% were relatives, 22.2% were health professionals or personal care attendants, and 19.1% were close friends. Census questions received low kappa scores of 0.24 to 0.55 (Table 1) among all 131 index-proxy pairs. None was 0.75 or higher, and 4 were below 0.40. Percentage agreement ranged from 66.7% to 86.8%.

Table 1 shows that agreement was better for relatives and friends than for health care professionals. For proxy pairs including relatives and friends, kappa values for 4 of the questions were above 0.40, but for those including health care providers or personal care

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TABLE 1—Proxy Reliability of the Census 2000 Questions on Disability

Proxy Type	Census 2000 Question						
	1—Sensory Impairment: Blind/Deaf, Severe Vision/Hearing Disorder	2—Limits Walking, Reaching, Lifting	3—Limits Learning, Remembering, Concentrating	4—Limits Dressing, Bathing, Getting Around Home	5—Limits Going Outside the Home Alone	6—Limits Working	7—No Limits
Overall pairs (n = 131)							
Yes response (index/proxy), %	17.5/17.5	76.6/78.1	31.8/32.6	41.9/50.4	41.1/56.6	46.5/58.1	10.9/8.5
Difference, ^a %	0	+1.5	+0.8	+8.5	+15.5	+11.6	-2.4
Agreement, %	80.9	84.4	66.7	77.5	69.0	72.9	86.8
Kappa	0.34	0.55	0.24	0.55	0.39	0.46	0.25
Spouse (n = 43)							
Yes response (index/proxy), %	17.1/17.1	72.1/72.1	32.6/39.5	34.9/48.8	51.2/53.5	44.2/48.8	14.0/11.6
Difference, ^a %	0	0	+6.9	+13.9	+2.3	+4.6	-2.4
Agreement, %	80.5	86.0	69.8	76.7	79.1	72.9	83.7
Kappa	0.31	0.65	0.35	0.36	0.58	0.44	0.27
All relatives (n = 78)							
Yes response (index/proxy), %	16.0/17.3	74.0/77.9	29.9/31.2	33.8/46.8	49.4/54.4	49.4/55.8	13.0/7.8
Difference, ^a %	+1.3	+3.9	+1.3	+13.0	+5.0	+6.4	-5.2
Agreement, %	80.0	88.3	76.7	79.2	74.0	72.7	87.0
Kappa	0.28	0.68	0.36	0.58	0.48	0.46	0.31
Friend (n = 32)							
Yes response (index/proxy), %	19.4/16.1	75.0/68.8	43.8/28.1	34.4/28.1	25.0/40.6	37.5/34.4	9.4/18.8
Difference, ^a %	-3.3	-6.2	-15.7	-6.3	+15.6	-3.1	+9.4
Agreement, %	83.9	81.9	71.9	81.3	71.9	78.1	84.4
Kappa	0.45	0.54	0.41	0.57	0.38	0.37	0.37
Health care professional/PCA (n = 34)							
Yes response (index/proxy), %	21.9/25.0	90.6/93.8	18.2/39.4	66.7/75.8	45.5/69.7	51.5/75.8	6.1/0
Difference, ^a %	+3.1	+3.2	+21.2	+9.1	+24.2	+24.3	-6.1
Agreement, %	78.1	84.4	60.6	66.7	57.6	63.6	94.0
Kappa	0.39	-0.08	0.09	0.20	0.18	0.26	— ^b

Note. PCA = personal care attendant.

^aPercentage and direction of proxy difference from index.

^bKappa not calculated because of zero marginal total in table.

attendants, all kappa values were below 0.40. Table 1 also shows the direction of disagreement. In general, except for friends, proxies reported that the people with disabilities had more impairment than was reported by the people with disabilities themselves, with health professionals reporting the most discordant levels of disability.

Table 2 displays agreement and kappa values for responses to ADL and BRFSS items compared with census questions. Agreement between responses to the ADL items and the Census 2000 questions varied considerably, even for questions with overlapping definitions or functions. For example, the ADL item “needing help walking across a small room” overlaps with both the second and fourth census questions (walking and getting around home, respectively). Agreement generally was higher between responses to ADL questions and responses to the corresponding census questions (66%–75%) than between BRFSS questions and corresponding census questions; however, kappa values were only 0.31 to 0.37. Agreement between the ADL question and the census question on visiting/shopping was modest (59%–61%), and kappa values were low. Agreement between the second census ques-

tion (walking, reaching, lifting) and both BRFSS disability definitions (limited, limited plus uses assistance) was high (79.6% for each). Other census questions had lower levels of agreement with the BRFSS and low kappa values.

