APPENDIX A

Bibliography
INCLUSION OF DISABLED POPULATIONS IN SOCIAL SURVEYS: BIBLIOGRAPHY

Jennifer A. Parsons
Sara Baum
Timothy P. Johnson

Prepared by the Survey Research Laboratory
University of Illinois at Chicago for
The National Center for Health Statistics

December 2000

An Internet survey to record respondent experiences and attitudes about using Braille. Offers alternate survey formats. Survey questions include descriptions of many reading methods and Braille tools.


Gives estimates of the numbers of blind or visually impaired adults who use Braille. Also describes the various ways that Braille is used by different people. Points out that Braille readers are a relatively small percentage of those who are legally blind in the United States and that Braille reading is associated with higher education, employment, and income.


The Americans with Disabilities Act of 1990 is a landmark piece of civil rights legislation. It has five main Titles—Employment (Title I), State and Local Governments (Title II), Public Accommodations (Title III), Telecommunications (Title IV), and miscellaneous. Each outlines the rights of people with disabilities and responsibilities of particular entities to provide reasonable accommodation and to refrain from discriminatory practices.


The authors explore the validity and proxy reliability of seven new questions used in the 2000 U.S. Census. The research showed that proxies reported more impairment than people with disabilities did and that agreement between respondents and proxies was low. There was moderate concordance between the Census questions and questions from other surveys (BRFSS and ADL instruments). Concludes that the Census 2000 disability questions may not provide an accurate profile of disability in America.


Discussion of a court case centered on the issue of whether HIV and AIDS are to be considered disabilities and the implications of this decision for policy.

Presents the results of a study done to determine the prevalence of telephone ownership in different deaf populations and to explore the implications for telephone-based surveys.


The authors conducted an expert review of two instruments that had questions measuring print reading disability (difficulty reading print). Print reading disability measurement questions in the 1984 National Health Interview Survey and 1992 Survey of Income and Program Participation instruments were explored in an attempt to explain why results of the two measures are so different. The authors explored differences in overall survey design and questions and conducted cognitive interviews to determine how respondents interpreted the instruments. They conclude with a discussion of the important differences between the two measures.


Discusses definitions of disability as well as considerations in the development of a coherent social policy for people with disabilities. Focuses on goal clarification, formulation of objectives, and the conceptual foundations of social policy for people with disabilities.


Researchers translated and back-translated the Minnesota Multiphasic Personality Inventory and tested the instrument. The authors discuss the success of the translation as well as future directions for translating other psychological assessment instruments.


Describes learning disabilities and outlines the implications of the ADA for learning-disabled individuals. Offers suggestions for accommodations to help with comprehension, vision, focus, and reading. Includes contact information for related organizations and professionals.


Addresses the issues of reasonable accommodation, considerations for accommodation during the job application and interview process, tips for interaction, and telephone/mail resources to contact for further information.

The goal of this survey was to determine the number and characteristics of people with disabilities employed at the casinos in Atlantic City. The report includes sections on methodology, questionnaire format, pretesting, problem areas, survey administration, participation, and response rates. An enlightening key informant interview was conducted with Monroe Berkowitz of Rutgers University, who worked on the project.


This study was designed to determine whether a reliable instrument could be developed to measure the loneliness experienced by workers with mental disabilities. Supervisors were also asked to rate workers. People with mild, moderate, and severe disability were surveyed.


Information on interpreter referral services, sign language classes, and other services available for those attempting to learn ways to communicate with people who have difficulty hearing.


The authors discuss matching research goals with the appropriate translation strategy, using a backtranslation process to change written English to ASL, and qualifications and role expectations for a research interpreter.


Addresses problems in determining the prevalence of disability, the difficulty in defining disability, and the implications for major national surveys. Includes recommendations for future research.


Used during the training of field interviewers for the National Health Interview Survey on Disability. The narrators talk about situations surrounding disability that might arise and ways in which these situations might be handled.

Discusses a survey conducted by the Association for Computing Machinery of its membership regarding computing and disability issues. Covers the ADA, definitions of disability, and briefly touches upon survey development and procedures.


The Final Report of the survey conducted by the Association for Computing Machinery. The survey instrument is included in the report. Most of the report consists of graphs and tables of results. There is also a section of comments made by respondents.


This document is a report of the cognitive evaluation of two proposed versions of the disability questions for the 1998 Dress Rehearsal questionnaire. The document outlines problematic questions, question types, and concepts, and the authors suggest revisions.


