

Bias in Proxies' Reports of Disability: Data From the National Health Interview Survey on Disability

ABSTRACT

Objectives. These studies examined whether differences between self-reports and proxy reports of disabilities reflect proxy response biases or only respondent selection factors.

Methods. The data were from the National Health Interview Survey on Disability (1994–1995, phases 1 and 2). In study 1, reports of disabilities were regressed on respondent status, self vs proxy, and demographic factors. In study 2, the ratios of the proportions of self-reports and proxy reports of disabilities were regressed on independent lay ratings of observability of these disabilities and their “interactional” nature. In study 3, the disability reports for people who differed in respondent status in one phase but self-reported the same disability in the other phase were compared.

Results. In study 1, proxies underreported disabilities for people aged 18 to 64 years but overreported for people 65 years or older. In study 2, the observability and interactional scores accounted for more than 60% of the variance of self and proxy differences in an inverse relationship. Study 3 confirmed the basic findings of study 1.

Conclusions. Use of proxies in representative surveys on disability introduces systematic biases, affecting national disability estimates. (*Am J Public Health*. 2000;90:1248–1253)

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Federal representative household surveys—notably, the National Health Interview Survey (NHIS) and the Survey of Income and Program Participation—are the main source of national estimates of the prevalence of impairments and disabilities. In these surveys, when a household is selected for an interview, the person who is contacted for the interview provides responses—“proxy responses”—for the entire household if the other family members who are 18 years and older are not available at the time of the interview. Although this interviewing strategy is more economical than interviewing all individuals, it rests on the assumption that the reference person would provide the same information that his or her family members would provide. However, several studies in the health domain have found differences between self-reports and proxy reports of health information.^{1–5}

An early controlled study within the NHIS provided evidence for consistent underreporting by proxies of chronic conditions, doctor's visits, bed days, and other health-related estimates.^{3,6} Other studies that examined self-reports and proxy reports for elderly people found evidence that proxies overreported impairments.^{2,5} Although these studies did not include independent measures of the accuracy of self-reports and proxy reports, the use of self-reports as the standard for evaluating proxy reports for adults capable of providing information seems justified. Other studies have found that self-responses are more accurate,⁷ and a recent study has shown that self-reported health information can be a better prognostic predictor of morbidity than physician-evaluated morbidity.⁸

Self and proxy differences have rarely been addressed in the context of disability,⁹ although in the 2 major federal surveys measuring disabilities, the NHIS and the Survey of Income and Program Participation, the proxy responses constituted more than 30% of all responses about adults. If self-reports and proxy reports of disabilities are found to differ sys-

tematically, the national estimates of disabilities will be affected.

In this article, we used data from the NHIS Supplement on Disability, 1994 and 1995 (NHIS-D), to address the differences between self-reports and proxy reports. This 2-part survey provided one of the richest sources of information about people with disabilities. In phase 1, all respondents were asked some questions designed to “screen for” disabilities during the same interview that included the set of annual “core” questions. In phase 2, respondents who reported disabilities in phase 1 were followed up a year later, on average, for an extensive interview.

From a cognitive-processing point of view, both the information available for self- and other-judgments and the strategies of forming these judgments can be different.^{10–13} When making other-judgments, people may recall behavioral information about the person but cannot know the person's internal states. For instance, one expression of disability is the behavioral difficulty the person has. Although this information may be available to other people, the pain one may experience is mainly available to oneself. This differential availability of information may lead to different judgments about what constitutes a disabling difficulty when one is answering for oneself rather than for another person. In addition, forming a judgment about another person may be more inferential than forming a judgment

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Note. All analyses, interpretations, and conclusions are the sole responsibility of the authors and not of the National Center for Health Statistics.

about oneself. For instance, reports for other people are likely to be based on estimation strategies rather than on recollections of specific behavioral examples.¹⁴

Two factors are critical for understanding differences between self-reports and proxy reports of disabilities: the nature of the disability and the age of the person for whom the disability is reported. Self-reports and proxy reports should differ to a lesser extent for disabilities that have immediate effect on interaction and are more observable. In fact, previous studies found that self and proxy discrepancies are larger for reports of more subjective psychosocial dimensions of illnesses than for less subjective physical dimensions.^{1,2,5,15} Because disabilities are strongly associated with aging, when the behavioral evidence for the disability is ambiguous or insufficient, proxy respondents may consider the person's age to decide whether the person has a disability. In the case of the same behavioral evidence, proxies might be more likely to infer that an elderly person has a disability than that a young person does.

