

**The Effects of Survey Nonresponse and Proxy Response  
on Measures of Employment for Persons with Disabilities**

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### **Abstract**

If many people do not respond to surveys, and those who do not respond are different from those who do, then survey estimates may be biased. This study examines potential bias in employment statistics for persons with disabilities arising from differences in the survey response patterns between persons with and without disabilities. Several types of response rate are considered: contact, cooperation, and self-response (*vice* proxy response). Also, several types of disability are considered: mobility, mental, seeing, hearing, and MR/DD/LD. The data are from the National Health Interview Surveys of 1994 and 1995, including the National Health Interview Survey on Disability, Phase 1 and Phase 2. Based on the evidence of this study, there is little reason to believe that household survey-based employment statistics for persons with disability are significantly biased by nonresponse or proxy response of respondents with disabilities.

## **Statement of the Problem**

Household interview surveys provide statistics on the employment characteristics of persons with disabilities that are used for policy making, program administration, public information, research, and education. All household interview surveys are subject to various kinds of error (Anderson, Kasper, Frankel, and associates, 1979), including nonresponse error, error caused by the fact that some kinds of people are less likely than others to participate in surveys at all, or if they participate, they participate in different ways. Given the restrictions on participation in many spheres of life experienced by people with disabilities, it would be surprising if their participation in surveys were not restricted in some way. Restrictions on survey participation by persons with disabilities are objectionable on a number of grounds, but from a survey design viewpoint, the most important is that they may cause errors in survey estimates. That is, if people with disabilities are restricted in their participation in surveys, it may cause errors in survey estimates of their employment characteristics. If that were the case, then the utility of those statistics for policy, program, research, education, and public information would be undermined. Because of that concern, this study was undertaken to make a preliminary evaluation of potential biases in survey-based employment statistics for persons with disabilities arising from restrictions in their survey participation.

## Background

Nonresponse bias. Surveys have many different designs. However, US employment statistics are usually based on interviews (in person or by telephone) of probability samples of the household population, and this study is limited to such surveys. “Unit nonresponse” (or “case nonresponse”) in household interview surveys refers to the failure to obtain interviews from sampled units (households or persons). “Item nonresponse” refers to the failure to obtain answers to particular questions in otherwise complete interviews. Both types of nonresponse can be important sources of error in surveys, but only unit nonresponse is considered in this analysis.

Unit nonresponse error is a systematic difference between sample-based estimates of population statistics and their true values, caused by nonresponse. For instance, if the true employment rate of a population subgroup was  $X$ , but because of nonresponse the sample-based estimate was  $X-y$ , there would be a nonresponse bias. The nonresponse bias is distinct from other sources of survey error, such as sampling error.

**“. . . if nonresponse is high and the difference between those who respond and those who do not is large, nonresponse bias is large.”**

It is common knowledge in survey research that the magnitude of nonresponse error (or bias) depends on two things: the amount of nonresponse and the size of the difference in the population characteristic being estimated (such as employment) between those who respond and those who do not (see Groves and Couper, 1998, for a discussion of this point). If nonresponse is very low and there is little difference between those who respond and those who do not respond, nonresponse bias is small. At the other extreme, if nonresponse is high and the difference between those who respond and those who do not is large, nonresponse bias is large.

Based on information given by persons with disabilities who respond in interview surveys, the rate of employment among persons with disabilities is estimated to be very low. How might nonresponse bias affect that estimate? Suppose that persons with disabilities had high nonresponse rates. Further, suppose that nonresponding persons with disabilities had much higher employment rates than responding persons with disabilities. In those circumstances, employed persons with disabilities would be systematically under represented in the sample of completed interviews, and the estimated population employment rate among persons with disabilities would be biased downward. That is, the estimated rate would be lower than the true rate because of nonresponse bias. If nonresponding persons with disabilities had much lower employment rates than responding persons with disabilities, the population employment rate among persons with disabilities would be biased upward.

These hypothetical situations correspond to Groves-Couper (1998) situations in which nonresponse is large and there are large differences between those who respond and those who do not. If nonresponse is small or there are small differences between those who respond and those who do not, the nonresponse bias would be small or nonexistent. The general purpose of this study was to examine the magnitude and direction of such nonresponse biases in estimates of employment rates and other employment characteristics for persons with disabilities.

Sources of nonresponse bias: contact and cooperation. As conceptualized by Groves and Couper (1998, pp. 26-27), successfully completing interviews (response) requires two activities: (1) locating and gaining access to sample households--contact, and (2) obtaining respondents' consent to conduct interviews—cooperation. Contact and cooperation are affected both by survey field operations (such as the training and motivation of interviewers) and characteristics of the sample households and respondents. In the data used for this study attention focuses on

characteristics of households and respondents as possible causes of variation in contact and cooperation.

The household characteristic most affecting contact is at-home patterns: households in which eligible respondents, often “responsible” adults, are frequently at home during day-time and early evening hours are more likely to be contacted. At-home patterns are largely determined by employment and childcare responsibilities: employed adults are less likely to be at home, while adults with young children are more likely to be at home. The characteristics of households and respondents that affect cooperation are more elusive. They tend to be psychological and situational, and are therefore difficult to observe and describe. Groves and Couper (1998) consider two theories for explaining variations in cooperation, social exchange and social isolation, and find greater support for the latter in the empirical evidence they consider (Chapter 5).

Another source of nonresponse bias: proxy response. Another factor will be considered in this study of nonresponse, although it is not considered by Groves and Couper (1998), namely, the type of respondent, self or proxy. Surveys have rules about who is eligible to answer survey questions, that is, to act as a respondent. In most surveys used to estimate employment rates, respondent rules specify that responsible adults at home at the time of the survey are eligible to act as respondents for the household. (In surveys about children, however, the respondent rule usually specifies an adult proxy respondent, both because it is difficult to obtain informed consent from children and because children are not accurate reporters of some kinds of information about themselves.) Eligible respondents can be asked employment questions about themselves (self response) or about other household members (proxy response). This respondent

rule yields high response rates and contains fieldwork costs, because cases can be completed for persons absent at the time of interview without costly repeat contacts.

