Cornell University
ILR School
Employment and Disability Institute

Cornell University Rehabilitation Research &
Training Center on Disability Demographics & Statistics

Surveying Persons with Disabilities:

A Source Guide

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I. INTRODUCTION

In 2003, The National Institute on Disability and Rehabilitation Research (NIDRR) funded a Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC) at Cornell University's Employment and Disability Institute (EDI). The goal of the Center is to "explore the reliability of existing data sources and collection methods and evaluate ways to improve and expand current data collection efforts" (EDI 2008). As a collaborator with the StatsRRTC, Mathematica Policy Research, Inc. (MPR), has been working on a project that identifies the strengths and limitations in existing disability data collection in both content and data collection methodology. The intended outcomes of this project include expanding and synthesizing knowledge of best practices and the extent to which existing data use those practices, informing the development of data enhancement options, and contributing to a more informed use of existing data.

In an effort to provide the public with an up-to-date and easily accessible source of research on the methodological issues associated with surveying persons with disabilities, in 2006 MPR prepared "Surveying Persons with Disabilities: A Source Guide." The first version of the Source Guide has 150 abstracts, summaries, and references pertaining to the following subjects:[1]

- Aged/Elderly
- Cognitive Disabilities[2]
- Deaf/Hard of Hearing
- Interviewer Training
- Nonresponse

[1] We do not present any literature specifically related to the conceptualization or definition of disability or on disability measures suitable for censuses and national surveys (for instance, the International Classification of Functioning, Disability, and Health), as these topics have been explored in depth by members of the disability and survey research communities.

[2] Includes mental retardation, developmental disabilities, and learning disabilities.

- Participatory Action Research (PAR) and the Survey Process
- Physical Disabilities
- Proxies[3]
- Psychiatric Disabilities/Mental Health
- Qualitative Research Methodologies
- Questionnaire Design and Development/Instrumentation
- Response Biases[4]
- Sampling and Sample Design
- Satisfaction/Quality of Life
- Survey Modes/Adaptive Data Collection Technologies[5]
- Vision Impairment and Blindness

Since the publication of the first version of the Source Guide, we have continued to gather material related to surveying persons with disabilities. Our intent was to periodically update this "living document." This second version of the Source Guide has 75 new abstracts and reference citations—more than half are from materials available from 2004 or later.

The references in this edition date from 1974 to 2007 and they are from multiple and diverse sources:

- Online journal articles and social science resources such as Web of Science, Web of Knowledge, Inter-University Consortium for Political and Social Research (ICPSR), Online Computer Library Center (OCLC) First Search, PsychLit, SocAbstracts in OVID, Academic Search Premier, and Sociological Collections in EBSCOHost
- Conference presentations, papers, and summaries
- Citations from articles and books

[3] Includes proxy bias and the comparison of proxy and self-reported data.

[4] Examples include acquiescence bias, social desirability bias, and recency effect.

[5] Includes articles that discuss telephone, in-person, mail, and Web-based surveys. Also includes American Sign Language-based (ASL) surveys and the use of Teletypewriters (TTYs) and speech reading as adaptive technologies.

- The websites of federal government agencies and federal government survey contractors
- Internet search engines, such as Google and Yahoo
- Working papers and dissertations

Following this introduction, the first section of the Source Guide is the complete Reference List that provides full citations with abstracts.

A triangle (▲) has been placed at the end of each citation in which an author's or publisher's abstract has been used to summarize the referenced source.

An asterisk (*) denotes abstracts and reference citations that have been added to the second version.

Next is the Subject Index, which cross references the sources from the Reference List under various subjects. Many of these sources are indexed under more than one subject in this section because references have been placed in all applicable categories. The final section, Additional Sources of Information, lists reference citations of works that are not summarized in the Reference List or listed in the Subject Index. As in the Subject Index, references in this section have also been placed in all applicable categories.

Readers who are interested in contributing to future Source Guide updates should send copies of relevant literature to MPR's librarian, Jan Watterworth.

E-mail: jwatterworth@mathematica-mpr.com

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REFERENCE

Employment and Disability Institute. Rehabilitation Research and Training Center on Disability Demographics and Statistics. Available at http://www.ilr.cornell.edu/edi/p-srrtc.cfm. Ithaca, NY: Cornell University, Employment and Disability Institute, 2008.

II. REFERENCE LIST

Agnew, Sarah E., Martine B. Powell, and Pamela C. Snow. "An Examination of the Questioning Styles of Police Officers and Caregivers When Interviewing Children with Intellectual Disabilities." ***Legal and Criminological Psychology,*** **vol. 11, 2006, pp. 35-53. ▲ ***

Purpose. This research provided a detailed analysis of the types of questions and verbal strategies used by police officers and caregivers when interviewing children with intellectual disabilities about events.

Method. Twenty eight children aged 9 to 13 years with mild or moderate intellectual disability participated in a staged event at their school. Each child was then interviewed on separate occasions by the child's primary caregiver and by a police officer who was authorized to conduct investigative interviews with children.

Results. While the approach used by the policy officers was broadly consistent with best-practice recommendations (i.e., their interviews contained few leading, coercive or negative strategies), they frequently interrupted the child's account and used relatively few minimal encouragers and other strategies designed to keep the child talking. The caregivers used a high proportion of direct, leading and coercive strategies to elicit information from their children. Even when caregivers used open-ended questions, their children provided less event-related information than they did to the police interviewers.

Conclusion. The quality of evidence obtained from children with intellectual disabilities is likely to be dependent (albeit in part) on the degree to which police interviewers adhere to best-practice guidelines, as well as the children's general experience with an open-ended style of communication.

Allen, Barbara, Nancy Meyers, John Sullivan, and Melissa Sullivan. "Using American Sign Language in Assessing the End-of-Life Care Educational Needs of Deaf Persons: Lessons on Language, Culture, and Research Practices." ***Towards Best Practices for Surveying People with Disabilities,*** **vol. 1, 2007, pp. 47-69. ▲ ***

This chapter reports on a community-based participatory research (CBPR) strategy for collecting health related data from a linguistic minority in the United States: self-identified members of the Deaf community. The meager literature available on deaf and hard of hearing persons' health and healthcare status suggests that these individuals rarely participate in government surveys of citizens' well-being. Culturally identified Deaf individuals, moreover, often view researchers from the "hearing world" with suspicion. Using CBPR and ASA-GLOSS (an American Sign Language—ASA—linguistics method), trained Deaf interviewers asked 130 Deaf senior citizens who depend on a signed language for communication questions about cultural practices and linguistic barriers to healthcare, focusing on end-of-life care information. Interviews were videotaped and a centrally located monitor received direct feeds from five enclosed interview booths. A mirror placed behind the respondents enabled interviewer and respondent to be captured on the same videotape. The closed-ended questions of the half-hour interviews were coded on-site by the Deaf interviewers for statistical analysis. A team of Deaf interviewers reviewed the tapes to check the reliability of the initial coding and to assign categories and codes to open-ended questions. A focus group comprised of expert Deaf

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interviewers, community leaders, and hearing researchers reviewed and interpreted the findings. The survey instrument and method revealed important findings concerning deaf senior citizens' perceptions about their end-of-life care needs, enabling the development of appropriate educational materials and information dissemination strategies. The research team concluded that the conceptual, sociocultural, and linguistic challenges of culturally identified deaf and hard of hearing persons can be addressed using CBPR strategies and ASL-GLOSS linguistic methods. These innovations in survey deign and method can have a significant impact on collecting valid and reliable data from this underrepresented population.

Andersen, Elena, Carol A. Fitch, Patricia M. McLendon, and Allan Meyers. "Reliability and Validity of Disability Questions for U.S. Census 2000*." American Journal of Public Health*, vol. 90, no. 8, August 2000, pp. 1297-1299. ▲

Objective: The authors investigated the validity and proxy reliability of seven new disability questions from the 2000 U.S. Census.

Methods: A total of 131 people with disabilities and their proxies from St. Louis, Missouri and Massachusetts were interviewed and responses were compared for concordance. Responses were also compared with responses to questions from the Behavioral Risk Factor Surveillance System (BRFSS) and the Activities of Daily Living (ADL) instrument.

Results: Overall, proxies reported more impairment than did people with disabilities, and agreement was low. Concordance was moderate between the Census questions and their BRFSS and ADL counterparts.

Conclusions: The Census 2000 questions may not provide an accurate profile of disability in America.

Andersen, Elena M., V.J. Vahle, and D. Lollar. "Proxy Reliability: Health-Related Quality of Life (HRQoL) Measures for People with Disability." *Quality of Life Research*, vol. 10, no. 7, 2001, pp. 609-619. ▲

Objectives: Research and surveillance activities sometimes require that proxy respondents provide key exposure or outcome information, especially for studies of people with disability (PWD). In this study, we compared the health-related quality of life (HRQoL) responses of index PWD to proxies.

Methods: Subjects were selected from nursing homes, other assisted living residences, and from several clinic samples of PWD. Each index identified one or more proxy respondents. Computer-assisted interviews used a random order of measures. Proxy reliability was measured by intraclass correlation (ICC) and kappa statistics. HRQoL measures tested included the surveillance questions of the Behavioral Risk Factor Surveillance System (BRFSS), basic and instrumental activities of daily living (ADLs and IADLs), medical outcomes study short-form 36 and 12 (SF-36 and SF-12).

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Results: A total of 131 index proxy sets were completed. In general, agreement and reliability of proxy responses to the PWD tended to be best for relatives, with friends lower, and health care proxies lowest. For example, the ICC for the physical functioning scale of the SF-36 was 0.68 for relatives, 0.51 for friends, and 0.40 for healthcare proxies. There was tendency for proxies to overestimate impairment and underestimate HRQoL. This pattern was reversed for measures of pain, which proxies consistently underestimated. The pattern among instruments, proxy types, and HRQoL domains was complex, and individual measures vary from these general results.

Conclusions: We suggest caution when using proxy respondents for HRQoL, especially those measuring more subjective domains.

Antaki, Charles, Natasha Young, and Mick Finlay. "Shaping Clients' Answers: Departures from Neutrality in Care-Staff Interviews with People with a Learning Disability." ***Disability & Society*****, vol. 17, no. 4, 2002, pp. 435-455. ▲ ***

What can happen when care staff interview clients with a learning disability? We examine tape-recordings of five questionnaire-based interviews designed to yield information on the clients' perceptions of the quality of the service provided to them. Of interest was the way in which the care staff, who were not formally trained in interview skills, delivered the 42-item questionnaire that formed the basis for the interview. It was discovered that interviewers replicated a number of non-neutral practices previously identified in a set of similar interviews administered by formally-trained professionals. They also introduced further deviations from neutral interviewing. The effect of these practices on the information recorded as the respondents' answers is discussed. We note that any interview is faced with a dilemma of choosing between literal (but potentially robotic and insensitive) and tailored (but potentially unstandardised and invalid) administration of a questionnaire. We argue that the deviations we see here show the interviewers falling on the side of "liberal" administration. The net effect was arguably to prompt "better" answers. When what is being recorded is an "audit" of services provided to respondents, there is a real-life danger that their perceptions are being improved by what is ostensibly a neutral interview.

Apgar, Dawn Hall, Paul Lerman, and Tameeka Jordan. "Comparison of Two Methods for Proxy Respondent Decision." Paper presented at the Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC) 2006 State-of-the-Science Conference, Arlington, VA, 2006. ▲ *

This presentation examines whether staff can serve as reliable proxies for persons with developmental disabilities and their families when assessing the impacts of deinstitutionalization on quality of life. Findings indicate that quality of life can be assessed using comparable measures for staff, family members/guardians, and consumers in the areas of safety, emotional well-being, autonomy, and community participation. Responses from staff, family members/guardians, and consumers provide strong empirical evidence that higher community participation, family phone contacts, self-care, freedom, mental health utilization, and productivity are positively linked to community living. There is moderately strong empirical evidence that promoting autonomy, family visits, and safety are also positively linked to

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* New entry.

community living. Little or no empirical evidence is found that health, emotional well-being, friendships, inappropriate behaviors, and material well-being are related to community living. The implications and limitations of this study and the use of proxies will be discussed.

Ball, Annie E., Elizabeth M. Russell, D. Gwyn Seymour, William R. Primrose, and Andrew M. Garratt. "Problems in Using Health Survey Questionnaires in Older Patients with Physical Disabilities." ***Gerontology*****, vol. 47, no. 6, 2001, pp. 334-340.** ▲

Background: The SF-36 Health Survey questionnaire has been proposed as a generic measure of health outcome. However, poor rates of return and high levels of missing data have been found in elderly subjects and, even with face-to-face interview, reliability and validity may still be disappointing, particularly in cognitively impaired patients. These patients may be the very patients whose quality of life is most affected by their illness and exclusion will lead to biased evaluation of health status. A possible alternative to total exclusion is the use of a proxy to answer questions on the patient's behalf, but few studies of older people have systematically studied patient-proxy agreement.

Objective: To compare the agreement between patients, lay and professional proxies when assessing the health status of patients with the SF-36.

Methods: The SF-36 was administered by interview to 164 cognitively normal, elderly patients (Mini-mental State Examination 24 or more) referred for physical rehabilitation. The SF-36 was also completed by a patient-designated lay proxy (by post) and a professional proxy. Agreement between proxies and patients was measured by intraclass correlation coefficients (ICCs), and a bias index.

Results: Professional proxies were better able to predict the patients' responses than were lay proxies. Criterion levels of agreement (ICC .04 or over) were attained for four of the eight dimensions of the SF-36 by professional proxies, but for only one dimension by lay proxies. In professional proxies, the magnitude of the bias was absent or slight (<0.2) for six of the eight dimensions of the SF-36 with a small (0.2 - .49) negative bias for the other two. Lay proxies showed a negative bias (i.e. they reported poorer function than did the patients themselves) for seven of the eight dimensions of the SF-36.

Conclusions: For group comparisons using the SF-36, professional proxies might be considered when patients cannot answer reliably for themselves. However, in the present study, lay proxy performance on a postal questionnaire showed a strong tendency to negative bias. Further research is required to define the limitations and potentials of proxy completion of health status questionnaires.

Barnett, Steven, and Peter Franks. "Telephone Ownership and Deaf People: Implications for Telephone Surveys." ***American Journal of Public Health*****, vol. 89, November 1999, pp. 1754-1756.** ▲

People with hearing loss represent approximately 9.35% of the U.S. population, or more than 23 million people. In the United States, people deafened after the acquisition of language

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are more likely to use English, have normally hearing friends and spouses or partners, and consider themselves culturally part of the majority population than are people deafened prelingually (before 3 years of age). The latter are more likely to communicate in ASL and often consider themselves part of a linguistic minority group within which they primarily socialize and find their spouses or partners. In this community, face-to-face communication is valued. Because ASL, like most of the world's languages, has no written form, text-based telephone communication among those who use ASL is conducted in a second language.

Barrett, Kirsten, Matt Sloan, and Debra Wright. "Interviewer Perceptions of Interview Quality." Paper presented at the 61st Annual American Association for Public Opinion Research Conference, Montreal, Canada, May 18-21, 2006. ▲ *

Interviewing individuals with disabilities requires increased attention to questionnaire construction and design to ensure ease of participation and to facilitate accurate and truthful responding. Researchers often make inferences about the extent to which the design is successful by looking at data related to refusals, early terminations, survey duration, and item non-response. It is less frequent that we rely on a primary source of information about these issues, the interviewer. Much can be learned about the interview process by querying interviewers about their perceptions of interview quality for each survey participant.

The National Beneficiary Survey, conducted by Mathematica Policy Research and sponsored by the Social Security Administration (SSA), is collecting four rounds of data from a nationally representative sample of approximately 7,000 SSA disability beneficiaries. The 45-minute, dual-mode (CATI/CAPI) survey gathers information about health, insurance, employment, income, and demographic characteristic. Also included are a number of post-interview questions asked of the interviewer him/herself. These questions provide data on the interviewer's perception of the sample member's intellectual capacity, response accuracy, comprehension, level of fatigue, and auditory barriers. Further, an open-ended question allows interviewers to report "special circumstances" that were encountered during the interview.

In this paper, we (1) describe interviewer perceptions of respondent participation; (2) examine how interviewer perceptions correspond to data quality indicators (such as duration of interview and extent of non-response), respondent characteristics (disability and functional status, cognition and need for proxy utilization, and various sociodemographics), and interviewer characteristics (tenure, experience, and number of previously completed NBS interviews); and (3) discuss the implications of our findings for survey design, administration, and interviewer training.

Bassett, Susan Spear, Jay Magaziner, and J. Richard Hebel. "Reliability of Proxy Response on Mental Health Indices for Aged, Community-Dwelling Women." *Psychology and Aging,* vol. 5, no. 1, 1990, pp. 127-132. ▲ *

The correspondence between respondent and proxy response was evaluated on 4 mental health measures (Affect Balance Scale, Center for Epidemiological Studies Depression Scale, Mental Status questionnaire, and Mini-Mental State Examination) with a sample of 538 respondent-proxy pairs. Results indicated that respondent and proxy responses were strongly

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associated, particularly for the cognitive measure. This association was found even for respondents classified as depressed or cognitively impaired. Although there was evidence of proxy bias, with proxies underrating affective status and overrating cognitive status, the magnitude of the bias proved small for all scales but the Mental Status Questionnaire. Examination of response comparability by proxy characteristics showed that choice of proxy affected agreement and bias. Implications of these findings for survey research are discussed.

Beatty, Paul, Wendy Hicks, Emilie Schmeidler, and Corinne Kirchner. "Investigating Question Meaning and Context Through In-depth Interviews." ***Quality & Quantity: International Journal of Methodology,*** **vol. 38, no. 4, August 2004, pp. 367-379.** ▲

The objective of this article is to demonstrate the usefulness of in-depth interviewing to illuminate the meaning of survey findings. In particular, the study described here was designed to explore the meaning of two survey statistics addressing the prevalence of visual impairment in the United States. Two surveys have been used in recent years to provide such estimates: the NHIS and the SIPP. Results of the interviews suggest that the central concepts addressed in the SIPP and NHIS print disability questions are very similar. Furthermore, respondents tended to base their answers to either question on a "functional ability" to read print—they indicated print reading disability if they could not read the text of a standard newspaper article through the use of "ordinary" devices such as glasses or contact lenses. However, the measures do specify different criteria for indicating print disability—respondents met the SIPP criterion of "having difficulty" more easily than the NHIS criterion of not being "able to see well enough" to read print.

Beatty, Paul, Wendy Davis, Emilie Schmeidler, and Corinne Kirchner. "Reading the Fine Print: Evaluation Discrepancies in Print Reading Disability Statistics." Paper presented at the Annual Conference of the American Association for Public Opinion Research, St. Louis, MO, May 1998.

In recent years, data from two national surveys have been used to generate estimates of the prevalence of visual impairment from a print reading disability measure: the NHIS of the National Center for Health Statistics, and the Survey of Income and Program Participation (SIPP) of the Census Bureau. The estimates from these two surveys differ substantially. Concerns about this apparent discrepancy led the National Library Service for the Blind and Physically Handicapped, along with a consortium of private agencies and consumer groups of blind people, to support research to investigate the discrepancy and improve prevalence statistics more generally. As a part of this effort, researchers from the U.S. Census Bureau and the National Center for Health Statistics, with the assistance of the American Foundation for the Blind, developed a research plan using cognitive interviewing methods to explore why responses to the two print disability measures differ so widely.

The NHIS and SIPP print disability questions appear to have very similar subject matter. Virtually all respondents felt the concept of "being able to read print" was equivalent across SIPP and NHIS questions. However, there are still important differences in how print disability is operationalized across the two questionnaires. The SIPP measure differentiates between levels of impairment: one question asks whether the respondent has difficulty seeing words and letters;

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another assesses whether he is able to see words and letters at all. These appear to be categorically different levels of severity. In contrast, the NHIS only asks whether the respondent can or cannot read newspaper print.

This analysis also suggested that the battery of questions preceding the NHIS measure creates a context effect influencing respondents' assessment of their ability to read print. When asked a series of visual-oriented questions before the print disability measure, respondents seemed to rate their ability to read print more favorably than without the preceding questions. This may at least partially account for the differences between estimates from the two surveys. Still, this potential context effect should be investigated in a more sophisticated experiment. Data should be collected through traditional interviewing techniques and larger samples, in order to isolate the unique effect of the context questions. Procedural factors that could have contributed to differences between NHIS and SIPP responses should be eliminated—specifically, proxy rules, and the age of the target population, should be fixed. Complex demographic adjustments due to variations in time of data collection could be avoided. Isolating the impact of context is an important step toward identifying the optimal measure of print disability. In any case, it is important to note that importing the NHIS or SIPP questions alone into other surveys would probably not yield the same results. Any attempt to develop a standard measure of print disability should also include standardization of the preceding context questions.

Black, Ken. "Measurement Issues." Paper presented at the First Workshop for Improving Disability Statistics and Measurement, Bangkok, Thailand, May 24-28, 2004.

This slide presentation describes instrument development, pre-testing of instruments, focus groups, cognitive interviews, field testing, context/mode effects, sample design, interviewing, data-processing, and dissemination/evaluation issues related to surveying people with disabilities.

Disability is a complex, multidimensional concept. It is perceived differently by different people, especially across age groups, cultures, and time. A good survey instrument overcomes the subjectivity and individual perceptions of disability and produces measures which are:

- Valid (measure what they say they measure)
- Reliable (give consistent results over repeated measures)

Bland, Roger C., and Stephen C. Newman. "Mild Dementia or Cognitive Impairment: The Modified Mini-Mental State Examination (3MS) As a Screen for Dementia." *Canadian Journal of Psychiatry*, vol. 46, August 2001, pp. 506-510. ▲ *

Objective. To examine the Modified Mini-Mental State Examination (3MS) as a screen for dementia.

Method. A group of 1092 elderly Edmonton community residents completed the 3MS and the Geriatric Mental State Examination (GMS). 3MS sensitivity and specificity were determined

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by comparing positive 3MS screens (score ≤77) with those classified as GMS "organic" (severity level 3, equivalent to a clinical diagnosis). In the Canadian Study of Health and Aging (CSHA), 2914 subjects received the 3MS and a clinical examination. A group described as having "cognitive impairment but no dementia (CIND)" was identified.

Results. In Edmonton, the 3MS showed 88% sensitivity, 90% specificity, 29% positive predictive value (PPV), and 99% negative predictive value (NPV). In the CSHA, 30% of subjects receiving both the 3MS and a clinical examination were classified as CIND. One-half of these were classified as having "age associated memory impairment (AAMI)" or as "unspecified."