The main problem in studying differences between self-reports and proxy reports in the context of federal surveys is that respondents are not randomly allocated to self or proxy status.¹⁶ For instance, a higher reported disability rate for self-respondents could mean either that self-reports and proxy reports are based on different information or that respondent selection factors are involved. One might hypothesize that people with disabilities are likely to be elderly and retired or, if at working age, to be unemployed. These are precisely the people who are more likely to be at home and thus to provide self-responses. That could account for the finding that self-respondents are more likely than proxy respondents to report disabilities. We used 3 research strategies to address the question of whether differences between self-reports and proxy reports of disabilities reflect cognitive differences in responding or respondent selection factors.

If differences between self-reports and proxy reports of disability reflect confounds of the self- and proxy-respondent status with relevant demographic factors, then these differences should not appear when the analysis adjusts for those factors. In the first study, we used phase 1 data to examine the relation of respondent status to disability reports after adjusting for demographic variables.

If the self and proxy differences reflect response strategies based on different information rather than demographic confounds, then they should be systematically related to the information necessary to conclude that a person has a particular disability or the inferences afforded by the behavioral manifestations of the disability. In the second study, we

tested whether informational aspects of different disabilities predicted the pattern of self and proxy differences found in phase 1. To do so, we gathered lay judgments of how observable and interactional the specific disabilities were.

Finally, we used data from both phases of the NHIS-D to identify 3 groups of respondents: (1) those who reported for themselves in both phases (self-self), (2) those who reported for themselves in phase 1 but for whom proxy reports were given in phase 2 (self-proxy), and (3) those for whom proxy reports were given in phase 1 but who reported for themselves in phase 2 (proxy-self). The first group, self-self, was used as a control group and was compared with the other 2 groups. Specifically, among people who self-reported a particular disability in one phase, the reports of the same disability were compared in the other phase when their respondent status differed (i.e., self-self and self-proxy in phase 2 and self-self and proxy-self in phase 1). If the differences between self-reports and proxy reports of disabilities reflected different response strategies, then the reported disability rates should be different.

Methods

Data Sources

The data for our studies came mainly from phases 1 and 2 of the NHIS-D (1994–1995).^{17,18} The NHIS is a representative continuing nationwide household survey. Data are collected each week on a probability sample. Personnel of the US Bureau of the Census conduct the face-to-face interviews.

Study 1

Because only proxy responses are obtained for respondents younger than 18 years, the current analyses were limited to respondents 18 years or older. The sample size for that age group was 145 007 in 1994 and 1995 combined. Respondents with unknown respondent status (8.8%, N = 12 750) were excluded from the analyses, leaving a sample of 132 257 respondents: 81 840 self-respondents (64 582 were aged 18 to 64 years and 17 258 were 65 years or older) and 50 417 proxy respondents (44 422 were aged 18 to 64 years and 5 995 were 65 years or older).

Disability questions. Analyses were performed on several sections of questions: sensory limitations, mental health, functional limitations, activities of daily living (ADL), and instrumental ADL (IADL). From the questions that screened for a disability, analytic variables were created for each section. The sensory limitations variable was based on 10 questions

about difficulty with seeing; hearing; communication; understanding; learning; dizziness; balance; ringing, roaring, or buzzing in the ears; sense of smell; and sense of taste. The mental health variable was based on 7 questions about frequent depression, troubles with making or keeping friends, getting along with other people, concentrating, coping with day-to-day stresses, frequent confusion, and phobias. The functional limitations variable was based on 8 questions about difficulties lifting, walking up 10 steps, walking a quarter of a mile, standing for about 20 minutes, bending down, reaching up or reaching out, using fingers, and holding a pen or pencil. The ADL and IADL variables were based on reports of the following circumstances applied to sets of basic and secondary activities: getting help, being reminded, experiencing difficulty, and using special equipment. The ADL included bathing or showering, dressing, eating, getting in and out of bed or chairs, using the toilet, and getting around inside the house. The IADL included preparing own meals, shopping for personal items, managing money, using the telephone, doing heavy work around the house, and doing light work.

