



Catalogue no. 11-522-XIE

**Statistics Canada International Symposium
Series - Proceedings**

**Symposium 2004: Innovative
Methods for Surveying
Difficult-to-reach Populations**

2004



INNOVATIVE APPROACHES TO INTERVIEWING PEOPLE WITH DISABILITIES

Gerry E. Hendershot¹

ABSTRACT

The past generation has seen a paradigm shift in disability. Once seen as a medical problem to be treated by health care providers, disability is now seen as a societal problem to be addressed by many professions. The paradigm shift has implications for all aspects of life, including surveys, but the survey community has been slow to respond to the new paradigm. The survey paradigm still limits participation of persons with disabilities in the survey process. Evidence of barriers to survey participation is reviewed and approaches to reducing barriers are discussed.

KEYWORDS: Disability; Interview Surveys; Response Rates

1. INTRODUCTION

1.1 The Problem

The past generation has seen a paradigm shift in disability. Once seen as a medical problem to be treated by health care providers, disability is now seen as a societal problem to be addressed by many professions (Altman, 2001). The paradigm shift has implications for all aspects of life, including surveys, but the survey community has been slow to respond to the new paradigm (Hendershot, 2003). The *survey* paradigm still limits participation of persons with disabilities in the survey process, including sample design, questionnaire design, data collection modes, field procedures, and data dissemination.

To reduce barriers to participation in surveys by persons with disabilities, the survey community should undertake two tasks: first, research on methods for surveying people with disabilities; and second, identification of “best practices” for facilitating the participation of persons with disabilities. In furtherance of those tasks, the U.S. government’s Interagency Committee on Disability Research sponsored a conference on “Best Practices for Surveying People with Disabilities” in Washington, D.C. on April 19-20, 2004.

Drawing on the work presented in that conference and my own work on this topic, I will present an overview of the barriers to survey participation by respondents with disabilities, and suggest some survey “best practices” that might reduce those barriers.

1.2 Population Surveys

I should begin by setting some limits for this discussion. I limit myself to “population surveys;” that is, surveys using representative samples, standardized data collection procedures, and personal interviews to gather data that can be used to make accurate estimates of statistics for a population of interest. Some typical approaches to sampling used in population surveys are area probability sampling and random digit dialing. Standard data collection procedures include rules for sample eligibility, rules for who may participate in the interview, and standardized questions, responses, and probes. Interviews may be done face-to-face or by telephone, and are designed to mimic conversation. Data collected using these methods can be used to estimate population statistics and their sampling errors.

¹ Gerry E. Hendershot, Consultant on Disability and Health Statistics

Population surveys of the kind I am discussing are done by government agencies, private companies, and academic research centers. In the United States, government surveys are illustrated by the Behavioral Risk Factors Surveillance System and the National Health Interview Survey. There are many private companies that conduct population surveys; two that have been especially active in the field of disability, for instance, are Harris Interactive and Forrester Research, Incorporated. Many U.S. universities and foundations operate population survey programs; the Survey Research Laboratory of the University of Illinois is one that has done some work on the accessibility of surveys. I am sure there are counterparts of all of these types of population survey in Canada as well.

2. BARRIERS TO SURVEY PARTICIPATION

2.1 The Argument

Having defined the scope of population surveys for present purposes, I turn now to an overview of the argument for identifying and reducing barriers to participation in population surveys by people with disabilities. First, many people in any general population have disabilities; the number varies depending on the definition of participation, but most estimates for developed nations are in the range of 10% to 20% (Fujiura and Rutkowski-Kmitta, 2001). I will argue that barriers tend to reduce the survey participation of persons with disabilities. Such barriers run counter to public policies in countries such as the U.S. and Canada that support full participation in life activities. Lower participation may also bias survey estimates, which runs counter to generally accepted standards for population survey performance. For these several reasons, survey organizations should attempt to reduce barriers to participation.

To be more explicit, I offer the following working definition: "A barrier to survey participation is any standard survey practice that prevents or limits full participation by persons with disabilities." Standard survey practices include (but are not limited to) sample designs, rules for who eligible to be included in the sample, rules for who may respond for the sample person, the mode of interview used (such as telephone or face-to-face), and the definition and computation of outcome rates for surveys, rates of response, refusal, cooperation, and so on. In the remainder of this paper I will illustrate barriers in each of these categories.

