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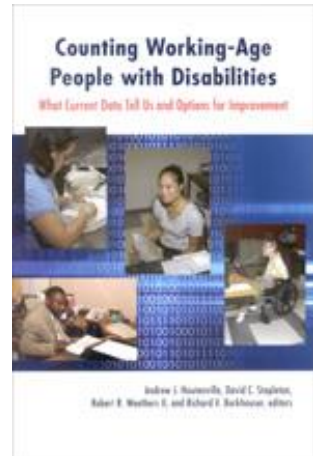
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# Survey Data Collection Methods

Janice Ballou  
*Mathematica Policy Research*

Jason Markesich  
*Mathematica Policy Research*



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**Counting Working-Age People with Disabilities: What Current Data Tell Us and Options for Improvement**

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# 8

## Survey Data Collection Methods

Janice Ballou  
Jason Markesich  
*Mathematica Policy Research, Inc.*

Prior chapters of this book have delved into the major national surveys providing specific types of information about people with disabilities. The purpose of this chapter is to review the survey methods that are used to obtain this information, prioritize methodological issues that need to be addressed, and provide guidelines for designing surveys to collect information about or from people with disabilities.

### **Guidelines Needed for Survey Methods**

Survey data are a critical source of information to support the development and management of programs and policies for people with disabilities. The methods used to collect this information may, however, exclude the very people whose input is most relevant and introduce bias into population estimates. Therefore, it is critical to provide guidelines to promote the full inclusion of people with disabilities as part of national surveys. The contents of this chapter are based on a systematic effort to organize, prioritize, and recommend considerations for disability data collection.

The main objective of the review of methodological issues related to disability research, and the presentation of possible solutions for making surveys more accessible to persons with disabilities, is to improve the quality of the data that are used for public policy decision making and program needs assessments and evaluation. There is no dearth of topics that can be discussed to improve disability data collection, and this chapter will focus on those that have been identified as essential.

## Use of Information

By outlining the methodological components that need to be considered prior to launching a survey, as well as the multiple trade-offs that need to be considered, the time and money invested in conducting disability research is likely to yield higher quality, more useful information. For those who are designing surveys, this chapter will provide a road map of the methodological considerations needed to expand the inclusion of people with disabilities in surveys and to identify the steps in the research process where vigilance can reduce total survey error. The discussion of survey best practices will also provide quality criteria that disability researchers can use to evaluate the data being used for analysis. As will be underscored in this chapter, a starting point for quality data collection is a review of the documentation that is available from prior research. With that in mind, the authors of this chapter in collaboration with others produced *Surveying Persons with Disabilities: A Source Guide* (Markesich, Cashion, and Bleeker 2006), which outlines key methodological topics and identifies relevant resources.

## Survey Methodology Information

Information about survey methodology is valuable to both those who use and those who produce data. For a user to have confidence in information about disability issues or people with disabilities, he or she needs detailed methodological documentation. There are multiple sources that can be used to develop an inventory of key questions that need to be asked about data to ensure this confidence. An easily obtained source, and one that is used to guide federal surveys, is the Office of Management and Budget's (OMB) *Questions and Answers When Designing Surveys for Information Collections*.<sup>1</sup> Table 8.1 shows an abbreviated listing of the minimal information that should always be referenced by data users so they have some basic information to assess survey quality. Too often data users assume that, just because survey data are available, they have passed some type of quality review, but this is not necessarily the case. To prevent the use of data of uncertain quality or, worse yet, of unknown quality when no documentation is provided, data users should find and review the information listed in Table 8.1. Those who are in the process of developing surveys can use

**Table 8.1 Basic Information for Survey Quality**

Essential information
Dates of data collection
Number interviews completed
Sample frame(s)
Respondent selection criteria
Proxy documentation
Data collection mode(s)
Response rate <sup>a</sup>
Cooperation rate <sup>a</sup>
Length of interview
Useful information
Full questionnaire
Questionnaire topic modules
Question wording and position (item #) of key analytic variables
Interviewer characteristics
Interviewer training (general)
Interviewer training (survey specific)
Editing guidelines
Coding guidelines
Missing information

<sup>a</sup> The American Association for Public Opinion Research provides documentation on how to calculate response rates and cooperation rates in Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys. See AAPOR (2008) for full documentation on the formula for these calculations plus a response rate calculator for easy and accurate computation.

this list to inform decisions that need to be made to design a quality survey.

## **IDENTIFYING SURVEY METHOD PRIORITIES FOR DISABILITY RESEARCH**

We set out to identify items for a research agenda to improve the quality of disability data collection and to develop a prioritized list of recommendations to address the key research gaps to inform best

practices (Ballou and Markesich 2006). To accomplish this task, we convened a planning group comprised of individuals with relevant experience in disability research and survey methods<sup>2</sup> to participate in a modified Delphi approach.<sup>3</sup>

The group discussions focused on the inclusion of persons with disabilities and how, at every stage in the survey research process, there are gaps in information about whether or not inclusion affects data quality. Although the current state of information can provide suggestions for best practices and standard procedures, without systematic and scientific research there are still unanswered questions at each phase of the survey process. However, it is clear that those conducting surveys can impact data quality, depending on the decisions that are made about the accommodations used to maximize the inclusion of people with disabilities.

