



# SURVEY RESEARCH LABORATORY

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## INCLUSION OF DISABLED POPULATIONS IN SOCIAL SURVEYS: REVIEW AND RECOMMENDATIONS

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# I. Introduction

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## A. Overview

It is estimated that approximately one-fifth of the non-institutionalized population of the United States (about 49 million persons) have some form of physical or developmental disability (LaPlante, 1996). Of these, approximately 38 million are estimated to have an activity limitation related to their disability. Because they are non-institutionalized, these individuals are also eligible for inclusion in the multitude of general population surveys that are conducted on a daily basis in the United States. Many, unfortunately, are commonly excluded or discouraged from participating as a consequence of common survey design features that may produce unintended barriers. In this review, we explore some of these potential barriers to survey participation and present recommendations designed to improve the representation of non-institutionalized persons with disabilities in social surveys.

Examination of the literature concerned with survey design quickly reveals that accommodation of persons with disabilities has received little consideration. In household surveys, for example, persons who are not otherwise able to communicate via telephone (hearing-impaired populations) or answer the door to an interviewer (persons with physical disabilities) are customarily excluded from participating on the basis of their disabilities. While the associated bias of the exclusion of this population is usually negligible for statistics on the general population, the bias is amplified in surveys where disability status may be related to key dependent measures of interest. Health-related surveys and those focusing on elderly and/or economically disadvantaged populations are obvious examples. To illustrate, there is evidence suggesting that between one and four percent of sampled persons have been classified

as nonrespondents in the National Survey of Family Growth and the National Health Interview Survey because they are “unable” to respond (Hendershot, Colpe, & Hunt, 1999). Given that persons with disabilities are likely to differ in their responses to survey questions concerned with fertility and health, the exclusion of these respondents from the surveys merits serious attention.

Discussion of survey design features that often prevent persons with disabilities from participating in surveys is a reminder of the dynamic, interactive process of survey interviews. There are several expectations of the respondent across all modes of data collection. In face-to-face and telephone surveys, the respondent needs to be comfortable with the survey topic; be able to hear, understand, and respond to the questions being asked; and be physically able to focus for the duration of the interview, be it fifteen minutes or two hours. And in mail or self-administered surveys, there are the obvious requirements of literacy and having sufficient visual ability to read questions and directions. Because of these expectations, people with various disabilities could potentially be excluded from social surveys if appropriate accommodations are not provided.

An important goal for survey researchers, therefore, is to adjust their procedures to minimize barriers and to maximize the participation of persons with disabilities. In this paper, we present a very broad overview of the issues involved in surveying persons with disabilities. In doing so, our goals are to (a) raise awareness within the survey research community of the importance of including persons with disabilities and (b) explore potential approaches to proactively broadening their inclusion.

An important consideration in this regard is the degree to which systematic exclusion of persons with disabilities from research which purports to offer generalizations regarding the total population violates, at least in spirit, the Americans with Disabilities Act (ADA) of 1990 and other federal regulations. Although there are no legal precedents, one can entertain scenarios in which the ADA might be applied to survey research. One example might be a situation in which reasonable accommodations are not made for otherwise selected and eligible individuals to participate in research studies, particularly when financial incentives are given to study participants.

Similarly, federal regulations governing the ethical treatment of research subjects might be cited in situations where persons with disabilities did not receive equitable treatment. The Code of Federal Regulations concerned with the protection of human subjects specifically requires that Institutional Review Boards “take into account...the setting in which the research will be conducted and...be particularly cognizant of the special problems of research involving vulnerable populations, such as...mentally disabled persons, or economically or educationally disadvantaged persons” (Dept. of Health and Human Services, 1991, p.8). Compliance with federal laws and regulations pertaining to equitable treatment of and opportunities for persons with disabilities is thus an additional reason why researchers should begin developing strategies for more aggressively expanding opportunities for persons with disabilities to participate in survey research.

What do we mean by “persons with disabilities”? We acknowledge that there are many different interpretations of the term. Definitions of disability have been the focus of much discussion in recent years. Issues that have complicated the process of arriving at a standard definition of disability include:

- Cultural, national, and individual differences in conceptualizing disability;
- A general shift from a medical to a social model of understanding disability;
- Diverse research and advocacy interests;
- Subjective distinctions between illness/disease and disability; and
- Involvement of courts in the process of defining disability for the purposes of the Americans with Disabilities Act (ADA).