Conclusions. The 3MS with a cutting score of 77/78 proved a reason able screening instrument; 1 case in 3 screening "positive" has dementia, but few (0.64%) will be missed by screening" negative. "CIND, accounting for 2 out of 3 cases screened positive by the 3MS in the Edmonton study, is a substantial, heterogeneous group that is not necessarily "predementia" but that in many cases merits further investigation.

Bonham, Gordon Scott, Sarah Basehart, Robert L. Schalock, Cristine Boswell Marchand, Nancy Kirchner, and Joan M. Rumenap. "Consumer-Based Quality of Life Assessment: The Maryland Ask Me! Project." ***Mental Retardation*****, vol. 42, no. 5, 2004, pp. 338-355. ▲ ***

The concept of quality of life currently impacts program development, service delivery, management strategies, and outcome evaluation in the area of intellectual disabilities. Maryland uses peer interviewers to assess consumer-perceived quality of life among adult recipients of MR/DD services and supports. In this article we describe the survey instrument and procedures and discuss assessment issues of quality of responses, acquiescence, and proxy respondents We present the psychometric properties for eight core quality of life domains among 923 people assessed in FY 2001. Results are summarized and development of a model for enhancing social inclusion, personal development, and self-determination was described. Service and personal characteristics relating to quality of life as well as some ways the results can be used for program enhancement are discussed.

Booth, Tim, and Wendy Booth. "Sounds of Silence: Narrative Research with Inarticulate Subjects." ***Disability & Society*****, vol. 11, no. 1, 1996, pp. 55-69. ▲ ***

This article addresses the challenge of using narrative methods with people who have learning difficulties. Such informants present four particular interview problems: inarticulateness; unresponsiveness; a concrete frame of reference; and difficulties with the concept of time. The authors focus on the first two of these problems and argue that neither of them constitutes an insuperable barrier to people telling their story. Drawing on detailed interview material from an informant with learning difficulties, the authors set out to show in practical terms how these problems might be tackled, emphasizing in particular the importance of being attentive to what goes unsaid. They conclude that researchers should put more emphasis on overcoming the barriers that impede the involvement of inarticulate subjects in narrative research instead of dwelling on their limitations as informants.

▲ The abstract was written by the author(s) or publisher.
* New entry.

Brauer, Barbara A. "Adequacy of a Translation of the MMPI into American Sign Language for Use with Deaf Individuals: Linguistic Equivalency Issues." *Rehabilitation Psychology*, vol. 38, no. 4, winter 1993, pp. 247-260. ▲

In order to determine the linguistic equivalency of a sign language translation of a psychological test for use with deaf individuals, the Minnesota Multiphasic Personality Inventory (MMPI) was translated into American Sign Language (ASL) via the back-translation procedure and recorded on videotape. The bilingual retest technique was conducted whereby both forms of the instrument were administered to 28 ASL-English bilingual deaf subjects. Due to the advent of the MMPI-2 during the conduct of this study, a new set of T scores was calculated from the present MMPI data in order to compare the effect of shifting to the MMPI-2 norms. The results of this study demonstrated adequate linguistic equivalencies of the ASL MMPI items and underscore the potential utility and practicality of future ASL translations of psychological tests for use with deaf individuals.

Brinton, Bonnie, and Martin Fujiki. "Ability of Institutionalized and Community-Based Adults with Retardation to Respond to Questions in an Interview Context." *Journal of Speech and Hearing Research*, vol. 37, April 1994, pp. 369-377. ▲ *

This study examined the ability of adults with mild and moderate levels of retardation to respond to simple and complex questions. The sample consisted of 20 subjects living in an institutional setting and 20 subjects living in the community. A 30-minute language sample, structured as a job interview, was elicited from each subject by an investigator. During the interview, the investigator asked a number of questions interspersed within the conversation. Two levels of questions were presented: simple and complex. Ten questions were presented at each level. Responses were scored in terms of how informative and truthful the subject was (specific scoring conventions were based upon the work of Grice, 1975). The community group produced a significantly greater number of appropriate answers to both simple and complex questions than did the institutional group. Group differences were observed along both parameters of informativeness and truthfulness.

Brown, Scott Campbell. "Revitalizing 'Handicap' for Disability Research: Developing Tools to Assess Progress in Quality of Life for Persons with Disabilities." *Journal of Disability Policy Studies*, vol. 4, no. 2, 1993, pp. 57-76. ▲ *

This paper argues that the World Health Organization's (WHO) (1980) concept of *Handicap* from the International Classification of Impairments, Disabilities, and Handicaps can be used to identify progress toward four goals regarding individuals with disabilities outlined by Congress in the Americans with Disabilities Act. The article proposes four linkages between ADA goals and ICIDH Handicap survival roles: (a) equality of opportunity to occupation; (b) full participation to social integration; (c) independent living to orientation, physical independence, and mobility; and (d) economic self-sufficiency. To monitor progress toward the goals through promotion of these roles, 10 accommodation indicators of how programs and services affect persons with disabilities are also proposed, with each indicator linked to at least one of the four ADA goals. In so doing, the Handicaps of the nation, as opposed to those of individuals, are assessed.

▲ The abstract was written by the author(s) or publisher.
* New entry.

Cambridge, Paul, and Rachel Forrester-Jones. "Using Individualised Communication for Interviewing People with Intellectual Disability: A Case Study of User-Centered Research." ***Journal of Intellectual & Developmental Disability*****, vol. 28, no. 1, 2003, pp. 5-23. ▲ ***

The importance of participative research methodologies is now widely acknowledged. A case study using individualized communication for interviewing people with intellectual disability in outcome and quality of life research is reported. The methodology and processes employed are described and lessons for the wider application of the model identified. In collaboration with Somerset Total Communication and local speech and language therapists, researchers from the Tizard Centre developed a flexible communication strategy for involving service users, drawing on core, local and individual vocabularies and using signs, graphic symbols and photographs to supplement spoken English. Individualized communication was used both to ascertain informed consent to participation in the research and to conduct the user interview. The initiative was part of a wider study looking at the outcomes and costs of community care 12 years on from de-institutionalization. The approach was found to facilitate user participation compared with previous follow-ups, with wider lessons evident for user involvement.

Cardone, Denise. "Exploring the Use of Question Methods: Pictures Do Not Always Help People with Learning Disabilities." ***The British Journal of Developmental Disabilities*****, vol. 45, no. 89, July 1999, pp. 93-98.**

Several types of response bias contaminate reliability and are common with people with learning disabilities (LDs): (1) acquiescence, or a person answering yes regardless of the question; (2) consistently choosing the last alternative in a multiple question; and (3) giving false information in response to a leading closed question.

The current study, using a sample of 28 people with learning disabilities, compared two methods for overcoming response bias:

Personal Questionnaire (PQ): choose answer from three printed words Pictorial Analogue (PA): choose answer by marking a line between two pictures. Findings:

- People with better language ability were more reliable using the PQ *and* the PA than people of lower ability.
- The use of pictures was not always helpful to people with lower language ability.
- Forced choices made responding difficult for this client group.
- More qualitative studies are needed.

▲ The abstract was written by the author(s) or publisher.
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Ciemnecki, Anne B., and Karen A. CyBulski. "Removing the Barriers: Modifying Telephone Survey Methodology to Increase Self-Response Among People with Disabilities." ***Towards Best Practices for Surveying People with Disabilities*****, vol. 1, 2007, pp. 13-31. ▲ ***

Information collected directly and cost-effectively from respondents with disabilities is necessary to determine how well public programs meet their needs. Mathematica Policy Research (MPR) has been making simple modifications to survey telephone designs and procedures to increase accessibility. Goals are three-fold: (1) to increase participation without using proxy respondents, (2) to keep survey costs affordable, and (3) to maintain data quality.

Minor modifications to questionnaire design to increase accessibility include short recall periods, concrete questions, elimination of high frequency sounds, inclusion of breaks to overcome fatigue, neutral encouragement, checks for unexpected responses, and structured probes. Procedural modifications include sensitivity training for interviewers, compassion fatigue support for interviewers, and modified expectations regarding time to administer questionnaires. Cooperation rates for our surveys are high (97 percent) and the vast majority of respondents answered for themselves (86 percent). Interview data are complete and accurate.

People with physical or sensory disabilities provide more compete information than those with mental illness, mental retardation or developmental disabilities, but the differences are not great. Shorter interviews (20 rather than 45 minutes) create less burden, require fewer breaks and needless interviewer encouragement. Self-respondents provide more complete information than proxy respondents.

It is both possible and desirable to collect data from large samples of people with disabilities by telephone. Respondents with disabilities do not pose extraordinary challenges for telephone surveys. The information collected from respondents with disabilities is consistent with information collected from similar populations without disabilities. Modifications to increase participation are neither costly nor difficult to implement.

Ciemnecki, Anne B., and Karen CyBulski. "Minimizing Item Nonresponse in Telephone Surveys of People with Disabilities." Paper presented at the International Conference on Questionnaire Development, Evaluation, and Testing Methods, Charleston, SC, November 14-17, 2002.

This study concludes the following:

- Patterns of non-response are not very different for respondents with disabilities than for the general public.
- People with physical or sensory disabilities provide more complete information than those with mental illness or mental retardation but the differences are not great.
- Self-responders provide more complete information than proxies.

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Ciemnecki, Anne, Karen CyBulski, Barbara Kolln, April M. Grady, Steven C. Hill, and Craig Thornton. "Interviewing Populations with Disabilities by Telephone: Data Quality Measures." Paper presented at the 55th American Association for Public Opinion Research Annual Conference, Portland, OR, May 18-21, 2000.

Mathematica Policy Research, Inc. conducted a computer-assisted telephone interview (CATI) survey of adults with disabilities who had physical or sensory disabilities (including blindness and deafness), mental retardation or developmental disabilities, or severe and persistent mental illness. This paper focuses on data quality measures (response rate, ability to self-respond, item non-response, consistency measures across key variables) for adult sample members. In general, person with physical and sensory disabilities tended to provide more complete information than those with mental illness, mental retardation, or developmental disabilities, although the differences were not great.

Response Rate. The overall response rate was 67.3 percent, with the inability to locate sample members being the most important source of non-response. Response rates varied by disabling condition (for example, 62 percent for adults with MR/DD and 70.2 percent for adults with physical disabilities). Once located, adults had high cooperation rates; in fact, compared to response rates of non-disabled adults from a similar study, persons with disabilities had higher response and cooperation rates.

Ability to Self-Respond. Overall, 86% of the sample was able to respond to the survey themselves; the most common reason for relying on a proxy respondent was to overcome cognitive challenges.

Item Non-Response. Persons with disabilities were able to answer most questions themselves. Non-response can be decreased by minimizing proxy use, asking about easy/salient concepts, and keeping the recall period short.

Reliability. Reliability was high for factual information, such as chronic conditions, access to care, and demographic characteristics; reliability was not as high, however, for attitudinal data.

Ciemnecki, Anne B., Kirsten Barrett, Karen A. CyBulski, Jason A. Markesich, Matt Sloan, and Debra L. Wright. "Comparison of Two Methods for Proxy Respondent Decision." Paper presented at the Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC) 2006 State-of-the-Science Conference, Arlington, VA, 2006. ▲ *

While self-response is desirable when conducting surveys of people with disabilities, it is not always possible or practical. Sometimes respondents' physical or cognitive limitations preclude self-response. Other times, data collectors do not have the resources or abilities to facilitate self-response. Historically, the decision to use a proxy has been left to interviewer judgment. Assessments of cognitive functioning such as the Mini-Mental State Examination (MMSE), Telephone Interview of Cognitive Status (TICS), or the Short Portable Mental Health Status Questionnaire (SPMSQ) are not designed to assess capacity to complete a telephone interview. MPR has attempted to design standard assessment methods to inform the need for a

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proxy. MPR is exploring two structured methods: (1) a three-question confirmation to see if the respondent understands the context and content of the interview and (2) a computerized test for a string of six don't know or missing responses at the beginning of the interview. Although structured, each method does not allow for the use of interviewer judgment. This presentation will describe the criteria for a good method for screening for proxy need; describe the two structured methods along with their advantages and shortcomings; and provide data on proxy use associated with each method. We will encourage a floor discussion on the "next steps" for producing a valid and reliable screener that can be administered by telephone.

Cheston, Rik, Mike Bender, and Sue Byatt. "Involving People Who Have Dementia in the Evaluation of Services: A Review." ***Journal of Mental Health*****, vol. 9, no. 5, 2000, pp. 471-479. ▲ ***

Government policy and good practice dictate that health and other care services should routinely involve service users in the evaluation of the services that they receive. While the care of people with dementia have been involved in this process relatively often, it has been much rarer for people with dementia themselves to be involved. This article reviews five methods of gathering the experiences of people with dementia as those experiences relate to the services that they receive: questionnaires and structured interviews; semi-structured interviews; observation; advocacy and focus groups. A number of ethical issues are highlighted including: consent; the capacity to make decisions, confidentiality and empowerment.

Clarridge, Brian R., and Michael P. Massagli. "The Use of Female Spouse Proxies in Common Symptom Reporting." ***Medical Care*****, vol. 27, no. 4, April 1989, pp. 352-366. ▲ ***

To determine the quality of proxy health reports by telephone, the 1984 Wisconsin Health Status Survey employed a repeated-measure design in an interview covering 22 recently occurring health and psychologic complaints. Comparisons on individuals in households containing two or more adults revealed a relatively weak correspondence between the respondent and proxy reports. While a previous analysis of these data found that certain characteristics thought to underlie reporting differences are not useful in explaining proxy underreporting, the current analysis focuses on spousal pairs and achieves greater success by applying somewhat more sophisticated methods. The authors examine the nature, persistence, and number of health complaints as factors in reporting bias. They find evidence that female proxies vary by symptom in their ability to report common complaints and also observed that proxy underreporting diminishes somewhat as the persistence of symptoms increases. Using multiplicative models, the authors show that the gross misclassification of complaints is concentrated in the respondent-proxy pairs with the shortest exposure to the symptom. Finally, an examination of the disagreements on all 22 health complaints simultaneously revealed that neither mutual misallocation by respondents and proxies nor a diminished health status of the individual reported on are important influences on reporting behavior.

▲ The abstract was written by the author(s) or publisher.
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Cohen, Helene, and Elaine Jones. "Interpreting for Cross-Cultural Research: Changing Written English to American Sign Language." ***Journal of the American Deafness and Rehabilitation Association*****, vol. 24, no. 2, October 1990, pp. 41-48.** ▲

The quality of cross-cultural research depends on the skills of the investigators and interpreters who participate in the study. This paper addresses sign language interpreters' participation in translating quantitative instruments from written English (source language) into American Sign Language (target language) for use in cross-cultural studies of people who are part of the deaf culture. First, research goals should be explicitly defined as either operational or comparative, and matched appropriately with an asymmetrical or symmetrical translation strategy. Next, interpreters often use a backtranslation process, with multiple checks on the conceptual integrity of the target language version of the instrument. Qualifications for a research interpreter are described in terms of language competencies and professional maturity. Data gathered through carefully translated instruments strengthens the validity of the study findings, and avoids misrepresentation of the people from the culture under study.

Cook, Judith A., Dennis D. Grey, Genevieve Fitzgibbon, Drew Batteiger, Sylvia Caras, Howard Dansky and Frances Priester. "Challenges in Defining Respondent Populations in a Web Survey of Individuals with Psychiatric Disabilities." ***Towards Best Practices for Surveying People with Disabilities*****, vol. 1, 2007, pp. 33-45.** ▲ *****

Web-based surveys may offer advantages in recruiting respondents and administering questionnaires for some populations whose disabilities are hidden or stigmatized. This study used Web-based survey technology to study self-determination among individuals with psychiatric disabilities. The web-based survey approach proved to be successful in recruiting a large number of study participants in a cost-effective manner. The mode of survey presentation allowed administration of a protocol with complex skip patterns yet accompanied by very little respondent burden. However, we also noted some concerns with regard to the overrepresentation in this study of college-educated women from Caucasian background. Another concern was the fairly high level of self-determination reported by the study respondents while a large volume of literature is pointing to the low levels of self-determination among individuals with psychiatric disabilities. Perhaps self-determination is higher among Internet users, or among some sub-groups of individuals with severe mental illnesses. While it may be fruitful to explore the use of Web-based surveys with psychiatric populations, caution must be applied by researchers in the interpretation of findings if respondents with different self-identifications have different background characteristics and clinical experiences and, most importantly, different levels of self-determination.

Cook, Judith A., Genevieve Fitzgibbon, and Drew Batteiger. "Web-Based Survey of Linkages Between Self-Determination and Technology Among Internet Users with Psychiatric Disabilities." Paper presented at the Federal Interagency Committee on Disability Research Conference on Best Practices for Surveying People with Disabilities, Washington, DC, April 2004. ▲

Background. The "digital-divide" has led to concerns about maximizing access to information technology (IT) by rehabilitation service consumers. The anonymity of IT use may

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be especially critical to those with "hidden" or stigmatized disabilities such as mental illness. In addition, this group can be especially difficult to study, given their reluctance to disclose their disability. For these reasons, the Internet was used to recruit and survey mental health consumers about their experiences with self-determination and technology.

Methods. A participatory action workgroup created the Web-based survey. Respondents self-identified as having mental health difficulties, a diagnosis of mental illness, and/or psychiatric hospitalization. A convenience sample of 619 was obtained through mental health listservs and Websites, mailings, and newsletter advertisements. The survey was hosted with WebSurvey or Corporation, and all transmitted data were encoded using Secure Sockets Layer encryption.

Results. The large majority of respondents were users of the formal mental health service delivery system, and had access to self-help and peer support. They reported relatively high levels of self-determination, with some exceptions. Most were satisfied with the degree of choice and respect they encountered from providers, but a notable minority reported dissatisfaction with specific aspects of care. They used the Internet an average of 3 to 5 times a week, often searching for disability related information and visiting government Websites. Those reporting greater self-determination used the Internet more frequently.

Conclusions/Implications. Since close to half of the respondents identified themselves as "advocates," they appear to be using tools, such as the Internet, to inform themselves. This may present them with opportunities to organize and advocate for each other.

Crews, J.E., and R.G. Long. "Conceptual and Methodological Issues in Rehabilitation Outcomes for Adults Who Are Visually Impaired." ***Journal of Visual Impairment and Blindness*****, vol. 91, no. 2, March 1997, pp. 117-130.** ▲

This article defines some of the conceptual and methodological issues in creating outcome measures in vision rehabilitation. It proposes a model to describe rehabilitation outcomes in the context of organizational activities and discusses such methodological problems as the classification and measurement of goals, aggregation of data, self-report and observational data, scaling, frequency of measurements and causal events.

Cusick, Christopher P., C.A. Brooks, and Gale G. Whiteneck. "The Use of Proxies in Community Integration Research." ***Archives of Physical Medicine and Rehabilitation*****, vol. 82, August 2001, pp. 1018-1024.** ▲ *****

Objective. To assess the level of agreement between persons with various disabilities and their proxies in reporting community integration outcomes using the Craig Handicap Assessment and Reporting Technique (CHART).

Design. Reliability study.

Setting. Participants living in the community for a minimum of 6 months after onset of disability or completion of inpatient rehabilitation.

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Participants. Persons (n = 983) with disability resulting from amputation, burn, multiple sclerosis, spinal cord injury (SCI), stroke, or traumatic brain injury and their self-selected proxies.

Interventions. Telephone interview of subjects (FIM instrument, CHART); proxies (CHART). FIM instrument assesses the degree of assistance with physical and cognitive subscales; CHART measures community integration in 6 subscales: physical, cognitive, and economic independence, and mobility, social integration, and occupation.

Main Outcome Measures. Intraclass correlation coefficients (ICCs) were used to assess participant-proxy agreement, and stepwise multiple regressions were used to identify patterns of difference in agreement based on disability type and demographic variables.

Results. Thirty-seven of the 38 items examined for the entire sample yielded moderate to strong ICCs. Multiple regression analyses indicated that proxies overrated participants with severe functional cognitive disabilities on the mobility subscale ($p < .001$), overrated participants with less than a high school education on the total CHART score ($p < .01$), and underrated participants with SCIs on the occupation subscale ($p < .01$). Differences in all cases, however, were less than 6 points out of a possible score of 100 per subscale.

Conclusions. Participant-proxy agreement across the 6 disability groups provided evidence in support of the inclusion of proxy data for persons with various types of disabilities in community integration research.

Cusick, Christopher P., Kenneth A. Gerhart, and David C. Mellick. "Participant-Proxy Reliability in Traumatic Brain Injury Outcome Research." ***Journal of Head Trauma Rehabilitation,*** **vol. 15, no. 1, February 2000, pp. 739-749. ▲ ***

Objective. To assess reliability between persons with Traumatic Brain Injury (TBI) and their self-selected proxies.

Design. Intraclass Correlation Coefficients were used to assess participant-proxy reliability on the Craig Handicap Assessment and Reporting Technique (CHART), the Community Integration Questionnaire (CIQ), and the Functional Independence Measure (FIM).

Setting. Participants had been discharged to the community from inpatient rehabilitation between sex months and approximately five years prior to the study's beginning.

Participants. 204 persons with moderate to severe TBI and their self-selected proxies.

Results. Eight-seven percent of the items on the three instruments exhibited moderate to high intraclass correlation (ICC), with strongest participant-proxy agreement for questions assessing concrete, observable information. Participant-proxy agreement was poorest when assessing cognitive and money management capacity as well as out-of-home activities.

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Conclusions. For many types of items, participant-proxy reliability is sufficient to merit the use of proxies in TBI outcome research when the participants are allowed to select their own proxy.

CyBulski, Karen, and Anne Ciemnecki. "Interviewing Populations with Disabilities by Telephone: Survey Design and Operations." ***Proceedings of the American Statistical Association, Survey Research Methods Section,*** **2002, pp. 1016-1021.**

As part of the Health Care Financing Administration's Evaluation of Section 1115 Medicaid Reform Demonstrations, MPR conducted a computer-assisted telephone interview (CATI) survey to assess how SSI recipients with disabilities fare in Medicaid managed care programs. Accommodations were made in order to minimize proxy response, give respondents with disabilities the opportunity to speak for themselves, and provide the client with a cost-effective way to collect data. Specifically, MPR did the following: (1) eliminated soft consonant sounds to overcome high frequency hearing loss, (2) built in "breaks" for respondents, (3) incorporated neutral encouragement, (4) designed checks for unexpected responses, and (5) used structured probes for questions that might be difficult to understand. Interviewers were also trained about the challenges of interviewing people with disabilities and were provided with guidance to overcome these challenges.

This study concludes the following:

- It is both possible and desirable to collect data from people with disabilities by telephone.
- Shorter interviews create less burden—require fewer break-offs and less need for interviewer encouragement.
- Following minor modifications to questionnaire design and survey procedures, high quality data can be acquired from long interviews.