The challenges of conducting research with persons who have disabilities or disability-related issues have been addressed in multiple venues by a range of different organizations.<sup>4</sup> Although a key disability research issue is how to define and identify people with disabilities, the planning group decided it was beyond the scope of its effort and deferred to the ongoing deliberations related to the International Classification of Functioning, Disability and Health (ICF).<sup>5</sup>

## **SURVEY BEST PRACTICES**

Survey data collection is a multi-phase process, with each phase requiring necessary attention to obtain the best quality information while at the same time reducing the potential for measurement error. This section has a review of what we know and what we still need to learn about best practices for conducting research with and about people with disabilities. The discussion follows the typical steps in the data collection process, beginning with guidelines for decisions related to the survey research design. Included are best practice suggestions for survey implementation: sample design, proxy decisions, questionnaire development, data collection, and interviewer training. A convenient reference for these guidelines is presented in Table 8.2.

**Table 8.2 Guidelines for Best Practices and Disclosure Considerations**

Survey process	Methods considerations/decisions
Research design	Participatory action research (PAR) Purpose of survey Statistical Program needs assessment, evaluation Analysis plan: key subgroups; descriptive statistics Quantitative, qualitative Primary, secondary (e.g., survey data, administrative records)
Sample	Unit sample frame: general population random digit dial or participant list Intentional exclusions (e.g., institutional and other non-household populations) Respondent selection: household inventory, last birthday, nonrandom, proxy guidelines Eligibility screening
Proxy decisions	Interviewer judgment Questionnaire screening assessment
Questionnaire design	Established items (ADL, IADL, ICF) New items: cognitive testing, pretesting Wording: understandability, cognitive difficulty, reading level Format: screening, skip patterns, visual assistance (e.g., smiley faces, storyboards) Context: items precede others, overall questionnaire focus Match conceptual with measurement/operational Respondent burden Translation
Data collection	Quantitative Mode: in person, mail, telephone, Web-based Single or multimode Plans for alternative modes; accessibility Qualitative Focus groups Cognitive interviews Case studies/individual interviews
Interviewer training	Standard interviewer training Specific guidelines for people with disabilities

## Research Design

The initial step in the survey process is to develop a research design that identifies the main purpose for conducting the research and a step-by-step plan that will be used to collect the relevant data. The overriding need identified by the planning group was the inclusion of people with disabilities when research is conducted with them or about issues related to people with disabilities. This approach is known as participatory action research (PAR), and the focus is to have people with disabilities involved right from the beginning of the research process so they can contribute to identifying research objectives, developing the survey instrument, planning approaches to increase the participation of people with disabilities, assisting in survey administration (possibly as interviewers), and conducting analysis and interpreting the findings. There is useful information about methods that have been used to improve inclusion of people with disabilities, particularly in the presentations at the “Best Practices for Surveying People with Disabilities” conference,<sup>6</sup> which are summarized in Kroll et al. (2007), but there is minimal scientific research on the effect of PAR contributions. One example that underscores the value of including people with disabilities is described in *Certain Unalienable Rights* (New Jersey Governor’s Task Force 1987). Thirteen services, not found in any other process, were identified in focus groups of people with disabilities.

More examples based on scientific research are needed to address and document the value of PAR. In particular, distinctions should be made between PAR needs related to surveys of the general population, such as the American Community Survey (ACS) or the Behavioral Risk Factor Surveillance System, and those related to surveys of disability populations, such as the Social Security Administration’s (SSA) National Beneficiary Survey, which is a recent survey of the SSA’s disability program beneficiaries. The purpose of the survey and the targeted survey population (general population or disability only) should be key factors guiding survey design decisions.

## Sample Design

Sample design decisions for surveys that are being used to report and analyze information about people with disabilities involve choices

that impact the inclusion of people with disabilities at two stages in this process: 1) the sample frame or unit coverage decision and 2) the within-unit or respondent selection. Also, similar to the overall research design guidelines, sample design planning is directly related to the survey objective and the population of interest. The planning group identified two sample design categories: 1) samples for general population surveys and 2) samples of individuals with particular types of disabilities used for research related to program evaluation, consumer satisfaction, and needs assessments.

### **Sampling frame**

A key research choice related to sample frames is the deliberate exclusion, for practical or other reasons, of nonhousehold units—institutions, nursing homes, group homes, assisted-living facilities, and other nontraditional, multi-person dwelling units—which can be problematic for inclusion in sampling frames, as are homeless people. Since many people with disabilities reside in these types of living situations, this exclusion prevents them from participating in surveys. Compounding the exclusion issue is the dynamic nature of tenure in some types of housing. Whereas some people with disabilities may permanently reside in nonhousehold locations, others may move in and out of a variety of locations depending on the nature of the disabling condition (She and Stapleton 2009). The mode of data collection—in person, mail, telephone, or Web—also determines the sampling frame choice, so information about which mode is the most or least inclusive of people with disabilities would be useful.

For general population probability samples, the most inclusive sample frame is an in-person household listing, but use of such a frame can be prohibitively expensive. Major improvements in U.S. Postal Service documentation support a mail sample frame as an inclusive alternative (Blumberg and Luke 2008; Link et al. 2007). Although there are documented coverage issues related to both telephone and Web-based sample frames, minimal information is available about the extent of their exclusion of people with disabilities.

There are other inclusion considerations for nonprobability sampling frames, including lists of participants in a particular program or of those who are targeted to receive local or regional services. For practi-



cal reasons, targeted or regional surveys use sampling frames that are easily accessible. These are commonly lists from organizations, such as centers for independent living and other disability consumer organizations. The planning group noted that an important research need is to develop sampling frames to meet this gap in coverage. In particular, it was noted that people with mental retardation and developmental disabilities are likely to be excluded from available disability service organization lists because they are less likely to participate in these programs. Even when a program list is supposed to include all participants, the quality of the contact information can be problematic. To reduce exclusion because of inaccurate or missing contact information, online databases, directory assistance, and other techniques should be used to locate individuals and obtain accurate information.