Proxy respondents' answers to questions about other household members are acceptable if they are as accurate as, or more accurate than, the responses that would have been given if the absent household members had been self respondents. This is assumed to be true when the survey questions are about objective and public circumstances or events. When the questions are about events or circumstances that are more subjective or private, the respondent rule may require that sample persons respond for themselves.

A self response requirement may be unconditional or conditional: if unconditional, no proxy responses are allowed; if conditional, proxy responses are allowed under specified conditions. In the latter case, while a proxy response may be accepted, it is acknowledged to be of inferior quality, and to be avoided if possible; in that sense it is like a nonresponse. In these survey circumstances, proxy response has the same potential for causing nonresponse bias as do failing to make contact or to win cooperation. That is, if proxy response rates are high, and proxy respondents answer differently from self respondents, then population estimates may be biased. In this study, therefore, proxy response will be considered analogously to nonresponse.

Disability and nonresponse bias. Little is known about nonresponse bias as it relates to disability. For instance, in their comprehensive study of household nonresponse, Groves and Couper (1998) neither present nor cite any empirical evidence on the relationship of disability to nonresponse bias, although they do identify the respondent's "inability" to undertake an interview as a potential cause of nonresponse (p. 29). A more recent review of survey measurement of work disability (Mathiowetz and Wunderlich, 2000) asserts that "no empirical

data exist that address the impact of nonresponse on estimates of persons with disabilities” (p. 68).

The only published research to address the issue directly was by the present author and colleagues (Hendershot, Colpe, and Hunt, in press). That study examined the relationship between severity of physical disability and patterns of response and nonresponse, using data from Phase 2 of the 1994-1995 National Health Interview Survey on Disability (NHIS-D). It found that contact and cooperation rates were relatively high for persons with physical disabilities, and that increasing severity of physical disabilities was associated with being more likely to be contacted and more likely to cooperate.

That persons with more serious physical disabilities should be contacted more frequently is plausible within the Groves-Couper framework: because of their mobility limitations and an environment lacking in accommodations, they may be less likely to participate in activities outside the home, and therefore may be more likely to be at home when survey interviewers attempt to contact them. There is substantial empirical evidence that persons with disabilities are less likely than those without disabilities to participate in activities outside the home; see, for instance, Harris Interactive (2000: pp. 68-82). That persons with more serious physical disabilities should cooperate more frequently is not so plausibly explained, although it is consistent with one of the social-psychological theories proposed by Groves and Couper (1998) to explain variations in cooperation, “social exchange theory ” (pp.125-132). The social exchange theory predicts that persons who benefit from public programs, such as disability programs, will tend to cooperate with public enterprises, such as Federally-sponsored household surveys. This assumes that persons with disabilities are more likely to benefit from government programs than persons without disabilities, which has not been empirically demonstrated. It can

be said, however, that persons with disabilities are more likely than other persons to benefit from government disability programs—in the 1997-1999 NHIS, for instance, persons with any mobility limitation, as defined in this study, were more than 15 times as likely as other persons to be receiving SSI or SSDI benefits (author's computation from public use files).

With respect to the third potential cause of nonresponse bias, proxy reporting, the study by Hendershot, Colpe, and Hunt (in press) found that proxy response rates were high and increased with severity of physical disability, reaching almost one-fourth among sample persons with the most severe physical disabilities. These findings suggest that a nonresponse bias in survey estimates of employment characteristics of persons with serious disabilities is not likely to result from differences in contact or cooperation, which are high for persons with serious physical disabilities. However, bias may be associated with the high rates of proxy response among persons with serious physical disability—if proxy and self respondents respond differently to questions about employment and disability.

There is evidence that proxies do respond to disability-related questions differently from self-respondents. For instance, in another study based on the NHIS-D, Todorov and Kirchner (2000) found that proxy respondents, compared to self-respondents, were less likely than self-respondents to report an activity limitation for sample persons of working age. (See also the earlier literature cited by Todorov: Bassett, Magaziner, and Hebel 1990; Epstein, Hall, Tognetti, Son, and Conant, 1989; Kovar and Wright, 1973; Mathiowetz and Groves, 1985; and Rothman, Hedrick, Bulcroft, Hickman, and Rubenstein, 1991). Iezzoni, McCarthy, Davis, and Siebens (2000), also using the NHIS-D, but using respondent-perceived disability as a measure, also found that proxies were less likely than self-respondents to report that a sample person of working age had a disability. If proxy reporting is more prevalent for sample persons with

severe disabilities, and if proxies tend to underreport disability, survey response patterns may be biased toward underreporting of severe disability, and of the low employment rates associated with disability. Additionally, if proxy respondents respond differently from self respondents with disabilities to employment-related questions, that also could bias estimates of employment statistics.

New analyses of disability and nonresponse. Based on survey theory and previous research, it has been argued here that nonresponse bias, especially nonresponse bias associated with proxy responses, may affect estimates of employment statistics for persons with disabilities. To improve understanding of this issue, three extensions of previous research were undertaken in this study. First, nonresponse bias was examined in a greater variety of disability types, including (in addition to physical disabilities) emotional and behavioral problems, blindness and low vision, deaf and hard-of-hearing, and learning disabilities and mental retardation/developmental disability. Second, this study examined the effects of nonresponse bias, especially proxy response, on the reporting of employment characteristics, such as current employment status and workplace discrimination. Third, this study examined aspects of the interview situation related to proxy response, including the reason given by the interviewer for accepting a proxy, the kin relationship of the proxy to the sample person, and residence of the proxy relative to the sample person.

Source and limitations of the data. The data for this study are from the National Health Interview Survey on Disability (NHIS-D), Phases 1 and 2, conducted by the National Center for Health Statistics. Phase 1 was conducted in 1994 and 1995 and included many questions on disability. Those questions were used to identify persons with disabilities for a follow-up interview, Phase 2, conducted 13 months after the Phase 1 interviews (on average). The

appendix table shows the numbers of persons eligible, the number of completed interviews, and the response rates for each Phase and year of the survey. All persons in cooperating NHIS sample households were eligible for the NHIS-D Phase 1 questionnaire. Persons were eligible for the Phase 2 questionnaire if they were reported in Phase 1 to have some indication of disability, as defined by the survey designers; indications of disability included health conditions, functional limitations, disability program participation, use of assistive technology, and perceptions of disability.