CyBulski, Karen A., Anne B. Ciemnecki, John W. Hall, and Barbara A. Kolln. "Evaluation of Five Section 1115 Medicaid Reform Demonstrations: Survey Methodology." Princeton, NJ: Mathematica Policy Research, Inc. April 2001.

During the 1990s, states used Section 1115 demonstration waivers to modify their Medicaid programs to provide services through managed care rather than through traditional fee-for-service arrangements. As part of this Centers for Medicare & Medicaid Services evaluation, MPR conducted computer-assisted telephone interview (CATI) surveys to assess how recipients of Supplemental Security Income (SSI) were faring in Medicaid managed care. The survey sample included people with physical and sensory disabilities, mental illness, and mental retardation. The surveys—conducted in Kentucky, New York, and Tennessee—addressed access to and satisfaction with care, utilization of medical services, insurance coverage, experience in the demonstration program, unmet needs and delays receiving care, health status, attitudes toward health care and health care risks, use of preventive services, and family

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demographics. MPR conducted more than 4,600 interviews of persons with disabilities between September 1998 and February 2000. Had MPR conducted the surveys in person instead of by telephone, the cost would have been about four to eight times as much—a cost that may well have been prohibitive.

Dailey, René M., and Ronald E. Claus. "The Relationship Between Interviewer Characteristics and Physical and Sexual Abuse Disclosures Among Substance Users: A Multilevel Analysis." ***Journal of Drug Issues*****, vol. 31, no. 4, fall 2001, pp. 867-888. ▲ ***

Data were collected at assessment for substance abuse treatment from 22 interviewers and 8,276 clients to assess the relationship between interviewer characteristics and disclosure of physical and sexual abuse. Characteristics examined were client and interviewer gender, race/ethnicity, and age. Multilevel regressions that adjusted for the clustering of clients within interviewers were compared to unadjusted logistic regressions to determine the effect of response similarity within clusters. Clustering accounted for only 2-5% of the unexplained variance; however, ignoring the clustering effect generated several misleading results. Adjusted models indicated that clients were more likely to disclose physical abuse to Caucasian interviewers than to African American interviewers and more likely to disclose sexual abuse to female interviewers than to male interviewers. Matching clients and interviewers on gender, race, and age did not increase disclosures of either physical or sexual abuse.

Delman, Jonathan. "Consumer-Driven and Conducted Survey Research in Action." ***Towards Best Practices for Surveying People with Disabilities*****, vol. 1, 2007, pp. 71-87. ▲ ***

A core flow of mental health systems in the United States is the lack of consumer direction in research and intervention design. When mental health consumers play a significant role in research and evaluation activities, they are in a position to provide early consideration of the relevance of the research topic and advise on how findings can best be applied to their communities.

Consumer Quality Initiatives, Inc. (CQI) has offered a direct response to this problem. CQI is a mental health consumer-directed and staffed quality improvement and research organization based in Massachusetts. CQI's mission is to give consumers a greater voice and an integral role in evaluating their treatment and to initiate changes based on data collected. CQI's overall approach is based on the principles of Community-based Participatory Action Research ("CPAR").

CQI conducts much of its work through in person interviews and focus groups, then writing in depth data driven reports. The "personal" approach, as opposed to telephone interviews and written questionnaires, is critical because many mental health consumers distrust "the system," and they are less likely to open up to staff or student interviewers. Because of their personal experience with mental illnesses, CQI interviewers are able to build a rapport with respondents that help them speak honestly and openly about their treatment experiences.

▲ The abstract was written by the author(s) or publisher.
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Department of Economic and Social Affairs. "Guidelines and Principles for the Development of Disability Statistics." New York, NY: United Nations, 2001.

This publication is aimed at assisting national statistical offices and other producers of disability statistics to improve the collection, compilation, and dissemination of disability data. This report addresses methodological issues in the area of disability by providing guidelines and principles related to data collection through surveys and censuses and also on the compilation, dissemination, and usage of data on disability. Of particular interest, Chapter III consists of modules giving detailed methodological information on specific types and aspects of data collections. These cover the following topics:

- Censuses. This module presents general issues in the use of a population census to collect data on disability, information on questions for use in a census and the use of a census to screen for a follow-up survey.
- Surveys. This module includes information on survey questionnaire design for collecting data on disability; addresses development of survey screening questions for the general population, children, and the elderly; and includes a section on screening for disability.
- Sampling for a Disability Survey. This module gives guidance on how to develop a sample for a disability survey including information on sampling frames, determination of sample size, and sampling techniques.
- Institutional Population. This module includes information on collecting disability data in institutional settings, ranging from lists of possible institutions to be considered in determining the questionnaire content to how to interview institution residents.

Doe, Tanis M. "Participatory Survey Design and Data Collection: California Narratives on AT." Paper presented at the Federal Interagency Committee on Disability Research Conference on Best Practices for Surveying People with Disabilities, Washington, DC, April 2004. ▲

Background. California Foundation for Independent Living Centers (CFILC) is a trade organization of Independent Living Centers in California. They received a NIDRR grant on community research for assistive technology. As part of this grant they developed and conducted a state-wide survey. This consumer led organization trained disabled researchers to implement a survey of disabled AT users throughout California.

Methods/Conceptual Framework. We engaged a participatory action research design that allowed people with disabilities to be participants at each level. From identifying the topics, the questions, the target audience, to recruiting respondents, conducting interviews and doing data analysis. We used a principal investigator who has disabilities and is a trained educator. We also collaborated with university researchers and worked to develop a high standard for

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the survey. We used consumers as pilot participants and made significant changes to the language and wording of the surveys.

Conclusions. AT is used by a range of people with disabilities for Independent Living, health, employment and function. Funding, insurance and information are mitigating factors in determining who gets what AT products and services. We expect to look at the characteristics of the consumers as variables as well as overall results of the different areas of inquiry. The next stage in the project is to disseminate the results widely and to set up action teams to address the most urgent issues.

Implications. Clearly there is potential for people with disabilities to be trained to conduct research. With appropriate training consumers can be active participants in the design and implementation of research. We expect this will increase the relevance and validity of survey research.

Durant, Sharon L. "A Case Study on Full Participation in Surveys." Paper presented at the Federal Interagency Committee on Disability Research Conference on Best Practices for Surveying People with Disabilities, Washington, DC, April 2004. ▲

Background. In 2002, the Bureau of Transportation Statistics (BTS) developed and conducted a transportation survey designed to obtain interviews from about 5,000 people, half of whom had disabilities. The methods BTS used provided the best opportunity for full participation by every survey respondent, and can serve as a good model for other survey organizations to follow when designing demographic surveys.

Methods/Conceptual Framework. BTS employed a strategy of, "Nothing about us, without us," which is a popular slogan within the disability community. In other words, at each stage of the survey life cycle, BTS sought and utilized the involvement of people with disabilities.

Results. Including people with disabilities at every stage resulted in a questionnaire that was more relevant to people with disabilities, and gave rise to survey data that were more reflective of this group than otherwise would have been possible. Offering alternative data collection formats resulted in participation rates that were higher than expected as well; the survey achieved a person-level response rate of 87.21 percent.

Conclusions. Regardless of the survey goal and objectives, its subject matter and resultant data will be changed and improved based on the involvement of people with disabilities at each stage of the project—from the beginning of the planning process through the data publication phase.

Implications. The implications of including people with disabilities in a survey's life cycle include: broadened perspectives, more relevant topics, improved questionnaire design, increased respondent understanding, greater interviewer sensitivity and expertise, reduced non-response bias, and improved data quality.

▲ The abstract was written by the author(s) or publisher.
* New entry.

Earl, Crista, and Jay Leventhal. "A Survey of Windows Screen Reader Users: Results and Recommendations." Paper presented at the California State Northridge, Northridge Center on Disabilities' 14th Annual International Technology and Persons with Disabilities Conference, Los Angeles, CA, 1999. ▲

With skill in the use of Windows now essential for employment, American Foundation for the Blind's (AFB's) technology program has updated its earlier survey of Windows-based screen reader users to find out how blind and visually impaired computer users are faring. The results of the survey and recommendations for screen reader selection and development derived from the results and from screen reader evaluations conducted in AFB's Product Evaluation lab are presented.

The purpose of the survey reported here was to gather information from the user's perspective. The survey asked blind or visually impaired people who use Windows with screen readers what tasks they perform in Windows and how comfortable they feel performing those tasks.

Economic and Social Data Service. "Legal and Ethical Issues in Interviewing People With Learning Difficulties." Available at http://www.esds.ac.uk/aandp/create/guidelineslearningdifficulty.asp. June 22, 2006.

These guidelines were written in 2002 to provide guidance for individuals conducting research among respondents with learning disabilities. Specific issues as they relate to this population that are addressed in these guidelines include the following:

1. Anonymity and Confidentiality—The meaning and purpose of the research as well as the choice between acknowledgement or anonymity should be discussed with participants at the start of the research. Explanations concerning issues of anonymity and confidentiality should coincide with discussions of the purpose of the research. All of these issues should be re-visited at intervals during the project to take account of any changes or updates to the research agenda and to allow participants to change their minds.

2. Informed Consent—It is important to aim at getting informed consent from people with learning disabilities. These guidelines highlight methods of helping participants to make as informed a decision as possible about their participation in the research and the archiving of their data.

The continuous interweaving of the two processes of updating and negotiating provides one way to safeguard the participants' role, to enable their participation in decisions, and to reduce the chance of unintentional pressure or misunderstandings.

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Edgerton, Robert B. "The Participant-Observer Approach to Research in Mental Retardation." ***American Journal of Mental Deficiency*****, vol. 88, no. 5, 1984, pp. 498-505.** ▲

Participant-observation, which calls for long-term immersion in the world of the persons being studied yet disciplined detachment from that world, has long been utilized in various social sciences. This method of data collection was seldom used in the study of mentally retarded people until recent years; however, it has now been employed in the study of many aspects of the lives of these people and their families. Although this method of research is expensive and time consuming, it has the advantage of allowing investigators to learn how people actually behave in a variety of contexts and to grasp the meaning these activities have for them.

Epstein, Arnold M., Judith A. Hall, Janet Tognetti, Linda H. Son, and Loring Conant, Jr. "Using Proxies to Evaluate Quality of Life." ***Medical Care*****, vol. 27, no. 3 (supplement), March 1989, pp. S91-S98.** ▲

Instruments using interview data to measure health status have been increasingly used to measure patient outcomes. To assess the potential utility of proxy responses about health status when subjects are unable to respond, the authors compared the responses of 60 subject and proxy pairs on instruments measuring overall current health, functional status, social activity, emotional health, and satisfaction with medical care. Proxies were asked to respond as they thought the subject would. Subject and proxy responses were strongly correlated with each other for overall health, functional status, social activity and emotional health ($p < .001$) and moderately correlated for satisfaction ($p < .005$). Proxies reported larger emotional health and satisfaction than did subjects ($p < .005$). Proxy and subject mean responses were generally similar for overall health, functional status, and social activity. However, those proxies who spent more time per week helping the subject rated the subject's functional status and social activity as more impaired than did the subject ($p < .05$). Subjects who had poorer overall health tended to rate their health relatively lower than did the proxies ($p < .05$). These results suggest that the use of proxies intermingled with subjects to measure health status through interview may lead to biased results.

Ericson, Kristine, Nitza Perlman, and Barry Isaacs. "Witness Competency, Communication Issues, and People with Developmental Disabilities." ***Developmental Disabilities Bulletin*****, vol. 22, no. 2, 1994.** ▲ ***

As a result of increased vulnerability to sexual abuse or assault individuals with developmental disabilities are increasingly coming into contact with the criminal justice system. However, skepticism about the witness competency of people with developmental disabilities remains a concern amongst members of the legal system. It is contended that there is a need to shift some of the responsibility or onus for competency from witnesses with developmental disabilities to the mental health and legal professionals involved with these individuals. Specifically, professionals must become competent interviewers of people with developmental disabilities by taking their developmental/cognitive difficulties into account when questioning them. Some important considerations to bear in mind when questioning individuals with developmental disabilities are discussed.

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Feldstein, Jerome. "A Rational Approach to Psychological Testing of Adults with Mental Retardation." *Maryland Medical Journal*, vol. 46, no. 6, July 1997, pp. 308-311. ▲

Intelligence (IQ) tests and scales of adaptive behavior are typically used to evaluate adults with mental retardation. Personality tests and instruments designed to measure behavior problems and psychopathology are also used. Repeated IQ testing is common but not useful for adults. Adaptive behavior scales and measures of psychopathology do not appear useful, although the latter are relatively new and not widely used in clinical practice. Tests requiring skilled language responses are not useful for people with severe and profound disabilities. The problem of administering the tests is addressed by interviewing people who are knowledgeable about the person being evaluated; this method is limited by the actual knowledge of the person interviewed. Neuroimaging, still in the research stage, may be especially relevant in the future.

Fenig, Shmuel, Itzhak Levav, Robert Kohn, and Nava Yelin. "Telephone vs. Face-to-Face Interviewing in a Community Psychiatric Survey." *American Journal of Public Health*, vol. 83, no. 6, June 1993, pp. 896-898. ▲

This study compared telephone with face-to-face interviewing in a community psychiatric survey. Two groups of women were investigated, Holocaust survivors and Europe-born respondents who were in pre-state Israel during World War II. Both were administered the Psychiatric Research Interview Demoralization Scale and a short item scale investigating World War II experiences. Results showed a high compliance rate to the telephone mode. The subjects' scores in the two modes were highly correlated. Telephone interviewing seems to be a reliable and efficient method in areas with a well-developed network of subscribers.

Finlay, W.M.L., and E. Lyons. "Methodological Issues in Interviewing and Using Self-Report Questionnaires with People with Mental Retardation." *Psychological Assessment*, vol. 13, no. 3, September 2001, pp. 319-335. ▲ *

Presents a study which reviewed methodological issues that arise when interviews and self-report questionnaires are used with people with mental retardation. Question content and phrasing; Psychometric properties and target population; Suggestions for interviews and questionnaire development.

Flynn, M.C. "Adults Who are Mentally Handicapped As Consumers: Issues and Guidelines for Interviewing." *Journal of Mental Deficiency Research*, vol. 30, 1986, pp. 369-377. ▲

This paper has arisen from an investigation of the lives and circumstances of 88 people who are mentally handicapped and living in their own homes or tenancies. This study is funded by the Economic and Social Research Council. The difficulties inherent in interviewing people who are mentally handicapped are outlined. This is followed by a consideration of the findings of previous research and listing of guidelines for interviewing. The paper also explores consent procedures and issues pertaining to the measurement of satisfaction.

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Folkins, A., G.R. Sadler, C. Ko, P. Branz, S. Marsh, and M. Bovee. "Improving the Deaf Community's Access to Prostate and Testicular Cancer Information: A Survey Study." ***BMC Public Health*****, vol. 5, no. 63, June 6, 2005.** ▲

Background. Members of the Deaf community face communication barriers to accessing health information. To resolve these inequalities, educational programs must be designed in the appropriate format and language to meet their needs.

Methods. Deaf men (102) were surveyed before, immediately following, and two months after viewing a 52-minute prostate and testicular cancer video in American Sign Language (ASL) with open text captioning and voice overlay. To provide the Deaf community with information equivalent to that available to the hearing community, the video addressed two cancer topics in depth. While the inclusion of two cancer topics lengthened the video, it was anticipated to reduce redundancy and encourage men of diverse ages to learn in a supportive, culturally aligned environment while also covering more topics within the partnership's limited budget. Survey data were analyzed to evaluate the video's impact on viewers' pre- and post-intervention understanding of prostate and testicular cancers, as well as respondents' satisfaction with the video, exposure to and use of early detection services, and sources of cancer information.

Results. From baseline to immediately post-intervention, participants' overall knowledge increased significantly, and this gain was maintained at the two-month follow-up. Men of diverse ages were successfully recruited, and this worked effectively as a support group. However, combining two complex cancer topics, in depth, in one video appeared to make it more difficult for participants to retain as many relevant details specific to each cancer. Participants related that there was so much information that they would need to watch the video more than once to understand each topic fully. When surveyed about their best sources of health information, participants ranked doctors first and showed a preference for active rather than passive methods of learning.

Conclusion. After viewing this ASL video, participants showed significant increases in cancer understanding, and the effects remained significant at the two-month follow-up. However, to achieve maximum learning in a single training session, only one topic should be covered in future educational videos.

Freeman, Sally T. "Cultural and Linguistic Bias in Mental Health Evaluations of Deaf People." ***Rehabilitation Psychology*****, vol. 34, no. 1, spring 1988, pp. 51-63.** ▲

Despite psychology's increased involvement in minority mental health, deaf people have seriously limited access to adequate psychological service. Assessment plays a central role in providing such service to this population, both in the number of hearing-impaired people evaluated and in the importance of assessment for providing optimal mental health service. Questions have been raised about the appropriateness of most instruments used with the deaf population, and about the lack of cultural sensitivity in psychologists who administer the examinations. This article examines the literature regarding the validity of the assessments of deaf individuals from both a psychometric and cultural/linguistic viewpoint. Recommendations for improving assessment services to this population are offered.

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Gallagher, Patricia M., Alexis Henry, Vickie L. Stringfellow, and Carol A. Cosenza. "Notes from the Field: The Contribution of Cognitive Interviews to Instrument Development for the Massachusetts Medicaid Employment & Disability Survey." Paper presented at the Federal Interagency Committee on Disability Research Conference on Best Practices for Surveying People with Disabilities, Washington, DC, April 2004. ▲

Background. The goals for the Massachusetts Medicaid Employment and Disability Survey included gathering information from members with disabilities about their employment experiences, barriers to employment, attitudes toward employment, and service use.

Methods/Conceptual Framework. One-on-one cognitive interviews with persons with various mental and physical disabilities were a key feature of the instrument development process for this dual mode survey. The cognitive interview protocol included a set of test questions from the nearly final survey instrument and a set of structured probes designed to understand how respondents understood questions and went about answering them. Separate instruments were created for respondents who were employed and unemployed.

Results. We learned that candidate question wording did not always mean the same thing to respondents and researchers. Even some legacy questions borrowed from other surveys did not prove to be directly portable into the current instrument. Based on findings from these interviews, the instrument was revised in terms of item selection, item order, response options and question wording. This made the questionnaire more user friendly, arguably enhanced response rates, and ultimately improved the quality of the survey data.

Conclusions. With ever-scarce research funding, questionnaire pretesting is often one of the first victims of the budget knife. The cognitive interviews we conducted were well worth the investment of resources.

Implications. Cognitive interviews—a relatively new tool—are a cost effective and powerful tool for instrument development, particularly for surveys of persons with disabilities.

Gardenire-Crooks, Alissa, Allen LeBlanc, and Conrad Mandasager. "Data Triangulation: Youth and Parent Perceptions and Attitudes in the Youth Transition Demonstration (YTD) Focus Groups." Paper presented at the Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC) 2006 State-of-the-Science Conference, Arlington, VA, 2006. ▲ *

Funded by the Social Security Administration, the YTD is a large-scale, random assignment demonstration and evaluation of programs designed to help youth with disabilities between the ages of 14 to 25 transition from high school to postsecondary education, work, and greater economic self-sufficiency. Our research team has begun conducting 90-minute focus groups with each of the categories of participants of relevance to YTD in select locales: (1) youth with disabilities; (2) parents of youth with disabilities; and (3) providers of disability-related services. This small focus group study is a qualitative add-on to the predominantly quantitative evaluation. It draws upon data triangulation that is gathering data on the same topic from various sources, to increase the validity of the findings and form the most complete picture of the transition

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experiences and service needs of the youth in question, and their families. Similarities and differences between youth and parental perceptions and attitudes will be presented using early data collected from these groups.

Garrow, A.P., A.C. Papageorgiou, A.J. Silman, E. Thomas, M.I. Jayson, and G.J. Macfalane. "Development and Validation of a Questionnaire to Assess Disabling Foot Pain." ***Pain*****, vol. 85, nos. 1-2, March 2000, pp. 107-113. ▲ ***

This study outlines the design and validation of a new self-administered instrument for assessing foot pain and disability. The 19-item questionnaire was tested on 45 rheumatology patients, 33 patients who had attended their general practitioner with a foot-related problem and 1000 responders to a population survey of foot disorders. Levels of reported disability were found to be greatest for rheumatology patients and least for community subjects. In addition, the instrument was able to detect differences in disability levels reported by community subjects who did and did not consult with a health care professional and those who did and did not have a history of past and current foot pain. A good level of agreement was found when items on the questionnaire were compared with similar items on the ambulation sub-scale of the Functional Limitation Profile questionnaire. A Cronbach's alpha value of 0.99 and item-total correlation values between 0.25 and 0.62 confirmed the internal consistency of the instrument. Finally the results of a principal components analysis identified three constructs that reflected disabilities that are associated with foot pain: functional limitation, pain intensity and personal appearance. The design of the foot disability questionnaire makes it a suitable instrument for assessing the impact of painful foot conditions in both community and clinical populations.

Gething, Lindsay. ***Person to Person*****:** ***A Guide for Professionals Working with People with Disabilities.*** **Baltimore, MD: Paul H. Brookes, 1992.**

The purpose of this book is to "give information and insights that will go towards reducing stereotypes and inaccuracies about people with disabilities." In each of the twelve chapters, the author discusses a single disability "by describing salient aspects such as incidence, associated anatomy, causes, treatment, associated medical problems, implications for everyday living, social and emotional aspects, family reactions, personal adjustment, sexuality, education, employment, and the attitudes of others. This is followed by the Person to Person section, which lists adjustments that can be made to disabled and non-disabled people to make interactions easier and more enjoyable" (x).

Gilbert, Keith A., and H. Heming. "Environmental Change and Psycholinguistic Ability of Mentally Retarded Adults." ***American Journal of Mental Deficiency*****, vol. 83, no. 5, March 1979, pp. 453-459. ▲**

Effects on linguistic ability of transferring retarded adults from a large institution to small "family" bungalows were examined. Effects of environmental change on linguistic ability were assessed using the Illinois Test of Psycholinguistic Abilities (ITPA) and by video-tape recordings of subjects engaging in speech. Results indicated that the bungalows had more resident-oriented as opposed to institution-oriented practices and more staff-resident interaction than did the large

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institution. The residents to be transferred were matched with control subjects who remained in the large institution. The ITPA was administered and resident interviews were video taped for both groups immediately before the transfer date and 9 months later. Psycholinguistic ability improved significantly more for transferred residents than for control subjects. Transferred residents increased the number of words used in affirmative and negative replies to simple questions during the videotaped interview, but there were no indications of any progression from this language stage to the next. The findings are comparable to previous studies concerning environmental change and increase in language ability of retarded children.