### **Respondent selection**

The next inclusion challenge is the selection of individuals who will participate in the survey. At the core of this process are two important research questions: 1) Who is eligible to participate; and 2) how will the eligible participant be selected? Possible respondent selection approaches are interviewing the first contact within the sample unit, selecting the person in the household who has had the last birthday, and doing a full household listing and then using a random process for selection. Whatever the method, people with disabilities may be excluded because someone—a household member or an interviewer—determines that the person with a disability is not eligible or competent to respond. This can result in a proxy being selected to represent the person with a disability.

Additional research is needed on the use of screening questions as an inclusion method. They are used when researchers want to improve the representation of people with disabilities by using a general population sampling frame rather than a list of people with disabilities, which can have the previously described bias problems. To determine eligibility to participate in a survey designed only for people with disabilities, screening questions are used. However, there are multiple inclusion considerations with this approach that can affect survey quality. A basic decision is the question or series of questions to be used to identify particular disabilities. Also, there is the potential for social

desirability response bias related to having the sample member (or a proxy) self-identify as having a disability.<sup>7</sup> Social desirability bias is of more concern when these questions are asked at the beginning of the contact, before the respondent has developed trust and rapport with the interviewer.

One way to monitor the exclusion of people with disabilities is to review the disposition codes that should be used in every survey to identify the outcome of the contact with each sample unit. The American Association for Public Opinion Research provides the most comprehensive method of describing disposition categories (AAPOR 2008). For example, included in the “Eligible, Non-interview” codes is the classification “physically or mentally unable/incompetent,” while classifications for “institutions” and “group quarters” are included in the “Not Eligible” group of codes. In an ongoing survey, analysis of the cases or recontacting of sample members with these codes could provide useful information about exclusion. The planning group also recommended expanding the current AAPOR codes and introducing new ones that would provide additional information about reasons for exclusion.

Suggesting best practices for sample design is challenging because there is minimal research that informs decisions on how to address recognized issues related to people with disabilities. More information is needed on the extent of the coverage problem and who is most likely to be excluded. For example, random digit dial (RDD) surveys are generally believed to underrepresent persons with disabilities because some may have limitations using a telephone. Research focusing only on Washington State suggests that RDD surveys do not underrepresent adults with disabilities (Kinne and Topolski 2005). Overall, issues related to coverage are getting more attention because of ongoing communication changes, such as increased cell phone use and Internet access. As we learn more about coverage and other measurement issues that incorporate various modes of data collection, we will be able to inform discussions and decisions about maximizing the inclusion of people with disabilities in surveys. Meanwhile, it is most important for disability researchers to recognize sampling issues that might result in survey measurement error. Documentation and disclosure of the sampling methods are essential, so data users know as much as possible

about the population included, and more importantly, excluded from a study. Getting the advice of sampling statisticians can also provide valuable information related to statistical power and sample design effects. Appropriate research designs are needed to address the sample design inclusion issues identified by the planning group. The sample frame is the entry point into the data collection process, so any error or bias introduced there has major consequences on survey quality.

### **Proxies**

Among the topics that the planning group identified as being a top priority was the use of proxies to respond for sample members who have disabilities. Its main recommendation was to learn more about the effects of both proxy and assistant respondents on data quality.<sup>8</sup> Generally, the rationale for using proxy respondents is to minimize either unit nonresponse (exclusion of a sample member from the survey) or item nonresponse (missing data when a question is not answered). Although there is useful information about the use of proxies, for both people with and without disabilities, this information is typically based on secondary analysis of data that had previously been collected rather than experimental research designed explicitly to assess the potential measurement error associated with proxy responses. General guidelines based on current information suggest the following: proxy respondents are more likely to report a sample member has poor health but less likely to report a disability (Hendershot, Colpe, and Hunt 2003); factual questions are more likely to have proxy and self-report agreement than subjective or attitudinal questions; and proxies who are in close proximity to the selected sample member, such as a parent or a spouse, are more likely to give responses that correspond to what the sample member would say. In particular, among sample members with disabilities, individuals with mental retardation (intellectual disabilities) or learning disabilities are more likely to require a proxy than those with other types of disabilities.

Although further research is necessary on the data quality consequences of using a proxy, it is possible to suggest best practices for researchers who want to establish proxy guidelines to manage the potential error from nonresponse. The primary goal should always be to

minimize the use of proxy respondents. To do this, researchers should take advantage of the various technology options that are available to make surveys more inclusive for people with disabilities such as planning telecommunication assistance to offer to those with hearing impairments.<sup>9</sup> Another basic best practice is documentation of when a proxy has been used, the relationship of the proxy respondent to the sample member, and the reason why a proxy interview was conducted as opposed to a self-interview. Figure 8.1 illustrates how the 2001 Canadian Participation and Activity Limitation Survey records proxy information.<sup>10</sup>

Interviewers play a key role in proxy decisions; therefore, the survey design should include an explicit training plan for proxy selection and instructions for when, or if, a proxy respondent is eligible. Several methods can be used to assess if a person with a disability is capable to respond for him- or herself. One is a subjective approach that depends on interviewer judgment, training to guide this judgment, and cues to look for in response patterns and other behavioral indicators. Another is a somewhat more objective approach where a “score” on a series of questions and answers assists the interviewer in determining the sample member’s ability to participate (Ciemnecki et al. 2006).

Methods used to analyze the quality of proxy and self-reports include comparisons of self-reports and proxy reports with administrative information (Wright et al. 2007), test/retest research designs where proxy and self-respondents are contacted again to compare the two sets of results (Lee, Mathiowetz, and Tourangeau 2004), and secondary analysis of databases that compares proxy and self-respondent answers (Todorov 2003; Todorov and Kirchner 2000). There are a number of self- and proxy response comparisons, but the research is inconclusive.