Discussion

These data suggest that the Census 2000 questions measure disability differently than the BRFSS and traditional ADL instruments. In addition, whereas family members and close friends may provide answers with moderate levels of agreement, their proxy responses will not provide an accurate count of disability and impairment. The difference between the Census 2000 questions and other standard definitions of sensory and mobility impairment is likely to add confusion to the already broad array of measures of disability.¹¹ In addition, temporal changes in prevalence will be difficult to track because of the changes from the 1990 census. The questions are complex in their wording; although some cognitive review of the questions with people with disabilities has been accomplished,¹² more is

needed (especially with proxies) to provide a better understanding of how respondents define disability.¹³

If the questions do provide a substantial improvement over previous disability definitions, more research and comparison are needed. Even more sobering than the differences from other disability definitions posed by the new census questions is the potential for reporting inaccuracies among proxy respondents. Overall, agreement between people with disabilities and proxies was only 80% to 84% for 2 questions (sensory conditions and limited physical activities). While spouses’ and intimate partners’ responses showed greater consistency than other proxies’ responses, these proxy groups overreported disability. Although the complexity of questions may be partly responsible for poor agreement, a tendency for proxies to overreport (or index subjects to underreport) functional limitations has been noted.^{14,15} Careful attention to these questions is needed during and following their use in Census 2000. If our report on the reliability and validity of the questions is confirmed by others, substantial work may be needed to provide the nation with an accurate reporting of the number of people with disabilities. □

TABLE 2—Comparison of Responses of People With Disabilities to Census 2000 Questions Regarding Activities of Daily Living (ADL) and BRFSS, by Kappa and Percentage Agreement

	Census 2000 Question								
	2—Walking, Reaching, Lifting			4—Limits Dressing, Bathing, Getting Around Home			5—Limits Going Outside the Home Alone		
	Yes Response, % (Census/ADL)	κ	% Agreement	Yes Response, % (Census/ADL)	κ	% Agreement	Yes Response, % (Census/ADL)	κ	% Agreement
ADL question: needs help with—									
1: Walking in small room	73.5/3.3	0.02	29.8	35.9/3.3	0.09	66.3	42.3/3.3	0.05	59.5
2: Moving from bed to chair	73.5/11.5	0.09	37.9	35.9/11.4	0.31	72.9	42.3/11.4	0.08	59.5
3: Exiting/entering home	73.5/4.6	0.03	31.0	35.9/4.6	0.12	67.1	42.3/4.6	0.09	60.8
4: Moving in wheelchair	73.5/3.3	0.02	29.8	35.9/3.3	0.09	66.3	42.3/3.3	0.07	60.0
5: Dressing	73.5/12.7	0.09	38.7	35.9/12.7	0.35	74.2	42.3/12.7	0.09	59.7
6: Bathing	73.5/13.5	0.09	38.9	35.9/13.4	0.37	74.9	42.3/13.4	0.12	61.0
7: Eating	73.5/4.8	0.03	30.8	35.9/4.8	0.14	67.8	42.3/4.8	0.07	60.0
8: Grooming	73.5/6.9	0.05	33.3	35.9/6.8	0.19	69.4	42.3/6.8	0.05	59.0
9: Bladder	73.5/8.1	0.05	33.6	35.9/8.1	0.23	70.6	42.3/8.1	0.08	59.7
10: Bowels	73.5/8.7	0.07	35.1	35.9/8.6	0.26	71.6	42.3/8.6	0.07	59.2
BRFSS question									
Limited by health/impairment	73.7/73.7	0.47	79.6	36.0/73.6	0.26	58.4	42.4/73.6	0.18	56.1
CDC disability definition ^a	73.5/92.9	0.32	79.6	35.9/92.9	0.08	42.0	42.3/92.9	0.06	46.8

Note. BRFSS = Behavioral Risk Factor Surveillance System; CDC = Centers for Disease Control and Prevention.

^aIf person with disabilities indicated at least 1 of the following: is limited in kind or amount of work; has any trouble learning, remembering, or concentrating; is limited in any way in any activities because of any impairment or health problem; uses walker; uses crutch or crutches; uses manual wheelchair; uses motorized wheelchair; uses electric mobility scooter; uses artificial leg; uses brace; uses service animal (i.e., guide dog); uses oxygen or special breathing equipment; other.

Contributors

E. M. Andresen and A. R. Meyers planned the study and supervised data collection at their respective sites. E. M. Andresen planned and supervised data analysis. C. A. Fitch conducted interviews and data analysis. P. M. McLendon also contributed to data analysis. All 4 authors contributed to the writing of this paper.

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Boards of both Saint Louis and Boston Universities approved the protocol.

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