In this report, disability is conceptualized as an interaction between individuals and their physical and social environments, rather than as the result of personal impairments. Our focus in this project was to develop recommendations for researchers who conduct social surveys and who wish to ensure that persons with disabilities are represented in their research. By not placing limitations on the definition of disability, we hoped to capture insights and experiences that would be helpful and relevant to a wide range of readers. For those interested in learning more about the discussions surrounding the definition of disability, see Nagler et al. (1995), Bickenbach (1993), Nagi (1991), LaPlante (1991), and World Health Organization (1999).

## *B. Methodology*

Several sources of information were consulted in the preparation of this report. First, a comprehensive literature review of the topic identified relevant methodological reports and empirical studies. We also took advantage of resources on the Internet and papers from the conference proceedings of a variety of professional associations. Bibliographies of these papers were checked for additional references. The final product of this review is the annotated bibliography that can be found in **Appendix A**. This bibliography is intended to

be a comprehensive resource of the available literature for researchers and disability activists and advocates alike.

In addition to the literature review, the recommendations presented in this report are guided and influenced by consultations with various experts. The advisory group for the project recommended potential key informants who were experts in disability research and survey methodology. An introductory letter was sent to these individuals describing the project and explaining that they would be contacted in the near future to set up a consultation date (see **Appendix B**). Early consultations also identified other key informants. Consultants included disability advocates and service providers ( $n=23$ ), academic survey methodologists and researchers ( $n=17$ ), and several with both disability and survey expertise ( $n=12$ ); a number of these consultants had disabilities themselves.

A total of 51 telephone and one in-person consultations were conducted, the length of which ranged from 30 minutes to 1.5 hours. The consultations were conducted between July 21, 1999, and August 19, 1999. A series of approximately 14 questions were asked of key informants (see **Appendix B**). With the informant's permission, each discussion was recorded and transcribed.

### *C. Scope of This Report*

It became clear in the data gathering phase of this project, especially after our key informant interviews, that there are two aspects of surveying persons with disabilities: (1) including (or rather, not excluding) persons with disabilities in general household surveys and (2) surveying persons with disabilities *about* their disabilities. The set of issues for each are at one level identical, in that the actual process of interviewing persons with disabilities is the same regardless of the survey topic. However, there is an additional set of complex issues surrounding surveys about disability per se that complicates discussion of the broader issues. We aim to present only a general overview of issues relevant to increased inclusion of persons with disabilities in general population surveys.

Another challenge in summarizing this literature is that the word “disability” encompasses so many different gradations, each of which has an implication for the conduct of surveys. While we stated earlier that our goal was not to define disability, the conceptualization of disability for survey researchers certainly does not encompass the entire range of disabilities that people experience. From our perspective of increasing opportunities for participating in general population surveys, our discussion is necessarily limited to a more narrow definition of disability, typically in terms of a disability that might require accommodation during the social survey research process. We will thus focus our report on these aspects of disability and explore common survey design features that may serve as barriers to participation.

## II. Recommendations for Inclusion of Disabled Populations in General Population Surveys

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In preparing this report, we ultimately focused on the key areas of concern as they relate to surveys and as defined by the key informants we interviewed, specifically sampling and respondent selection, the use of proxy respondents, and adaptive technologies (obviously specific to surveys with persons with disabilities). Our interviews with key informants were invaluable in identifying the most important issues and in framing our recommendations. In this section we present an overview of the issues, followed by a set of general recommendations for including persons with disabilities in general household surveys.

### *A. Sampling*

For standard household surveys on topics unrelated to disability, few investigators have made a concerted effort to ensure that persons with disabilities are represented. (At the same time, few consciously exclude them, either.) Consider, for example, a telephone survey of Illinois residents. A random-digit-dial (RDD) sample is generated, and rules are made about how the cases should be worked, such as whether to leave messages on answering machines or voice mail, the number of contact attempts that will be made, and the number of refusal conversions that will be attempted. These rules by themselves may favor people without disabilities (Meyers, 1999).

For instance, consider a survey that requires interviewers to let the phone ring ten times before hanging up. Ten telephone rings take approximately one minute, and individuals with sensory disabilities (e.g., hearing impairment) may not immediately hear the phone ringing, or some people with physical disabilities might not be able to reach the telephone to answer in

time. People with cognitive disabilities and/or mental illnesses may also be excluded from telephone surveys if interviewers are not able to be patient, flexible, and clear in order to make the questions understood. In addition, many survey organizations do not permit interviewers to leave messages on answering machines, a policy that likely has a disproportionate impact on the chances of communicating with persons with disabilities.