Additional experimental research is needed to identify what is gained and what is lost with respect to data quality when proxies are substituted for the selected respondent. For example, a test/retest research design was developed to learn more about the differences in proxy and self-responses. Interviewers first collected baseline information from self-responders and proxies before returning to ask similar questions 14 days later (Lee, Mathiowetz, and Tourangeau 2004). The result was three groups that could be used for an analysis of proxies compared to self-responders: time 1/time 2 self-reports; time 1/time 2 proxy reports;

Figure 8.1 Canadian Proxy Questions

INFORMATION SOURCE		
	<b>Proxy Information</b>	
<b>Source:</b>	<b>Relationship to respondent:</b>	<b>Reason for proxy:</b>
(1) Respondent .... <input type="radio"/>	(1) Parent ..... <input type="radio"/>	(1) Does not speak English or French ..... <input type="radio"/>
(2) Respondent (via interpreter) ... <input type="radio"/>	(2) Guardian ..... <input type="radio"/>	(2) Unable to respond ..... <input type="radio"/>
(3) Proxy ..... <input type="radio"/>	(3) Child ..... <input type="radio"/>	(3) Absent – duration of survey. ... <input type="radio"/>
	(4) Other household member ... <input type="radio"/>	(4) Parent wishes to respond for child (15 or older). .... <input type="radio"/>
	(5) Other, specify <input type="checkbox"/>	
<b>Proxy name:</b>	<input type="text"/>	
First name(s)	<input type="text"/>	
Family name	<input type="text"/>	

and time 1/time 2 mix of proxy and self-reports. Not only did this study provide multiple results to inform various data quality dimensions, it identified several suggestions to improve future studies as well. In particular, the researchers speculate that using the last birthday method for respondent selection may have had an effect on the response to a core item in the first wave of data collection. Approximately 16 percent of proxies and self-reports responded in the same way to the question: Do you consider yourself (target person) to have a disability?

### **Questionnaire Design**

The planning group did not focus on questionnaire design primarily because, as noted before, of the numerous efforts related to developing concepts and questions used to identify the overall incidence of people with specific types of disabilities. However, because questionnaire design can contribute to survey measurement error and nonresponse, it is useful to provide researchers with some guidelines related to this phase of the survey process.

Disability researchers have expressed interest in identifying a standard set of questionnaire items that can be added to ongoing national surveys or used for new surveys being developed. Also, the Census Bureau (Stern and Brault 2005) and Bureau of Labor Statistics (BLS) (McMenamin 2006) have conducted methodological research and recently committed to using a common set of questions in the ACS and the Current Population Survey (CPS; see Stapleton, Livermore, and She 2009). Having the ability to identify disability subpopulations at relatively low cost using a standard set of questions can expand analysis opportunities. Interest in adding disability questions to other surveys is also growing. For example, the National Bureau of Economic Research's Shared Capitalism Research Project has already added the question, "Do you have a health problem or impairment lasting six months or more that limits the kind or amount of work, housework, or other major activities you can do?" on its employee survey. Without the inclusion of this single question, the experiences of employed people with disabilities could not have been reported (Shure et al. 2006).

Both to frame the discussion of the choices when developing questionnaire items and to provide inclusion guidelines for best practices, it

is useful to review the following four issues that can contribute to measurement error or differences in measurement when designing and using survey items related to disabilities: 1) question wording and response choices, 2) type of question (e.g., open-ended, close-ended, screening, or mark-all-that-apply list), 3) question context, and 4) questionnaire format. Each of these issues has to be considered when developing any questionnaire, but they take on heightened importance when designing a disability survey because researchers need to be vigilant for measurement errors related to social desirability bias and how people with disabilities perceive their abilities. Also, useful measurements of disabilities need to consider both duration (how long has the person had the disability) and extent of severity (e.g., visual problems can range from permanent total blindness to conditions that can be corrected by glasses, surgery, or other types of devices).

### **Question wording and response choices**

Some examples of surveys used for national disability statistics are the National Health Interview Survey (NHIS), the 2000 Decennial Census, the ACS, the Survey of Income and Program Participation (SIPP), and the CPS (see Weathers 2009). Many of the questions in these surveys ask for yes/no responses. However, the response choice decision may be more complex for a person with a disability. The selection of an answer might often be subject to interpretation, depending on his or her views about the severity of disability, its duration, or whether he or she is experiencing a “good” or “bad” period with respect to a chronic condition.

Beatty (2007) provides another example of a measurement issue related to how questions are asked. He pretested the question “Are you limited in any way, in any activities because of any impairment or health problem?” and found that, in multiple cases, people who “unambiguously” had physical and sensory disabilities, responded to this question with a “no” answer. He also observed that researchers treat disabilities as an objective fact when the reality is more complex. According to Beatty, people with disabilities view their limitations as a “gap” between what they want and can potentially do, and what they can actually do. This gap is not static; it changes due to a variety of fac-

tors and circumstances in their environment that can support or hinder an activity (Beatty 2007).

As common disability questions are introduced to the ACS and the CPS, and perhaps eventually added to other major surveys, it will be important to study the extent to which they fail to identify individuals that might be considered to have disabilities for some purposes and to mistakenly include some individuals with conditions that would rarely be considered a disability (e.g., readily corrected vision problems).