A description of the purposes, sponsorship, and content of the NHIS-D can be found at the following Web site: [http://www.cdc.gov/nchs/about/major/nhis\\_dis/nhisddes.htm](http://www.cdc.gov/nchs/about/major/nhis_dis/nhisddes.htm). A forthcoming publication by the Hendershot and Larson describes the field work, data processing, and data dissemination of the NHIS-D. The sample design and estimation procedures for the 1994 and 1995 samples are described, respectively, in Massey, Moore, Parsons and Tadros (1989), and Botman, Moore, Moriarity, and Parsons (2000).

Although both Phase 1 and Phase 2 included persons of all ages, this study included only persons of working age, defined as 18-64 years. About 120,000 working age persons were interviewed in Phase 1 and about 25,000 in Phase 2. Interviews were conducted in person if possible, or by telephone if necessary. The NHIS-D was based on area probability samples designed to represent the civilian household population of the United States; not included were persons on active military duty or living in institutions (such as prisons and nursing homes). The public use files for the NHIS-D were used for the analyses (National Center for Health Statistics, 1999a; National Center for Health Statistics, 1999b).

The NHIS-D is subject to the limitations found in all household interview surveys based on probability samples, and some limitations specific to its design. Those limitations include

sampling error, coverage error, nonresponse error, reporting error, etc. Sampling error was estimated in this study using statistical computing software that accounts for complex sample designs such as that of the NHIS-D (StataCorp, 2001). Coverage error could arise in the NHIS due to its exclusion of persons in long-term care institutions, such as nursing homes and prisons, among whom are many persons with disabilities, especially severe disabilities. Active duty military personnel are also excluded, among whom persons with disabilities are presumably rare. Nonresponse error, including proxy bias, is the subject of the analyses that will be described below.

A potential source of reporting error in this study is the interval of time between the Phase 1 and Phase 2 interviews. In much of the analysis reported here, respondents are classified with respect to disability according to information provided in the Phase 1 interviews, and classified with respect to employment characteristics according to information provided in Phase 2 interviews. However, the average (mean) interval between interviews was 13 months, sufficiently long for disability status to have changed, for better or for worse. Thus, for some unknown proportion of the cases, the Phase 1 disability measure used may have been inaccurate at Phase 2. For much of the study, the logic of the analytic design is that disability existing just prior to Phase 2 affected participation in Phase 2; to maintain that logic, the possible inaccuracy of the Phase 1 disability measure as a measure of disability just prior to Phase 2 could not be avoided.

There is another limitation of these data that is specific to, and very important for, the interpretation of the analyses of self and proxy responses presented in this report. Ideally, differences between self and proxy reports for the same sample person would be studied by randomly assigning self or proxy respondents to sample persons and comparing their survey

responses. Random assignment would guarantee that the selection of respondent type (the independent variable) was not causally related to survey responses (the dependent variable). In this study, however, the decision to use self or proxy respondents was made in the field by interviewers applying general guidelines to the interview situations they encountered. Their decisions were based on the expected effects on the interview, primarily on its successful completion, the primary criterion for evaluating interviewer performance. Under these circumstances, interviewers would be expected to choose a proxy respondent for interviews they believed might not be completed by the sample person. If, for instance, the sample person had a disability that the interviewer thought would make it difficult or impossible to complete the

**“. . . there is no way to avoid the confounding of independent and dependent variables inherent in the data used for this study.”**

interview, the interviewer would have good reason to substitute a proxy respondent. Under the field procedures in effect in Phase 2 of the NHIS-D, this would not have been bad practice; however, it would have tended to confound the “assignment” of proxy and self respondents with the outcomes of interest—differences in self and proxy responses to questions about persons with disabilities. Beyond “controlling” for the type and level of disability of the sample person, which is done herein, there is no way to avoid the confounding of independent and dependent variables inherent in the data used for this study. Nevertheless, in the absence of experimental data (which would be very expensive to collect), the present study can provide useful insights into the self-proxy bias issue.

## **Data Analysis and Findings**

Disability and response outcomes. Table 1 is modeled after a table shown in Hendershot, Colpe, and Hunt (in press). The cell entries are conditional probabilities of each survey outcome identified by the labels heading columns (2) – (5) for sub samples of persons with the types of disabilities identified by the line labels shown in column (1). The total sample on which the statistics in Table 1 is based comprises the 120,811 persons of working age who were interviewed in Phase 2. The entries in column (2) are the probabilities of having been eligible for Phase 2, conditional on having been included in the full Phase 1 sample. Similarly, the entries in column (3) are the probabilities of having been contacted in Phase 2, conditional on having been eligible; the entries in column (4) are the probabilities of having cooperated in Phase 2 (consented to an interview), conditional on having been contacted; and the entries in column (5) are the probabilities of having been a self respondent (*vice* a proxy respondent), conditional on having consented to an interview. The conditional probabilities are estimates of the percents for the population, not sample statistics. The standard errors of the estimated population percents are given below each estimated probability.

[Table 1 about here]

Table 1 replicates the analysis of Hendershot, Colpe, and Hunt (in press) for persons with physical disabilities (although physical disability is defined somewhat differently in this study). More importantly, Table 1 extends the previous analysis to other types of disability. Figure 1 summarizes the operational definitions of each type of disability shown in Table 1. The definitions of disability used are relatively narrow; that is, the criteria for disability are fairly demanding. For instance, in the category of mobility limitation, to be classified as having a

limitation, a person must have been reported to “unable” to perform one or more of the mobility activities—having “a lot of difficulty” was not sufficient. This analytic decision was motivated by the fact that the effect of disability on employment is by far greater among persons with serious disability; and the theoretical effect of disability on response rates is expected be far greater among those with serious disability. Because the effects under investigation are found at “serious” levels of disability, it was appropriate to define disability in a way that restricted it to serious disability.