These are just a few examples of how standard procedures for conducting surveys can be inherently biased against persons with particular types of disabilities. Moreover, there is the issue of whether persons with disabilities enjoy an equal probability of selection. Many household surveys routinely exclude persons in group homes and institutionalized populations. Approximately one-third of all persons receiving services for mental retardation or developmental disabilities in non-family settings were living in residences with three or fewer persons in 1997 (Anderson, 1998). These and other small residential settings, often considered institutions by survey researchers, might be more appropriately classified as eligible for inclusion in survey sample frames whenever encountered. Decisions to exclude these facilities from sample frames may also systematically exclude persons with certain types of disabilities from representation. Further, a common thread in discussions of sampling issues with the key informants we interviewed concerns the term “institution” in the disability community and that survey definitions of institutions are not current with reality. For example, there are assisted living quarters designed for the specific purpose of keeping persons with disabilities in the community, but these would be excluded from

most standard sample frames because they would be defined as institutions. The question of whether these should be considered households is but one area of debate.

If appropriate representation of persons with disabilities is desired, researchers might consider augmenting sample frames with supplemental lists of long-term care and other health institutions. Compared to conventional dwelling units, these types of residences will be overwhelmingly inhabited by persons with disabilities. Their inclusion would also serve to expand the proportions of persons with disabilities defined as being eligible to participate in the survey.

An additional approach is for researchers to consider, whenever possible, using mixed-mode approaches to accommodate greater proportions of potentially eligible respondents who may not be able to participate in the survey if only one mode of data collection is used. For example, an important step toward ensuring that people with disabilities are represented in surveys would be an advance letter to respondents that (1) acknowledges awareness of disabilities, (2) expresses a willingness and flexibility to accommodate persons with disabilities, and (3) encourages any persons with disabilities in the sample to contact researchers using the most convenient method available to them.

Another important point with regards to sampling and sample frames is that just because persons with disabilities have a probability of selection does not mean that they will be able to participate unless other barriers to their inclusion are addressed. While there are several approaches that researchers can take to accommodate persons with disabilities in the interview situation, one approach is consideration of proxy interviews.

## *B. Proxy Interviewing*

This section considers the controversial question of the appropriateness of utilizing proxy interviews to represent persons with disabilities. Before addressing this topic, however, it is also important to acknowledge that survey interviewers would benefit from training that addresses the communication needs of persons with disabilities. Incorporation into interviewer training of communication strategies for interacting with persons with various disabilities, for example, can improve both the quality of the survey information collected and the quality of interpersonal exchanges. Hayden (1998) provides an excellent example of the basic practices and expectations that should be understood by survey interviewers in this regard with respect to persons with mental illness, mental retardation, and developmental disabilities. As a general guideline, interviewers should also be trained to recognize fatigue in respondents and offer to complete the interview at a later time when necessary. Further, interviewers should learn to recognize and understand the functioning of assistive devices that persons with disabilities might use during the interview process (e.g., communication boards, voice synthesizers).

There is considerable debate regarding the appropriateness of using proxy survey respondents to represent persons with disabilities in surveys, and it is an issue that polarizes survey methodologists and disability advocates more than any other on the topic, as evidenced by our key informant interviews. Survey methodologists approach proxy response from a measurement perspective: how much, if any, measurement error is introduced when proxy response is accepted? In contrast, disability advocates strongly feel that a proxy cannot give persons with disabilities adequate voice, given the subjective phenomenon of the disability experience.

From a survey perspective, the decision to use proxy respondents is in part a balancing of costs and precision (Mathiowetz & Groves, 1985), and the pervasive opinion is that self-response is preferred whenever possible (Moore, 1988). As the cost of conducting surveys has increased, however, there has been a trend towards rules that are more inclusive of proxy respondents, especially in household surveys. For several decades, the National Health Interview Survey (NHIS) has found it more economical to interview one member of the household versus all members. Traditionally, most survey researchers would consider the use of proxy respondents to be preferable to non-response, especially in situations where the selected respondent is willing but unable to participate in the interview. However, some disability experts strongly disagree and believe that nonresponse may under some circumstances be preferable to inaccurate reports from proxies (Kirchner, 1998).

There are indeed several reports of differences between self-reports and proxy reports of health information. Studies examining self vs. proxy effects in the reporting of the activities of daily living (Andersen et al., 2000; Mathiowetz & Lair, 1994; Rodgers & Miller, 1997) indicate that self-reports of functional limitations are lower than those offered by proxies. Another study found close agreement between self and proxy responses on measures of overall health, functional status, social activity, and emotional health, but interestingly (in the context of disability studies), those proxies who spent more time helping the subject in activities of daily living tended to rate the subject's functional status and social activity as more impaired than did the subject (Epstein et al., 1989). None of these studies, however, randomly assign respondents to self vs. proxy conditions prior to the interview so that the conclusions must be

considered with this bias in mind (Moore, 1998).