### **Type of question**

Research conducted by the National Science Foundation (NSF) illustrates how different question types can affect responses. The NSF uses two different types of questions to measure disabilities among the same population: the 2002 Survey of Earned Doctorates (SED; Figure 8.2) and the Survey of Doctorate Recipients (SDR; Figure 8.3). The SED uses a self-administered questionnaire with a yes/no screening question to identify people with disabilities. When a person self-identifies as having a disability, he or she is given five types of disabilities plus an “other” category to describe the disability. The SDR also uses a self-administered questionnaire, but it does not use the word disability or a yes/no response. Rather, the question asks the respondent to rank the degree of difficulty for two sensory and two physical activities. An analysis of data that compares the answers to each type of question from the same group of respondents showed that a higher percentage of people reported some type of difficulty in the SDR than reported a disability in the SED (Ballou et al. 2006).

### **Question context and format**

The experience of Statistics Canada shows how the context of the questionnaire overall, not just a specific item or set of questions, may contribute to measurement error. Currently, there are two core disability questions that are asked on its major surveys. Although the wording of the questions used for the disability rate is the same, the results differ depending on the overall survey topic (Table 8.3). The highest percentage of disability occurs when these questions are asked on the Canadian Community Health Survey (31.3 percent) and the lowest on the Par-



**Figure 8.2 Disability Questions from the June 2002 Survey of Earned Doctorates**

**C10. Are you a person with a disability?**

1. Yes  → **GO TO C11**

2. No  → **SKIP TO C12**

**C11. (IF YES) Which of the following categories describes your disability(ies)?**

*Mark (X) one or more*

a.  Blind/Visually Impaired

b.  Deaf/Hard of Hearing

c.  Physical/Orthopedic Disability

d.  Learning/Cognitive Disability

e.  Vocal/Speech Disability

f.  Other – Specify

SOURCE: Survey of Earned Doctorates, n.d.

ticipation and Activity Limitation Survey (14.8 percent). Although additional research is planned to learn more about the reasons for the variation in results, the prime consideration is that, within the context of the Canadian Community Health Survey, people think more about how their health contributes to what they can and cannot do (Stobert 2006).

An example of how several dimensions of questionnaire design can influence response, in particular the questionnaire format, is outlined in Stern's (2001) comparison of the results of the 2000 Decennial Census and the Census 2000 Supplementary Survey (C2SS). Stern notes that, although the disability-related questions were similar, the format of the questions and the mode of data collection resulted in a smaller percentage of people with a "go-outside-home" disability reported in the C2SS as compared with the 2000 Census. Stern speculates that these results could be due to the following four differences: 1) layout

**Figure 8.3 Disability Questions from the 2003 Survey of Doctorate Recipients**

**E18. What is the USUAL degree of difficulty you have with . . .**

Mark (X) one answer for each item.

	None	Slight	Moderate	Severe	Unable to Do
1. SEEING words or letters in ordinary newsprint (with glasses/contact lenses if you usually wear them).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
2. HEARING what is normally said in conversation with another person (with hearing aid, if you usually wear one)..	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
3. WALKING without human or mechanical assistance or using stairs.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
4. LIFTING or carrying something as heavy as 10 pounds, such as a bag of groceries.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

**E19.**  ← Mark (X) this box if you answered “None” to all the activities in question E18, and go to question E21.

**E20. What is the earliest age at which you first began experiencing any difficulties in any of these areas?**

AGE        OR       ← SINCE BIRTH

SOURCE: Survey of Earned Doctorates, n.d.

**Table 8.3 Example of Disability Rates for Those Aged 16 and Over for Major 2001 Canadian Surveys**

Survey type	Survey results (%)
Census	18.5
Survey of Labor and Income Dynamics	20.5
Canadian Community Health Survey	31.3
Participation and Activity Limitation Survey (all)	14.8

Questions used to create disability rates:

- 1) Does this person have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning, or doing any similar activities?
  - Yes, often
  - Yes, sometimes
  - No
- 2) Does a physical condition or mental condition or health problem reduce the amount or kind of activity this person can do:
  - a. At home?
  - b. At work or school?
  - c. In other activities, for example, transportation or leisure?
    - Yes, often
    - Yes, sometimes
    - No

NOTE: The same question wording was used in the different survey contexts.

of the 2000 Decennial Census enumerator form (used for interviewer-assisted responses) varied from the self-administered mailback forms, 2) text on the enumerator form was bolded and check boxes were located in a different place than on the mailback form, 3) presentation of the information related to question skip instructions was in italics on the enumerator form and in parentheses on the mailback form, and 4) the enumerator form had a column break in the middle of the disability questions.

As noted in these examples, additional research is needed to identify how different dimensions of the questionnaire can contribute to measurement error. Disability researchers need to further investigate the effects of the wording of questions to develop best practices related to questionnaire design.

## Data Collection

Accessibility to alternative data collection modes is another area to explore to promote full participation of people with disabilities in surveys. A benefit of expanding alternative modes is the reduction of both unit and questionnaire item nonresponse as described in the sample design section. Although most of the planning group's discussion was related to maximizing accessibility in the modes used for quantitative research, it was also suggested that there is a need to learn more about using qualitative data collection techniques.

### Quantitative data collection modes

Three research needs related to alternative modes of data collection should be addressed prior to making recommendations for surveys that include people with disabilities: 1) the effect of the data collection mode on the quality of the data, 2) the resources available to survey organizations to offer multiple modes, and 3) the availability and usefulness of alternative modes to the sample members who have disabilities.