Analyses. For each of the above sections, a summary variable was created to indicate whether the respondent did or did not report a disability. Respondents who reported 1 or more specific disabilities were contrasted with respondents who reported none. In logistic regression analyses, the reports of disabilities were regressed on respondent status and demographic factors. In addition to the section variables, eligibility status for phase 2, the Disability Followback Survey, was analyzed. Respondents 18 years and older who were classified as eligible and thus as effectively having a disability were contrasted with noneligible respondents.

The initial analyses were adjusted for 11 demographic factors. However, because the odds for the respondent status remained robust after the first 8 factors were included, only these factors were used in the final analyses: age, sex, race (coded as White or non-White), education (years of schooling), family income (coded as below or above \$20 000), employment (coded as employed or unemployed), marital status, and family size. (The parameter estimates for these demographic variables are available on request from the authors.) Separate analyses were performed for respondents aged 18 to 64 years and those 65 years or older. All analyses were weighted for the probability of respondent selection and adjusted for the survey design.

Study 2

Study 2 explored whether the pattern of self and proxy differences at the level of the

specific disability questions was systematically related to lay judgments of how observable and interactional these disabilities are. Twenty-seven undergraduate students from the Department of Psychology at New York University were recruited for a study and asked to rate the 37 disabilities that had been used to create the summary variables for study 1 on 2 scales. The study was approved by the Human Subjects Committee of New York University.

For the ADL and IADL sections, the analyses were performed on the first questions about getting help from another person in doing any of the activities. The disabilities were worded in the same way as in the NHIS questionnaire and rated on 2 scales: "How likely is it that a family member living with the person will notice this difficulty?" and "How likely is it that a family member will consider this as a serious difficulty?" (ranging from 0=not likely at all to 10=extremely likely). Another group of 11 students classified the 37 disabilities into 2 categories: detectable and directly affecting social interaction—"interactional"—and not necessarily detectable in social interaction—"not interactional." The ADL and IADL items were coded as interactional because they referred to "getting help."

Analyses. The mean ratings for these 2 groups of participants were correlated with the ratio of the proportions of self-respondents who reported a particular disability and proxies who reported the same disability. For instance, "serious difficulty seeing" was reported by 4.0% of self-respondents and by 2.3% of proxies. The ratio of these 2 proportions, 1.74, was used as a measure of the discrepancy between self-reports and proxy reports. In addition, for each disability, the ratio adjusting for the survey design and demographic factors was computed. In a logistic regression, the report of each disability was regressed on the respondent status and the demographic factors from study 1. The odds for respondent status from these analyses were used as adjusted ratios of self and proxy differences. For "serious difficulty seeing," this ratio was 1.11. The unadjusted and adjusted ratios were regressed on the mean of the participants' ratings of disabilities.

It should be noted that the ratings measure informational properties of disabilities and are not an attempt to model individual responses. They are used to predict a specific response bias at the level of proportions. The most important issue in such a procedure is the ratings' reliability and not their representativeness of a particular group of people. The reliability measured at the level of participants was high for all ratings: Cronbach α was 0.94 for "observability," 0.89 for "seriousness," and 0.91 for "interaction."

Study 3

Respondents who were identified as having a disability in phase 1 were followed up in phase 2 of the NHIS-D, the Disability Followback Survey. Thus, 3 groups of reference people could be identified: (1) those who reported for themselves in both phases (self-self), (2) those who reported for themselves in phase 1 but for whom proxy reports were given in phase 2 (self-proxy), and (3) those for whom proxy reports were given in phase 1 but who reported for themselves in phase 2 (proxy-self). The sample size for the Disability Followback Survey was 25805 (15265 self-self, 1081 self-proxy, and 4061 proxy-self). The proxy-self group was larger than the self-proxy group because every effort was made to reduce the number of proxy respondents in the Disability Followback Survey. Either the remaining 5398 respondents had unknown respondent status in one of the phases or proxies who reported in both phases (it was not possible to establish whether the same person served as a proxy both times), or other people helped the respondents to respond in phase 2.