A more recent review (Todorov & Kirchner, 2000) has significant implications for the use of proxies in surveys about disability specifically. Through analysis of data from the two largest federal surveys that estimate disability for the U.S. population, the authors find significant differences between self-reports and proxy reports on the extent of disability among household members. Proxy respondents are likely to underreport disabilities for persons aged 65 years of age or younger but overreport disabilities for persons over 65. As the authors note,

*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 . . . 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.* (p. 1253)

Clearly, when a survey is designed to provide estimates of disability, the use of proxy respondents must be seriously considered in light of these findings. It should be noted that less is empirically known about the effects of proxy reporting on other topics commonly included in survey interviews.

Disability advocates view the issue of proxy from a somewhat different perspective. Few would argue that a proxy respondent should never be used, as a no-proxy rule automatically would exclude those who may not be able to communicate directly with the interviewer. However, concerns have been expressed, especially for those who have severe disabilities,

that survey researchers assume that potential respondents who are assessed as having impairments cannot function as respondents. As articulated by one informant,

*Many researchers believe that if the person is incompetent intellectually that they are not a reliable survey participant, when in fact, they may be. This person might have a guardian because they aren't capable of high-order decision-making, but they might be able to reliably tell you their preferences and experiences. I have been doing research with people with intellectual disabilities and am just amazed at how much they can tell me and how reliably they can do it.*

The message of the advocacy community is that researchers should always assume that the respondent can answer for himself or herself, even if the assistance of special technology or a translator is required. Most individuals, with or without disabilities, do not want families or other persons speaking for them. When a proxy is used, there should also be an attempt to incorporate the respondent's assessment of the proxy's answers. For example, one consultant gave the example of a woman she had interviewed with cerebral palsy. This woman's mother served as the proxy, but the interviewer was nonetheless able to learn from the respondent if she agreed or disagreed with each of her mother's survey responses via body signals.

Another issue of debate is the selection of proxy respondents. In the experience of many of our key informants, choosing proxies is a delicate issue. At a minimum, asking the respondent to nominate a proxy would seem appropriate. While proxies are typically chosen on the basis of their relationship with the respondent, difficulty arises when the proxy also serves as the respondent's caretaker. Moreover, people with disabilities experience a high rate of physical, sexual, and emotional abuse, frequently at the hands of those who

care for them (Sobsey, 1994). The selection of a proxy would also depend on the subject of the interview; for example, in surveys concerned with quality of care issues, a proxy who is in the role of caretaker (whether family or institutional) would likely introduce considerable bias. Thus, there is an added layer of concern with the use of proxies among persons with disabilities that does not exist with the general population.

Privacy issues should also be considered when interviewing persons with disabilities. As mentioned earlier, it is not uncommon for persons with disabilities to sometimes be abused by their caregivers. The physical presence of caregivers during interviews that address sensitive topics such as abusive experiences may thus jeopardize respondents when they are honest and caregivers are vindictive. Providing respondents with a private environment within which to answer highly sensitive survey questions is a topic receiving considerable methodological attention (Harrison & Hughes, 1997). Similar consideration should be invested in addressing other potential privacy considerations when interviewing persons with disabilities.

### *C. Adaptive Technologies and Procedures*

Issues related to adaptive technologies are of primary importance to persons who are deaf or hard-of-hearing, visually impaired, or who have speech impairments or speech disabilities. It is estimated that 9.4% of the population of the United States has hearing loss, and of those, about 20% cannot hear or understand speech (Collins, 1997; Ries, 1994). Furthermore, the language of many in the deaf community is American Sign Language, or ASL, which is third only to English and Spanish among the most commonly used languages in the country (Lotke, 1995). In addition, LaPlante (1996) notes that approximately half a million persons

in the United States have speech disabilities. It is likely that a significant proportion of this population is being systematically excluded from participation in telephone surveys. This is an important shortcoming of current telephone survey methodology. Research suggests, for example, that deaf persons are distinct from the general population on various measures of health behavior and health-care utilization (Zazove et al., 1993; Barnett & Franks, 1999). Their exclusion from telephone surveys thus contributes a systematic bias.