Outlines the types of jobs that people with visual impairments can perform, ways to accommodate people with visual impairments in the workplace, job interview strategies for interviewing people who are visually impaired, and modifications that can be made to facilitate productivity and satisfaction. Includes other resources for those interested in the topic.


This Web page offers information on assisting test-takers with disabilities. It outlines adaptive technologies and accommodations available through the Educational Testing Service and explains how to register to take alternate formats of ETS tests.


Discusses the relevance of IQ and personality tests for adults with mental retardation and briefly addresses the problem of requiring complex language responses from people with mental retardation.

Compared telephone and face-to-face interviewing in a community psychiatric survey of Holocaust survivors and European-born respondents who were in pre-state Israel during World War II.


The researchers collected information on thoughts and feelings about casual social interaction between nondisabled college students and peers with various physical disabilities.


Comprehensive information regarding the content of disability survey questions. Offers an in-depth background of such questions and provides a bibliography of surveys that have used disability questions. For most sources, provides a summary, the questions used, testing methods, methodology issues, and key words.


Examines the literature regarding the validity of the assessments of deaf individuals from both a psychometric and a cultural/linguistic viewpoint. Recommendations for improving mental health assessment and services are included.


This is a guide for professionals working with people with disabilities. Provides, for a diversity of disabilities, information regarding the disability, appropriate language and behavior, and strategies for successful interaction (geared toward both people with and without disabilities).


Briefly explains brain injury, the implications of the ADA for people with brain injury, and accommodating a job applicant or employee with brain injury. Techniques for interviewing people with brain injury and a resource guide with other information sources are included.

Experimenters portraying people with and without disabilities asked directions to a college bookstore. Conversations were recorded and verbal interaction patterns were analyzed. Response to students with disabilities was different than the response to students without disabilities.


The results of the Survey of Income and Program Participation with respect to rates of labor force activity. Discusses the low rates of labor force activity among people with disabilities.


A manual used to train interviewers with developmental disabilities to interview other adults with developmental disabilities. Includes information on purpose, consent, confidentiality, privacy, starting the interview, location of interview, during the interview, nonverbal communication, and possible difficult situations that might arise.


 Discusses response biases in interviews with people with mental retardation. Addresses acquiescence and the role of status in determining the effects and discuss question formats that seem to reduce acquiescence and nay saying.


Addresses the implications of the Groves-Couper model of nonresponse in household interviews for respondents with disabilities. Addresses the issues of nonresponse among people with disabilities, interviewer assessment of the ability to respond, contact and cooperation, and the interviewer field experience. Outlines the importance of obtaining accurate information regarding people with disabilities.


Addresses reasons for the need for research on disability survey methodology. Provides an outline of what types of research are needed and discusses mechanisms for funding research.

Uses the nonresponse framework of Groves and Couper to discuss factors related to nonresponse for people with disabilities. Discusses the issues of contact, cooperation, proxy, barriers created by survey procedures, and interviewer techniques and training.


A description of IntelliKeys, a special keyboard which can be custom-designed by the user to facilitate typing and mouse use.


This collection of Interagency Subcommittee on Disability Statistics meeting minutes includes information on a variety of current topics in disability research and statistics as well as contact information for subcommittee members.


A project in which cognitive interviewing techniques were used to investigate problems in comprehension, information retrieval, and estimation of answers among older respondents.


Addresses potential cross-cultural implications with respect to question interpretation, memory retrieval, judgment formation, and response editing through the provision of the results of a study evaluating the cognitive processes used by respondents to answer survey questions.


Describes research done in the deaf community by two researchers, one deaf and one hearing. The authors engage in a dialogue about the process of working with each other and with the respondents and the impact that researcher hearing status might have on the research process.


Discusses labor force trends of persons with disabilities; includes a section on methods.

Touces upon several aspects of life for people with disabilities in the United States, including demographics, employment, social integration, barriers to independence, and transportation. Prepared by Disability Rights Advocates, Inc., with statistical information provided by the Disability Statistics Center at the University of California at San Francisco.


The researchers conducted intensive interviews with 36 older people, using think-aloud and cognitive probes, to study response errors in measuring functional status in health surveys. Different interpretations of concepts and problems in recollection are discussed, and the authors offer recommendations for questionnaire design.


Discusses ways to adapt conventional research techniques to accommodate people with disabilities and provides examples of the problems associated with surveying people with disabilities, including issues related to telephone use, print questionnaires, and use of proxies. Also presents reasons why the inclusion of people with disabilities is important for research. Makes recommendations to researchers, including a general awareness of the issue and the use of adaptive technologies.