Analyses. One section of the Disability Followback Survey contained questions similar to the questions about functional limitations and ADL and IADL difficulty from phase 1. For the present analysis, we used only questions that either were worded in the same way (for functional limitations) or referred to the same activities (for ADL and IADL). The analytic variables were created in the same way as in study 1. Two comparisons were made. For the self-self and self-proxy groups, among respondents who reported functional, ADL, or IADL limitations in phase 1, the self-reports and proxy reports of the same disability in phase 2 were compared. For the self-self and proxy-self groups, the self-reports and proxy reports in phase 1 were compared for respondents who reported the same disability in phase 2. In that way, the analysis controlled for self-reported disability status. The disability reports in the phase in which self- and proxy respondents reported were regressed on the respondent status in this phase and on the demographic variables used in study 1.

Results

The age-specific proportions of reported disabilities in Table 1 (columns 1 and 2) indicate that respondent status affects the reports for people aged 18 to 64 years but not for those 65 years or older. However, after adjustment for demographic factors, a consistent pattern across disabilities emerged. For respondents aged 18 to 64 years, in all categories except ADL, proxies underreported disabilities. In the

only exception, ADL, the difference was not reliable. In contrast, for respondents 65 years or older, in all categories, proxies overreported disabilities. Because elderly respondents constitute a substantially smaller group (17.6%) than younger respondents, the overall effect was proxy underreporting for all disabilities except the arguably most severe, difficulty in ADL and IADL.

Thus, the direction of the differences between self-reports and proxy reports varied not only across age groups but also across disabilities. Proxy respondents were less likely to report functional limitations, sensory limitations, and mental health problems than self-respondents but more likely to report ADL and IADL difficulties. The self and proxy status also reliably predicted who was screened in for phase 2 of the Disability Followback Survey. These people were classified as having a disability and were followed up for detailed information about the nature of their impairment and the barriers and accommodations affecting their social participation. Even after control for demographic factors, self-respondents were 1.23 times more likely to be included in phase 2 than persons described by proxy respondents.

Disabilities that directly affect interactions with other people are more detectable than disabilities not necessarily related to interactions. For instance, among sensory limitations, proxy respondents were more likely to report "difficulty communicating" than self-respondents but less likely to report "problems with balance." We examined this pattern more systematically by comparing specific disabilities in study 2. If self-reports and proxy reports differ systematically as a function of the observability and the degree of effect on interaction characteristic of the disabilities, then these differences should correlate with such ratings of the disabilities.

As shown in Table 2, the mean classifications of the disabilities as "interactional" and the observability ratings were highly correlated with the size of differences between self-reports and proxy reports of disabilities. The more interactional and observable the disability, the less the discrepancy between self-reports and proxy reports. The correlation of the interactional score with the unadjusted ratio was as high as 0.81. The correlation was also high (0.61) with the mean observability ratings. The correlations with the ratings of "how serious the disability is considered" were weaker but in the same direction. As shown in Table 2, the interactional and observability scores accounted for more than 60% of the variance of the differences between self-reports and proxy reports.

In study 3, self-reports and proxy reports of functional, ADL and IADL limitations in one phase for respondents who self-reported the same disability in the other phase were

TABLE 1—Weighted Rates of Eligibility for the Disability Followback Survey and Reported Disabilities as a Function of Respondent Status and Age: National Health Interview Survey on Disability, Phase 1, 1994 and 1995^a