In the past, most surveys used a single mode of data collection (e.g., in-person interviews, telephone interviews, mail, or Web-based, self-administered questionnaires) because there had been minimal research conducted on the advantages and disadvantages of using a mixed-mode approach. However, ongoing concerns about sampling frame coverage, particularly for telephone surveys, and reductions in response rates have increased the attention of researchers (de Leeuw 2005; Link et al. 2007). Currently, information about the impact of using mixed-mode designs on data quality and other dimensions of survey data collection operations is inconclusive, but as the general information about modes expands, it can inform data collection related to individuals with disabilities.

Although offering multiple modes of data collection on every survey can be expensive, most organizations have the technology available to provide these alternatives. However, it is often challenging to develop survey procedures to recognize and accommodate people with disabilities using the appropriate technologies, and there is minimal information about best practices to meet this operational inclusion issue. Individuals with hearing, visual, or cognitive disabilities may benefit

from having the option of selecting a preferred data collection mode. For example, Web-based survey innovations, such as a video of an interviewer using American Sign Language, would be more inclusive for people with hearing impairments, and a visual presentation of symbols such as “smiley” faces (Culbert 2002) or storyboards could be used for people with cognitive impairments. Creative data collection solutions exist and can be particularly effective when information is being collected from specific populations with identified disabilities.

A useful example of how research can inform the development of appropriate data collection modes is a project conducted for the New Jersey Commission for the Blind and Visually Impaired. Initially, sample members were mailed a survey packet with options for four self-administered formats (large-print, Braille, computer disk, or audiotape). Even with these options, the response rate was low and an analysis indicated that the respondents differed from those in the total population. When a toll-free telephone number was offered as a fifth option, response rates increased by 10 percent. Low utilization of the audiotape and computer disk resulted in the decision to omit these options in subsequent data collection rounds (Murray 2004).

Even when data collection mode options are in place, people with disabilities need to be able to access them. An analysis of the 1998 and 1999 CPS found that people with disabilities are much less likely to have some types of technology available to them than those without disabilities. For example, access to household computers (24 percent for people with disabilities versus 52 percent for those without disabilities) and the Internet at home (7 percent versus 26 percent; Kaye 2000). Both of these technologies could be used to expand the modes of data collection. Although the actual percentages may have changed since these data were reported, it seems likely that a technological gap continues to exist between individuals with and without disabilities. These examples underscore the need for additional research to inform recommendations about how the mode of data collection affects survey accessibility.

### **Qualitative methods**

Another approach to include people with disabilities is to use qualitative techniques such as individual, unstructured interviews; cognitive interviews; and focus groups. The key advantage of qualitative methods

is the flexibility to adapt to the needs of people with particular disabilities. Examples include using Communications Access Realtime Translation (CART),<sup>11</sup> signing for people with hearing impairments, visual presentations (storyboards, scenarios), or assisted response (the use of a personal assistant or job coach) for people with mental retardation or learning disabilities. There is anecdotal information about the benefit of using qualitative methods, but little systematic research has been conducted in this area. La Plante et al. (2004) used focus groups with 100 people with disabilities during a questionnaire development phase. The response from these groups resulted in a shift in the underlying concept of questions about day-to-day activities from the traditional focus on what people cannot do to an assessment of the different ways similar activities could be accomplished. Another example comes from a pretest when a structured interview using a questionnaire elicited no response from a person with a disability. When a qualitative approach was used with the same person, however, it became clear that the person did not have a cognitive impairment, was knowledgeable about his health, and could talk about it in a conversation—what he could not do was respond to structured questions (Beatty 2007).

Whether a researcher is considering qualitative or quantitative research, mode of data collection is a core issue related to inclusion. The planning group discussed research that could provide the information needed to address this issue and recommended that research could begin with studies that focus on people with particular disabilities in order to identify their responses using various modes. While there are lessons to be learned from the research being conducted on the overall issue of the consequences of mixed-mode data collection on survey quality, a valuable extension of this research would be to focus on people with disabilities.

Recommendations for best practices are based on available information and practical solutions that have already been applied. For surveys of populations where there are known disabilities, such as a consumer study of people with hearing impairments, alternative modes should be in place. For general population surveys, it is helpful to train interviewers to identify or ask about accommodations, provided that survey organizations have the resources available to make these accommodations. For example, a simple, but important, improvement is

training interviewers to identify the tone that signals a text telephone device in a household so that the sample member can be recontacted using the appropriate technology.

## **Interviewers**

Related to data collection, the planning group noted the importance of the role of the interviewer in obtaining quality information. A set of guidelines for the selection and training of interviewers who conduct research with sample populations of people with disabilities is a priority action for best practices. Specifically, the planning group recommended developing a comprehensive interviewer training guide that focuses on the following three things: 1) sensitizing interviewers to issues faced by the respondents who have a range of disabilities; 2) training interviewers on how to overcome communication, stamina, and cognitive barriers; and 3) providing techniques that support interviewers to reduce stress and burnout. In addition, related to the theme of best practices that are inclusive, the planning group suggested that researchers learn more about using persons with disabilities as interviewers. Experimental studies comparing interviews conducted by individuals who have disabilities with those who do not will provide an opportunity for a PAR-centered research approach in addition to expanding information about response quality when interviews are conducted by individuals with disabilities.

### **Interviewer training**

Current information about interviewer training that focuses on ensuring full participation of persons with disabilities is minimal. Of note are two sources that provide a foundation for the development of a standard interviewer training guide: “Training Temporarily Able-Bodied Survey Interviewers” (Glazier 2007) and “Removing the Barriers: Modifying Telephone Survey Methodology to Increase Self-Response Among People with Disabilities” (Ciemnecki and CyBulski 2007).