The conceptual approach used in defining the measures generally follows the World Health Organization’s International Classification of Functioning, Disability, and Health (2001), both with respect to categories and terminology. The categories Mobility, Mental, Seeing, and Hearing are based on body functions and personal activities, not medical diagnoses. The category “Learning disability, mental retardation, and developmental disability” combines limitations of learning activity with selected medical diagnoses sometimes referred to as “birth defects.” They were combined for two reasons: they are often combined for purposes of determining eligibility for programs benefits, such as special education; and while they are all important disabilities, they are too rare to be analyzed individually with a sample the size of the NHIS-D.

It should be noted that the disability categories 1-4 defined in Figure 1 are not mutually exclusive: a person may be classified in two or more of those categories. Such “co-morbidity” is an important issue that is not addressed in this study. It should also be noted that category 7, “Other disability,” can include persons with a disability or disabling chronic condition that is not included in categories 1-4. That is, categories 1-4 do not define disability exhaustively.

It should also be noted that the definitions of disability used in this report are not necessarily consistent with definitions of disability used elsewhere. (Nor is terminology necessarily the same, because the author has chosen to use the terminology of the International Classification of Functioning, Disability, and Health wherever possible). There are numerous definitions of disability in use, each developed for particular applications. A definition of disability potentially relevant to this study is that used by the Social Security Administration to determine eligibility for disability benefits, as follows:

The law defines disability as the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months (Social Security Administration, 2001).

Although the definition is short and seemingly straightforward, its application in the disability determination process is not. The process is based on “listings” of conditions that are presumed to be disabling and can be medically diagnosed using standard measurement instruments; for instance, having a hearing threshold sensitivity for air conduction of 90 decibels or greater as measured by an audiometer. The listings are just part of the process, which also considers past work experience, severity of medical conditions, age, education and work skills. A summary of the 5-step process used by SSA to determine eligibility for disability benefits is reproduced as an appendix to this report.

Because of its requirement for *medical* determination of conditions in the listings, the SSA definition cannot be replicated precisely in a household interview survey such as the NHIS-D. The NHIS-D does include a wealth of *respondent-reported* information about impairments and chronic conditions that might be used to roughly approximate the SSA listings; however,

medical record-check studies have shown that survey respondents' reports of many medical conditions are often invalid (Edwards et al., 1994). Respondents do better at reporting what they can and cannot do (functional status), which is a principal reason for using the functional criteria that predominate in Figure 1. Furthermore, because a major dependent variable in this study is employment status, defining the independent variable (disability) as "inability to engage in any substantial gainful activity" (the SSA definition) would confound independent and dependent variables.

[Figure 1 about here]

From the viewpoint of arguments presented earlier in this report, the most important findings from Table 1 include first, the conditional probabilities of contact (given eligibility) and cooperation (given contact) are uniformly high for all disability categories. For instance, comparing persons with any of the four types of disability (the "Any" line) to persons with none of those disabilities (the "None" line), the contact rates are 96.1 and 95.8, respectively, a difference that is not statistically significant. The rates of cooperation for those two disability categories are 96.9 and 95.0, also a difference that is not statistically significant. Similarly, differences in rates of contact and cooperation between other pairs of disability groups are statistically insignificant. The high rates of contact and cooperation, and the absence of variation in those rates by disability category, together suggest that contact and cooperation can contribute very little nonresponse bias to estimates of employment statistics.

The second important finding from Table 1 is that the conditional probability of self response (given cooperation) is lower for persons with one or more types of disability than it is for persons who have none of those types of disability. Probabilities of self response are lower for persons with each of the particular types of disability than for persons with none of those

disabilities, but only in the case of mental disabilities is that difference statistically significant. Close to 20% of persons with mental disabilities were represented by proxy respondents, compared to about 10% of persons with none of the four types of disability. This suggests that for sample persons with mental disabilities, and perhaps for those with other disabilities, there is a potential for nonresponse bias attributable to proxy responses.

Disability and employment rates. Table 2 presents data that comprise a direct test of the hypothesis that differences in contact, cooperation, and self response bias estimates of employment statistics derived from the NHIS-D, Phase 2. It has the same column headings and row label as Table 1, but the cell entries in Table 2 are estimates of employment rates for subpopulations defined by stage in the survey process (eligible, contacted, cooperated, or self responded) and disability category. The employment rate for a subpopulation is simply the number of people in that subpopulation reported to have jobs divided by the total number of person in that subpopulation, expressed as a percent (with its standard error in parentheses below it).

[Table 2 about here]

Overall, 75% of the working age population represented by the NHIS-D Phase 1 sample was employed, and 52% of those eligible for Phase 2 were employed (figures not shown in Table 2). Because Phase 2 eligibility required some evidence of a disability, it is not surprising that the employment rate was lower among eligible persons. Table 2 shows that among persons with any of the four types of disability considered, 44.3% were employed, and among those with none of those disabilities (but some other indication of disability) 58.3% were employed. Reading across those two lines of Table 2 (“Any” and “None”) it will be noted that the estimates of employment rates change only negligibly, and never significantly, at each survey stage. That is,

whether the estimate is based on samples of those eligible, those contacted, those cooperating, or those self responding, very nearly the same proportions are estimated to be employed. In other words, the “loss” of sample cases at each survey stage is not biased with respect to employment status.

Generally, the same can be said about persons in each of the four specific disability categories; that is, for each category, differences in estimated employment rates between survey stages are small and not statistically significant. There are two exceptions, however: persons in the categories “Mental” and “LD, MR, DD” have higher levels of employment for self response than for cooperation, although only the difference for the latter is statistically significant. This can be interpreted to mean that for persons in the “LD, MR, DD” category, and possibly for persons in the “Mental” category, including proxy respondents would bias estimates of employment rates downward; or, alternatively, excluding proxy respondents would bias estimates upward. The implication is that self respondents in those disability categories are more likely to report that they are employed than are the proxy respondents for sample persons in those disability categories.

Comparing self and proxy reports of employment. Table 3 directly compares reporting of employment by self and proxy respondents. The comparison can be made for two sets of data, the NHIS-D Phase 2 data and the 1994-95 NHIS “Core” data. The data on employment status already used in Tables 2 and 3 were collected as part of the NHIS-D Phase 2 survey. Those same data are used in columns 2 and 3 of Table 3 to compare reports of self and proxy respondents in Phase 2. Data on employment status were also collected in the NHIS “Core” surveys for 1994 and 1995, the surveys that provided the frame for the NHIS-D Phase 1 sample.