Discusses methodological issues in research related to vision impairment. Discusses a broad range of topics, spanning the entire research process, related to the inclusion of people with vision impairments in social research. Argues that the researcher’s perspective on disability can shape the research in important ways.


The aims of this study were to determine the usefulness of a telephone survey to assess health status among people with high risk for morbidity and disability and to evaluate the value of a telephone interview for making judgments about individual patient management.


Addresses definitions of disability and provides demographic information on disability.

This report presents data on the prevalence of disability among the civilian non-institutionalized population in the U.S. in 1992. Data come from the National Health Interview Survey. Prevalence estimates are presented in detailed tables for various population subgroups. The 1992 estimates are compared with earlier reports.


Traces the development of the Interactive Video Questionnaire for interviewing deaf people by using manually signed questionnaires on video. Also discusses obstacles to gaining information from people who are deaf regarding substance abuse and other issues.


Researchers examined the validity and reliability of instruments for assessing mathematics, communication, interpersonal relations, and reasoning skills among people who were deaf, legally blind, or visually impaired. The authors discuss ways in which the instruments were adapted for administration to students with disabilities.


Examined applicants’ with disabilities and interviewers’ without disabilities perceptions of the employment interview process.


Discusses the implications of the ADA for people with psychiatric disabilities, popular misconceptions about this population, ways to assess whether a person has a psychiatric disability, helpful accommodations, and resources for additional information.


Addresses federal government efforts to define methods related to the measurement of work disability. Discusses sampling, coverage and nonresponse error, observation error, proxy respondent use, interviewer effects, question wording, and other factors related to the measurement of work disability status. Also examines the divergent work disability prevalence rates found by various government surveys.

Focuses on the reassessment of previous self/proxy comparisons and presents findings from a telephone adaptation of the National Health Interview Survey designed to investigate response error associated with self and proxy reports. The results show that when self-response is limited to a randomly selected respondent, the self-respondents report fewer health events for themselves versus for others in their household.


Describes the need to ensure access to health research and health research instruments for people with disabilities and discusses “disabling” features of health research and proposes remedies to assure wider access.


Discusses ways that people with severe disabilities can answer questions using an electroencephalogram-based brain-computer interface.


Focuses on developing interventions that can prevent pathology from developing into impairment, then functional limitation, then disability, and ultimately disability with secondary conditions. Discusses definitions and conceptions of disability.


Deals with issues surrounding the definitions of disability.


An extensive report which addresses education, vocational rehabilitation, employment, empowerment, mental and physical health, prevention, substance abuse, and research needs as they relate to minorities with disabilities. Presents recommendations for research.

Synthesizes recommendations by researchers and consumers regarding disability statistics policy in light of the Americans with Disabilities Act. Addresses the “new paradigm” of disability and offers suggestions for refining data collection efforts, using existing data, developing new instruments, and broadening dissemination. Also offers recommendations for improving a number of large national surveys.


NexTalk software allows for the use of voice modems to make TTY calls. The Web page outlines product features, pricing, modem requirements and upgrades, phonebook conversion, and available services. The reader can also download an Adobe Acrobat version of the NexTalk software flyer.


In this presentation, the author described the process of attempting to include deaf respondents in the National Immunization Survey. Issues such as telephone penetration, TTY recognition, advance letters, and letter postscripts were discussed. Concludes that the number of households that require special assistance is unknown and that efforts to proactively identify sampled households that needed assistance were not successful.


A compilation of tables and charts from data gathered from a survey on use and opinions of video description. The report itself is in “described” format.


Addresses the issues of proxy response, confidentiality, exclusion, and alternate formats for people who are visually impaired. Includes detailed suggestions for translation to large print, Braille, voice, and digital formats.


Discusses the applicability of contemporary cross-cultural ethical principles and practices in deafness research, focusing on the importance of framing deafness research as cross-cultural and ways in which ethical practices affect both individual participants and the larger community.

Addresses the need for a redesigned process for eligibility for the Social Security program. Includes information on background, framework for research, and the research plan for the redesigned disability decision process.


Presents data on annual estimates of prevalence of use of assistive technologies related to vision, hearing, mobility, and orthopedic impairments. Also presents statistics for prevalence of use of certain assistive technologies for 1980, 1990, and 1994. Concludes that assistive technology use has increased due to changes in population, age composition, and rates of use. Medical and technological advances and certain public policies have contributed to increased use of assistive technologies.


Expresses the need for quality data on disability. Gives a brief history of disability surveys and examines frameworks for conceptualizing disability. Also addresses the reliability and validity of responses to disability questions and self-identification of disability.