Table 8.4 provides a summary of the key guidelines included in the sensitivity training module that Glazier developed for in-person interviewers who will be collecting data from persons with disabili-

**Table 8.4 In-Person Interviewer Sensitivity Training Guidelines**

- 1) Always treat the person with a disability as a person and maintain eye contact with him or her.
- 2) Do not to make assumptions about the person's mental or physical capacities that could be unwarranted or insulting.
- 3) Keep in mind who the actual respondent is and focus attention on him or her in situations where there is a third party, proxy, or interpreter present.
- 4) Free the room of other distracting influences (like a noisy TV or radio, pets, playing children); suggest closing doors where it will help ensure privacy and/or cut down on background noise.
- 5) Position yourself at the respondent's eye level when interviewing someone in a wheelchair.
- 6) Repeat the question and response options as necessary, without taking on a condescending tone. Take notice of the respondent's demeanor and facial expressions; if he or she appears confused, offer to repeat the questions and response categories.

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SOURCE: Glazier (2007).

ties. Ciemnecki and CyBulski have developed a training program for overcoming barriers to interviewing persons with disabilities over the telephone. The training program consists of a question-by-question review of the instrument, sensitivity exercises, and a discussion of contact protocols and refusal avoidance techniques. It also incorporates modules on how to overcome communication, stamina, and cognitive challenges, including the following:

- Communication challenges (e.g., speech and hearing impairments): use a normal tone of voice and do not restrict conversations to single-syllable words; use controls on headsets to amplify incoming and outgoing sounds; do not pretend to understand something—go back and build from the point at which responses were understood.
- Stamina challenges (e.g., mental and physical fatigue): be cognizant of behaviors that might suggest the respondent is too fatigued to continue with the interview; ask whether the respondent needs a call back, and set appointments for times when the respondent is more alert.



- Cognitive challenges (e.g., emotional disturbance, difficulty processing questions and responses, and confusion about the purpose of the interview): learn nonbiased, nondirective probing methods (silence, repeating the question and response categories, and stressing generality and subjectivity); use active listening skills and remain patient during the course of the interview.

### **Interviewer morale**

Training that emphasizes the needs of respondents with disabilities is at the core of best practices for quality interviewing. Researchers can also maximize the benefits of having a well-trained staff by being attentive to interviewer needs. They need to know that the usual production standards (hours per completed interview) are not as important as taking time to ensure that the respondent understands the question and response categories, is comfortable with the interview process, and has ample time to formulate a response (Ciemnecki and CyBulski 2007). A method to reduce compassion fatigue and burnout felt by people who are exposed to difficult circumstances experienced by others is to schedule periodic debriefings so that the interviewing staff can discuss their experiences, provide support for one another, and receive encouragement from supervisors (Markesich and Ballou 2006). Another advantage of interviewer debriefing is that they can identify opportunities to improve future questionnaires (e.g., through simple, clear wording that reduces the need for repetition).

### **Persons with disabilities as interviewers**

Using interviewers who have disabilities is another way to promote a PAR-centered research approach. The survey research literature, although inconclusive, has information about the effects on data quality when interviewers and respondents are matched on sex and race. But there is little research on the feasibility of using persons with disabilities as interviewers or the impact it would have on data quality. Available information suggests that persons with disabilities can be trained to conduct interviews with their peers, and they may obtain improved responses compared to interviewers without disabilities (Bonham et al. 2004; Perry and Felce 2004).

Bonham et al. provide a description of Maryland's "Ask Me!" project (Arc of Maryland n.d.), including information about the recruitment and training of people with disabilities to be interviewers, the in-person data collection procedures and modifications made to accommodate interviewers with various disabilities, and the results of the survey, including an analysis of data quality. Although this research did not have comparison information for people without disabilities, the documentation is useful for those considering using people with disabilities as interviewers.

Perry and Felce (2004) describe the experience of using one person with a mild intellectual disability to conduct quality of life interviews with his peers and include a comparison with data collected by an interviewer without a disability. They found that the inter-rater reliability was high on two of the three measures included in the research. However, where there was low inter-interviewer agreement, greater satisfaction, choice, or importance was reported on 13 items for the interviewer without a disability and on 10 items for the interviewer with the impairment.

## **SUMMARY AND RECOMMENDATIONS**

This chapter summarizes the best practices for disability survey methods identified by a planning group comprised of disability and survey researchers. It is a road map of best practices that should be used to improve the quality of disability surveys and notes where available research is inconclusive. Use of the recommendations summarized below will improve disability surveys and systematically provide documentation that can be incorporated into the growing body of knowledge. Federal agencies, through the request for proposal process and the Government Performance and Results Act, have the mechanisms to encourage the use of these best practices. Conducting the research proposed in this chapter and summarized below will further inform recommended best practices and increase confidence in establishing standards for methods used to conduct surveys with or about people with disabilities.

## **Recommended Best Practices**

### **Include people with disabilities**

PAR must be considered. Although there is limited research to document the differences in research conducted with and without the participation of people with disabilities, current evidence suggests data quality can be improved by including people with disabilities. Researchers should be vigilant about addressing the need to include people with disabilities in all phases of the survey process.

### **Use available resources**

*Surveying Persons with Disabilities: A Source Guide* (Markesich, Cashion, and Bleeker 2006) provides a starting point for any disability research project. Although the research included in the collection of sources may not be definitive, these citations provide extensive information related to the methodological issues associated with surveying persons with disabilities and include documentation on approaches that have been used to improve accessibility.

### **Plan your research**

Using the guidelines listed in Table 8.2, researchers must keep in mind the key steps in the process that can impact data quality, particularly for research about and with people who have disabilities. At a minimum, reviewing these guidelines can help in making thoughtful and deliberate decisions about survey methods. In addition, information in this chapter identifies steps in the survey process where particular attention is needed to improve measurement quality.