Gilbert, Tony. "Involving People with Learning Disabilities in Research: Issues and Possibilities." ***Health and Social Care in the Community*****, vol. 12, no. 4, 2004, pp. 298-308. ▲ ***

Advances in the social position of people with learning disabilities have led to a situation where research and evaluation studies are increasingly required to include the views and opinions of people with learning disabilities. One key outcome of this shift is that some of the major funding bodies now insist on the inclusion of people with learning disabilities as a condition of research funding. This has produced new possibilities and new challenges for researchers, and it has real consequences for people working in health and social care. The present paper sets out to explore some of the developments and challenges in research with people with learning disabilities. The author provides a selective overview of developments with the aim of demonstrating the richness, ingenuity, and potential of research involving people with learning disabilities. The paper is divided into three broad section that focus on: (1) the ethics and philosophy of participatory research; (2) the methodologies employed at particular points in the research process that are designed to ensure the involvement of participants in research; and (3) building capacity in participatory research as a precondition to the further development of this approach. An investment in capacity would enable this approach to move into the mainstream of research activity involving people with learning disabilities.

Glazier, Raymond E. "Training Temporarily Able-Bodied Survey Interviewers." ***Towards Best Practices for Surveying People with Disabilities*****, vol. 1, 2007, pp. 89-103. ▲ ***

Even though one in five Americans has a disability, novice survey interviewers are often young people with little first-hand knowledge of different disabilities that they may encounter in the field. Therefore all in-person general population surveys, as well as those specifically targeting persons with disabilities, require interviewer training regarding, and sensitivity to various disabilities. This chapter summarizes an interviewer Training Program developed by the author at Abt Associates Inc. An Interviewer Disability Training Manual, excerpted below, is custom-tailored to the specific survey's content, context, and particular population. Each trainee receives the bound copy of this manual, which is structured with reminder bullets and a quick reference Ten Commandments page, to read in advance of the training session.

The Americans with Disabilities Act of 1990 expanded the concept of disability to include:

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- Persons with a history of disability or thought of by others as disabled.
- Persons with a history of psychiatric treatment.
- Excluded are persons with, for example, pyromania or pedophilia diagnoses, who might be thought likely to injure themselves or others.
- Persons in substance abuse recovery (but not active abusers).
- Protection is included for family members of persons with disabilities.
- Recent Supreme Court decisions have limited some of these protections.

In the one-day training session, the author, who has multiple severe disabilities (quadriplegia, speech impairment), first reviews the manual's content in a PowerPoint presentation. This is followed by a wide-ranging, free-wheeling discussion session in which no question is out of bounds. Each trainee then draws a Chance Card that presents a problem interview situation, to which the trainee must role play and/or explain his/her response to the scenario. Both the trainer and the other trainees critique the response of each trainee, providing suggestions, feedback, and positive input.

Abt interviewers trained with the first version of this manual successfully conduced 4,900 in-home interviews with persons with diverse disabilities in an evaluation of Project NetWork, a Social Security Administration return-to-work experiment for SSI and SSDI beneficiaries. More recently the program was used to prepare site visitors, most of them able-bodied young women, to do in-home interviews with residents of subsidized housing projects for a Congressionally mandated HUD research project exploring residents' housing project size preferences. Respondents they successfully interviewed including adult males diagnosed with chronic mental illness and newly released prison inmates, as well as persons with developmental disabilities. The training program was found effective, in the view of the author's Abt Associates colleagues, in promoting interviewer confidence and capabilities, contributing to the accurate collection of difficult-to-obtain personal data. Field interviews benefited from targeted training provided by a trainer with disabilities, in the view of their supervisors.

The interviewer training program abstracted here can readily be customized and replicated. The author is available to tailor the interviewer training program to any in-person survey and administrator the training on-site for clients by consulting arrangement with Abt Associates Inc., 55 Wheeler Street, Cambridge, MA 02138. Dr. Glazier can be contacted by telephone at (617) 394-2481/617-489-1009 or via e-mail: Ray_Glazier@AbtAssoc.com or Ray_Glazier@post.Harvard.edu.

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Goldstein, Marjorie E., Elizabeth Eckhardt, and Patrice Joyner. "The Inclusion of Deaf Individuals in Survey Research." Paper presented at the Federal Interagency Committee on Disability Research Conference on Best Practices for Surveying People with Disabilities, Washington, DC, April 2004. ▲

Background. Our research group has developed four computerized, self-administered surveys in American Sign Language (ASL). These surveys have measured substance abuse, tobacco use among deaf youth, psychiatric diagnoses, and HIV/AIDS knowledge.

Methods/Conceptual Framework. Deaf persons have been included in the conduct of each of these projects in different roles. This presentation will report on the increasing inclusion of deaf persons in all stages of this research, and the benefits of doing so. The project functions carried out by our deaf team members have included: research associate; research/administrative assistant; translation team leader and members; back translator; sign language linguist; advisor; consultant on signs for specific content area; sign model (for computer delivery of videotaped questions); survey subject recruiter; community contact/outreach worker; presenter at professional conferences; co-author on professional publications; and presenter at deaf conferences. In the formative stages of our survey research, input has also been sought from deaf persons through their participation in focus groups and in-depth interviews.

Results. The contributions of deaf staff and consultants to this research has come from both from their intimate cultural knowledge of the deaf community and from their ability to communicate with many subgroups in the deaf population.

Implications. Research in the deaf community cannot be carried out without the active professional input from deaf professional staff and consultants.

Gouvier, William. "Verbal Interactions with Individuals Presenting with and Without Physical Disabilities." *Rehabilitation Psychology*, vol. 39, no. 4, winter 1994, pp. 263-268. ▲

Four experimenters (two male and two female) requested directions to the bookstore from male and female college students on a university campus. Each experimenter portrayed a student with disability using a wheelchair and student without a disability. Conversations were surreptitiously recorded and verbal interaction patterns were analyzed. Significant differences were observed on all dependent variables, word counts, frequency of interrogatives, and the use of locator words. These findings suggest that individuals with a disability are addressed differently than individuals without disabilities, and provide limited behavioral replication of research documenting differential responses of college students to persons with and without disabilities.

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Heal, Laird W., and Carol K. Sigelman. "Response Biases in Interviews of Individuals with Limited Mental Ability." ***Journal of Intellectual Disability Research*****, vol. 39, no. 4, August 1995, pp. 331-340.** ▲

The validity of responses by individuals with mental retardation during interviews is threatened by a number of biases. Acquiescence (the disposition to answer "yes" regardless of the question asked) is a commonly observed response bias committed by respondents to questionnaires and interviews, and this disposition is significantly more pronounced when persons of low status are questioned by high-status interviewers. Research on the acquiescence bias suggests that it can be reduced in mentally retarded respondents by replacing the usual "yes/no" question format with an "either/or" format. Enhancing the either/or choices with accompanying picture representations of each choice is beneficial in increasing mentally retarded subjects' responding and in reducing their tendency to choose the latter of two either/or choices. "'Nay-saying" (the disposition to say "no" regardless of the question asked), while less common than "yea-saying" (i.e., than acquiescence), has also been noted in response to certain question formats and taboo topics. This review implies that the validity of an interview with respondents of limited intelligence depends greatly on the format of its questions.

Heal, Laird W., and Carol K. Sigelman. "Methodological Issues in Measuring the Quality of Life of Individuals with Mental Retardation." In ***Quality of Life: Perspectives and Issues*****, edited by Robert L. Schalock and Michael J. Begab. Washington, DC: American Association on Mental Retardation, 1990, pp. 161-176.** ▲

Presents some of the key methodological issues that arise in assessing quality of life among mentally retarded individuals. Offers some guidance on how to resolve these issues, drawing on research that has systematically evaluated methodologies for interviewing individuals both with and without mental retardation.

Hendershot, Gerry E. "Innovative Approaches to Interviewing People with Disabilities." Paper presented at the Statistics Canada 21st International Methodology Symposium: Innovative Methods for Surveying Difficult-to-Reach Populations, Gatineau, Quebec, Canada, November 3-5, 2004. ▲

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

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Hendershot, Gerry E. "The Effects of Nonresponse and Proxy Response on the Measures of Employment for Persons with Disabilities." Dissemination Paper, ver. 6, January 24, 2003. ▲

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

Hendershot, Gerry E., Lisa J. Colpe, and Peter C. Hunt. "Persons with Activity Limitations: Non-Response and Proxy Response in the U.S. National Health Interview Survey on Disability." *Research in Social Science and Disability*, vol. 3, 2003, pp. 41-54. ▲

This article presents an application of survey nonresponse theory to a specific population with disabilities. From 1994 to 1997, the U.S. National Health Interview Survey (NHIS) did a special, two-phase study of disability. This survey format allowed for response patterns of the disabled population to be operationalized into contact, cooperation, and proxy/assisted vs. self-response categories. Using these data, the authors investigated the effects of severity of activity limitation at first interview on response patterns at second interview, with statistical controls for other characteristics related to the response outcome. The statistical results of the study show that respondents with moderate or severe activity limitation are more likely than those with mild activity limitation to be contacted and to cooperate, yielding higher response rates. However respondents with a higher degree of activity limitation are also more likely to have proxy/assisted responses at re-interview. Barriers to self-response in household surveys are discussed in the concluding remarks.

Hennessey, David Hugh. "The Consumer Feedback Survey: Integrating Quality Assurance and Quality of Life for Persons with Developmental Disabilities (Disabled Persons, Product Quality)." *ProQuest DAI (Dissertation Abstracts International)*, vol. 56, no. 07B, 1995, p. 4061. ▲ *****

The purpose of this study was to design and test an interviewing and reporting process that creates a lifestyle profile of people with disabilities who receive services in residential settings. The Consumer Feedback Survey was developed and, in testing its effectiveness, 21 individuals and/or their advocates were interviewed. The evaluation of the effectiveness and applicability of the Consumer Feedback Survey was a systematic process of thematic analyses and narrative assessments. Feedback from surveyors and advocates indicated that the Survey addresses the many proper questions and that it has been useful in illuminating relevant issues for some

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individuals. Many statements from surveyors and advocates praised the design and reporting process of the interview. Also, many advocates who are familiar with the life of the consumer perceived accuracy in the lifestyle profile presented in the Surveyor's Report. And, test-retest procedures gave credibility to the structured interview format.

Concerns and issues raised by interviewers or detected by the researcher were redundancy or repetitiveness, the length of the interview, choppiness of the report, how to get feedback from staff or others, and accuracy and consistency in reporting. Interview modifications and strategies to address the research findings are proposed.

Henry, Alexis D., Patricia Gallagher, Vickie Stringfellow, Leslie Olin, Fred Hooven, and Jay Himmelstein. "Notes from the Field: Contemporary Strategies for Developing Surveys of People with Disabilities: The MassHealth Employment and Disability Survey." ***Towards Best Practices for Surveying People with Disabilities*****, vol. 1, 2007, pp. 127-146. ▲ ***

Health services and health policy researchers interested in the experiences and perceptions of people with disabilities commonly employ surveys as data collection tools. Yet, the best approaches to use in developing and administering surveys of people with disabilities have not been widely discussed in the literature (U.S. Department of Education, 2004). In this chapter, we describe the development and administration of the MassHealth Employment and Disability Survey (MHEDS), which was developed under the Massachusetts Medicaid Infrastructure Grant. The MHEDS was designed to gather information on disability and health status, employment status, and experiences with health care and other services among working age adults with disabilities enrolled in the state Medicaid program, called MassHealth. We discuss the key approaches that we used to define and refine the survey content and format, to conduct cognitive testing of the survey prior to fielding, and to administer the survey to nearly 3000 adults with disabilities in three MassHealth programs. In particular, we highlight the strategies that we used to involve multiple stakeholders, especially individuals with disabilities, in these development efforts. These approaches represent state-of-the-art strategies and can help ensure that the experiences and perspectives of people with disabilities are effectively captured.

Ho, Pei-Shu, Melinda Neri, Thilo Kroll, and Matthew Kehn. "Enhancing Content Validity and Relevance of Surveys Through Consumer Participation: Development of a Survey of People with Spinal Cord Injury." Paper presented at the 133rd Annual Meeting of the American Public Health Association, Philadelphia, PA, December 10-14, 2005. ▲

Objective. To describe the process of developing a national mail survey that assesses physical activity and exercise among adults with spinal cord injury (SCI), incorporating the participation and input of consumers with SCI.

Methods. Based on a detailed literature review we identified primary content areas that were consistent with study objectives. Survey items were selected from existing national survey instruments and refined with input from clinical experts such as physiatrists and physical therapists. The survey draft was presented to consumers with SCI using interactive webcast technology. Consumers provided detailed suggestions that led to modification of survey items.

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Survey items were further refined after six cognitive interviews with adults with SCI from various socio-demographic backgrounds (gender, race, and education).

Results. This mail survey includes 45 core items that ask questions concerning chronic and secondary conditions, functional health, physical activity and exercise, health risk behaviors, community integration, exercise, self-efficacy, and demographics. Clinicians and consumers' input led to changes concerning content, clarity, wording, sequencing, response options and format. The cognitive interviews showed that multiple questions in a table were confusing and too difficult. Specific, non-general instructions that incorporate examples enhance comprehension.

Conclusions. Consumer participation in survey development produces greater acceptance and comprehension for people with SCI, as well as enhances the content validity and relevance of the survey. Survey developers are well advised to look to consumers for input when designing surveys.

Houtenville, Andrew J., S. Antonio Ruiz-Quintanilla, Robert Weathers, and William A. Erickson. "Moving Toward a National Disability Survey." Paper presented at the 133rd Annual Meeting of the American Public Health Association, Philadelphia, PA, December 10-14, 2005. ▲

The National Health Interview Survey on Disability (NHIS-D) was conducted 10 years ago. There is renewed and growing interest in a National Disability Survey (NDS). One goal of an NDS is to facilitate evidenced-based policy formation in public health and other policy areas. The purpose of this paper and presentation is to frame the issues around an NDS in a way that moves these discussions forward in a systematic and inclusive manner.

We outline and discuss the creation of an NDS from multiple vantage points: (1) the necessary conditions for the creation of an NDS (e.g., demonstration of need, funding), (2) fundamental content and design elements of an NDS (e.g., sampling frame, specificity of disability types), (3) key phases of development, implementation, and utilization (e.g., initial instrument design), and (4) essential elements of each step along the way (e.g., stakeholder input, accessibility and inclusion, scientific rigor, process evaluation). We go further for one of the fundamental conditions for the creation of an NDS—a demonstration of need, and in particular the unmet needs of public health researchers and officials.

Our paper and presentation utilize input and feedback from the designers of the NHIS-D, as well as, key informants from the public health, disability and broader policy communities. In addition, we draw upon our utilization of existing data, a literature review, and our experience responding to inquiries from the field.

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Hubbard, G., M. G. Downs, and S. Tester. "Including Older People with Dementia in Research: Challenges and Strategies." *Aging & Mental Health*, vol. 7, no. 5, September 2003, pp. 351-362. ▲ *

This paper examines key challenges and strategies for including older people with dementia in an ethnographic study of quality of life in institutional care settings. The methods of interview and observation are described in relation to meeting four research challenges: verbal communication impairment, memory loss, decision-making capacity, and emotional disposition. A range of strategies for privileging the voice of the person with dementia is recommended which include: using different methods bespoke to each person with dementia; greater flexibility and time; preliminary meetings with the person with dementia; discussions with formal and informal carers; and research training. The researchers also conclude that the use of observation and interview are 'meaning-making occasions' which are qualitatively different but equally valuable for understanding quality of life in care settings.

Iezzoni, Lisa I., Ellen P. McCarthy, Roger B. Davis, and Hiliary Siebens. "Mobility Problems and Perceptions of Disability by Self-Respondents and Proxy Respondents." *Medical Care*, vol. 38, no. 10, October 2000, pp. 1051-1075. ▲ *

Background. The Americans With Disabilities Act defines disability on the basis of physical or mental impairments or external perceptions of impairment.

Objectives. The objective of this study was to examine perceptions of disability among people with lower-extremity mobility difficulties.

Research Design. This study used a cross-sectional, nationally representative survey, the 1994 to 1995 National Health Interview Survey-Disability (NHIS-D) supplement. Using SAS-callable SUDAAN for all analyses, we produced national population estimates.

Subjects. This study included 142,572 non-institutionalized, civilian residents of the United States who were ≥ 18 years of age, with 80,423 self-respondents and 49,883 proxy respondents.

Measures. We created a 4-level mobility variable using NHIS-D questions about the ability to walk, climb stairs, stand and the use of mobility aids. We examined associates between mobility and answers to 2 questions about self- and external perceptions of disabilities.

Results. The results showed that 3.1% (estimated 5.82 million persons) reported major mobility difficulties, including 3.7% of self-respondents and 2.7% of those with proxy respondents. Among persons with major mobility problems, 70.8% perceived themselves as disabled, whereas 64.8% thought other people see them as disabled. Also, 80.5% of manual wheelchair users saw themselves as disabled. Proxies were somewhat more likely to perceive disability than self-respondents, although differences were not generally statistically significant. In multivariable regressions, mobility level was the strongest predictor of self-perceived disability, followed by general health status.

Conclusions. Mobility problems increase the likelihood that people will see themselves as disabled, but these perceptions are not universal. Although the schematic of wheelchair users has

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become an international symbol of disability, many people with serious mobility problems do not view themselves as disabled.

Isaacs, Barry J. "Witnesses with Developmental Disabilities and the Cognitive Interview: The Effects of Time Delay on Recall and Suspect Identification." ***ProQuest DAI (Dissertation Abstracts International),*** **vol. 66, no. 01B, 2004, p. 617. ▲ ***

The witness recall and perpetrator identification capabilities of individuals with and without developmental disabilities (DD) under immediate and delayed interview conditions were compared. The Cognitive Interview (CI) was used to elicit recall. Participants (40 with and 40 without DD) were shown a video depicting a purse snatching. Half the participants from each group were interviewed about the video immediately after the viewing and the remaining half were interviewed one week later. Following the interview participants were presented with a perpetrator identification task. Groups made similar numbers of errors, but the group with DD recalled less correct information that the group without DD. Overall the group with DD was less accurate than the group without DD. There was little difference between groups in accuracy during free recall, but the group with DD was less accurate than the group without DD when responding to specific questions. Contrary to previous research finding, the group with DD was also less accurate than the group without DD in response to open-ended questions following free recall. The groups exhibited very similar declines in accuracy over time. The declines, however, resulted from different patterns of recall with respect to correct information and errors over time. Finally, individuals with DD were as likely as those without DD to correctly identify the perpetrator, but also more likely to make an incorrect identification. Generally, individuals with DD showed a higher propensity toward choosing in the line-up task compared to individuals without DD. Based on this and previous research studies it seems that individuals with DD are at higher risk for falsely identifying innocent suspects. It is concluded that consideration of the special needs and abilities of individuals with DD is necessary to properly support them in the legal system. Blanket application of the CI, as is, to interviewing witnesses with DD could increase the risk of procuring inaccurate information. With the development of specialized procedures and supports it is likely that many individuals with DD could serve as reliable witnesses, but much more research is needed. Specific recommendations for interviewing are made and directions for future research are discussed.

Jans, Lita, and Susan Stoddard. "In-Depth Interviews with People with Disabilities: Use of Multimedia Technology." Paper presented at the Federal Interagency Committee on Disability Research Conference on Best Practices for Surveying People with Disabilities, Washington, DC, April 2004. ▲

Background. InfoUse's Open Futures project was funded by the National Institute on Disability and Rehabilitation Research to produce multi-media interviews with a variety of successful working people with disabilities.

Methods/Conceptual Framework. We generated a database of over 300 successful working candidates with a variety of different disabilities and jobs. From that database, we used an iterative process to select dozens of examples of Role Models working in six different interest

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categories. We interviewed the Role Models at their worksites, using a field-tested protocol for gathering information on their careers and life experiences. All interviews were videotaped.

Results, Conclusions, and Implications. The resulting videotaped interviews with people working in different careers provide a rich source of qualitative data on the real-life experiences of people with disabilities. The Open Futures materials use multi-media technology to present highlights from those interviews to different audiences. The multi-media products of the study highlight conceptual ideas and practical suggestions for conducting research with people with disabilities. Videotaped interviews demonstrate use of sign language interpreters, accommodations for people with speech limitations and other communication methods essential for conducting exploratory in-depth interviews with people with disabilities. Using these techniques, in-person interviews can be an especially effective way to identify experiences and barriers in employment and other life activities.

Jobe, Jared B., and David J. Mingay. "Cognitive Laboratory Approach to Designing Questionnaires for Surveys of the Elderly." ***Public Health Reports*****, vol. 105, no. 5, September-October 1990, pp. 518-524.**

This project investigated whether new techniques of questionnaire design, adapted from the theories and methods of cognitive psychology, could be used effectively in interviewing older respondents. The techniques used in this study (e.g., concurrent think-aloud interviews with follow-up questions) have been shown recently to be effective with younger respondents. Problems that elderly respondents have in comprehending survey questions, retrieving relevant information from memory, and using decision processes to estimate and provide answers were investigated. Analysis of respondents' think-aloud protocols and responses to probes suggest that the cognitive interview procedures were effective in identifying problems with the survey questions that would result in data of poorer quality and in suggesting the wording of questions that would be likely to result in answers of greater validity and reliability. Implications of these results for survey design and validation studies are discussed.

Jones, Lesley, and Gloria Pullen. "Cultural Differences: Deaf and Hearing Researchers Working Together." ***Disability and Society*****, vol. 7, no. 2, 1992, pp. 189-196.** ▲

This article is based on several years of research done by the two authors, one whom is Deaf and the other hearing. The paper discusses research done within the Deaf community using sign language. This is an estimated 50,000 people—the same as those whose first language is Welsh. The Deaf community sees itself as a linguistic and cultural minority and as such is quite distinct from an acquired hearing loss, or those who are hard of hearing and who usually rely on written and spoken English through lip-reading or writing things down. The paper sets this research in the context of cross-cultural research and looks at its connections with emancipatory research. The central discussion is in the form of a dialogue between the Deaf and hearing researchers and their personal responses to cultural differences. In the past, Deaf people have been denied the opportunity of making their opinions known because research has used written or spoken language. The authors' research, using video-cameras to record sign language and Deaf research using sign language to interview, provides a means of interviewing more suited to Deaf people than to hearing researchers. However, as the hearing culture is likely to be perceived as the

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dominant culture, there are bound to be differences when a hearing and Deaf researcher are working together within the Deaf community. These are the issues which the authors discuss within Deaf research.