In the Core survey, self and proxy respondents were allowed, and the reports of employment by those types of respondents are compared in columns 4 and 5 of Table 3.

Although self and proxy respondents occurred in both the Phase 2 and Core surveys, it is important to note that the respondent rules in the two surveys were different. In Phase 2 interviewers were instructed to obtain self responses if at all possible; only in unusual circumstances were proxy respondents to be accepted. In the Core survey, on the other hand, adults at home at the time of interview were encouraged to respond for themselves and for any adults who happened to be absent. In a sense, the respondent rules made it more difficult to accept proxy respondents in Phase 2 than in the Core survey. The difference in respondent rules could be expected to produce different average characteristics in proxy respondents in the two surveys, and possibly differences in their reporting of employment status for sample persons.

Comparison of the employment rates for self and proxy respondents in Phase 2 (columns 2 and 3), confirms the inference from Table 2: for sample persons in the disability categories “Mental” and “LD, MR, DD” self respondents report significantly higher employment rates than proxy respondents. For the other three disability categories and for “Any of the above” the difference is reversed (proxy higher than self), but none of those comparisons is statistically significant. The finding for sample persons in the “Mental” category is partially confirmed by comparisons of self and proxy respondents in the Core survey (columns 4 and 5)--self respondents report higher employment rates than proxy respondents--but the difference falls short of statistical significance. For all other comparisons (except “None”), proxy respondents reported higher rates than self respondents, although the differences are statistically significant only for the categories “Mobility,” “Hearing,” and “Any of the above.”

The stability of self and proxy reports of employment. A summary of the evidence in Table 3 is that employment rates of sample persons with disabilities are often higher when reported by proxy respondents than when reported by self respondents, but the differences are small, usually not significant, and reversed for some types of disability. This is a confusing picture. In a further attempt to evaluate self and proxy reports of employment status, we might assess the relative accuracy of reports from the two sources. Unfortunately, there is little evidence on which to base such an assessment. There is no independent information about employment status that might be used to assess validity. There is some evidence, however, that might be interpreted as bearing on the reliability of reports of employment status; namely, reports of employment status at two points in time.

[Table 3 about here]

As noted above, questions about employment status were asked in both the Core survey and the NHIS-D Phase 2 survey. The questions were not identical but they yield comparable operational definitions of employment status and population estimates that do not differ greatly, as seen in Table 3. For each survey it is known whether the employment information was provided by the sample person (self response) or another person (proxy response). For some sample persons the information was given by self response in both surveys; for others it was given by a proxy in both surveys; and for yet others it was given by self response in one survey and proxy response in the other survey. The employment statuses reported in the two interviews can be the same or different. If it is assumed that actual changes in employment status are not related to the types of respondents in the two surveys, then differences in the change rates between survey-to-survey respondent types could indicate the relative reliability of respondents.

Table 4 shows data for such an analysis. It shows the percent of sample persons whose reported employment status did not change between Core and Phase 2 interviews, according to types of respondents in the two surveys. For instance, in the line for “Any of the above,” column (2) shows the percent of persons whose reported employment status did not change from Core to Phase 2 for cases in which there was self response in both surveys, 88.3%. For cases in which the employment responses were given by a proxy in both surveys, 84.7% of responses were unchanged, and for cases in which the responses changed from self to proxy or *vice versa*, 86.6% of responses were unchanged. For each type of respondent pair, the rates of unchanged employment status is high, consistent with the assumption that relatively few people change

**“. . . neither the type of respondent nor changes in the type of respondent are related to the reliability of reports of employment status.”**

employment status in a short interval. More importantly for this analysis, the differences between types of respondent pairs are small and statistically insignificant. These same statements apply to each of the disability categories considered in Table 4. This is not conclusive evidence, but it is consistent with the hypothesis that neither the type of respondent nor changes in the type of respondent are related to the reliability of reports of employment status. That is, proxy respondents and self respondents are equally likely to give reliable reports of employment status.

[Table 4 about here]

Proxy and self responses to subjective questions. In the analyses presented to this point, there is little evidence to suggest that proxy reporting introduces bias into survey-based estimates of employment characteristics; however, only one employment characteristic as been considered,

whether or not the sample person was employed. Employment is an objective and usually public characteristic, and that may account for the apparent lack of difference in its reporting by self and proxy respondents. It might be expected that differences in self and proxy reporting would be greater for characteristics that are more subjective and private. Evidence bearing on that speculation is presented in Table 5, which shows the percent of persons giving selected responses to four questions about matters that are by their nature subjective and often private. Only Phase 2 sample persons with one of the types of disability considered in this report are included in Table 5.

[Table 5 about here]

Questions 1 and 2 are from the Phase 1 survey, and they asked if the respondent considered the sample person to have a disability and if the respondent believed that “other” persons would consider the sample person to have a disability. Self respondents were less likely than proxy respondents to report that they are perceived to have a disability, either by themselves or by others; however, the differences are small and not statistically significant.

Questions 3 and 4 in Table 5 are from Phase 2. Question 3 was asked about sample persons who were not working and were reported to have a work-limiting disability. The respondent was asked “if enough accommodations were made in transportation and at the work place, would [the sample person] be able to work?” Responding to that question requires a complex thought process involving hypothetical situations and value judgments. Different persons evaluating the same objective circumstances might be expected to arrive at different conclusions. In fact, self respondents, evaluating their own job prospects, were more likely than proxy respondents to conclude that work would be possible if accommodations were made; however, the differences are not large and do not reach the level of statistical significance.

Question 4 in Table 5 was asked about Phase 2 sample persons who were workers, job seekers, or former workers who were not yet retired; that is, they were employed or employable persons who had been exposed to the risk of disability-related job discrimination, either by being denied a job they had sought or by being fired or laid off from a job they had held. They were asked if, in the five years preceding interview, they had, in fact, experienced such discrimination. Answering this question, like the question about work accommodations, requires subjective evaluations and personal knowledge, which might be expected to result in different responses by different persons assessing the same circumstances. Nevertheless, the difference in positive responses by self and proxy respondents is small (8.5 % and 10.8%, respectively), and not statistically significant.