### **Train interviewers**

Current research identifies what interviewers should know to make sure they have the tools needed to communicate with people who have disabilities. This training should include recognition of types of disabilities, criteria for the selection of proxies, and options that can be used when interviewing people with disabilities, such as alternate wording of questions and qualitative approaches that may differ from interviews with people who do not have disabilities.

### **Provide documentation**

The information presented in Table 8.1 shows what is needed to provide full disclosure of survey methods. It is feasible to provide complete and easily accessible documentation on disability survey information, and doing so has the added benefit of describing how various methods improve survey quality. This documentation is also essential for analysis to assist researchers in evaluating data quality.

### **Perfecting Best Practices**

#### **Meta-analysis of current research**

A useful next step would be to conduct a meta-analysis that synthesizes data on similar topics. A systematic analysis of information would identify consistent research results that can be used to set best practice standards with increased confidence and to target the knowledge gaps that require research.

#### **Conduct methodological and experimental research**

We described examples of research that is needed to inform a set of best practices for surveying persons with disabilities in our discussion of the steps in the survey process: sampling, questionnaire design, and data collection methods. A goal of the planning group was to establish priorities for future research. This was a tremendous challenge because there are multiple issues that need to be addressed. Information from a meta-analysis could provide guidance on future research priorities.

Educating researchers, both those using data for analysis and those designing surveys to obtain data from and about people with disabilities, will result in improved disability information. One of the major changes needed in disability research is the inclusion of people with disabilities in all phases of the process. Being attentive to the methods used to collect survey information will increase the confidence that the data used for a range of public policy and service provision decisions more accurately represents people with disabilities.

## Notes

1. See Office of Management and Budget (2006a).
2. Members of the group (and their affiliations at the time of the meetings) were Barbara Altman, Paul Beatty, and Jennifer Madans, National Center for Health Statistics; Marjorie Goldstein, Institute for AIDS Research and Center for Drug Use and HIV Research at the National Development and Research Institutes; Gerry Hendershot, consultant in Disability and Health Statistics; Corrine Kirchner, American Federation for the Blind; Thilo Kroll, University of Dundee; Douglass Kruse, Program for Disability Research at Rutgers University; Charlie Lakin, Institute on Community Integration at the University of Minnesota; Andrew Houtenville and David Stapleton, StatsRRTC members participating from Cornell; and Janice Ballou, Anne Ciemnecki, Karen CyBulski, and Jason Markesich from Mathematica Policy Research, Inc. The group met by conference call on October 7, 2005, and November 8, 2005. Between meetings, the members completed a questionnaire and exchanged other information related to best practices on surveying persons with disabilities.
3. The Delphi Method is based on a structured process for collecting and distilling knowledge from a group of experts by means of a series of questionnaires interspersed with controlled opinion feedback (Adler and Ziglio 1996).
4. Examples of other organized efforts to study and improve disability research include The Washington Group (ongoing meetings with an international focus whose goal is to define and develop question wording to identify people with disabilities); research and conferences of the World Health Organization's ongoing International Classification of Functioning, Disability and Health; the Institute of Medicine and National Research Council's Workshop on Functional Capacity and Work (June 1998) and Workshop on Survey Measurement of Work Disability (May 1999); 2000 National Center for Health Statistics review "Inclusion of Disabled Populations in Social Surveys: Review and Recommendations"; and the Interagency Committee on Disability Research, Interagency Subcommittee on Disability Statistics, "Workshop on Best Practices for Surveying People with Disabilities" (April 2004). The Committee to Review the Social Security Administration's Disability Decision Process Research produced a text, *The Dynamics of Disability: Measuring and Monitoring Disability for Social Security Programs*, that has useful insights on disability research methods (Mathiowetz 2002a,b).
5. See World Health Organization (n.d.).
6. The Interagency Committee on Disability Research, Interagency Subcommittee on Disability Statistics, "Workshop on Best Practices for Surveying People with Disabilities" was held in Washington, DC, on April 19–20, 2004. This conference focused on providing information about how researchers were addressing the needs related to conducting disability research. Kroll et al. (2007) summarizes the presentations from this conference.
7. Social desirability, or the need to present oneself favorably, is a possible reason that respondents give biased or inaccurate responses. There are some questions in

which the respondent may become uncertain on how to answer because there is a perceived norm that defines or directs the answer that is most likely to be approved or considered positive. For example, a person with a disability may consider his or her condition as undesirable and not want to give this information to an interviewer.

8. Assisted interviews are means of facilitating self-response without relying on a proxy. Sample members respond for themselves, but another person, familiar with the respondent's abilities, is present who may occasionally help interpret or in other ways assist so the respondent can answer a question.
9. With changing technology, there are various assisted listening devices that can be used by people with hearing impairments to participate in telephone interviews. These include telephone typewriters (TTY), instant messaging, and video relay services.
10. Statistics Canada conducts the Participation and Activity Limitation Survey (PALS) to identify Canadians whose day-to-day activities may be limited.
11. CART facilitates communication for people who are deaf or hard of hearing. Also known as realtime captioning, CART is a word-per-word translation of spoken English onto a laptop or notebook computer by use of realtime software and a steno machine. Set-up time is moderate and the CART reporter usually provides the necessary equipment.

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# **Counting Working-Age People with Disabilities**

## **What Current Data Tell Us and Options for Improvement**

Andrew J. Houtenville  
David C. Stapleton  
Robert R. Weathers II  
Richard V. Burkhauser  
*Editors*

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W.E. Upjohn Institute for Employment Research  
300 S. Westnedge Avenue  
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