Kaye, Stephen H. "Inclusion of People with Disabilities in the NHIS and NHIS-D: Non-Response, Proxy Response, and Assisted Response." ***Towards Best Practices for Surveying People with Disabilities*****, vol. 1, 2007, pp. 105-125. ▲ ***

Proxy response, which occurs when a person responds to a survey on behalf of another family member, is often used to obtain information about people who cannot respond for themselves, do not wish to respond, or are not available to do so. Although proxy response is generally better than non-response, it can introduce bias, especially when questions are personal, sensitive, or highly subjective. This chapter evaluates two efforts by the U.S. National Center for Health Statistics to increase self-response to surveys. In Phase II of the National Health Interview Survey on Disability, a substantial increase in self-response was achieved among a broad sample of people with disabilities. However, people with severe physical, cognitive, or speech disabilities were very likely to be responded for by proxy. Non-response to the survey was generally quite low. In contrast, introduction of a self-response only rule to the Sample Adult section of the National Health Interview Survey resulted in high non-response overall, in particular for people with mobility or cognitive impairments. Subsequent relaxation of the rule to allow proxy response in certain cases greatly reduced non-response, but at the cost of abandoning the goal of obtaining self-responses from all types of respondents, including those with severe disabilities. Assisted response, in which the person responds with help from a family member or caregiver, is proposed as a middle ground between self- and proxy response for people who have difficulty answering survey questions.

Kinne, Susan. "Telephone Surveys of People with Disabilities: Whom Do We Miss?" Paper presented at the 131st Annual Meeting of the American Public Health Association, San Francisco, CA, November 2003. ▲

Individual or household telephone surveys are the most common way to collect population, health, and economic data on people with disabilities, although there are significant questions about the degree to which these methods exclude people with some kinds of limitations. With the release of population disability data from the Long Form of the 2000 Census, it is possible to address some of these questions by comparing Census to telephone survey estimates of disability prevalence and demographics. In 2000, the Washington State Office of Financial Management conducted the State Population Survey (SPS), a random digit dial household survey of the Washington population based on the Current Population Survey. The household head in 6,726 households was asked about the 17,697 individuals age 5 or older in those households, including their disability status as measured by the six 2000 Census disability questions. The SPS sample was weighted to match the age, sex, education, and race of the Washington State population. The people with disabilities identified by the SPS had significantly less education, higher household poverty and included few Hispanics and more Native Americans than the Census disability population. The SPS found higher population prevalence of overall disability (21.4% vs. 18.2%), physical, mental and sensory disability and lower rates of work and going-outside-

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the-home disability than did the Census. This supports the hypothesis that the SPS disability sample is not statistically representative of the Washington population of people with disabilities, but some of the discrepancies are not those we might expect.

Kinne, Susan, and Tari D. Topolski. "Inclusion of People With Disabilities in Telephone Health Surveillance Surveys." ***American Journal of Public Heath*****, vol. 95, no. 3, March 2005, pp. 512-517.** ▲

Objectives. Telephone survey data are widely used to describe population health, but some fear that people with disabilities cannot participate. The authors tested the hypothesis that a telephone survey would under-represent adults with disabilities, and that the adults with disabilities who responded would report lower prevalence of sensory, mental, self-care, and multiple limitations than those observed in people with disabilities in the general population.

Methods. The authors compared characteristics of adults with disabilities identified by the 2001 Washington State Behavioral Risk Factor Surveillance Survey (BRFSS) to Washington adults with disabilities in the Census 2000 Supplementary Survey (C2SS), to two BRFSS Disability Supplements, and to the Washington State Population Survey. All except the C2SS are telephone surveys.

Results. Contrary to expectations, post hoc analyses of all telephone surveys found significantly higher prevalence of disability in the Washington adult population than did the C2SS. The hypothesis of more sensory, mental, and self-care limitation in telephone disability samples was supported in only 2 of 11 instances in which a disability sample was asked about 1 of these limitations. Findings were not explained by differences in disability definition or type of informant.

Conclusions. These results suggest that population telephone surveys do not under-represent adults with disabilities. The counterintuitive finding of their higher survey participation raises further questions.

Kirchner, Corinne. "Methodological Strategies and Issues in Social Research on Vision Impairment and Rehabilitation." In ***The Lighthouse Handbook on Vision Impairment and Vision Rehabilitation: Volume 2*****, edited by Barbara Silverstone, Mary Ann Lang, Bruce Rosenthal, and Eleanor E. Faye. Oxford, England: Oxford University Press, 2000, pp. 1111-1118.**

This chapter addresses the distinctive methodological concerns that arise when social and psychological researchers turn their attention specifically to the field of vision impairment. The main challenge posed by a population characteristic such as vision impairment is sampling. Sampling, in turn, affects analytic options. Vision impairment also affects data collection techniques (for instance, access to completing print survey questionnaires) and may also influence other aspects of research participation, including serving as the researchers.

This chapter also summarizes the concept of Participatory Action Research (PAR), which calls for involvement of people with disabilities that goes beyond serving as respondents or as

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pre-testers. Participation also means that people with disabilities, who have insider knowledge about a topic, should have a significant say at each stage of the a project—from defining the important research questions, through selecting tools for study, to drawing conclusions and implications of findings.

Kirchner, Corinne. "Improving Research by Assuring Access." *Footnotes*, vol. 26, no. 7, July/August 1998, p. 7.

This article provides a brief summary of the challenges associated with surveying persons with disabilities and the reasons why the issue of access is important for research. The author concludes by offering some practical solutions to overcoming barriers to survey participation for persons with disabilities, including "ways to adapt conventional techniques so that they become accessible to all."

Kitchin, Rob. "The Researched Opinions on Research: Disabled People and Disability Research." *Disability and Society*, vol. 15, no. 1, January 1, 2000, pp. 25-47. ▲

Thirty-five disabled people with a range of physical, sensory and mental impairments were interviewed about (1) their experiences of research; (2) their general opinions concerning research; (3) whether they thought research had served/was serving disabled people well; (4) how research on disability should be conducted; (5) who should conduct research on disability; and, finally, (6) what they would like to be researched. In this paper, the results of aspects two to five are reported. It was found that the opinions of disabled people mirror quite strongly the recent arguments forwarded by disabled academics concerning the need for emancipatory and empowering research strategies. In particular, the respondents articulated a need for inclusive, action-based research strategies, where disabled people are involved as consultants and partners not just as research subjects. There were few arguments, however, for an exclusive approach, where disability research would be conducted solely by researchers who were themselves disabled.

Kohl, Frances L., Margaret J. McLaughlin, and Katherine Nagle. "Alternate Achievement Standards and Assessments: A Descriptive Investigation of 16 States." *Exceptional Children*, vol. 73, no. 1, fall 2006, pp. 107-123. ▲ *

Since the implementation of the No Child Left Behind Act of 2001 states have experienced continual change in how they define and implement alternate assessments. A subset of 16 states was randomly selected to determine how each state is implementing alternate assessments and achievement standards for students with the most significant cognitive disabilities. Telephone interviews were conducted from January to August 2005, and a 32-item questionnaire was used to collect information on alternate assessment procedures. This article focuses on the ways states are interpreting how students with the most significant cognitive disabilities are held to the same content standards as their peers without disabilities, whether states exert quality control over the administration of the alternate assessments, and the costs of implementing alternate assessments.

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Kroll, Thilo, and Brenda Gilmore. "Communication Barriers for the Spinal Cord Injury Patient." Paper presented at the Neurosciences in the New Millennium: The Future is Now Symposium, Washington Hospital Center, Washington, DC, March 4, 2005.

A presentation detailing this program was presented by key individuals associated with the Consumer Professional Partnership Program (CPPP) at National Rehabilitation Hospital (NRH) Center for Health & Disability Research. The CPPP is a consumer-directed education program for health care professionals and students of the health professions. It is a flexible educational approach to strengthen the role of consumer teaching in academic and medical environments.

The program consists of three core modules:

- Disability awareness and skills
- Prevention of secondary conditions
- Healthy living through physical activity and exercise

Specifically trained consumers with spinal cord injuries (SCI), called Spinal Cord Injuries Educators are teaching medical students and residents, physical and occupational therapists, and nurses about "disability awareness," "communication," "prevention of secondary conditions," "physical activity," and "exercise" with each module consisting of multiple talks which can be combined and modified for specific target audiences. Typically, the SCI Educator co-teaches an education module focused on spinal cord injury. Apart from providing a "real life view" to the clinical education, the SCI Educator is responsible for teaching the communication and disability awareness components.

Kroll, Thilo, David Keer, Paul Placek, Juliana Cyril, and Gerry Hendershot (Eds.). *Towards Best Practices for Surveying People with Disabilities*: *Volume 1*. Hauppauge, NY: Nova Science Publishers, Inc., 2007. ▲ *

The chapters in this book focus on three central themes: (1) Current Challenges in Survey Development for People with Disabilities; (2) Strategies to Promote Inclusion of People with Disabilities in Survey Development; and (3) Issues for Future Development. This book is primarily a book for researchers and practitioners in the disability field.

Since the topics presented in this book crosscut multiple disciplines and thus may be suited for students and experts of various disciplines. It hopefully also finds many interested readers among students and teachers of medical, social and disability sciences studies at colleges and universities. While some chapters highlight the currently unresolved barriers towards obtaining accurate measurements for certain disability populations, others introduce innovative ways to plan for and to conduct inclusive surveys. In many instances, the work presented is work in progress and as such it is important that it is expected to stimulate debate and future research work.

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Kroll, Thilo, Rosaline Barbour, and Jennifer Harris. "Using Focus Groups in Disability Research." ***Qualitative Health Research*****, vol. 17, no. 5, May 2007, pp. 690-698. ▲ ***

Qualitative health service research has increasingly drawn on focus groups to inform health policy and intervention design. Focus groups provide opportunities to engage in the development and evaluation of health services for those service users who are often excluded from other forms of data collection. Increasingly, people with disabilities have been recognized as a marginalized group in health research. To provide appropriate accommodation and to maximize the utility of focus groups with people who have disabilities, careful preparation and planning are necessary. In this article, the authors highlight critical issues in conducting focus groups with people who have various impairments and provide advice on what to consider in terms of preparation and analysis.

LaPlante, Mitchell P., H. Stephen Kaye, Joseph T. Mullan, and Alice Wong. "Initial Development of the Disability and Activity Impact Screener (DAIS): An Example of Qualitative Measurement Discovery." ***Towards Best Practices for Surveying People with Disabilities*****, vol. 1, 2007, pp. 147-164. ▲ ***

Survey measures of disability have been developed without sufficient consideration of how people with disabilities see themselves, and are focused negatively on what people cannot do or have difficulty with doing. The validity of that approach has been seriously challenged. We conducted a series of focus groups with over one hundred participants to explore how people with disabilities think about disability in their daily lives. Transcripts were analyzed independently by three researchers to identify common themes. People with disabilities are more concerned with how they do things differently, and the problems they encounter in doing so, rather than what they cannot do or have difficulty doing. Doing things differently included using personal assistants, assistive technology, taking more time, and avoiding or minimizing physical and social barriers. We developed a new instrument, the Disability and Activity Impact Screener (DAIS), to capture these ideas. It is possible to identify people with disabilities by focusing on differences in the way that people perform day-to-day activities. This approach is positively oriented, or more consistent with how people with disabilities view themselves, and is potentially more valid. Including people with disabilities from the start of instrument development can lead to more valid questionnaire items and measures and is recommended as a best practice.

Lee, Sunghee. "I Am Disabled On and Off! A Study of Proxy Response in a Disability Survey." College Park, MD: University of Maryland Joint Program in Survey Methodology, 2002. ▲

It is a prevailing belief that a self-respondent provides better data than a proxy respondent because self-respondents have much richer information than proxies. However, proxy respondents are widely used in health-related surveys, especially those related to disability. Even though the word "disability" seems as if it should be conceptually clear, it is actually quite vague. The concept of disability is perceived differently from one person to another because disability is understood not as a fixed inherent inability of the person, but as a social or environmental barrier imposed on a person. This conceptual ambiguity of disability increases

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doubts about use of proxy respondents. Still, the findings from past research fail to support the intuition that self-reports are superior to proxy reports.

In a two-wave disability survey, I find differences in reports and response behavior between self- and proxy respondents. People reveal their own disability (self-response) at a higher rate than other person's disability (proxy-response). However, self-respondents provide less consistent answers than proxy respondents. This suggests that self- and proxy respondents may have different amounts and types of information and may not rely on the same information when judging the disability of the same person. When separating the proxy respondents according to their 'social relationship' to the target subjects, spouse proxies are found to be most consistent in reporting disability; other types of proxies report less consistently than self-respondents. Memory capacity of a proxy respondent and duration of relationship between a target and a proxy affect the reporting consistency level. These findings imply that categorizing all respondents other than the target person as a proxy-respondent group may not be the right approach to examining the effect of the respondent rule because there seems to be an unignorable effect of social relationship between a proxy and the target person on the proxy-response behavior.

Lee, Sunghee, Nancy A. Mathiowetz, and Roger Tourangeau. "Perceptions of Disability: The Effect of Self- and Proxy Response." ***Journal of Official Statistics,*** **vol. 20, no. 4, 2004, pp. 671-686. ▲ ***

This study compares estimates of persons with disabilities based on self- versus proxy reports. In addition, it examines the consistency of reports across two waves of data collection. The findings indicate that self-response tended to produce higher rates of persons with disabilities than proxy reports, although only in the second wave of data collection. In addition, self-respondents provided less consistent responses across the two interviews than proxies did. These findings support theoretical and empirical literature that suggests that self-respondents rely on more dynamic information than proxies in responding to the survey questions. We classified proxy respondents according to their relationship to the target subjects and found that spouse proxies were significantly more likely to provide consistent answers than other proxies. These findings suggest that classifying all proxy reporters as one group may mask the effects of the respondent, since there seem to be significant effects of the proxy-target relationship and the characteristics of proxy respondents on the quality of the data.

Lewis, Ann, and Jill Porter. "Interviewing Children and Young People with Learning Disabilities: Guidelines for Researchers and Multi-Professional Practice." ***British Journal of Learning Disabilities,*** **vol. 32, 2004, pp. 191-197. ▲ ***

We argue that it is important for researchers and service providers to not only recognize the rights of children and young people with learning disabilities to have a "voice", but also to work actively towards eliciting views from all. A set of guidelines for critical self-evaluation by those engaged in systematically collecting the views of children and young people with learning disabilities is proposed. The guidelines are based on a series of questions concerning: research aims and ethics (encompassing access/gatekeepers; consent/assent; confidentiality/anonymity/

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secrecy, recognition, feedback and ownership; and social responsibility) sampling, design and communication.

Lipton, Douglas, Marjorie Goldstein, F. Wellington Fahnbulleh, and Eugene N. Gertz. "The Interactive Video-Questionnaire: A New Technology for Interviewing Deaf Persons." ***American Annals of the Deaf*****, vol. 141, no. 5, December 1996, pp. 370–378.** ▲

This paper traces the development of a new technology, the Interactive-Video Questionnaire, for interviewing Deaf persons by using manually signed questionnaires. After encountering numerous obstacles to conducting surveys with Deaf persons about substance abuse using the same methods typically used with hearing persons, the researchers, with a Small Business Innovative Research grant from the National Institute on Drug Abuse, piloted a survey method that uses videodisc and bar code readers to present survey questions signed on screen in American Sign Language and Signed English. Following consultations with Deaf participants, deficiencies of this method were identified and corrected. An interactive multimedia program was created in Phase II of this research effort that offered questions visually in American Sign Language, Signed English, or Speechreading. All questions were subtitled in written English, with Touchscreen entry and automatic data capture and storage. The potential exists for many important uses of the Interactive-Video Questionnaire.

Lloyd, Vicki, Amanda Gatherer, and Sunny Kalsy. "Conducting Qualitative Interview Research with People with Expressive Language Difficulties." ***Qualitative Health Research*****, vol. 16, no. 10, December 2006, pp. 1386-1404.** ▲ *****

Despite the increasing application of qualitative interviewing and analysis approaches, individuals with expressive language difficulties are still frequently excluded from such research. In this article, the authors seek to clarify the role for and importance of conducting qualitative interviews with respondents with impaired expressive language. They review current research with reference to studies conducted with individuals with intellectual disabilities or dementia, or those who have experienced stroke or traumatic brain injury, and identify deficits within existing research. They consider the challenges and difficulties that contribute to the limited inclusion of individuals with impaired expressive communication in qualitative interviews and discuss the way forward with suggestions of possible means of overcoming these obstacles. They argue that a willingness to adapt methods appropriately and to modify expectations is an important factor in ensuring that researchers hear the voice of respondents with expressive language deficits.

MacDonald, James, Valerie Sinason, and Sheila Hollins. "An Interview Study of People with Learning Disabilities' Experience of, and Satisfaction with, Group Analytic Therapy." ***Psychology and Psychotherapy Theory, Research Practice*****, vol. 76, 2003, pp. 433-453.** ▲ *****

A number of clinicians have developed psychodynamic treatments for people with learning disabilities, but there have been few studies assessing the impact of psychodynamic therapy with this population. In particular, there have been no studies in which investigators have asked

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clients about their experience of psychodynamic treatment. The current study is an attempt to rectify this by exploring people with learning disabilities' experiences of, and satisfaction with, two psychodynamic groups provided by an inner city service. Nine learning-disabled clients, four from a sexual offenders' group and five from a women's group, were interviewed about their experience of psychodynamic group psychotherapy. Their responses were analysed using Interpretive Phenomenological Analysis. Participants suggested that they valued the therapists and the group, and appreciate the opportunity to talk about painful experiences and be including and valued in the group. However, participants also indicated that they found the group emotionally painful, on occasion found it hard to identify with other group members, and were often unaware of any positive change in themselves. These interview findings complement ongoing quantitative attempts to establish the impact of psychodynamic treatment for this population.

Mactavish, Jennifer B., Michael J. Mahon, and Zana Marie Lutfiyya. "'I Can Speak for Myself': Involving Individuals with Intellectual Disabilities As Research Participants." *Mental Retardation*, vol. 38, no. 3, 2000, pp. 216-227. ▲ *

The Lifespan and Disability Project, a 2-year qualitative study, was designed to enhance understanding of social integration by including the perspectives of individuals with intellectual disabilities. Procedures and strategies employed to involve these individuals in the project were documented. Specifically, we describe the use of individual interviews and focus groups (e.g., purpose, rationale, facilitation techniques) to collect data, and verification meetings in which a prompting hierarchy and cueing were employed to assist participants in confirming or disconfirming the researchers' interpretations of the emerging findings. Highlights of the results were presented to illustrate the efficacy of the strategies in enabling the participants with intellectual disabilities to share their perspectives on social integration.

Margellos, Helen. "Developing a Survey of Health Status, Knowledge, and Experiences for Persons Who are Deaf." Paper presented at the 131st Annual Meeting of the American Public Health Association, San Francisco, CA, November 17, 2003. ▲

Persons who are deaf and depend on sign language for communication represent a distinct linguistic and cultural population. Prior studies have suggested that multiple socioeconomic factors in this population contribute to health status, knowledge, and utilization of health services which differ from other groups. This abstract reports on the initial phase of a longer-term project intended to improve access to care, health knowledge and behavior, and outcomes in the deaf community in the Chicago metropolitan area. In this first phase, a survey was developed to characterize the current status for persons who are deaf in the Chicago area, including racial/ethnic minorities. Survey results will be used to guide subsequent interventions in health service delivery and health education, and will provide a baseline for evaluation purposes. Survey domains included: demographics, access to care (including interpretation), knowledge of diseases and wellness behaviors, and satisfaction with care. The choice of these domains took into account the findings of previous studies, extensive prior experience in service delivery to this community, and the potential for comparison of findings with other populations. Similar considerations led to specific inclusion factors distinguishing our study population, including

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communication preferences and age of onset of deafness. Input of deaf team members was critical throughout. The communication styles and literacy levels of our subjects required the development of particular surveying techniques, with appropriate translation of written materials into sign language. Our presentation will illustrate this process further, including unique challenges, experiences, preliminary findings, and subsequent adjustments in the surveying approach.

Margellos-Anast, Helen, T. Hedding, T. Perlman, L. Miller, R. Rodger, L. Kivland, D. Degutis, B. Giloth, and S. Whitman. "Developing a Standardized Comprehensive Health Survey for Use with Deaf Adults." ***American Annals of the Deaf*****, vol. 150, no. 4, 2005, pp. 388-396.** ▲

There is limited information on how communication barriers impact on the health of deaf individuals. The present article describes the development of a standardized interview tool to collect health-related information from deaf adults via face-to-face interviews in American Sign Language (ASL). Questions were selected largely from existing standardize questionnaires. Key steps in standardizing the instrument included the creation of an ASL gloss version of the survey and extensive interviewer training. The instrument was pilot-tested and revised prior to implementation. There were 139 questions on the final instrument. A total of 203 interviews were conducted between November 202 and March 2003. A standardized interview survey administered in ASL proved an effective and well-accepted means of collecting health-related information from a diverse sample of deaf individuals. Several challenges were encountered throughout the process, and the resulting lessons will be useful to future research efforts.

McLean, L.K., N.C. Brady, and J.E. McLean. "Reported Communication Abilities of Individuals with Severe Mental Retardation." ***American Journal of Mental Retardation*****, vol. 100, no. 6, 1996, pp. 580-589.** ▲ *

Little is known about the distribution of communication skills among individuals with severe mental retardation. The present study was designed to obtain basic descriptive information about the reported expressive communication status and other associated sensory and behavioral characteristics of four representative samples of this overall population. These samples include both children and adults and individuals living in large residential facilities as well as those living at home or in smaller, more natural community environments. Results of this study, based on completed questionnaires for 211 subjects, revealed a wide range of communication abilities in this population, with a significantly larger percentage of adults than children communicating at symbolic levels.

McNutt, James, and Susan Leri. "Language Differences Between Institutionalized and Non-Institutionalized Retarded Children." ***American Journal of Mental Deficiency*****, vol. 83, no. 4, January 1979, pp. 339-345.** ▲

The linguistic performances of 15 non-institutionalized and 15 institutionalized retarded children were compared on usage of grammatical categories and structure of spoken language (Length-Complexity Index) and for underlying skills (Illinois Test of Psycholinguistic Abilities).

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Differences were not found between the groups for usage of grammatical categories or structures but were found for subskills of Auditory Reception. Auditory Sequential Memory, Verbal Expression, and Auditory Closure. Further analysis by multiple stepwise regression indicated that non-institutionalized and institutionalized retarded children may be differentiated by examining a number of linguistic variables. The grammatical structure of language appeared less affected by environment than were the semantic and auditory elements.