	Self-Reports (n=81 840)	Proxy Reports (n=50 417)	Unadjusted Odds	Adjusted Odds	95% CI
Eligibility for phase 2 (disability status)					
18–64 y	18.5%	11.7%	1.72	1.39	1.33, 1.45
65 y or older	43.5%	41.9%	1.07	0.89	0.83, 0.97
All ages	23.6%	15.1%	1.74	1.23	1.19, 1.28
Sensory limitations					
18–64 y	11.2%	7.3%	1.61	1.40	1.34, 1.47
65 y or older	32.2%	32.4%	0.99	0.86	0.80, 0.93
All ages	15.5%	10.1%	1.63	1.21	1.17, 1.25
Mental health problems					
18–64 y	11.6%	5.4%	2.28	1.68	1.60, 1.77
65 y or older	15.4%	15.2%	1.02	0.73	0.67, 0.81
All ages	12.3%	6.5%	2.02	1.42	1.36, 1.48
Functional limitations					
18–64 y	11.7%	5.4%	2.30	1.72	1.63, 1.81
65 y or older	37.2%	35.2%	1.09	0.86	0.80, 0.93
All ages	16.9%	8.8%	2.10	1.36	1.30, 1.43
Difficulty with IADL					
18–64 y	6.1%	3.5%	1.75	1.23	1.14, 1.33
65 y or older	22.6%	25.4%	0.86	0.58	0.53, 0.64
All ages	9.4%	6.0%	1.62	0.91	0.86, 0.97
Difficulty with ADL					
18–64 y	1.8%	1.3%	1.34	0.91	0.81, 1.03
65 y or older	8.0%	15.0%	0.49	0.32	0.28, 0.37
All ages	3.0%	2.9%	1.06	0.54	0.49, 0.59

Note. CI=confidence interval; IADL=instrumental activities of daily living; ADL=activities of daily living.

^aAll analyses were performed on data weighted for the probability of selection and adjusted for the survey design. The odds were adjusted for age, sex, race, education, income, employment, marital status, and family size.

TABLE 2—Unstandardized Regression Coefficients (and Correlations) of Mean Lay Disability Ratings and Classifications as Predictors of Differences Between Self-Responses and Proxy Responses: National Health Interview Survey on Disability, Phase 1, 1994 and 1995

Lay Disability Ratings	Ratio of Self-Reports and Proxy Reports of Disabilities	
	Raw Ratio	Adjusted Ratio
Observability	-0.14 ($r=-0.61^*$)	-0.19** ($r=-0.61^*$)
Seriousness	-0.02 ($r=-0.36^{**}$)	-0.09 ($r=-0.30$)
Effect on social interaction	-1.29* ($r=-0.81^*$)	-0.78* ($r=-0.75^*$)
Explained variance	$R^2=0.70$	$R^2=0.63$

Note. The observability and seriousness ratings were made on 2 scales, "How likely is it that a family member living with the person will notice this difficulty?" and "How likely is it that a family member living with the person will consider this as a serious difficulty?" ranging from 0 (not likely at all) to 10 (extremely likely).

The interaction scores are mean classification scores of the 37 disabilities into 2 categories: "interactional" vs "noninteractional." The adjusted ratio of self-reports and proxy reports was computed in logistic regression adjusted for the survey design and demographic variables (see note in Table 1).

* $P<.01$; ** $P<.05$.

compared. The pattern of differences between self-reports and proxy reports in phase 2 for people who self-reported the disabilities in phase 1 (Table 3) was similar to the pattern found in study 1. For both functional and IADL limitations, proxies underreported for people aged 18 to 64 years relative to self-respondents. As in the case of ADL in study 1, this difference was not reliable for people aged 18 to 64 years. For those 65 years or older, proxies

overreported both functional and ADL limitations. The difference was not reliable for IADL.

It should be noted that the estimates of the effect of respondent status were practically unchanged by the inclusion of the demographic factors. The mean difference between the unadjusted and adjusted odds was 0.02, and the correlation was 0.97 ($P<.0001$). This finding suggests that the 2 groups, self-self and self-proxy with reported disabilities in

phase 1, had a very similar demographic composition, even though extra effort was made to use self-respondents in phase 2.