Reasons for using proxy respondents. It is perhaps surprising that even when answering questions that seem to require knowledge of a disabled sample person's interior feelings and personal history, proxy respondents usually gave responses like those of self respondents. Some insight into that finding may be given by the data in Table 6, which shows the reasons given by interviewers for using proxy respondents in Phase 2. (As in other analyses presented in this report, only persons of working age are included.) Interviewers were given a preprinted list of reasons from which to choose, but they could choose more than one reason on the list, which included unspecified categories to accommodate unlisted reasons.

[Table 6 about here]

The most frequently cited disability-related reason for using a proxy was “memory problem” (actually listed in the questionnaire as “poor memory, senility, or confusion”), which was given as a reason for about one-third of the proxy interviews. The most frequently cited reason overall, however, was an unspecified “other non-health related reason,” given for nearly

half of the proxy interviews. As indicated in the last three lines of Table 6, in fewer than half of the proxy interviews did interviewers give only disability-related reasons. For most proxy cases interviewers gave reasons that were not disability-related, either alone or in combination with disability-related reasons.

As noted earlier, the design of the NHIS-D Phase 2 assumed that self-response was superior to proxy response for the purposes of this survey. Therefore, interviewers were instructed, “If at all possible, the sample person should respond for him/herself” (U.S. Bureau of the Census, 1994, p. 5-3). Proxies were allowed, however, because “it is expected . . . that some sample persons will be unable to respond because of a mental or physical limitation...” (U.S. Bureau of the Census, 1994, p. 5-3). That is, proxies were allowed if the sample person had limitations in those activities integral to the interview situation. Selecting proxy cases by that criterion would tend to maximize specifically those differences between the sample person and the proxy most likely to produce differences in their response to survey questions. As seen in Table 6, however, in practice the proxy option was used more liberally by interviewers, diluting the potential effect of its selective tendency, and thereby reducing the observed differences between proxy and self respondents. This interpretation is admittedly speculative, and should be regarded as a hypothesis for further study. The hypothesis is, however, supported by a comparison of estimates of employment rates reported by proxies used for disability reasons and those used for other reasons: 19.6% and 62.4%, respectively, a large and statistically significant difference.

Relationships between proxy and sample persons. Further to understanding who the Phase 2 proxy respondents were, and therefore the differences in responses between them and the sample persons for whom they responded, Table 7 presents data on the kinship and

residential relationships of proxies and sample persons with disabilities. Proxies were, by and large, close family members who lived in the same household as the sample respondents for whom they responded. Close kin sharing the household of the sample person are not necessarily accurate reporters of the sample person's characteristics, but they are certainly in a better position than many others persons to be accurate reporters.

[Table 7 about here]

### **Summary and Conclusions**

This study used data from the National Health Interview Survey on Disability (NHIS-D) to examine potential biases in reporting of employment statistics for persons with disabilities resulting from survey nonresponse and proxy response. The principal findings can be summarized as follows:

1. Rates of survey contact and cooperation are very high among sample persons with disabilities, both for disabilities in general and for particular types of disability. This essentially precludes that nonresponse bias could arise from these sources.
2. Rates of proxy response (as opposed to self response) are moderately high for sample persons with disabilities, especially among persons with mental disabilities. This could allow for proxy response bias if proxy and self respondents respond differently.
3. Comparisons of rates of employment for different stages of the survey process-- contact, cooperation, and self response—show no evidence of nonresponse bias at contact and cooperation stages, and little or weak evidence of proxy response bias.

4. Comparisons of reports by proxy and self respondents of the employment status of sample persons with disabilities shows some evidence that proxies report higher rates, but the evidence is weak and the differences inconsistent across disability types.
5. Comparisons of proxy and self responses of employment status for the same person at different points in time shows no evidence that either type of respondent is more accurate (reliable, stable) than the other.
6. Comparisons of responses by proxy and self respondents to questions about subjective and private matters show little or weak evidence that the answers of the two types of respondents differ significantly.
7. Interviewers' reasons for using proxy respondents for sample persons with disabilities often have little or nothing to do with the disabilities of the respondents.

**“. . . nonresponse (contact and cooperation) does not seriously bias survey estimates of employment characteristics of persons with disabilities. . .”**

8. Most proxy respondents are close kin of the sample persons with disabilities for whom they report, and they live in the same households.

Based on these findings, the most important conclusions are that nonresponse (non-contact and non-cooperation) does not seriously bias survey estimates of employment characteristics of persons with disabilities, and that proxy reporting probably does not bias estimates--at least insofar as these data indicate. That conclusion should be tempered by awareness that in the data used for this analysis, there may be serious confounding of the causes and consequences of self and proxy reporting. Other studies are needed, especially experimental studies in which self and proxy treatments are randomly assigned to sample persons with

disability (see Kovar and Wright, 1973, and Mathiowetz and Groves, 1985, for examples of such designs). Also, it should be noted that there were statistically marginal indications of proxy bias in reporting of employment for persons with psychological and cognitive disabilities.

From the viewpoint of survey design and operations, it may be concluded that no substantial changes are indicated by the findings of this study. At least with respect to nonresponse and proxy bias, the existing design parameters and field operations as represented by the NHIS and NHIS-D are adequate. There may be other reasons, however, to consider changes in survey design and operations. For instance, even though it may not result in significant changes in population estimates of employment characteristics, public opinion and civil rights law may make it desirable, and perhaps necessary, to afford respondents with disabilities equal access to participation in the surveys that measure their participation in employment. Changes in survey design and field operations could make it possible for more sample persons with disabilities to respond for themselves rather than being represented by proxy respondents and many of those changes could be made with little or no cost.