2.2 Sample Design Barriers

I begin with barriers to participation resulting from standard practices in designing samples. One of the most pervasive and pernicious barriers to survey participation by persons with disabilities is the use of sample designs that do not include the institutionalized population. For reasons of cost and convenience, many large and policy-relevant U.S. government sponsored surveys, such as the Current Population Survey, the main source of employment statistics, sample households only. But a large minority of the population with disabilities does not live in households: the 2000 Census of Population in the U.S. shows that there were about 1.5 million persons who need help with activities of daily living who resided in institutions, about 30% of the total number of persons with limitations in activities of daily living. Furthermore, there is reason to believe that persons who live in nursing homes, the largest part of the institutional population, not only are more likely to have disabilities, they are also more likely to have significant disabilities, exacerbating the problem of bias when they are excluded from surveys.

Another example barriers arising from standard sampling practices applies to telephone surveys. Samples for telephone surveys are selected by dialing telephone numbers at random, but retaining only those that are voice lines connected to households--businesses and data lines are screened out. However, many people who are deaf do not use voice lines, but telephone devices for the deaf, or TDD's. For instance, a 1994-1995 National Health Interview Survey on Disability found that about 60% of persons with serious hearing limitations used a TDD (computed by the author). These people are systematically screened out of most telephone surveys. Having become aware of this potential bias, the firm conducting a large U.S. telephone survey on immunization of children tried experimentally to train its interviewers to identify a TDD connection; they found, however, that interviewers could not reliably distinguish between a TDD connection and a Fax connection (Olson, 1999).

2.3 Eligibility Barriers

Having considered how sample designs may create barriers to survey participation for people with disabilities, I will now consider some examples of barriers created by eligibility rules, rules about who may or may not be included in the sample. I will use data from the US National Health Interview Surveys of 1985, 1990, 1995, and 1998. The National Health Interview Survey (NHIS) is a large, continuous, sample survey of the household population of the United States. The survey is designed and sponsored by the National Center for Health Statistics, and face-to-face interviews are conducted in sample households by field representatives of the Bureau of the Census.

In 1985, 1990, 1995, and 1998 the NHIS included nearly identical questions on the recent frequency and intensity of participation in 20 specific sports exercises (Caspersen, 1986), but there was a change in the eligibility rule in the last of the surveys. These are the explanations in the NHIS Interviewer's Manual about eligibility for the questions on exercise in the years before 1998 and in 1998:

Pre-1998: "Interpret this term in each individual situation. What may be a physical handicap to one person may not be to another. *Obviously*, "confined to a wheelchair" or "bedridden" are physical handicaps. Also include conditions that may make it *impossible to participate* in one or more of the activities listed [in a list of 20-plus activities]."

1998: "Use your best judgment on whether or not the respondent has a disabling condition that would make him or her *uncomfortable answering* a series of questions about sports activities."

Thus, the key criterion for eligibility changed from being unable to participate in any of the sports exercises to discomfort answering questions about sports exercises. If an interviewer decided the respondent should not be asked the detailed questions, a box was checked indicated the respondent was "physically handicapped," and an open-ended question about any recent sports exercises by the respondent.

How did this change in the eligibility rule affect response? I calculated the percent of sample adults judged by the interviewer to be "physically handicapped" and therefore ineligible for the complete module of questions on sports activities in 1985, 1990, 1995, and 1998. In the first three data years the eligibility rule excluded persons whose disability made it "impossible to participate" in sports activities, and in 1998 the rule excluded those who would be "uncomfortable answering" questions about those sports activities. As shown in Table 1, in 1985, 1990, and 1995, some 2% to 4% of adults were declared not eligible because of disability, but in 1998 the ineligibility rate jumped to more than 10%. Clearly, the change in the eligibility rule resulted in excluding many more people with disabilities from participating in this part of the survey.

1985	1990	1995	1998
1.7	2.5	3.7	10.3

The eligibility rules excluding persons with disabilities from the sports exercise module were intended by the survey designers to avoid asking unnecessary, burdensome, or offensive questions to people who obviously are very unlikely to engage in sports exercise. However, I found that about one-fourth of adults judged to be "physically handicapped" did report having engaged in one or more exercise activities. (Remember that although they were not asked the detailed questions about every exercise, they were asked a general question about any exercise.) Furthermore, some of them reported participating in some sports activities generally regarded to be quite vigorous, such as biking and weight lifting. Some important public health information was lost because of eligibility rules that were inappropriately concerned about respondent burden and sensitivity.