An alternative analysis is to compare the self-reports and proxy reports of disabilities in phase 1 for people with the same self-reported disabilities in phase 2. As in study 1 and the above comparison, for people aged 18 to 64 years, proxies underreported functional and IADL limitations, and the difference for ADL was not reliable (Table 4). This was the case for all ages, too. For those 65 years or older, the differences between self-reports and proxy reports were not reliable after adjustment for demographic factors. However, the general pattern across types of disabilities and age groups was quite consistent with the findings of study 1 and the comparison of the self-self and self-proxy groups in study 3. The correlations of the adjusted odds with those from the latter comparisons were both 0.94 ($P<.0001$).

Discussion

The findings of the 3 studies provide convergent evidence that differences between self-reports and proxy reports of disabilities in nationally representative surveys reflect different response strategies rather than only respondent selection factors. Study 1 showed that the effect of respondent status on reports of disabilities was highly reliable, even after adjustment

TABLE 3—Rates of Reported Disabilities in Phase 2 for Respondents With Self-Reported Disabilities in Phase 1 as a Function of Respondent Status in Phase 2 and Age: National Health Interview Survey on Disability, Phases 1 and 2, 1994 and 1995

Phase 2	Self-Reports	Proxy Reports	Unadjusted Odds	Adjusted Odds ^a	95% CI
Functional limitations					
18–64 y	76.9% (2906)	63.1% (113)	1.94	2.01	1.45, 2.80
65 y or older	82.2% (2641)	88.5% (292)	0.60	0.64	0.45, 0.92
All ages	79.4% (5547)	79.6% (405)	0.99	1.19	0.94, 1.51
Difficulty with IADL					
18–64 y	64.7% (1747)	53.9% (89)	1.57	1.57	1.13, 2.20
65 y or older	64.5% (1590)	61.5% (84)	1.13	1.12	0.86, 1.46
All ages	64.6% (3337)	58.5% (173)	1.28	1.29	1.05, 1.59
Difficulty with ADL					
18–64 y	70.4% (501)	63.6% (35)	1.36	1.07	0.57, 2.04
65 y or older	78.5% (556)	91.2% (114)	0.35	0.39	0.20, 0.78
All ages	74.4% (1057)	82.8% (149)	0.61	0.71	0.46, 1.11

Note. CI = confidence interval; IADL = instrumental activities of daily living; ADL = activities of daily living.

^aThe odds were adjusted for age, sex, race, education, income, employment, marital status, and family size.

TABLE 4—Rates of Reported Disabilities in Phase 1 for Respondents With Self-Reported Disabilities in Phase 2 as a Function of Respondent Status in Phase 1 and Age: National Health Interview Survey on Disability, Phases 1 and 2, 1994 and 1995

Phase 1	Self-Reports	Proxy Reports	Unadjusted Odds	Adjusted Odds ^a	95% CI
Functional limitations					
18–64 y	69.9% (2906)	55.5% (587)	1.86	1.56	1.33, 1.82
65 y or older	75.2% (2641)	67.4% (370)	1.46	1.09	0.88, 1.37
All ages	72.3% (5547)	59.6% (957)	1.77	1.38	1.21, 1.56
Difficulty with IADL					
18–64 y	53.6% (1747)	42.9% (333)	1.54	1.41	1.18, 1.67
65 y or older	60.6% (1590)	50.4% (200)	1.52	1.12	0.87, 1.43
All ages	56.7% (3337)	45.4% (533)	1.57	1.31	1.14, 1.51
Difficulty with ADL					
18–64 y	25.9% (501)	20.8% (107)	1.34	1.09	0.84, 1.42
65 y or older	30.0% (556)	30.5% (85)	0.98	0.82	0.59, 1.12
All ages	27.9% (1057)	24.2% (192)	1.22	0.95	0.78, 1.17

Note. CI = confidence interval; IADL = instrumental activities of daily living; ADL = activities of daily living.

^aThe odds were adjusted for age, sex, race, education, income, employment, marital status, and family size.

for demographic factors, which influence the selection of respondents as self or proxy. Study 2 showed that the differences between self-reports and proxy reports were not randomly distributed across disabilities but were systematically related to lay judgments of how interactional and how observable these disabilities are. This systematic relation between self and proxy differences and lay judgments is predicted by a theory attributing these differences to the different information available to self-respondents and proxy respondents but not by a theory attributing them to demographic confounds. Finally, study 3 showed that self-reports and proxy reports of disabilities differed, even when respondents were matched on self-reported disabilities. The pattern of these longitudinal data confirmed the pattern found in study 1.