This study has used data from the National Health Interview Survey, and its conclusions are most relevant to that survey. However, other ongoing national surveys are frequently used to analyze the employment characteristics of persons with disabilities, especially the Current Population Survey (CPS) and the Survey of Income and Program Participation (SIPP). While the CPS and SIPP have some differences from the NHIS in design and content, they are also like the NHIS in important respects: they are nationally representative household interview surveys conducted by the Bureau of the Census. (See Burkhauser, Houtenville, and Wittenburg, 2001, for an analysis of the survey designs and employment estimates of the NHIS, CPS, and SIPP.) It

seems likely, therefore, that CPS and SIPP are subject to the same risks of nonresponse and proxy biases as the NHIS, and that the conclusions of this study also apply to those surveys.

The results of this study may also be useful to a new and ambitious undertaking of the Social Security Administration: the National Study of Health and Activity (NSHA). NSHA will screen a nationally representative sample of nearly 100,000 persons by telephone, conduct household interviews with about 10,000 persons with disabilities, and conduct medical examinations and functional tests on about 5,000. The study is designed to obtain the kind of information used to determine eligibility for disability benefits, something surveys such as NHIS, CPS, and SIPP do not (and cannot) do. The designers of NSHA are aware of the potential for nonresponse and proxy response biases in the household interviewing stages of the project, and are taking steps to facilitate participation of respondents with disabilities. By identifying some types of disability for which proxy biases may be a significant consideration, this study contributes to the planning and successful execution of NSHA.

## Appendix

The following is a brief description of the Social Security Administration's 5-step procedure for determining eligibility for disability benefits. It is copied from the SSA Web site at <http://www.ssa.gov/disability/>. It should also be noted that persons who are not approved for benefits following this five-step procedure have a right to appeal the decision, and may be approved on appeal.

### How We Decide If You Are Disabled

To decide whether you are disabled, we use a step-by-step process involving five questions. They are:

Are you working? If you are working in 2002 and your earnings average more than \$780 a month, you generally cannot be considered disabled. If you are working in 2003 and your earnings average more than \$800 a month, you generally cannot be considered disabled. If you are not working, we go to Step 2.

Is your condition "severe"? Your condition must interfere with basic work-related activities for your claim to be considered. If it does not, we will find that you are not disabled. If your condition does interfere with basic work-related activities, we go to Step 3.

Is your condition found in the list of disabling conditions? For each of the major body systems, we maintain a list of medical conditions that are so severe they automatically mean that you are disabled. If your condition is not on the list, we have to decide if it is of equal severity to a medical condition that is on the list. If it is, we will find that you are disabled. If it is not, we then go to Step 4.

Can you do the work you did previously? If your condition is severe but not at the same or equal level of severity as a medical condition on the list, then we must determine if it interferes with your ability to do the work you did previously. If it does not, your claim will be denied. If it does, we proceed to Step 5.

Can you do any other type of work? If you cannot do the work you did in the past, we see if you are able to adjust to other work. We consider your medical conditions and your age, education, past work experience and any transferable skills you may have. If you cannot adjust to other work, your claim will be approved. If you can adjust to other work, your claim will be denied.

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Table 1. Conditional probabilities (percent) of survey eligibility, contact, cooperation, and self-response (and standard error) by type of disability: United States, 1994-1997 (See "Data Analysis and Findings" for explanation and interpretation of this table.)

Type of disability (1)	Conditional probability of:			
	Eligibility (2)	Contact (3)	Cooperation (4)	Self-response (5)
	Percent (Standard error)			
Mobility	84.2 (1.5)	97.6 (0.3)	97.4 (0.4)	87.4 (1.2)
Mental	87.0 (1.3)	94.3 (0.7)	96.1 (0.6)	80.6 (2.6)
Seeing	76.2 (2.0)	96.3 (0.5)	97.3 (0.4)	83.7 (2.9)
Hearing	58.3 (2.4)	97.1 (0.4)	96.4 (0.5)	85.9 (1.4)
LD, MR, DD	86.3 (2.0)	95.6 (0.6)	97.2 (0.5)	85.9 (1.4)
Any of the above	74.8 (1.1)	96.1 (0.3)	96.9 (0.3)	82.6 (1.1)
Other disability	9.0 (0.3)	95.8 (0.3)	95.0 (0.8)	89.0 (0.8)

(1) Categories are not mutually exclusive

Table 2. Percent employed (and standard error) by survey eligibility, contact, cooperation, and self-response by type of disability: United States, 1994-1997  
 (See "Data Analysis and Findings" for explanation and interpretation of this table.)

Type of disability (1)	Percent employed			
	Eligibility	Contact	Cooperation	Self-response
	Percent (Standard error)			
Mobility	20.6 (1.7)	20.7 (1.7)	20.2 (1.7)	20.3 (2.1)
Mental	36.3 (4.0)	36.7 (4.3)	36.8 (4.4)	41.7 (5.2)
Seeing	45.6 (3.5)	45.5 (3.7)	45.7 (3.7)	45.7 (4.1)
Hearing	53.1 (4.1)	53.1 (4.3)	53.0 (4.4)	51.0 (5.1)
LD, MR, DD	45.6 (2.0)	45.4 (2.1)	45.4 (2.1)	51.4 (1.7)
Any of the above	44.3 (1.8)	44.3 (1.8)	44.2 (1.9)	44.6 (2.4)
Other disability	58.3 (1.5)	58.5 (1.5)	58.5 (1.6)	59.2 (1.7)

(1) Categories are not mutually exclusive

Table 3. Percent employed (and standard error) by type of disability, type of respondent, and phase of survey: United States, 1994-1997 (See "Data Analysis and Findings" for explanation and interpretation of this table.)

Type of disability (1)	Disability Phase 2 Survey		Core Survey	
	Type of respondent		Type of respondent	
(1)	Self-respondent (all or part) (2)	Proxy respondent (3)	Self-respondent (all or part) (4)	Proxy respondent (5)
	Percent employed (Standard error)			
Mobility	16.6 (2.3)	24.2 (4.7)	18.4 (2.6)	33.0 (3.3)
Mental	41.0 (8.3)	14.1 (4.7)	40.1 (8.2)	26.2 (5.8)
Seeing	49.8 (4.3)	63.5 (14.7)	46.9 (6.2)	58.7 (3.6)
Hearing	44.9 (7.3)	65.5 (4.6)	41.2 (7.3)	77.9 (2.8)
LD, MR, DD	50.4 (2.1)	32.2 (6.8)	40.1 (4.2)	48.1 (3.1)
Any of the above	42.8 (3.6)	46.1 (6.7)	40.2 (3.7)	55.3 (3.2)
Other disability	58.4 (2.4)	62.1 (5.8)	55.7 (2.6)	69.2 (2.4)

(1) Categories are not mutually exclusive

Table 4. Percent with no change in reported employment status between Core and Phase 2 surveys (and standard error) by type of disability and respondent type in each survey: United States, 1994-1997  
 (See "Data Analysis and Findings" for explanation and interpretation of this table.)