TTY (teletypewriter) or TDD (Telecommunications Device for the Deaf) technologies and relay services are the technologies typically used by the deaf community. Teletype machines were initially used by the military and telegram operators for sending telegrams and coded messages. Eventually, they were converted to transmit information over telephone lines, allowing persons who were not able to communicate by telephone to “talk” with one another. It is estimated that 104,000 people in the United States used a TTY in 1994 (Russell et al., 1997). In addition, relay services are an extension of the teletype technology. All states now offer TTY services in which the teletype user types a message to an operator, who reads it aloud to the hearing person on the other end. The operator then converts the replies back into text for the deaf or hard-of-hearing person.

While there is little published data on surveys being adapted for TTY administration, the consultants we spoke with had considerable experience with TTY technologies in surveying persons who are deaf or hard of hearing. They report it to be a difficult procedure to implement in practice. First, there are several different types of TTY machines. Some have printers attached that can print out an entire question; some do not. Moreover, some TTY machines have word and character limits as low as 20 characters, which is a serious restriction

for those who cannot print out the questions. Without knowledge about the respondents’ hardware and how questions appear on their teletype machines, surveys are really limited to short questions with simple “yes-no” answers. This is especially limiting when you consider the “newness” of phone surveys for people who are deaf or hard of hearing, as described by one key informant:

*Deaf people don't get a lot of surveys. It's new to them. There's a cultural component to giving questions, because they're not going to know what the NHIS is, and they might not know what phone surveys are. So there are basic issues about saying, "No, I'm not selling you anything, we're here to collect information that will be of benefit." There's a greater amount of basic information that needs to be conveyed, and that may be more difficult on a TTY.*

Yet another limitation of TTY technology is that ASL does not have a written format, so that TTY communication with someone who uses ASL may have to be done in a second language (i.e., English), depending on at what age hearing loss first occurred. Persons who lose their hearing after the acquisition of language are more likely to use English, whereas people who were prelingually-deafened (before age 3) are more likely to communicate in ASL (Barnett & Franks, 1999). Moreover, telephone ownership among persons who are prelingually-deafened has been found to be significantly lower than that of the population as a whole and other population subgroups (Barnett & Franks, 1999).

In addition, there are distinct symbols and abbreviations used by the ASL and TTY user communities that interviewers would need to learn. And, it has been documented that the median reading and vocabulary levels of deaf high school graduates in the United States is at the 4<sup>th</sup> or 5<sup>th</sup> grade level (Holt, 1993; McEwen & Anton-Culber, 1988). Taken together, these

statistics illustrate the difficulties of adapting TTY technology for survey administration.

Still, a few of our informants reported on their progress adapting their computer systems and CATI software to TTY technology. Some have developed an interface between the TTY and their in-house CATI systems so that interviewers would not have to type in the questions each time, allowing responses to be entered directly into the computer. We also learned about NexTalk software, which uses the respondent's personal computer and a special modem that supports telecommunications devices (NexTalk, 2000). The software allows users to program and store survey questions so that they need not be typed during interviews. The questions are retrieved and transmitted using only a few keystrokes. However, NexTalk cannot control skip patterns, so it requires the interviewers to work simultaneously between NexTalk and the CATI program. The interviewer has to enter the response from NexTalk into the CATI program to see what question should be transmitted next and then send it. As a result, it requires extra time to conduct the interviews. With just under ten percent of the population currently experiencing hearing loss and this proportion likely to increase as the Baby Boomer generation continues to age, further refinement of these technologies can be expected.

Identifying TTY numbers remains perhaps the most significant challenge for implementation of any possible accommodation. Several of our informants spoke of the difficulty in distinguishing a TTY tone from a fax tone, especially given the variations in teletype equipment (all of which produce different tones). Thus, the numbers of those persons with TTY signals are more often than not misclassified as ineligible or nonworking when contacted as part of an RDD telephone survey. In fact, few telephone survey interviewers are trained to distinguish TTY

signals from other devices such as fax machines. One report of an experiment to train telephone interviewers on how to identify and code TTY tones did not yield promising results (Olson et al., 1999). In a sample of about 12,000 telephone numbers, interviewers coded 64 as TTY numbers. Of these, 55 were later confirmed to be fax or modem numbers rather than TTY numbers.

An important consideration with the use of adaptive technologies is how they may change the dynamic of the interviewer-respondent relationship. In some instances this dynamic may be completely lost, as many of these technologies provide no opportunity for the interviewer to follow up on respondent cues or even probe, changing the nature of the interview situation dramatically. As phrased by the same informant who had experience with the NexTalk software:

*When we have worked with relay services we have asked the questions verbatim, which is problematic because certain wordings that work for voice don't work typed. When you are talking about studies with complex concepts...the question wordings are pitched at a level above the verbal or linguistic levels that would be average for a [deaf] person. But given the nature of the surveys that we do, we don't have much freedom to change it.*

It is ultimately a trade-off, then, as are many decisions in the survey design process. However, it is an important option for persons who otherwise would not be represented in social surveys.