These findings taken together suggest that self-reports and proxy reports of disabilities

differ systematically. The direction of this difference depends on the nature of the disability and the age of the reference person. For younger persons (i.e., 65 years or younger), proxy respondents are likely to underreport disabilities. For elderly people, proxy respondents are likely to overreport disabilities. This finding is consistent with previous controlled small-scale studies.^{2,5} Presumably, because the base rate for disabilities among the elderly is higher, proxy respondents are more likely to infer that a person from this age group has a disability if they are given ambiguous or insufficient information about the disability.

Our analyses and conclusions are limited to cases in which the reference person is capable of providing responses but is absent at the time of the interview. In cases in which the reference person is judged unable to respond (e.g., severe cognitive disabilities), the issues require different approaches.¹⁹ Although infor-

mation about the reasons for using proxies in phase 1 was not collected, our general conclusions about the effect of proxy reports on the national estimates of disabilities should not be seriously affected by not considering the cases in which proxies reported because the reference person was not capable of responding. In phase 2, only 10.9% of the sample, all of whom had disabilities, was based on proxy reports because of health or impairment reasons.

Unfortunately, in phase 1 of the NHIS-D, detailed information about the proxy respondent was not collected when the reference person was older than 18 years, thus limiting the research questions one can address. For instance, the age of the reference person might interact with the age of the proxy respondent to produce even stronger response biases. People's decisions about other people's attitudes, opinions, and behaviors are strongly influenced by their own position.²⁰ One's age can serve as

an anchor for the decision about what it means to be disabled. In cases in which younger respondents respond for elderly people (e.g., children for parents), proxies' overreporting biases can be expected to be even stronger. In a similar vein, when elderly respondents report for younger people, the underreporting biases probably will be stronger.

Disabilities that require one-on-one help or that are easily detectable in social interaction are likely to be overreported by proxy respondents because these disabilities are more likely to be noticed by them, but other disabilities are likely to be underreported. The pattern of self and proxy differences across disabilities closely resembles findings in personality psychology on self-other agreement.^{21,22} This research has shown that differences between self- and other-ratings on personality traits are strongly related to the observability of these traits. Relative to others' ratings, people rate themselves higher on traits low in observability (e.g., engages in personal fantasy) but lower on traits high in observability (e.g., is verbally fluent).

Because most disabilities are less observable and most respondents in federal surveys are younger than 65 years, the use of proxy reports in such research will underestimate the prevalence of disability in general and especially the prevalence of specific disabilities. Our data seem to indicate that the best recommendation is to avoid using proxy respondents in household surveys on disability. However, this is not realistic given the cost of nationally representative surveys.⁶ A realistic and promising strategy is to try to model the expected differences between self-reports and proxy reports of disabilities and to adjust the disability estimates for these differences. Use of simple rating procedures, such as those in study 2, can help to estimate the expected bias in aggregated data from proxy responses and to explain the dynamics leading to bias.

An interesting assumption to consider is that the variance accounted by such procedures is due to response biases and that the remaining variance is due to true differences between self-respondents and proxy respondents as well as to possible sources of error. For instance, apart from respondent status, the national estimate of people with disabilities, aged 18 to 64 years, is about 22 714 000. From the statistical analyses on phase 1 data, it can be estimated that the use of proxies underestimated this number by

about 2 681 000. Generalizing from study 2, it can be argued that at least 60% of this underestimate (i.e., 1 609 000) is due to a proxy response bias. The remaining 40% may be due to true differences or sources of error. Thus, a conservative estimate of the number of people with disabilities, aged 18 to 64 years, adjusted for a proxy bias should be 24 323 000. □

Contributors

A. Todorov conceptualized the report, performed all statistical analyses, and conducted study 2. C. Kirchner was involved in clarifying the design and in the interpretation of the data. A. Todorov wrote the first draft of the report, and both authors cowrote and edited subsequent drafts.

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