Type of disability (1)	Type of respondent in each survey		
	Self respondent in both surveys	Proxy in both surveys	Changed from self to proxy or proxy to self
	Percent with no change in reported employment status (Standard error)		
Mobility	90.5 (1.7)	92.2 (4.7)	87.4 (2.4)
Mental	86.6 (2.6)	90.1 (3.4)	87.1 (3.8)
Seeing	89.3 (1.5)	84.8 (6.0)	90.7 (2.9)
Hearing	88.1 (2.6)	89.7 (4.0)	86.2 (2.6)
LD, MR, DD	84.1 (2.0)	82.4 (3.6)	85.9 (3.4)
Any of the above	88.3 (1.2)	84.7 (2.4)	86.6 (1.7)
Other disability	81.2 (2.5)	87.7 (3.7)	84.5 (1.3)

(1) Categories are not mutually exclusive

Table 5. Percent giving selected responses to selected subjective questions (and standard error) by type of respondent: persons with a disability  
 (See "Data Analysis and Findings" for explanation and interpretation of this table.)

Responses to selected subjective questions (1)	Type of respondent	
	Self-respondent (all or part) (2)	Proxy respondent (3)
	Percent (Standard error)	
1. Respondent considers the sample person to have a disability (Phase 1)	45.1 (3.1)	50.3 (3.8)
2. Respondent believes that other people would consider the sample person to have a disability (Phase 1)	42.1 (3.1)	47.3 (3.8)
3. Respondent believes that the sample person could work if enough accommodations were made (Phase 2)	20.4 (2.1)	13.4 (3.4)
4. Respondent believes that the sample person has been denied a job because of disability or health problems (Phase 2)	8.5 (1.3)	10.8 (2.6)

Table 6. Percent of proxy responses for which interviewers gave selected reasons for using a proxy respondent (and standard error) (See "DataAnalysis and Findings" for explanation and interpretation of this table.)

Reasons given by interviewer for using a proxy or assistant respondent	Percent of interviews for which reason was given	<i>(Standard error)</i>
Disability reasons		
Hearing problem	18.4	(1.3)
Speech problem	9.9	(0.9)
Memory problem	31.9	(2.5)
Alzheimer's disease	5.1	(0.5)
Mental illness	22.2	(2.5)
Other illness or disability	27.8	(2.2)
Non-disability reasons		
Hospitalization	2.5	(0.4)
Institutionalization	8.7	(2.4)
Language problem	12.2	(1.1)
Other non-disability reason	46.5	(2.8)
General type of reason		
Disability only	44.4	(2.5)
Both disability and other	39.3	(2.0)
Other only	16.3	(2.4)

Table 7. Percent distributions of proxy respondents (and standard error) by kinship and residential relationships to sample person (See "Data Analysis and Findings" for explanation and interpretation of this table.)

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Kinship and residential relationship of proxy and sample person	Percent distribution	<i>(Standard error)</i>
Kinship of proxy and sample person		
All kinships	100.0	<i>n/a</i>
Nuclear family	83.0	<i>(1.1)</i>
Other family	11.1	<i>(0.9)</i>
Non-family	6.0	<i>(0.8)</i>
Residence of proxy and sample person		
All residences	100.0	<i>n/a</i>
Same residence	77.3	<i>(1.4)</i>
Different residence	22.7	<i>(1.4)</i>

Appendix table. Eligible sample persons, completed interviews, and response rates by year and phase: National Health Interview Survey on Disability

Year and Phase	Eligible persons	Completed interviews	Response rate
1994			
Phase 1	116,179	107,469	92.50%
Phase 2	22,081	20,410	92.40%
1995			
Phase 1	102,467	95,091	92.80%
Phase 2	13,927	12,378	88.90%
Both years			
Phase 1	218,646	202,560	92.60%
Phase 2	36,008	32,788	91.10%

Figure 1. Summary definitions of types of disability

1. **Mobility** (includes body movement). Is unable to do one or more of the following activities:
  - a. lifting something as heavy as a bag of groceries,
  - b. walking up 10 steps without resting,
  - c. walking a quarter of a mile,
  - d. standing for about 20 minutes,
  - e. bending down to pick up something from the floor,
  - f. reaching over the head or out as to shake someone's hand,
  - g. grasping something with the fingers, such as picking up a glass,
  - h. holding a pen or a pencil.
  
2. **Mental** (includes interpersonal relations). During the last 12 months, there was serious interference with work, school, or day-to-day activities due to one or more of the following:
  - a. having a lot of trouble
    - (1) making or keeping friends,
    - (2) getting along with people in social situations,
    - (3) concentrating enough to complete everyday tasks;
  - b. having serious difficulty coping with day-to-day stress;
  - c. being frequently confused, disoriented, or forgetful;
  - d. having unreasonable fears.
  
3. **Seeing**. Has serious difficulty seeing, even when wearing glasses.
  
4. **Hearing**. Has trouble hearing what is said in normal conversation (even with a hearing aid, if one is used).
  
5. **Learning disability, mental retardation, or developmental delay**. Has one or more of the following:
  - a. A learning disability or serious difficulty learning things that others can learn;
  - b. A one or more of the following medical conditions:
    - (1) cerebral palsy,
    - (2) cystic fibrosis,
    - (3) Down syndrome,
    - (4) Mental retardation,
    - (5) Muscular dystrophy,
    - (6) Spina bifida,
    - (7) Autism,
    - (8) Hydrocephalus.
  
6. **Any of the above**. Has one or more of the disabilities defined in 1 through 5 above.
  
7. **Other disability (none of the above)**. Has none of the disabilities defined in 1 through 5 above.