Regardless, it is important to weigh the advantages and disadvantages of extending the effort and resources to include deaf and hard of hearing persons in telephone surveys using TTY and relay services, especially for surveys where disability is not known to be correlated with the key outcome variables. If the decision is made to identify TTY households and survey

respondents who are deaf and hard of hearing, comprehensive lists of TTY numbers are now available (see <http://www.tdi-online.org/publications.htm>).

Concern with respondent hearing difficulties should also be a consideration when constructing survey questions. Questions with high frequency sounds, for instance, should be minimized. Take as an example the following question:

“How satisfied are you with the quality of care you are receiving from your primary care physician? Would you say very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied?”

An alternative with lower frequency sounds is:

“How satisfied are you with the quality of care you are receiving from your primary care physician? Would you say very much, somewhat, a little, or not at all?”

Revising the wording of survey questions is sometimes difficult, particularly when replicating an earlier survey. Consideration of question comprehension by persons with hearing difficulties is nonetheless something that researchers can accomplish with minimal difficulty when designing surveys for the general population. Assessments of survey items via cognitive techniques are in general a practical approach to addressing questionnaire design issues among persons with disabilities. Beatty and Davis (1998) provide an example of the use of these commonly accepted techniques to investigate survey items concerned with print reading disabilities.

Adaptive technologies are not limited to TTY services alone or to people who are deaf or hard of hearing. Self-administered surveys are as problematic as telephone surveys for some persons with disabilities. Our key informants offered several examples of steps

they have taken to accommodate these persons in self-administered surveys:

- Offer the survey in a Braille version (though there are translation issues that make this process complex, and only a small proportion of the visually impaired use Braille [American Foundation for the Blind, 1996]).
- Offer the survey on audiocassette, with another blank audiocassette for the respondent to record his or her answers.
- Offer a toll-free number the respondent can call to complete the survey by telephone, or a visually-impaired respondent can request an interview by telephone.
- Offer large-print versions of questionnaires.
- Use high-contrast, low-glare paper.
- Offer on-line or Web-based surveys, particularly using voice-activated technologies.
- Ensure that the questions are as clear and simple as possible, so that people with cognitive disabilities and mental illnesses can participate.

Whenever practical, the use of computer-assisted technologies such as audio computer assisted survey interviews (A-CASI) can provide additional stimuli to persons with disabilities. This approach is particularly attractive for enhancing the participation of persons with less severe visual or hearing impairments. Another option is that of Interactive Video Questionnaire (IVQ), a touchscreen video technology where the survey is shown on video in a choice of sign or spoken languages allowing the respondent to answer by touching the appropriate response (Lipton et al., 1996). A voice element could be added to the IVQ so that people with visual impairments could hear the questions and then respond by

speaking into a tape recorder or typing their responses in text or Braille.

Most of these options for self-administered surveys are relatively low-cost and easily adaptable to general population surveys. The key is to be adaptable to the respondent's needs and to not assume that what works for one will work for all. For example, some visual conditions render black print on a white page illegible, so that the questionnaire would need to be printed in blue ink on yellow paper. Such accommodations will increase the opportunities for persons with disabilities to participate in general household surveys. Where possible, an advance letter should be sent to all households. Even with an RDD sample, a dual-frame design

can be adopted. Technically, a dual-frame design for telephone surveys involves selecting a list frame sample using telephone directories and combining it with a sample selected from an RDD frame. This can be easily modified by having an RDD frame checked by a reverse directory service to identify numbers in the frame that have addresses. In our experience, addresses can be identified for approximately 40% of an RDD frame. Advance letters can be sent to those households with instructions for how to proceed if a disability prevents the respondent from participating in a telephone interview. This letter can be two-sided, with the opposite side containing instructions in large-print for the visually impaired.

### III. Conclusion

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Survey researchers regularly interview persons with disabilities; they just are not always aware they are doing so. There is little attention given in the academic survey literature (and most probably, in common survey practice) to how many “standard” procedures serve to systematically exclude persons with disabilities from research of the general population. For example, there is great reliance on the interviewer to make the assessment of a potential respondent’s ability to perform as a survey informant, but it is likely that only a very few interviewers are trained or encouraged to negotiate the reasonable accommodations that would enable many respondents with disabilities to participate (Hendershot, Colpe, & Hunt, 1999). Moreover, survey researchers typically think of the populations they survey only in terms of demographic characteristics such as race, age, and gender. There has been little emphasis on other personal characteristics, such as disabling conditions, that may make surveys inaccessible to many potential respondents. It is thus fair to say that most surveys are designed with the assumption that respondents will be able to “move, see, hear, attend, understand, and talk within the performance range expected by survey designers” (Hendershot, Colpe, & Hunt, 1999, p. 1).