2.4 Respondent Rule Barriers

Having briefly considered barriers associated with sample design and eligibility rules, I turn now to barriers associated with respondent rules. Respondent rules determine who may respond to questions about the sample person. The NHIS questionnaire introduced in 1997 (and still in use) has three "core" modules: a family module that obtains information on all members of sample families; a child module that obtains additional information on

one randomly selected child in the sample family; and an adult module that obtains additional information on one randomly selected adult in the sample family (Lethbridge-Cejku et al., 2004). From 1997 through 1999, the respondent rule for the adult module required self-response—only the adult sample person was allowed to answer the questions. Beginning in 2000, the rule was relaxed, and allowed another adult member of the family to act as proxy respondent for the sample person. I investigated the effect of the change in the respondent rule on response rates for persons with disabilities, with special attention to those with mental retardation.

I computed response rates for adults with no disability and adults with mental retardation for NHIS data years 1997 through 2002 (Table 2). For the years 1997, 1998, and 1999, when self response was required, the response rates for adults with no disability were about 80% and the response rates for adults with mental retardation were about 60%. (The disability information used here was obtained in the family core questionnaire that preceded the adult questionnaire and did not require self-response.) Beginning in 2000, when the response rule was changed to allow proxy respondents, and continuing through 2002, the response rates for adults with mental retardation increased significantly. By 2002 they actually exceeded the response rates for adults with no disability.

Activity limitation	1997	1998	1999	2000	2001	2002
No limitation	88.8	83.5	80.7	82.3	83.6	83.9
Mental retardation	63.0	61.8	57.1	65.0	74.7	90.4

The reason that response rates improved so dramatically for adults with mental retardation is, of course, that interviewers were allowed to use proxy respondents for sample persons whom they regarded as unable to respond for themselves. Table 3 shows the percent of sample adults for whom a proxy responded, according to activity limitation: no limitation, any limitation, and limitation in vision or hearing, and mental retardation. While proxy respondents were more common for people with any limitation, vision limitation, and hearing limitation than for those with no limitation, the proxy rate is very large—nearly 60%—for adults with mental retardation. Now the change in respondent rule was made, at least in part, to increase the overall response rate for the adult module, which it did. Even when the proxy rate is very high, as it is for adults with mental retardation, it can be argued that proxy information is better than no information.

No limitation	Any limitation	Vision	Hearing	Mental retardation
1.0	6.5	10.5	13.8	59.3

It can be argued, also, that proxy respondents can give accurate responses to questions about objectively observable circumstances and events in the life of the sample person. However, a proxy may not be able to answer questions accurately that are subjective or sensitive. To measure this effect, I looked at item nonresponse rates for three subjective and three sensitive questions in the 2002 NHIS. An example of a subjective question is “In general, how satisfied are you with your life?” An example of a sensitive question is “What are your chances of GETTING HIV?” Among respondents with no limitations, the percents who did not respond to one or more of the subjective or sensitive questions were 2.1 and 6.0, respectively. The corresponding item non-response rates for persons with mental retardation were 25.5% and 21.6%, respectively. The item nonresponse rates were much higher for sample adults with mental retardation, presumably because the respondent was usually a proxy who did not know the answers.

2.5 Mode of Interview Barriers

We now consider examples of barriers to survey participation associated with mode of interview. In face-to-face interviews, the primary mode of communication is voice, but voice is often supplemented by using printed lists of answers, a visual mode of communication. In telephone interviews, it is not possible to hand the respondent a printed list, so the mode is limited to voice. Voice and visual communication may be limited by many different kinds of disability, but I will focus on respondents who are deaf or hard-of-hearing, for whom the voice mode is a barrier; and respondents who are blind or have low vision, for whom the print mode is a barrier.

Are the numbers of persons with vision and hearing problems great enough to be of concern for survey designers? The number of sample adults in the NHIS for the years 2000-2002 who were blind or deaf is small--about 150 blind people and 100 deaf people a year. However, these are enough cases to make some useful estimates for those populations with a single year of data, and by aggregating data across years many more statistics can be estimated. The number of NHIS sample persons who have low vision is over 3,000 per year, and the numbers who are hard of hearing is about 1,000 per year. In a total sample of about 30,000 adults, these are relatively large numbers.