Discusses one of the first major surveys of people with hearing impairments. Includes information on survey design, execution, diversity within the “deaf” community, sampling, interviewer recruitment, deaf interviewers, and an interviewer’s manual.


Describes the Interagency Committee on Disability Research, current trends in disability research, and recommendations for new methods for collecting information on medical rehabilitation, technology, and employment.


The authors conducted a survey of people with mental disabilities to assess their needs, attitudes, and circumstances. Extensive attention is given to study design and administration. Offers suggestions for interviewing, obtaining consent, scheduling, and questioning approaches.

The researchers conducted interviews and collected data on the impact of using pictures to accompany survey questions. The use of pictures had no impact on yes-no questions but did improve responsiveness to multiple-choice and either-or questions.


The researchers conducted interviews to measure responsiveness and examined the impact of various question types and the use of pictures.


Comprehensive study of the issue of disability, violence, and abuse. The first section covers research and conceptual models of abuse, reviewing almost 30 studies that have examined the relationship between abuse and disability. The second section offers suggestions for intervention in abuse situations. An appendix includes contacts and resources.


Investigated reactions by people to interviewers who had an apparent physical disability and the role that their physical appearance played in the interaction.


The authors sought to understand the deaf community’s knowledge, attitudes, and beliefs about mental health and illness. Discusses the issues inherent in translating mental health-related concepts between American Sign Language and English.


The authors investigated the feasibility of translating the National Institute of Mental Health Diagnostic Interview Schedule-III, Revised, Computer version, for deaf individuals. The study involved translation of the interview schedule into American Sign Language, signed English, and speech reading. Focus groups and reviews were used to assess the feasibility of translation.

Examines the experience of loneliness among those who are deaf and in the working population. Addresses difficulties in translating the concept of loneliness into ASL and in applying “hearing” concepts of loneliness to a “non-hearing” culture.


Examines the potential bias associated with proxy effect (inaccurate reporting about characteristics of others) and saliency effects (reporting of only the most salient disability features) in a mail survey about disableness.


Three different analyses using data from the National Health Interview Survey on Disability were analyzed to examine differences between self-reports and proxy reports of disabilities. Data suggest that use of proxies does introduce systematic biases, which in turn affects national disability estimates.

Transcripts from Focus Group with National Health Interview Survey field interviewers. October 15, 1997.

Moderators discuss opinions and concerns about the interview process with NHIS Field interviewers. They address questions that did/didn’t work, communication problems, high mobility of respondents, subjective conceptualization of disability, support of field supervisors, and issues relating to disability that interviewers encountered and attempted to resolve.


Addresses sample size and techniques for increasing efficiency of sampling of people with disabilities. Discusses dual- and multi-frame approaches, two-phase sampling methods with questionnaire screening, and the use of large clusters.


Offers a brief summary of data on disability collected by the United States Bureau of the Census through the SIPP, the decennial census, and the Current Population Survey. Briefly discusses question coverage, as well as some of the drawbacks of these surveys.

Includes a description of the Disability Followback Survey, guidelines for asking questions, types of questions, and probing techniques. Also addresses the issue of contacting the sample person and the use of proxy interviews. Chapter 12 focuses specifically on interviewing persons with disabilities and includes general tips, disability-specific tips, and information on institutionalized persons.


Discusses the background of thinking about disability measurement and the issue of parsimony, presents results from two projects using different types of disability items, and draws conclusions about the use of detailed and global disability items.


Guide to developing an ADA-compliant Web page that is easy to read and navigate for people with disabilities. Explains ways to improve and describe graphics, links, tables, lists, and color scheme. Addresses issues such as white space, simplicity, consistency, and contrast. Also includes list of other Web sites devoted to this topic.


Web-based tool that analyzes Web pages for their accessibility to people with disabilities and indicates any errors found on the page so that they can be remedied.


Web page offering a variety of adaptive technology products for assisting people with disabilities in the use of computers. Various mouse types, voice synthesizers, and other software are described and offered for purchase.


Outlines the ICIDH-2, a conceptualization of disability which is an attempt to establish a common language of disability, to stimulate better care and services, to permit international comparison of data, and to provide a systematic coding system for recording data on people with disabilities.

The authors examine telephone interviews as a way to collect data from elderly people after their release from the hospital. The article includes a literature review and firsthand accounts of the interview experience. The authors discuss the problems interviewing people who had difficulty hearing or were unwell.

www.als.uiuc.edu/infotechaccess/win-ZoomText-about.html


Examined the ethnic and socioeconomic factors relating to older Latino adults who report for themselves in survey research versus those who use a proxy respondent.