There is, in fact, little question that traditional household-based, general population surveys are biased at multiple levels against persons with disabilities, from representation in the sample frame to calling rules that favor persons without disabilities to concern with communication and privacy issues. The extent to which efforts should be made to widen the net to include more persons with disabilities is a question not only of the additional costs involved in doing so but also of ethical and data

quality standards. Attention to inclusion and measurement issues relevant to persons with disabilities, we conclude, should be built into the general design of social surveys in the future. Unfortunately, there are few generally accepted “cookbook” solutions to the issues acknowledged in this review. We thus also believe that research designed to address many of these methodological difficulties should be an immediate priority. Such research, of course, would be greatly expedited by government willingness to underwrite the costs of doing so.

The key lessons from this review:

- Ensuring that persons with disabilities have an equal probability of selection in the sample frame does not mean that they are equally able to participate. It is important for researchers to focus attention on sampling issues related to persons with disabilities, as well as the inclusion of respondents who have already been sampled.
- TTY/TDD technology is available, but there are limitations to translating surveys with this technology. Researchers should continue to explore the development of technologies that will empower greater numbers of people with disabilities by enabling them to participate directly in social surveys. In addition, survey interviewers should be trained regarding the adaptive technologies that people with disabilities use in their daily lives so that interviewers will feel comfortable using these technologies to communicate with respondents with disabilities.
- Researchers can begin reaching out immediately to more persons with disabilities if they offer respondents

alternative methods of response (e.g., respondents with hearing difficulties can request a written instrument, or people with visual impairments can request an interview by phone and/or large-print versions of questionnaires and other materials).

- In telephone surveys, researchers can consider changing the rules for RDD surveys—for example, allowing a greater number of rings per call or leaving messages on answering machines—in order to afford persons with disabilities more time to respond.

We recognize that even these modest recommendations have increased costs associated with them. They are nonetheless important steps toward increasing accessibility

to surveys for persons who have until recently been excluded from most population-based survey research.

A final recommendation is that researchers pay more attention to the environments in which they conduct their research. Virtually every feature of survey design can influence the likelihood that those with disabilities will have an opportunity to participate. Routine consideration of how various elements of survey design may influence the inclusion of persons with disabilities and what might be done within the time and cost constraints of each survey is a low-cost opportunity for all survey researchers to begin proactively improving opportunities for persons with disabilities to be more fully represented in all social surveys.

## REFERENCES

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- American Foundation for the Blind. (1996, May/June). Estimated number of adult Braille readers in the United States. *Journal of Visual Impairment & Blindness*. Retrieved July 28, 2000, from the World Wide Web: [www.braille.org/papers/jvib0696/jvib9603.htm](http://www.braille.org/papers/jvib0696/jvib9603.htm)
- Americans with Disabilities Act of 1990, Pub. L. No. 101-336, § 2, 104 Stat. 328 (1991).
- Anderson L., Lakin, K. C., Polister, B., & Prouty, R. (1998). One third of residential service recipients live in homes with three or fewer residents. *Mental Retardation*, 36(2), 249.
- Andersen, E. M., Fitch, C. A., McLendon, P. M., & Meyers, A. R. (2000). Reliability and validity of disability questions for U.S. Census 2000. *American Journal of Public Health*, 90, 1287–99.
- Barnett, S., & Franks, P. (1999). Telephone ownership and deaf people: Implications for telephone surveys. *American Journal of Public Health*, 89(11), 1754–56.
- Beatty, P., & Davis, W. (1998). Evaluating discrepancies in print reading disability statistics. *Cognitive Methods Staff Working Paper Series, No. 25*. Hyattsville, MD: National Center for Health Statistics.
- Bickenbach, J. E. (1993). *Physical disability and social policy*. Toronto: University of Toronto Press.
- Collins, J. (1997). Prevalence of selected chronic conditions: United States, 1990–92. *Vital Health Statistics*, 10, 194.
- Department of Health and Human Services. (1991). *Code of Federal Regulations: Title 45—Public Welfare, Part 46—Protection of human subjects*. Washington, DC: U.S. Government Printing Office.
- Epstein, A.M. et al. (1989). Using proxies to evaluate quality of life. *Medical Care*, 27(3 suppl), 91–98.
- Harrison, L. & Hughes, A. (1997). *The validity of self-reported drug use: Improving the accuracy of survey estimates*. Rockville, MD: National Institute on Drug Abuse.
- Hayden, M. (1998). *Interviewing adults with mental retardation and related conditions: Interviewer training manual*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.
- Hendershot, G., Colpe, L., & Hunt, P. (1999). *Participation of persons with disabilities in household surveys: A conceptual framework for empirical investigations*. Unpublished manuscript.
- Holt, J. (1993). Stanford Achievement Test, 8<sup>th</sup> ed: Reading Comprehension Subgroup results. *American Annals of the Deaf*, 138, 172–75.
- Kaye, H. S. (1998). *Disability watch: The status of people with disabilities in the United States*. San Francisco: University of California.
- Kirchner, C. (1998). Improving research by assuring access. *Footnotes*, 26(7), 7.
- LaPlante, M. (1991). The demographics of disability. In J. West (Ed.), *The Americans with Disabilities Act: From policy to practice* (pp. 55–77). New York: Milbank Memorial Fund.
- LaPlante, M., & Carlson, D. (1996). Disability in the United States: Prevalence and causes, 1992. *Disability Statistics Report (7)*. Washington, DC: U.S. Department of