There are standard “work arounds” for deaf or blind respondents. For deaf respondents who use sign language, a family member who both hears and signs may interpret for the interviewer; or a professional sign language interpreter may be recruited. There are some problems with these procedures, however: unlicensed interpreters may lack the skills needed to translate accurately, and licensed interpreters can be very expensive—in the Washington DC area interpreters cost \$60-\$80 per hour, and there is often a two-hour minimum. Whether or not an interpreter is fully qualified, the presence of a third party in the interview may cause problems for the confidentiality and privacy protocols of a survey.

The standard work around for people who are blind or cannot see well enough to read printed lists is to read the responses aloud. This may work well when the lists are short, but is cumbersome when lists are long. In the NHIS, for instance, when a sample person is reported to have a limitation in activity such as work, school, or personal care activities, the respondent is asked the cause of the limitation and handed a card with a list of 13 possible causes. This is a long list for the interviewer to read aloud, and a long list for the blind respondent to listen to and remember.

Reading is not much help, either, when the visual aid is not a list of words but a picture. Figure 1 (Card F4), for instance, is handed to respondents when they have reported pain, aching, swelling, or stiffness in a joint. It shows front and rear line drawings of the human body with each joint identified by name. The respondent is asked to read the name or point to the affected joint, a task a blind or low vision respondent could not accomplish.

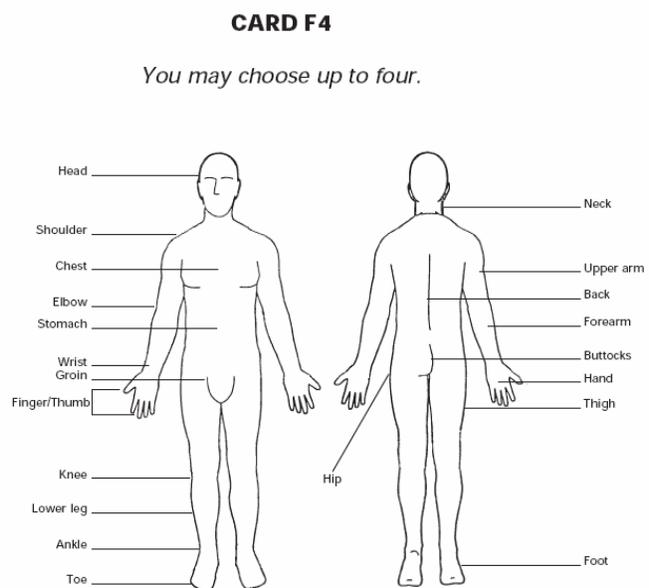


Figure 1

The challenge is to design interview techniques that accommodate respondents whose limitations in hearing and seeing make it difficult or impossible to answer questions asked in the standard modes of voice and vision. I have focused on blindness and deafness, but some cognitive and speech impairments present similar challenges to the standard modes of survey interviewing.

2.6 Outcome Rates Barriers

In this illustrative overview of barriers to participation, I turn finally to outcome rates for surveys. There several professional and industry associations that set standards or recommend best practices for population surveys. Among these is the American Association for Public Opinion Research, or AAPOR. AAPOR’s members include survey professionals from survey organizations of all kinds—academic, nonprofit, and for-profit. AAPOR recognized that response rates, or more generally “outcome rates,” are important criteria for evaluating a survey; however, survey organizations were calculating and reporting outcome rates in so many different ways, that they were of little use in comparing the performances of different surveys. To correct this problem, AAPOR undertook a study of outcome rates and published a document titled “Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys” (2000).

To compute outcome rates for a survey, it is first necessary to classify the outcome of each case selected for the sample. AAPOR's "Standard Definitions" lists and defines comprehensive codes for both interview and telephone surveys, the main categories of which are "Refusal," "Interview," "Non-contact," and "Other". (I am simplifying here.) Once the final disposition of each sample case has been coded, the numbers in different code categories can be used to compute a variety of "outcome rates." For instance, a refusal rate can be computed as the number of refusals divided by the sum of refusals, interviews, non-contacts, and other cases. A response rate can be computed as the number of interviews divided by the sum of refusals, interviews, non-contacts, and other cases. As a cooperation rate, AAPOR recommends the number of completed interviews divided by the sum of refusals, interviews, and non-contacts. Note that "other" cases are omitted from the denominator of the cooperation rate.

AAPOR's "Standard Definitions" defines the "other" sample cases as follows: "Other cases represent instances in which there is a respondent who did not refuse the interview, but no interview is obtainable. They include: a) death; b) *the respondent's physical and/or mental inability to do an interview*; c) language problems; and d) miscellaneous other reasons" (p. 15). Physical and mental inability to do an interview is not further defined or explained, nor is any guidance offered on who should make that decision, how it should be made, or what record should be made of it.