McVilly, Keith R., Roseanne M. Burton-Smith, and John A. Davidson. "Concurrence Between Subject and Proxy Ratings of Quality of Life for People With and Without Intellectual Disabilities." ***Journal of Intellectual and Developmental Disability*****, vol. 25, no. 1, March 2000, pp. 19-39.** ▲

The purpose of this investigation was to examine concurrence between subjects' self-reported quality of life (QOL) and assessments of their QOL made by proxies who were either a first degree relative, or were acting in a supportive role similar to that of a family member. Two studies were conducted. The first study, using ComQol-A4 (Cummins, 1993), examined the degree of concurrence between non-disabled subjects QOL and ratings made on their behalf by proxies who were either a parent or sibling (n = 78 subject/proxy pairs). The second study utilized ComQol-ID4 (Cummins, 1993), and examined the agreement between QOL ratings made by subjects with mild intellectual disability and proxies who were either parents or support workers (N = 24 subject/proxy pairs). In both studies, the effects on agreement of variables including the subject/proxy living arrangements, gender similarity, and proxy gender and empathy were examined. In contrast to research utilizing non-standardized approaches to QOL, assessment, results from both studies indicated overall a high degree of subject/proxy concurrence. Overestimation or underestimation of ratings by proxies was minimal. These findings endorse the use of standardized approaches such as ComQol for proxy-based measures of QOL. Also, none of these factors investigated directly affected agreement between subject/proxy QOL reports. If standardized approaches to QOL are employed, and if proxies are selected on the basis of close and regular contact, it does not seem to matter if they are male or female, cohabitating family members or non-cohabitating support workers.

Meyers, Allan R. "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, August 1999. ▲

Enablement is a process that helps to assure full access and social participation by people with disabilities. Though supporting the goal of enablement, as a research community, we have done little to assure access to our most important research instruments. Consequently, unintentionally, or in the guise of methodological rigor, we have systematically excluded from our research—and therefore from our health planning, policy and evaluation activities—some of the most frequent users of health services; those with the greatest number and widest range of health services needs, and those who may be the greatest beneficiaries (or bear the greatest burdens) of health care reform. Not incidentally, we also have violated the letter, and the spirit of the ADA.

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This presentation first highlights some of the most disabling features of health services research: (1) sampling methods that are less likely to reach people with disabilities; (2) modes of administration that do not allow them to complete those instruments, or, to complete them so comprehensively as other people do (nor so comprehensively as we and they would like to do), and (3) research instruments whose contents and concepts are so offensive or so alien to their experiences that people with disabilities cannot or will not take part. Then, it proposes remedies, to reduce handicaps and assure wider access to research instruments. These remedies are designed to reconcile needs of research vigor, with principles of equity, fairness and universal design.

Miner, Laurie, Dennis McFarland, and Jonathan Wolpaw. "Answering Questions with an Electroencephalogram-Based Brain-Computer Interface." ***Archives of Physical Medicine and Rehabilitation*****, vol. 79, no. 9, September 1998, pp. 1029-1033.** ▲

Objective. To demonstrate that humans can learn to control selected electroencephalographic components and use that control to answer questions.

Methods. For adults (one with amyotrophic lateral sclerosis) learned to use electroencephalogram (EEG) mμ rhythm (8 to 12HZ) or beta rhythm (18 to 25Hz) activity over sensorimotor cortex to control vertical cursor movement to targets at the top or bottom edge of a video screen. In subsequent sessions, the targets were replaced with the words YES and NO, and individuals used the cursor to answer spoken YES/NO questions from single- or multiple-topic question sets. They confirmed their answers through response verification (RV) procedure, in which the word positions were switched and the question was answered again.

Results. For 5 consecutive sessions after initial question training, individuals were asked an average of 4.0 to 4.6 questions per minute; 64% to 87% of their answers were confirmed by the RV procedure and 93% to 99% of these answers were correct. Performances for single and multiple topic question sets did not differ significantly.

Conclusions. The results indicate that (1) EEG-based cursor control can be cued to answer simple questions with a high degree of accuracy, (2) attention to auditory queries and formulation of answers does not interfere with EEG-based cursor control, (3) question complexity (at least as represented by single versus multiple-topic question sets) does not noticeably affect performance and (4) the RV procedure improves accuracy as expected. Several options for increasing the speed of communication appear promising. An EEG-based brain computer interface could improve a new communication and control modality for people with severe motor disabilities.

Mitchell, Susan. "National Survey of SSI Children and Families: Data Collection and Survey Content." Paper presented at the 129th Annual Meeting of the American Public Health Association, Atlanta, GA, October 23, 2001. ▲

The NSCF is planned as a computer-assisted telephone interview with computer-assisted personal interviewing of telephone nonrespondents. Interviews will be conducted with about 9,900 children and young adults who have experience with the SSI program, either as current

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beneficiaries, former beneficiaries, or applicants who never received benefits. The 60-minute questionnaire is designed to collect a rich array of data on children's health and socioeconomic status. By drawing on questions used in other national surveys on children's health and disability, the NSCF questionnaire will yield data for comparative analysis. There are two questionnaire versions: (1) the child version for children under age 17, and (2) the young adult version for children between 17-24. The versions are similar in content but allow for differences in living situations, SSI eligibility, and other age-specific issues between children and young adults. Both versions ask about the child's health status and functional limitations, health care utilization, health insurance coverage, education, receipt of services, and experience with the SSI program. Data are also collected about the impact on the family of having a disabled child in the household. Finally, data are collected about the socioeconomic status of the children's households, including parental employment, earned and unearned income, and housing characteristics. For children under 18, the respondent will be the parent or legal guardian; children over 18 will respond for themselves if they are living away from their parents.

Mitchell, Susan, Anne Ciemnecki, Karen CyBulski, and Jason Markesich. "Removing Barriers to Survey Participation for Persons with Disabilities: Final Report." Princeton, NJ: Mathematica Policy Research, Inc., January 2006.

The National Institute on Disability and Rehabilitation Research (NIDRR) has recently defined a new paradigm of disability (NIDRR 2000). Under the new paradigm, disability is a "deficit in the person-community relationships that should be addressed by social interactions." The goal of the new paradigm is to facilitate the full participation of people with disabilities (PWD) in society. Implied by the shift are survey research methods that require new approaches to measuring disability in federally funded surveys and new approaches to making surveys accessible to people with disabilities.

MPR has gained experience in conducting surveys of PWDs through contracts sponsored by the Centers for Medicaid and Medicare Services (CMS) and the Social Security Administration (SSA). This paper synthesizes the major points from these projects and draws on MPR's broader survey experience to formulate a set of practical recommendations for conducting surveys with PWDs.

MPR's instrumentation procedures have attempted to address three broad categories of common challenges: (1) communication, (2) stamina, and (3) cognitive barriers. Communication challenges include both hearing and speech impairments. The term "stamina challenges" refers to both physical and mental fatigue. Cognitive challenges include, but are not limited to, emotional disturbance, difficulty processing questions and responses, lack of complete or specific knowledge, and confusion about the purpose of the interview. Modifications to instrumentation include: (1) minimizing high-frequency sounds, (2) interviewer checkpoints, (3) structured probes, (4) follow-up items for non-response, (5) measurement of disability, (6) consideration of self-reports of disabling conditions, (7) accommodation for differences in living situations, and (8) awareness of the diversity inherent in the PWD population. MPR has also modified data collection procedures with PWD to ensure high-quality data. Special interviewer training, adjusted interviewer productivity standards, advance contact and

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notifications, incentives, and use of proxy respondents and assisted interviews can contribute to respondent and interviewer comfort.

Montoya, Louise A., Reginald Egnatovich, Elizabeth Eckhardt, Marjorie Goldstein, Richard A. Goldstein, and Annie G. Steinberg. "Translation Challenges and Strategies: The ASL Translation of a Computer-Based Psychiatric Diagnostic Interview." ***Sign Language Studies*****, vol. 4, no. 4, summer 2004, pp. 314-344.** ▲

This article describes the translation goals, challenges, strategies and solutions employed in the development of a computer-based, self-administered, psychiatric diagnostic instrument, the Diagnostic Interview Schedule for the Deaf (D-DIS-IV) in American Sign Language (ASL) with English captions. The article analyzes the impact of the difference between ASL and English as well as the influence upon psychiatric content of the life experiences of respondents with normal hearing and deafness. The authors describe solutions for bridging these differences in the translation of a self-administered, computer-based, psychiatric diagnostic interview.

Moore, David J., David Sitzer, Colin A. Depp, Lori P. Montross, Jennifer Reichstadt, Barry D. Lebowitz, and Dilip V. Jeste. "Self-Administered Cognitive Screening for a Study of Successful Aging Among Community-Dwelling Seniors: A Preliminary Study." ***International Journal of Geriatric Psychiatry*****, vol. 22, no. 4, April 2007, pp. 327-331.** ▲ *****

Background. Cognitive functioning is a central component of successful aging. Yet, there are few published instruments for brief and reliable self-administered cognitive assessment that could be used in large population-based studies of community-dwelling elderly people.

Objective. We examined the utility of a self-administered cognitive screening instrument in a group of community-dwelling older adults, and we evaluated correlations of the performance on this measure with demographic variables and specific indicators of self-rated successful aging.

Method. We assessed 182 well-educated adults ages 58 to 99 with a modified version of a previously published cognitive screening instrument (Cognitive Assessment Screening Test—Revised; CAST-R), a measure of cognitive complaints (Cognitive Failures Questionnaire; CFQ), and a self-rating of successful aging. We used the SF-36 Physical and Mental Composite Scores as measures of physical and mental health-related functioning.

Results. As expected, most individuals performed well on the CAST-R; only 7% of participants fell below a previously established cut score for cognitive impairment. CAST–R scores were positively correlated with level of education, income, SF-36 Mental Composite Scores, and a self-rating of successful aging, and negatively correlated with chronological age. Scores on the CAST-R were not correlated with cognitive complaints (CFQ total score) or SF-36 Physical Composite Scores.

Conclusions. A self-administered cognitive screening tool may be a useful, albeit limited, way of screening for cognitive disabilities among well-educated, community-dwelling older

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adults. Although preliminary, significant associations with several successful aging-related variables in expected directions represent the first step in establishing the validity of the CAST-R.

Mulhorn, Kristine A. "Addressing Recommendations for Increasing the Rate of Response by Persons With Disabilities: A Comparison Across Six National Surveys." ***Towards Best Practices for Surveying People with Disabilities*****, vol. 1, 2007, pp. 1-11. ▲ ***

This chapter summarizes the efforts in six countries to increase the response rate of persons with disabilities in their national disability surveys. The strategies presented by the members of DISTAB (*DIS*ability *TAB*ulations)—a group sponsored by the National Center for Health Statistics to examine cross-national comparability of disability statistics—present a set of recommendations for future surveys. The countries included in DISTAB are Australia, Canada, France, the Netherlands, South Africa and the United States. Each country's disability survey is described according to basic information such as methodological aspects, time frame, response rate and sample size. The description of the strategies for increasing the response rate of persons with disabilities follows an outline of topics described by the National Council on Disability in 1998. The topics include 1) choosing topics, objectives, and variables; 2) choosing methods of data collection; 3) designing the sample; 4) designing the questionnaire; 5) collecting the data; and 6) analyzing and reporting the data;. These topics were summarized into five questions that can be considered in the development of disability surveys, and for each of these questions, examples for the participating counties are described. For example, almost all of the countries used specific strategies to involve persons with disabilities in the planning or developing of the survey. The questions and the answers to them for each survey make up what is called a quality profile. These questions can be asked for all disability surveys, providing the start of a "gold standard" for conducting disability surveys.

Murray, Patrick. "A Multi-Mode Approach for Surveying Visually Impaired Population." ***Towards Best Practices for Surveying People with Disabilities*****, vol. 1, 2007, pp. 165-179. ▲ ***

This case study examines the efficacy of conducting a self-administered survey with a visually impaired population. The study was conducted with clients of the Vocational Rehabilitation Program at the New Jersey Commission for the Blind and Visually Impaired. The basic design was multi-modal, involving a mailed survey packet with options for completing the survey in four self-administered formats (in writing on a large-print document, by Braille, computer disk, or audio tape) and one interview-assisted mode (by contacting a staffed toll-free telephone line). A follow-up survey as conducted with a sample of non-participants to assess reasons for non-response. The study was later replicated. The study found that less expensive self-administered modes can be used to conduct valid probability surveys with a visually impaired population. However, it may be important that an interviewer-assisted mode by available, if not for the final survey results to be representative of the full population, then to fulfill other accessibility obligations.

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National Council on Disability. "Reorienting Disability Research." Washington, DC: National Council on Disability, April 1, 1998.

This document is the product of a yearlong initiative sponsored by the National Council on Disability (NCD) and the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education. It was prompted by the National Council on Disability's Disability Policy Summit in April 1996 and subsequent release of the report *Achieving Independence: The Challenge for the 21st Century in July 1996*. At the Policy Summit, people with disabilities articulated their keen interest in disability statistics and identified a need for changes in federal data collection activities. Their interest in disability statistics reflects their recognition that such data are often used in policy decisions and that better data will enhance their ability to pursue changes in government policies that will benefit people with disabilities. Recommendations to improve data collection are included in Achieving Independence.

For many years, disability research has appeared to be essentially a scientific exercise, based on academic procedures applied in an area of health care. People with disabilities have learned, however, that underlying values and assumptions have guided research in ways that are not necessarily important or helpful to them as the ultimate beneficiaries. Choices are made, either consciously or not, at each stage of research design, collection, and dissemination that affect the utility of the research to individuals with disabilities. Given limited federal resources, which questions should be studied? How should they be studied? What should be done with the results?

This report recommends action steps to reorient the answers to these questions based on the thinking that disability is a natural part of the human experience, that people with disabilities should participate in the production and consumption of research about them, and that disability data should be an integral part of population statistics and socioeconomic measures of progress.

The following action steps are recommended to infuse the disability paradigm embodied in ADA into federal data collection activities.

- Improving Organizational Structure
- Refining Current Data Collection Efforts
- Using Existing Data
- Developing New Data Collection Instruments
- Broadening Dissemination

Norton, P.G., B. van Maris, L. Soberman, and M. Murray. "Satisfaction of Residents and Families in Long-Term Care: Construction and Application of an Instrument." *Quality Management in Health Care*, vol. 4, no. 3, 1996, pp. 38-46.

In the fall of 1994, a consortium of eight long-term care facilities in Ontario devised a new survey instrument to measure patient satisfaction in long-term care settings. A standardized protocol for administration was developed that included a program to train volunteers to conduct

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in-person interviews. Nine facilities administered the survey using the standardized protocol. This article, the first in a series of articles detailing this project, outlines the construction and pilot-testing of the new survey instrument for the target population as well as a parallel survey instrument for the family member/friend who visited the resident most frequently. The research team's overall experience with the new survey instrument's initial application is described in this initial article. The team reported that the new questionnaires helped their organizations become more patient focused and that the information obtained from the data that were collected provided staff with insight and direction for their quality improvement efforts.

Olson, Lorayn, Ann-Sofi Roden, T. Christopher Brogan, Robert A. Wright, J. Michael Dennis, and Corinna A. Crawford. "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, IL, November, 1999.

In this presentation, new methods being developed to include deaf respondents in the NHIS to make it possible for all sampled households to participate in this telephone survey are presented. In attempting to define and work with this particular population, the following questions were raised, but unanswered:

- Proportion of the U.S. population that is unable to communicate by voice using a telephone
- Proportion of hearing impaired population that lives alone or in a household where all household members are hearing impaired
- Proportion of the hearing impaired population that has a child between 18 months and 35 months of age
- Proportion of hearing impaired population that uses a TTY or TDD machine
- Proportion of hearing impaired population that does not use a TTY but does use a computer

Other issues such as the inability to detect a number using a TTY machine, advance letters inviting hearing impaired respondents to initiate contact, and letters with postscripts providing instructions on how to contact the study using a TTY machine are discussed in detail.

The presenters concluded that the actual number of households that require special assistance is unknown and that efforts to proactively identify sampled households that needed assistance were not successful.

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Packer, Jaclyn. "Assuring Inclusiveness in Data Collection Among People with Visual Impairments." ***Proceedings in the Society for Disabilities Conference*****. Portland, ME: Portland University of Southern Maine Society for Disability Studies and Edmund S. Muskie Institute of Public Affairs, 1995.**

This paper presents some practical suggestions on how to make self-administered written surveys accessible for blind or visually impaired persons:

- To ensure greatest accessibility, the survey materials should be prepared in a number of formats including Braille, large print, digital, and voice.
- It may be possible to mail and receive questionnaires free of postage (that is, as "Free Matter for the Blind") if the respondent is legally blind and if no part of the document is in regular print.
- Large print questionnaires are easy to produce if the document was created using a word processor. The font size should be increased to at least 14 points.
- Surveying by telephone is another alternative for people who cannot, or do not want to, use Braille or large print.

Parent, Wendy, and John Kregel. "Consumer Satisfaction: A Survey of Individuals with Severe Disabilities Who Receive Supported Employment Services." ***Focus on Autism & Other Developmental Disabilities*****, vol. 11, no. 4, winter 1996, pp. 207-222.** ▲

This study was designed to investigate the supported employment experiences of persons with disabilities to determine what they liked and disliked about their jobs and the services received, and how much involvement they had or would like to have had in choosing their jobs and support services. It expands upon earlier efforts in several ways. First, individuals with disabilities were involved in all aspects of its development and implementation, including designing the instrument, establishing administration procedures, conducting face-to-face satisfaction interviews, and completing a Consumer Satisfaction Survey. Second, it takes a broad view of the concept of satisfaction, which includes the individuals' perceptions of their pay and benefits, supervisor and co-worker relations, job and work conditions, job coach, and supported employment. Third, the study developed and validated instrumentation and interview protocols for evaluating supported employment services that include individuals with severe disabilities. Fourth, the investigation provides important feedback for service providers, policymakers, and rehabilitation professionals regarding consumer choice and satisfaction in supported employment for individuals who are working and receiving services. The findings from this study and their implications for supported employment will be discussed.

Parker, M.G., M. Gatz, and M. Thorslund. "Brief Cognitive Screening in a Field Survey of the Oldest Old." ***Aging (Milano)*****, vol. 8, no. 5, October 1996, pp. 354-359.** ▲ *****

A nationally representative survey of living conditions among persons aged 77 to 98 years included a short instrument for cognitive impairment consisting of items from the Mini-Mental

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State Examination (MMSE). Because of the wide range of social, health, and economic domains included in the survey, it was necessary that the instrument could be administered in a short time by interviewers without experience in neuropsychological testing. Because of the age of the subjects, the instrument must be relatively independent of sensory or motor disabilities, and be acceptable to both interviewers and older adults. There were very few problems with the use of the instrument and very little missing data. A cut-off point for cognitive impairment was ascertained for the items included in this instrument using other data sets where diagnostic confirmation was available. Being able to identify subjects who are probably cognitively impaired is helpful in a multipurpose survey study of the oldest old, both in documenting the cognitive status of the sample and in evaluating the quality of other information being collected in the study.

Parsons, Jennifer, Sara Baum, and Timothy P. Johnson. "Inclusion of Disabled Populations in Social Surveys: Review and Recommendations." Chicago, IL: University of Illinois at Chicago, December 2000.

This paper focuses on the key areas of concern as they relate to social surveys and as defined by the key informants interviewed. Specifically, these key areas are sampling and respondent selection, use of proxy respondents, and adaptive technologies specific to surveys with persons with disabilities. As survey researchers, one of their primary objectives was to adjust procedures to minimize barriers and maximize participation of persons with disabilities. By presenting a broad overview of the issues involved in surveying persons with disabilities, their goals were to raise awareness within the survey research community and explore potential approaches to proactively broadening their inclusion.

Key lessons from this review include the following:

- Attend to inclusion and measurement issues relevant to persons with disabilities should be built into the general design of social surveys.
- Continue to explore the developments in technology that will empower greater numbers of people with disabilities by enabling them to participate directly in social surveys.
- Reach out to more persons with disabilities by offering alternative methods of response, such as self administered questionnaires for respondents with hearing difficulties, or interviews by phone and/or large-print versions of questionnaires for people with visual impairments.
- Develop greater awareness of the environments in which researchers conduct their research so that virtually every feature of survey design can influence the likelihood that those with disabilities will have an opportunity to participate.

The abstract was written by the author(s) or publisher.
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Paterson, Barbara, and Shannon Scott-Findlay. "Critical Issues in Interviewing People with Traumatic Brain Injury." ***Qualitative Health Research*****, vol. 12, no. 3, March 2002, pp. 399-410. ▲ ***

People with cognitive impairments often cannot effectively recall and articulate experiences, feelings, and perceptions. Therefore, interviewing them can be fraught with pragmatic and methodological difficulties. Given this situation, the authors' experience in a study on the allocation of rehabilitative services to survivors of traumatic brain injury is discussed. Participants had physiological impairments affecting their ability to focus on interview questions. The authors discuss the unique challenges, including participants' recall of events, intolerance to stimuli, and image management and other strategies for mitigating these concerns. The traditional view that reality is captured only in the subjective accounts of articulate people who can remember events in a precise and reflective manner is challenged.

Perry, Jonathan. "Subjective and Objective Quality of Life Assessment: Their Interrelationship and Determinants." ***The Research Findings Register*****, summary number 747, March 27, 2002. ▲**

The purpose of this study was to explore the use of a number of objective and subjective measures of three commonly assessed quality of life domains: choice, constructive activity, and social and community affiliation.

Specifically, the aims were to:

- Investigate the extent to which people of differing abilities could respond to the user-respondent measures and do so without response bias,
- Explore whether service users reported their satisfaction with life to another person with learning disabilities similarly or differently to a professional researcher,
- Compare staff proxy responses with resident responses where the latter have been given without response bias,
- Investigate the extent of correlation between objective and subjective measures of the same quality of life domain,
- Explore whether a different resident perspective is obtained if residents are given a more free opportunity to talk about areas of dissatisfaction rather than being asked to respond to a scale of satisfaction, and
- Explore the service structure, process and staff performance predictors of outcome.

Conclusions. The sample used was randomly selected and therefore likely to be representative of the population of people with learning disabilities in staffed housing services. Given that two-thirds of people were unable to report the extent to which they were satisfied with their lives, this study has demonstrated the continued utility of objective measurement. Like

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many other studies, it has also shown considerable variation in all outcomes between settings. Similarly, the importance of ability as an influence on outcome has been highlighted here, as it has in several previous studies.

Perry, Jonathan, and David Felce. "Initial Findings on the Involvement of People with an Intellectual Disability in Interviewing Their Peers About Quality of Life." ***Journal of Intellectual and Developmental Disability*****, vol. 29, no. 2, June 2004, pp. 164-171.** ▲

There are relatively few examples of emancipatory research in which people with an intellectual disability become co-workers in the research process. The current study examined the feasibility of training someone with an intellectual disability to conduct quality of life interviews with peers. The extent to which response bias in a sample of 21 people with an intellectual disability varied according to whether interviews were conducted by a researcher or a person with an intellectual disability was also investigated. Response bias was found not to be related to the characteristics of the interviewer. Amongst people who responded without bias, responses were not tailored to interviewer characteristics. The study demonstrated that people with an intellectual disability can be trained and supported to be competent data collectors and to hold positions of responsibility in the research process.