- Education, National Institute on Disability and Rehabilitation Research.
- Lipton, D., Goldstein, M., Wellington Fahnbulleh, M., & Gertz, E. (1996). The Interactive Video Questionnaire: A new technology for interviewing deaf persons. *American Annals of the Deaf* 141(5), 370–78.
- Lotke, M. (1995). She won't look at me. *Annals of Internal Medicine* 123, 54–57.
- Mathiowetz, N., & Groves, R. (1985). The effects of respondent rules on health survey reports. *American Journal of Public Health*, 75, 639–44.
- Mathiowetz, N., & Lair, T. (1994). Getting better? Change or error in the measurement of functional limitations. *Journal of Economic and Social Measurement*, 20, 237–62.
- McEwen, E., & Anton-Culver, H. (1988). The medical communication of deaf patients. *Journal of Family Practice*, 26, 289–91.
- Meyers, A. (1999, August). *Enabling our instruments: Universal design and assured access to health status and health services research*. Paper presented at the National Center for Health Statistics National Conference on Health Statistics, Washington, DC.
- Moore, J. (1988). Self/proxy response status and survey response quality: A review of the literature. *Journal of Official Statistics*, 4, 155–72.
- Nagler, M., & Wilson, W. (1995). Disability. In A. Orto & R. Marinelli (Eds.), *Encyclopedia of disability and rehabilitation* (pp. 257–60). New York: Simon & Schuster.
- Nagi, S. (1991). Disability concepts revised: Implications for prevention. In A. M. Pope & A. R. Tarlov (Eds.), *Disability in America: Toward a national agenda for prevention* (pp. 309–27). Washington, DC: National Academy Press.
- NexTalk-VM Software for Voice Modems Web Page. 2000. <www.nextalk.com>
- Olsen, L., et al. (1999). *The National Immunization Survey: Development of strategies to include deaf respondents in an RDD telephone survey*. Presented at the American Public Health Association Conference, Chicago.
- Ries, P. W. (1994). Prevalence and characteristics of persons with hearing trouble: United States, 1990–91. *Vital Health Statistics* 10: No. 188.
- Rodgers, W., & Miller, B. (1997). A comparative analysis of ADL questions in surveys of older people. *The Journals of Gerontology*, 52B, 21–36.
- Russell, N., Hendershot, G. E., LeClere, F., Howie, J., & Adler, M. (1997). Trends and differential use of assistive technology devices: United States, 1994. *Advance Data from Vital and Health Statistics: No. 292*. Hyattsville, MD: National Center for Health Statistics.
- Sobsey, D. (1994). *Violence and abuse in the lives of people with disabilities: The end of silent acceptance?* Baltimore: P. H. Brooks Publishing.
- Todorov, A., & Kirchner, C. (2000). Bias in proxies' reports of disability: Data from the National Health Interview Survey on Disability. *American Journal of Public Health*, 90(8), 1248–53.
- World Health Organization. (1999). *ICIDH-2: International Classification of Functioning and Disability. Beta-2 draft*. Geneva: Author.
- Zazove, P., Niemann L. C., Gorenflo, D. W., Carmach, C., Mehr, D., Coyne, J. C. et al. (1993). The health status and health care utilization of deaf and hard-of-hearing persons. *Archives of Family Medicine*, 2, 745-52.