In explaining the cooperation rate—completed interviews divided by refusals, interviews, and non-contacts—AAPOR says "Those unable to do an interview [are] also *incapable of cooperating* and they are excluded from the base" (p. 38). It is noteworthy that inability to be interviewed is equated with inability to cooperate, especially since inability to be interviewed is not equated with inability to refuse. Thus, respondents with disabilities whom survey staff decides are unable to be interviewed can refuse to be interviewed, but cannot "cooperate" by indicating a willingness to participate in an interview if somehow accommodated. Failure by the survey staff to interview a respondent with a disability does not reduce the cooperation rate of the survey, which reduces the incentive to accommodate those respondents.

AAPOR's "Standard Rules" says that "In reporting response rates and all other outcome rates calculated according to the rules and formulas indicated above, researchers must precisely define which rates are being used. For example, a statement that "the response rate is X" is unacceptable. . . . In addition, *a table showing the final disposition codes for all cases should be prepared for the report and made available upon request*" (p. 40). As I said earlier, the disposition codes identify in considerable detail what happened to each case selected for the sample.

The outcome codes for "other" cases, those that resulted in neither refusal, interview, or non-contact, are "Other, unspecified," "Dead," "Language," and "Physically or mentally unable/incompetent." I would suggest that the code for "Physically or mentally unable/incompetent" be further specified by adding two subcategories: "*No accommodation attempted*," and "*Accommodation attempted, but unsuccessful*." The addition of those codes would give us, for the first time, information about attempts by survey organizations to accommodate respondents with disabilities, and provide an incentive for doing so.

3. CONCLUSION

In this paper I have described and illustrated some standard procedures in interview surveys that are barriers to participation by respondents with disabilities, including standard procedures in the areas of sample design, eligibility rules, respondent rules, mode of interview, and outcome rates for surveys. Most survey organizations have given little attention to these barriers, and fewer still have attempted to reduce or eliminate them. There are, however, some hopeful developments in this area.

In April of this year, the US Interagency Committee on Disability Research, which has a mandate to coordinate disability research in the US federal government, sponsored a two-day invitational conference on "Best Practices for Surveying People with Disabilities." It brought together representatives of survey organizations, public and private, government agencies, and universities to share what they had learned about barriers to survey participation by respondents with disabilities. Most had gained their knowledge of participation barriers by doing surveys that focused on disability issues, but the accommodations they have developed are applicable to population surveys on other topics. A report on the conference proceedings will soon be released and a book based on papers presented at

the conference is planned for publication next year. It will include recommendations, developed at the conference, on the needs for further research and development to reduce or eliminate barriers. That research and development will provide the scientific basis for changes to standards of survey practice that will give people with disabilities the same opportunities to participate as others.

REFERENCES

- Altman, B. M. (2001), "Disability Definitions, Models, Classification Schemes, and Applications", in G. L. Albrecht et al. (eds.), *Handbook of Disability Studies*, Thousand Oaks CA, Sage Publications, pp. 97-122.
- American Association for Public Opinion Research. (2000), *Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys*. Ann Arbor, Michigan: AAPOR.
- Caspersen C. J., Christenson G. M. and Pollard R. A. (1986), "Status of the 1990 physical fitness and exercise objectives--evidence from NHIS 1985", *Public Health Reports*, 101(6), pp. 587-592.
- Hendershot, G. (2003), "Nothing about Us without Us: Removing Barriers to Survey Participation by Persons with Disabilities", *Survey Research*, 34(2), pp. 1-3.
- Fujiura, G. T. and Rutkowski-Kmitta V. (2001), "Counting Disability", in G. L. Albrecht et al. (eds.), *Handbook of Disability Studies*, Thousand Oaks CA, Sage Publications, pp. 69-96.
- Lethbridge-Çejku M., Schiller J. S, and Bernadel L. (2004), *Summary health statistics for U.S. Adults: National Health Interview Survey, 2002*. National Center for Health Statistics. Vital Health Stat 10(222). Washington D.C.: Government Printing Office.
- Olson L. (1999), "The National Immunization Survey: Development of Strategies To Include Deaf Respondents in An RDD Telephone Survey", paper presented at the annual meeting of the American Public Health Association, Chicago.