Perry, Jonathan, and David Felce. "Quality of Life Outcomes for People with Intellectual Disabilities Living in Staffed Community Housing Services: A Stratified Random Sample of Statutory, Voluntary and Private Agency Provision." ***Journal of Applied Research in Intellectual Disabilities,*** **vol. 16, 2003, pp. 11-28.** ▲ *****

Small scale, community-based, staffed housing is a significant form of residential provision for people with intellectual disabilities. Such services are provided by health and local authorities, and voluntary and private agencies, yet little is known about how provision varies between provider sectors.

Methods. This study compared sectors in terms of the processes operating within residential services, and objectively and subjectively assessed quality of life (QOL) resident outcomes. Measures of setting structure and processes and resident outcomes were undertaken on a stratified random sample of 47 small scale, community-based residential settings which accommodated a total of 154 people with intellectual disabilities.

Results. In general, provider agencies did not differ in terms of the characteristics of the residents they served, the structure of settings, the processes underlying service operation or resident outcomes. However, across agencies there were considerable variation in residents' life conditions when they were measured objectively. Better outcome tended to be significantly correlated with the ability of residents. This was not the case with results on subjective measures (which were also higher than those on objective measures).

Conclusions. The results reinforce the need to design services which effectively support people across the ability spectrum. Also, an argument is made for the continued utility of objective measurement in the assessment of service quality.

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Perry, Jonathan, and David Felce. "Subjective and Objective Quality of Life Assessment: Responsiveness, Response Bias, and Resident-Proxy Concordance." ***Mental Retardation*****, vol. 40, no. 6, December 2002, pp. 445-456.** ▲

Low language ability and response bias are frequently cited as impediments to valid responding to items on interview schedules. Structured interviews with a random sample of 154 adults with mental retardation showed that around two thirds of respondents were either unable to respond or exhibited response bias. There was a significant difference in scores on the Adaptive Behavior Scale between those who exhibited response bias and those who did not. In cases of non-response or response bias, the substitution of the respondent with a proxy respondent has been proposed as an alternative method of gathering subjective data. In this study concordance between individuals' responses and those of proxies was low on a subjective measure and high on an objective scale.

Pollard, Robert. "Research Involving the Deaf Population: Cross-Cultural and Other Unique Obligations." Paper presented at the 133rd Annual Meeting of the American Public Health Association, Philadelphia, PA, December 10-14, 2005. ▲

The Centers for Disease Control and Prevention recently funded the establishment of a Prevention Research Center solely devoted to investigating health and disease prevention in the deaf population. The National Center on Deaf Health Research (NCDHR) is organized via a community-participatory model wherein the deaf population is framed as a linguistic and cultural minority rather than a disability group. This is a significant departure from the perspective of prominent deafness research organizations (e.g., the National Institute on Deafness and other Communication Disorders, the Deafness Research Foundation) whose research missions involve the treatment and prevention of hearing loss, not the general health and well-being of individuals who happen to be deaf. In contrast, the NCDHR recognizes that the unique characteristics, strengths, and struggles of the deaf population—sign language use, Deaf culture, generally limited English literacy, lack of access to sign language interpreters in healthcare settings, limitations in access to healthcare information—present a wholly unique mosaic of issues relevant to effective healthcare and related research, unlike any other disability or language minority group. These unique issues lead to unique frameworks, obligations, and strategies for conducting ethical research with the deaf population. Arguably, such research is more akin to cross-cultural research than research with vulnerable populations or other models. The NCDHR presenter has published and lectured widely on ethics in deafness research. This presentation will delineate the central tenets of ethical research involving the deaf population, highlighting the relationship to cross-cultural research in general and matters unique to deaf research participants.

Pugh-Yi, Robin, Laurie Ringaert, Betsy Tewey, Anita Cobb, Christine Mason, and Shelia Newman. "Using National Survey Data to Inform Universal Design: A Case Study." Paper presented at the 132nd Annual Meeting of the American Public Health Association, Washington, DC, November 6-10, 2004. ▲

A critical aim of universal design is to make the built environment more accessible to people with disabilities. Consumer input is important for determining how best to accomplish this, as well as for assessing how much progress has been made toward this goal. Architectural

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engineers and other universal designers typically rely on small samples of consumer data, often collected by designers who are untrained in social science methods. Conversely, social scientists trained in collecting large representative data samples are typically unaware of the processes involved in engineering projects and the types of consumer input that would be most valuable for these projects. The current study involves a collaboration between social scientists and universal design architects to: (1) incorporate consumer feedback into universal design projects, and (2) determine better practices for collecting consumer data. The social scientists collected survey data from over 700 consumers and service providers about the needs of people with disabilities. Many respondents described barriers and facilitators to functioning in the built environment. Universal design architects will review survey results to inform current projects. The social science team will use observational data and interviews to assess the utility of the data, the process of incorporating consumer feedback into design projects, and how data quality can be improved to be most useful to the design team. Results are expected to lead to improved methods of needs assessment for people with disabilities that allow more effective responsiveness by the designers and engineers who aim to address these needs.

Rapley, Mark, and Charles Antaki. "A Conversation Analysis of the 'Acquiescence' of People with Learning Disabilities." ***Journal of Community & Applied Social Psychology*****, vol. 6, 1996, pp. 207-227. ▲ ***

Contrary to received wisdom, 'acquiescence bias' in the responses of people with learning disabilities to questioning is not a simple phenomenon, and certainly not one to be laid at the door solely of people with learning disabilities themselves. Rather, it is probably an artifact of the conversational organization of interviews as tests. Analysis of Quality of Life assessment interviews show, we argue, that there is probably no uniform 'acquiescent' motivation which accounts or all inconsistencies and agreements that might be produced under such circumstances. Rather, the interview's logic produces a range of pseudo-acquiescent responses in the face of interviewers' reformulations, and their pursuit of plausible and acceptable answers. There is also evidence of 'anti-acquiescence', in which respondents resist pressure to change their answers We conclude that the traditional notion of submissive, willing-to-please acquiescence is probably unsustainable on current evidence, and ought to be replaced by a more respectful account of the linguistic and interpersonal competence of people with learning disabilities.

Robinson, Julie, and James McGuire. "Suggestibility and Children with Mild Learning Disabilities: The Use of the Cognitive Interview." ***Psychology, Crime & Law*****, vol. 12, no. 5, October 2006, pp. 537-556. ▲ ***

The aims of this paper were firstly to identify any differences in the level of suggestibility between 20 7–9-year-old children with mild learning disabilities and 20 children with average academic ability using the Gudjonsson Suggestibility Scale 2 (GSS2) and, secondly, to note the impact of the cognitive interview on the response patterns of children with mild learning disabilities.

On the GSS2, average academic ability children recalled significantly more correct details than children with mild learning disabilities. There was no significant difference between the two

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groups of children on distortions, fabrications, total confabulations or on any of the four measures of suggestibility.

In the second part of the study, 38 children with mild learning disabilities watched a filmed event and then were interviewed using either a standard or a modified version of the cognitive interview. Following this, all participants were asked specific questions, some of which incorporated misleading information. One week later each participant was re-questioned. This time critical questions were included about the truth of the presuppositions introduced in the initial interview session. It was found that the cognitive interview elicited significantly more correct and incorrect details than a standard interview with no significant difference in fabrications. Use of the cognitive interview did not significantly affect susceptibility to subsequent misleading suggestions.

Rogler, Lloyd H. "Methodological Sources of Cultural Insensitivity in Mental Health Research." ***American Psychologist*****, vol. 54, no. 6, June 1999, pp. 425-433. ▲ ***

The concept of procedural norms, which is taken from the analysis of science as an institutionally structured social process, is used to explain the persistence of cultural insensitivity in research. The concept refers to the canons of research that tell scientists which should be studied and how, and they are taught to successive generations of researchers. An examination of cross-cultural studies in mental health reveals that cultural insensitivity stems from procedural norms in the development of content validity based on experts' rational analysis of concepts, in linguistic translations that try to conform to the exact terms of standardized instruments, and in the uncritical transferring of concepts across cultures. We need a wide-ranging examination of our procedural norms, with the objective of keeping such norms from suppressing, biasing, or deflecting cultural understandings. This article proposes a dialogue on the intricate connections between culture and our customary methodologies.

Rothman, Margaret L., Susan C. Hedrick, Kris A. Bulcroft, David H. Hickam, and Laurence Z. Rubenstein. "The Validity of Proxy-Generated Scores As Measures of Patient Health Status." ***Medical Care*****, vol. 29, no. 2, February 1991, pp. 115-124. ▲ ***

This study examines the validity of proxy assessments as substitutes for patient assessments of patient physical and psychosocial health status. Data were obtained from 275 patient-proxy pairs who were enrolled in a national study of Adult Day Health Care. Patients and proxies (informal caregivers such as spouses) were asked to complete the Sickness Impact Profile (SIP) based on the patients health status. Findings showed that patient-generated and proxy-generated physical scores were highly correlated, although proxies rated patients as slightly more impaired than the patient's rated themselves. The correlation between psychosocial scores was not high enough to consider proxy responses as valid substitutes for patient response. We explored these differences in response by comparing regression equations predicting patient-generated and proxy-generated physical and psychosocial SIP dimension scores. Variance in the patient-generated psychosocial score was explained by physical function, psychological distress, cognitive status and patient age. Proxy-generated psychosocial scores were primarily explained by the caregiver's psychological distress and perceived burden. These findings point out the

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importance of considering the source of patient health status estimates when interpreting the results of research studies.

Rumrill, Phillip D. Jr., Richard T. Roessler, and Lynn C. Koch. "Surveying the Employment Concerns of People with Multiple Sclerosis: A Participatory Action Research Approach." *Journal of Vocational Rehabilitation*, vol. 12, no. 2, 1999, pp. 75-82. ▲

The article describes the results of a survey of the employment concerns reported by a random sample (N=227) of people with multiple sclerosis (MS). From an item pool generated in previous research, state chapter members of the National Multiple Sclerosis Society identified 34 employment concerns as most reflective of the career development implications of MS. Survey respondents considered each item along two dimensions, the importance of the item to career development and their satisfaction with the adequacy of services to address that concern. Results regarding high importance items indicated that respondents were most satisfied with issues such as health insurance coverage, potential to work and take control of their lives, wages and benefits, and workplace accommodations. They were most dissatisfied with issues including fair treatment by employers in the hiring process, access to service providers who understand their needs, access to adequate information about Social Security programs, optimism regarding their future, and issues related to re-entering the workforce. Implications for vocational rehabilitation practice and future research are discussed.

Rupp, Kalman. "National Survey of SSI Children and Families: Background and Objectives." Paper presented at the 129th Annual Meeting of the American Public Health Association, Atlanta, GA, October 23, 2001. ▲

The National Survey of SSI Children and Families (NSCF) will collect data on children with disabilities and their families who are receiving or have applied for Supplemental Security Income (SSI). The survey, sponsored by the Social Security Administration's (SSA) Office of Research, Evaluation, and Statistics, has two major objectives: (1) to provide information on the characteristics, experiences, and needs of current SSI child recipients and their families, and (2) to evaluate the effects of welfare reform on SSI children. The NSCF, planned for administration in 2001, will be the first national survey of SSI children since 1978. Since then, many changes have taken place in the SSI program for children. In 1990-1991, as a result of the Supreme Court's Zebley decision, regulatory changes were introduced that led to a large-scale growth in the number of children receiving SSI benefits. In 1996, welfare reform made eligibility for childhood SSI benefits more restrictive and about 100,000 children lost SSI benefits. Aside from SSA's administrative data, there is little information for evaluating the effects of these changes on SSI children. Further, competing views about how best to structure the childhood SSI program require timely, credible data. The NSCF will fill a critical data need by providing current information on the health and well-being of SSI children and their families. Survey data will be used by SSA for policymaking and program planning, and by external researchers interested in children's health and disability issues.

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Ryan, Trina Catherine. "Children with Disabilities Need Protection Too! A Module to Improve Investigative Practices of the Royal Newfoundland Constabulary When Interviewing Children with Disabilities." ***ProQuest MAI (Masters Abstracts International),*** **vol. 40, no. 3, 2001, p. 609. ▲ ***

Children with disabilities are faced, on a daily basis, with challenges and obstacles that affect their quality of life. As a consequence of their disabilities, they are often reliant on others to provide basic care. It is this relationship that society as well as the disabled child assumes is with a caregiver who is trustworthy and responsible. Unfortunately, current statistics reveal otherwise and too many children with disabilities have been subject to abuse.

In today's society, children with disabilities are recognized as having equal rights and are protected under the same laws as everyone else. However, these laws and the agencies that protect children have not adequately recognized that children with disabilities require adjustments and understanding to make sure that they are protected. One cannot assume because a child has a disability that they are not capable of understanding or communication what they are feeling or what they may have experienced. The purpose of this module is to provide information about children with disabilities and to develop an understanding of what types of strategies may be utilized when interviewing a child with a disability the strategies provided will assist police officers designated to conduct interviews with these children to be cognizant of the best approach to use with a child with a particular disability. The module is expected to be used as an insert for the current training manual used by the Royal Newfoundland Constabulary.

Sample, Pat T. "Beginnings: Participatory Action Research and Adults with Developmental Disabilities." ***Disability and Society,*** **vol. 11, no. 3, September 1996, pp. 317-332. ▲**

This paper discusses the emergence of Participatory Action Research (PAR), and its use with individuals with cognitive disabilities. A brief history of PAR is given, with a focus on its uses for empowerment and self-determination for persons with disabilities. Using literature-based standards for participatory action and emancipatory research approaches, a 3-year research project with goals of increasing community participation by adults with developmental disabilities is described and evaluated. The "Transition into Community Life" project used an adaptive form of the "Farmer-back-to-Farmer" PAR model (Rhoades and Booth, 1982), and the article discuses the successes and challenges of the model in a context quite different from how it was originally designed. The author describes lessons learned concerning the use of PAR with people with developmental disabilities. The article concludes with a brief discussion of the feasibility of PAR with individuals with cognitive challenges.

Sando, Martin. "Conducting Surveys Among People with Physical and Cognitive Disabilities: Experiences from a Survey." Paper presented at the Annual Meeting of the Nordic Network on Disability Research, Oslo, Norway, 2005. ▲

It is possible to conduct surveys among people with severe physical, communicative, and cognitive disabilities. Nevertheless, this group of people is usually not present as respondents in most surveys. Researchers tend to regard this group as being to difficult to interview or their

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answers are seen as unreliable. The Danish Information and Research Centre for People with Disabilities carried out a survey among residents in eleven institutions for disabled people. The objective of the survey was, from a user perspective, to examine some of the services offered by the county to this group. The survey included a questionnaire distributed to 408 persons living in the aforementioned institutions. The response rate was 67%. From a methodological point of view the survey indicates that a successful survey demands careful planning and cooperation with the professionals and head of the institutions.

Schiffrin, Holly, William Frey, Rene Gonin, and Carla Maffeo. "Screening for Disability: The Effects of Interview Mode and Type of Respondent." Paper presented at the Federal Interagency Committee on Disability Research Conference on Best Practices for Surveying People with Disabilities, Washington, DC, April 2004. ▲

Background. Identifying an effective method to screen for disability has become an international priority (Washington City Group on Disability Statistics, 2003). This study examined the effects of two methodological issue (i.e., mode of interview and type of respondent) on disability measurement in a pilot study on health and disability.

Methods/Conceptual Framework. Screening questions were based on Nagi's Model of Disability (Nagi, 1976; 1991) and the Institute of Medicine's conceptual framework of disability (Pope & Tarlov, 1991). Screening for disability was conducted either in-person or over the telephone with either a self-respondent or a proxy household reporter. An in-person follow-up interview was conducted to confirm disability status with a sub-sample of household members for whom screener data were collected.

Results. Overall consistency of disability classification between the screener and the follow-up interview was high, $_K$= 0.72 (95% CI = 0.68 to 0.77). A logistic regression found that mode of interview was a significant predictor of agreement in disability classification, but type of respondent (self-report vs. proxy) was not. However, overall power for the analysis was only 48%.

Conclusions. When disability screening was conducted in-person rather than over the telephone, sampled persons were approximately 50% more likely to have the same disability classification during the in-person follow-up interview.

Implications. Screening for disability in-person rather than over the telephone should yield a more reliable and valid classification of disability. Further research should be conducted to determine the effect that type of respondent has on disability classification.

Schroedel, John G. "How to Reach the <<Invisible Populations>> of Hard of Hearing Americans." *Towards Best Practices for Surveying People with Disabilities*, vol. 1, 2007, pp. 181-215. ▲ *****

That 22 million hard of hearing Americans comprise one of the most underresearched groups of persons with a disability underscores the need for this chapter. The first part of this chapter presents it's needs and objectives and defines the project's target population of persons

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with a hearing loss. The auditory and socio-demographic characteristics of these persons are described as are their employment patterns. Major flaws in prior research, such as a predominant prevalence of unrepresentative convenience samples, are identified. The attributes of social environments in which hard of hearing persons face difficulties in understanding speech are specified and proactive and reactive responsive coping styles are exemplified. Two theoretical research models were used or integrating diverse study variables. Patterns in knowing about and needing communication devices and workplace accommodations are elucidated. Variations in the severity of hearing loss were identified as a major influence upon many variables within the above listed topics. Examples of these variables are displayed in Figure 1.

The second part of this chapter depicts unique methods of project design and data collection. First, a nationwide sample of hard of hearing persons was identified via 66,000 random phone tracking calls. A follow-up mail survey yielded a first-ever comprehensive data file on respondents' employment experiences and use of human services. Finally, the representativeness of the obtained mail sample was compared to results from a federal survey with benchmark attributes of the target population. The socio-demographic, geographic, auditory and other characteristics of he sample were compared to the characteristics of the population.

Schroedel, John G. "Analyzing Surveys on Deaf Adults: Implications for Survey Research on Persons with Disabilities." ***Social Science & Medicine*****, vol. 19, no. 6, 1984, pp. 619-627.** ▲

Differences in operationalizing definitions of disability. variations in methods of data collection and diversities in salient characteristics of disabled persons are generic problems in conducting social research surveys with persons who have disabilities. These problems are of concern not only to social scientists seeking to improve survey methods, but they also have practical significance to decision makers needing high quality information to guide social policies that influence the provision of health care education and social services to persons with chronic impairments. Reports of 41 surveys on deaf adults in the United States and Canada conducted between and 1959 and 1981 were analyzed to determine how rates of response, a key indicator of reliability of survey data are affected by three methods of data collection, degree of verification efforts, scope of the sample and socio-demographic characteristics of those in the survey populations. Measurable results are provided so that planners of future surveys can correct for anticipated rates of sample attrition under various survey conditions. Other data indicate that trade-offs can be made between changes in the size of the sample and method of data collection to lead to more effective surveys. Important terms such as deafness, deaf population and deaf community are discussed as these relate to interpreting the results of survey studies on deaf adults. Discussion is also given to conducting social surveys with groups of individuals having other disabilities besides loss of hearing.

Schwarz, Nobert, Denise C. Park, Barbel Knauper, and Seymour Sudman (Eds.). ***Cognition, Aging, and Self Reports.*** **Philadelphia, PA: Psychological Press, 1999.**

This publication offers an overview of age-related changes in cognitive functioning and explores the implications of these changes for the self-report of attitudes and behaviors. The first

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section of the book includes a review of late 1990s cognitive aging research, covering topics such as working memory, inhibition, autobiographical memory, meta cognition, and attention. Another section examines issues associated with aging, language comprehension, and interpersonal communication; the final section reviews research into age-related differences in survey responding. Of particular interest is how age-related changes in cognitive and communicative functioning influence the question-answering process in research situations. Experimental research illustrates that older and younger respondents are differentially affected by question order, question wording, and other features of questionnaire design. As a result, many age-related differences in reported attitudes and behaviors may reflect age-related differences in the response process rather than differences in respondents' actual attitudes or behaviors.

Key topics from the final section delve into the issues confronted when measuring cognitive functioning of older respondents in surveys:

- Asking Survey Respondents About Health Status—Judgment and Response Issues
- Cognitive Testing of Cognitive Function Questions
- Dynamics of Survey Interviewing and the Quality of Survey Reports—Age Comparisons
- Cognitive Performance Measure in Survey Research on Older Adults
- Age Differences in Question and Response Order Effects

Sigelman, Carol K., and Edward C. Budd. "Pictures as an Aid in Questioning Mentally Retarded Persons." ***Rehabilitation Counseling Bulletin,*** **vol. 29, 1986, pp. 173-181.** ▲

In an attempt to identify techniques for improving ability of mentally retarded individuals to speak for themselves, samples of institutionalized and noninstitutionalized children and adults were asked the same questions with and without accompanying drawings intended to clarify question content. Drawings had no impact as an adjunct to yes-no questions, but did improve responsiveness to multiple-choice and either-or questions. On these types of questions there was only a slight reduction in agreement with informants. In a low-verbal sample, pictures also tended to reduce a bias toward choosing the last of the two options in either-or questions, thus showing some promise as an aid in interviewing and assessing retarded individuals who have verbal limitations.

Sigelman, Carol K., Carol J. Schoenrock, Cynthia L. Spanhel, Sherrilyn G. Hromas, Jane L. Winer, Edward C. Budd, and Paulette W. Martin. "Surveying Mentally Retarded Persons: Responsiveness and Response Validity in Three Samples." ***American Journal of Mental Deficiency,*** **vol. 84, no. 5, 1980, 479-486.** ▲

In an exploration of the feasibility and utility of survey research with retarded populations, interviews were conducted with 52 institutionalized children, 58 institutionalized adults, and 57

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community children, as well as with their parents or attendants. Analyses indicated that higher IQ interviewees were generally more responsive to questions, more often in agreement with the nonretarded informants, and less acquiescent on yes-no questions than were lower IQ interviewees. Although these relationships varied in strength from sample, overall differences among samples were nonsignificant. Implications for researchers interviewing retarded persons were discussed.

Sigelman, Carol K., Edward C. Budd, Cynthia L. Spanhel, and Carol J. Schoenrock. "Asking Questions of Retarded Persons: A Comparison of Yes-No and Either-Or Formats." ***Applied Research in Mental Retardation*****, vol. 2, 1981, pp. 347-357.** ▲

In view of evidence that mentally retarded persons frequently acquiesce when asked yes-no questions, these readily answered questions were systematically compared to either-or questions on the same topics in interviews with four samples of mentally retarded children and adults. Although slightly fewer interviewees could answer either-or questions than could answer yes-no questions, either-or questions yielded answers that were more consistent from wording to wording, less invalidated by systematic response bias, and somewhat more in agreement with answers given by outside informants, either attendants or parents. The use of pictures in conjunction with either-or questions, while failing to produce significant improvements, tended to increase responsiveness and eliminate the slight bias toward choosing the last of the two options that characterized answers to verbal either-or questions.

Sigelman, Carol K., Edward C. Budd, Cynthia L. Spanhel, and Carol J. Schoenrock. "When in Doubt, Say Yes: Acquiescence in Interviews with Mentally Retarded Persons." ***Mental Retardation*****, vol. 19, no. 2, 1981, pp. 53-77.** ▲

Acquiescence, or the tendency of individuals to respond *yes* to questions regardless of their content, is examined in samples of mentally retarded children and adults. Rates of acquiescence are alarmingly high in institution as well as community samples; lower IQ respondents tend to acquiesce more than higher IQ respondents; and acquiescence is found to have major effects on the content of responses. The danger of relying on yes-no questions as a means of obtaining information from mentally retarded persons is discussed as well as the need for increased concern with the issue of response validity.

Sigelman, Carol K., Edward C. Budd, Jane L. Winer, Carol J. Schoenrock, and Paulette W. Martin. "Evaluating Alternative Techniques of Questioning Mentally Retarded Persons." ***American Journal of Mental Deficiency*****, vol. 86, no. 5, 1982, pp. 511-518.** ▲

In an examination of methodological issues involved in interviewing retarded persons, alternatively worded or structured questions were embedded in interviews with three samples. Questioning techniques were evaluated according to the extent to which (a) interviewees could provide answers, (b) their answers agreed with parallel responses given by attendants or parents, and (c) answers were free of systematic response bias. Open-ended questions were found to be unanswerable by many persons, and supplementing them with clarifying examples and probes for additional information only exacerbated response bias. By comparison, yes-no checklists

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enhanced responsiveness but introduced serious acquiescence bias, whereas multiple choice questions, particularly with pictures, yielded valid answers from high proportions of interviewees. Implications for question design were discussed.

Sloan, Matt, Debra Wright, and Kirsten Barrett. "Data Comparability in a Telephone and Face-to-Face Survey of Persons with Disabilities." Paper presented at the 61st Annual American Association for Public Opinion Research Conference, Montreal, Canada, May 18-21, 2006. ▲ *

Research suggests that while data quality overall is fairly comparable between telephone and face-to-face surveys, there may be some differences in specific response patterns between these two modes. Krosnick and others have suggested that telephone interviewing may pose more of a cognitive burden on respondents than face-to-face interviewing resulting in higher rates of acquiescence and satisficing. Further, this effect may be more pronounced for individuals with less cognitive ability. There is also evidence that respondents to telephone surveys may be more likely to provide socially desirable answers to sensitive items. However, despite substantial research on mode effects in surveys of the general population, little research has been done to examine the effects of different interview modes on individuals with disabilities.

To determine whether there are differences in data quality between telephone and face-to-face modes we compare data collected in both modes from the National Beneficiary Survey (NBS). The NBS is a longitudinal survey of approximately 7,000 disability beneficiaries conducted by Mathematica Policy Research and sponsored by the Social Security Administration. The survey is done via telephone with a face-to-face followup for nonrespondents. We report response rate by mode and describe the demographic characteristics of respondents to each mode. Since participants were not randomly assigned to mode, we control for the non-experimental nature of the study by comparing subsets of respondents matched by demographic characteristics. As indicators of data comparability across modes, we examine item non-response, number of options checked for check-all-that-apply items, non-differentiation among items in a series, proportion of agree/yes responses, length of responses to open-ended items, and distribution of responses or means for sensitive items. In addition, we examine response effects by type of disability (cognitive or physical). Finally, we discuss particular methods of reducing method effects for this population.

Small, Jeon, Pamela Schallau, Karen Brown, Daria Ettinger, Sue Blanchard, Gloria L. Krahn, and Richard Appleyard. "Making the Web Accessible for People with Developmental Cognitive Disabilities: A Second Look at Navigation." Paper presented at the 133rd Annual Meeting of the American Public Health Association, Philadelphia, PA, December 10-14, 2005. ▲

This pilot study investigated individuals with developmental cognitive disabilities (DCD) navigating W3C accessibility-compliant Web sites and the impact of four cognitive determinants: situation awareness, spatial awareness, task-set switching, and anticipated system response. Participants were placed into one of two search conditions and were asked to complete information-finding tasks. The usability evaluation demonstrated that the majority of users with DCD were able to access the Web but they were unable to successfully use the W3C

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accessibility-compliant Web sites. The use of navigation aids were examined, different Web navigation problems were identified as well as user satisfaction and perceived usability. It is clear from this study that current Web accessibility guidelines do not sufficiently address the needs of people with cognitive disabilities. Additional research is needed to further describe several potentially confounding factors that were identified.

Smith, Elisha, Debra Wright, and Susan Mitchell. "Including Persons Who Are Hard of Deaf and Hard of Hearing in Surveys." Paper presented at the 60th Annual American Association for Public Opinion Research Conference, Miami, FL, May 12-15, 2005. ▲ *

When interviewing persons with disabilities it is important that every effort be made to ensure that all persons, regardless of disabling condition, are able to participate in the survey process. The National Beneficiary Survey (NBS), sponsored by the Social Security Administration's (SSA) Office of Disability and Income Security, collects data from nationally representative samples of SSA disability beneficiaries. In 2004, data were collected by means of a CATI survey with CAPI follow-up of nonrespondents. To conduct the NBS, we made a series of modifications to standard instrumentation and data collection procedures to ensure representation of the broadest spectrum of the beneficiary population. This paper focuses on the modifications we made for people with hearing impairments, a growing segment of the population.

The literature on interviewing persons with hearing impairments is sparse. In this paper, we summarize the literature and update what is known by describing our experiences conducting interviews using assistive technologies. These technologies include amplifier telephones, text typewriters (TTY), telecommunications relay service, and instant messaging. In addition, we discuss in-person interviewing using sign language interpreters and other methods. Finally, we report the proportion of the hearing-impaired population that responded by each mode, and the overall response rate. Our experience suggests that interviewing persons with hearing impairments does not present extraordinary challenges. The barriers to response can often be overcome through modifications to data collection procedures, and the use of assistive technologies.

Smith, Pamela M., Sandra Bennett Illig, Roger C. Fielder, Byron B. Hamilton, and Kenneth J. Ottenbacher. "Intermodal Agreement of Follow-Up Telephone Functional Assessment Using the Functional Independence Measure in Patients with Stroke." *Arch Physical Medicine Rehabilitation*, vol. 77, May 1996, pp. 431-435. ▲ *

Objective. To examine the intermodal agreement of Functional Independence Measure (FIM) ratings when obtained by two commonly used approaches: telephone interview and in-person assessment of functional performance.

Design. A random sample of 40 persons with hemiparesis was tested by two registered nurses trained in FIM definitions and telephone interview techniques. The two assessments occurred within 5 days of each other. The raters were blind to previous assessments. The administration of assessments was alternated to minimize bias and order effects.

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Setting. All subjects were assessed at home, between 3 and 10 months after discharge from rehabilitation.

Patients. The criteria for inclusion were: (1) diagnosis of cerebral vascular accident (CVA); (2) completion of a minimum of 2 weeks in an acute rehabilitation program; (3) currently living at home; (4) living within a 30-mile radius of the hospital; and (5) cognitive and verbal skills adequate to complete a telephone interview. From a population of 103 patients, 40 subjects were randomly selected, 18 women and 22 mean ranging in age from 37 to 90 years.

Main Outcome Measures. The intermodal agreement between FIM ratings obtained by telephone interview and in-person assessment was examined using the intraclass correlation (ICC). FIM item scores were analyzed for agreement using the Kappa coefficient. The stability of the responses was determined by computing the coefficient of variation and plotting the data to visually examine the relationship between the two methods of administration.

Results. Data analysis revealed that there was no statistically significant difference ($p > .05$) between the two methods of administration for total FIM score. The total FIM ICC was .97. ICC values for FIM subscales ranged from .85 to .98, except for social cognition. Kappa scores for noncognitive items ranged from .49 (bowel movement) to .93 (grooming). The coefficient of variation computed to examine cognitive and communication items with reduced variability indicated good stability across all items.

Conclusion. The results indicated good intermodal agreement for follow-up telephone assessment using the Functional Independence Measure. The findings were limited to persons with effective communication skills.

Sneeuw, Kommer C.A., Neil K. Aaronson, David Osoba, Martin J. Muller, Ming-Ann Hsu, W.K. Alfred Yung, Michael Brada, and Edward S. Newlands. "The Use of Significant Others As Proxy Raters of the Quality of Life of Patients with Brain Cancer." ***Medical Care*****, vol. 35, no. 5, 1997, pp. 490-506. ▲ ***

Objectives. The use of self-report questionnaires for the assessment of health-related quality of life (HRQOL) is increasingly common in clinical research. This method of data collection may be less suitable for patient groups who suffer from cognitive impairment, however, such as patients with brain cancer. In such cases, one can consider employing the patients' significant others as proxy raters as the patients' health-related quality of life. The authors examined the response agreement between patients with brain cancer and their significant others on a health-related quality of life instrument commonly used in cancer clinical trials, the EORTC QLQ-C30, and on a brain cancer-specific questionnaire module, the QLQ-BCM.

Methods. The study sample consisted of 103 pairs of patients, with either recently diagnosed or recurrent brain cancer, and their significant others (75% spouses, 22% relatives, and 3% friends). Patients and proxies independently completed the EORTC QLQ-C30 and the QLQ-BCM at three different times.

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Results. Approximately 60% of the patient and proxy scores were in exact agreement, with more than 90% of scores being within one response category of each other. For most HRQOL dimensions assessed, moderate to good agreement was found. Statistically significant differences in mean scores were noted for several dimensions, with proxies tending to rate the patients as having a lower quality of life than the patients themselves. With the exception of fatigue ratings, this response bias was of a limited magnitude. Less agreement and a more pronounced response bias was observed for the more impaired patients, and particularly for patients exhibiting mental confusion. This finding was confirmed by longitudinal analyses, which indicated lower levels of patient-proxy agreement at follow-up for those patients whose physical or neurologic condition had deteriorated over time.

Conclusions. In general, patients and their significant others provide similar ratings of the patients' quality of life. Lower levels of agreement and more biased ratings can be expected among those patients for whom the need for proxies is most salient. It is argued, however, that discrepancies between patient-proxy ratings should not be interpreted, a priori, as evidence of the inaccuracy or biased nature of proxy-generated data. Future studies are needed to examine the relative validity and reliability of patient- versus proxy-generated health-related quality of life scores.

Soberman, L.R., M. Murray. P.G. Norton, B. van Maris, and K. Tasa. "Satisfaction of Residents and Families in Long-Term Care: III. Dissemination of Results." ***Quality Management in Health Care,*** **vol. 5, no. 3, 1996, pp. 63-71.**

In previous articles in this series, the creation and use of a survey instrument, the Long Term Care Resident Survey to measure how residents and their families assess the care provided in long-term care facilities, were discussed in great detail. This third article in the series begins with the premise that however challenging it was to develop a useful survey tool and however difficult it was to get timely and representative feedback from the residents, getting these results back to the "right people" and getting them implemented is even harder. This article describes dissemination efforts by the Sunnybrook Health Science Centre (SHSC) team. Basically, the dissemination efforts fell into five phases: (1) getting management and staff ready to receive resident/family feedback, (2) creating anticipation of feedback dissemination, (3) determining final feedback format, (4) disseminating initial feedback, and (5) creating dissemination follow-up methods. Finally, this article describes several new strategies that were implemented in one long-term care setting and discusses evidence of their success.

Stancliffe, Roger J. "Proxy Respondents and Quality of Life." ***Evaluation and Program Planning,*** **vol. 23, no. 1, February 2000, pp. 89-93.** ▲

Scahlock, Bonham and Marchaud (2000) used self-reports or proxy responses in their analysis of quality of life. This paper examines the appropriateness of that approach and reviews broader issues concerning the use of proxies and consumer-proxy agreement. These issues include: dealing with data from different sources (i.e., consumers and proxies), confounding of information source and consumer characteristics, response biases in self-reports, and future research on proxies.

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Stancliffe, Roger J. "Proxy Respondents and the Reliability of the Quality of Life Questionnaire Empowerment Factor." *Journal of Intellectual Disability Research*, vol. 43, no. 3, June 1999, pp. 185-193. ▲

Previous studies have questioned the reliability of Quality of Life Questionnaire (QOL-Q) Empowerment scores, and reported marked disagreement between consumers' self-reports and proxy data from staff informants. The present study examined agreement between consumer self-reports and proxy responses from community staff for 63 adults with intellectual disability. Substantial positive correlations between consumers and staff were evident. No significant difference was found between total QOL-Q Empowerment scores for self- or staff reports. It was concluded that the QOL-Q Empowerment factor is sufficiently reliable for use both by self-report and proxy respondents. Even so, proxy data are not a substitute for consumer self-reports and the two data sources should not be treated as being interchangeable.

Stancliffe, Roger J. "Assessing Opportunities for Choice-Making: A Comparison of Self- and Staff Reports." *American Journal of Mental Retardation*, vol. 99, no. 4, 1995, pp. 418-429. ▲

Self-report responses by adults with mental retardation about the availability of choice were compared with staff responses. Self-reports and staff responses were in clear disagreement on 3 of 10 items. In each case, subjects reported that they had significantly more choice than was perceived by staff members. These items involved issues of major life impact for which less choice was available than for other items. Intermingling self-report and third party responses in research about choice seems unwise because their equivalence cannot be assumed. In contrast to previous studies, high levels of choice were reported on most items.

Stancliffe, Roger J., and Trevor R. Parmenter. "The Choice Questionnaire: A Scale to Assess Choices Exercised by Adults with Intellectual Disability." *Journal of Intellectual and Developmental Disability*, vol. 24, no. 2, June 1999, pp. 107-132. ▲

Although choice is widely regarded as an essential component of quality of life, researchers have made few attempts to develop and evaluate psychometrically sound instruments to measure the availability of choice to people with intellectual disability. This paper presents information on the development and evaluation of the *Choice Questionnaire*. The scale can be administered by interviewing the consumer or may be completed by a knowledgeable proxy. Used in either of these ways, the *Choice Questionnaire* was found to have very satisfactory reliability and validity. Its use as a research and evaluation tool is discussed.

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Steinberg, Annie G., Douglas S. Lipton, Elizabeth A. Eckhardt, Marjorie Goldstein, and Vicki Joy Sullivan. "The Diagnostic Interview Schedule for Deaf Patients on Interactive Video: A Preliminary Investigation." *American Journal of Psychiatry,* vol. 155, November 1998, pp. 1603-1604. ▲

Objective. The authors investigated the feasibility of translating the National Institute of Mental Health Quick Diagnostic Interview Schedule-III, Revised, computer version, for deaf individuals.

Method. The study involved translation of selected scales into American Sign Language, Signed English, and speech reading; review by an advisory panel and back translator; and collection and analysis of deaf individuals' reactions to translations.

Results. Focus groups responded favorably, translation problems were revealed, and solutions were suggested.

Conclusions. The findings support the feasibility of translation of the Quick Diagnostic Interview Schedule-III. Revised, into American Sign Language, Signed English, and speech reading for deaf patients.

Steinberg, Annie G., Vicki Joy Sullivan, and Ruth C. Loew. "Cultural and Linguistic Barriers to Mental Health Service Access: The Deaf Consumer's Perspective." *American Journal of Psychiatry*, vol. 155, no. 7, July 1998, pp. 982-984. ▲

Objective. The authors investigated knowledge, attitudes, and beliefs about mental illness and providers held by a group of deaf adults.

Method. The American Sign Language interviews of 54 deaf adults were analyzed.

Results. Recurrent themes included mistrust of providers, communication difficulty as a primary cause of mental health problems, profound concern with communication in therapy, and widespread ignorance about how to obtain services.

Conclusions. Deaf consumers' views need due consideration in service delivery planning. Outreach regarding existing programs is essential.

Stephens, Susan, Joy Gianolio, and Rita Stapulonis. "Design for a National Survey of Persons with Developmental Disabilities: Prototype Instrument." Princeton, NJ: Mathematica Policy Research, Inc., February 1990. ▲

This volume of the Final Report of the Project to Design a Survey of Persons with Developmental Disabilities presents the prototype instrument developed for the survey and provides, module by module and question by question, detailed description and analytic justification of the content of the instrument. Organized into twenty-two modules, the survey instrument contains individual questions recommended to measure key aspects of the characteristics and life circumstances of persons with developmental disabilities: demographic

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and household characteristics (including income and income supports), living arrangements and characteristics of the residential setting, functional status in the seven life areas, formal service utilization, reimbursement sources and out-of-pocket expenses, informal support and social interaction and behaviors.

Stern, Sharon, and Matthew Brault. "Disability Data from the American Community Survey: A Brief Examination of the Effects of a Question Redesign in 2003." Washington, DC: U.S. Census Bureau, Housing and Household Economic Statistics Division, January 28, 2005. ▲

In response to evidence suggesting that mail respondents were reporting certain disabilities in error, the Census Bureau introduced changes to the ACS questionnaire in 2003. The initial review of the data shows that fewer people reported go-outside-home disability and employment disability. Since the Census Bureau has no independent evidence of a national trend with regard to these types of conditions, and the apparent change coincided with the question redesign, additional analysis was essential. Since the changes only involved the ACS mail questionnaire, the focus of this preliminary review was differences between people reporting by mail and people reporting by telephone or personal interview. Comparison of these groups to each other and across time shows that the question redesign had the expected effect on the mail respondents, lowering the rates of disability overall by reducing over-reporting in the go-outside-home disability and employment disability.

Tasse, M. J., R. Schalock, J. R. Thompson, and M. Wehmeyer. "Guidelines For Interviewing People With Disabilities: Supports Intensity Scale." Washington, DC: American Association on Mental Retardation, 2005.

Traditionally, a person's level of developmental disability has been measured by the skills the individual lacks. Supports Intensity Scale (SIS) shifts the focus from lacks to *needs.* The SIS is a unique, scientific assessment tool specifically designed to measure and evaluate the level of practical supports required of a person with an intellectual disability to lead independent and quality lives in society. The SIS measures support requirements in 57 life activities and 28 behavioral and medical areas. The assessment is done through an interview with the consumer and those who know the person well. The SIS should be administered by a professional in the human services field with a baccalaureate degree. Under exceptional circumstances others with experience conducting individual assessments and possessing extensive knowledge of behavior rating or psychological testing principles may be acceptable. This manual provides helpful suggestions for conducting interviews with people with developmental disabilities. Key suggestions for interviewers include (1) be prepared that the interview process may require additional time and patience, (2) use your usual tone and volume of voice, (3) make every effort to keep your language simple and clear, (4) treat all adults with developmental disabilities in an age-appropriate manner, and (5) offer help or support in a sensitive and respectful manner. Several considerations SIS interviewers should also take the following into account when interviewing people with developmental disabilities: (1) recognition that disability is often associated with stigma, (2) acquiescence, (3) processing time, and (4) memory difficulties.

▲ The abstract was written by the author(s) or publisher.
* New entry.

Tennant, A., E.M. Badley, and M. Sullivan. "Investigating the Proxy Effect and Saliency Principle in Household Based Postal Questionnaires." ***Journal of Epidemiology and Community Health*****, vol. 45, 1991, pp. 312-316.**

The aim was to investigate two possible sources of bias inherent in using a household based postal questionnaire, the "proxy effect," inaccurate reporting about characteristics of others, and the "saliency principle," reporting of only the most salient features. This is of importance in surveys concerned with screening the population to identify individuals with certain characteristics, and so possibly relying on one member of the household to reply on behalf of all others.

Design and Setting. A two stage survey of disablement in the population was undertaken. A first phase postal questionnaire was sent to 25,168 households in Calderdale, West Yorkshire, England, to ascertain the prevalence of physical disability and of troubles with the joints. The second phase comprised in depth interviews with a sample of individuals identified in the first phase as being disabled.

Respondents. A total of 21,889 postal questionnaires were returned (87%) representing households containing 42,826 people aged 16 years and over. A disproportionately stratified random sample of 950 respondents reporting disability was taken in the second phase. Of these 891 were still available, and 838 (94%) were interviewed.

Measurements and Main Results. The postal questionnaire found that almost 29% of those who lived "alone" (without another adult) reported some level of disability, compared to only 10% of those who lived with others. The difference remained significant after standardization. This apparent underreporting or "proxy effect" was present for reporting about disability overall, but not for severe disability (dependence on help of others), which suggests the operation of the "saliency principle." Reporting on joint troubles appeared to be affected by the proxy effect both for any joint problems, and when more than five joints were affected. Analysis of a small set of postal questionnaires from respondents who reported joint problems only at interview and where we could identify who had completed the postal questionnaire supports the hypothesis of a proxy effect; two thirds of the original postal questionnaires had been completed by a proxy. The results were further complicated by an interaction between reporting of disability and joint troubles: the greater the level of disability, the less likely the reporting of joint troubles.

Conclusions. The findings have general implications for studies involving postal household screening questionnaires, and raises additional concerns about those that are multitopic in content. In surveys of symptoms and minor disability, a proxy effect is likely to be operative. This effect is not apparent for obvious and long standing problems such as dependence on others for help. However the interaction between the reporting of disability and joint symptoms carries important implications for the development of multitopic postal screening questionnaires.

The abstract was written by the author(s) or publisher.
* New entry.

Thornton, Craig, Susan Stephens, Brian Burwell, James Conroy, Bradley Hill, and Charlie Lakin. "Design for a National Survey of Persons with Developmental Disabilities." Princeton, NJ: Mathematica Policy Research, Inc., February 1990. ▲

This paper presents a survey design that would provide the data needed for improving our understanding of the population of persons with developmental disabilities and facilitating the improvement of programs intended to serve those individuals. It begins with the definition of developmental disabilities and a review of the types of persons who would be the subjects of the proposed survey. The paper then provides an overview of the trends in program and policy development and the information needs those trends create. The paper then reviews the critical gaps in existing data and the specific issues and types of information that the survey would address. The recommended survey design is then presented. The paper concludes with a research agenda that would build on a national survey to address more specific programmatic issues pertaining to persons with developmental disabilities.

Todorov, Alexander. "Cognitive Procedures for Correcting Proxy-Response Biases in Survey." ***Applied Cognitive Psychology*****, vol. 17, 2003, pp. 215-224.** ▲

To reduce survey costs, major surveys rely on self- and proxy-responses. The use of proxies can reduce data quality introducing biases in the survey estimates. This paper identifies one source of systematic differences between self- and proxy-reports: proxies' higher reliance on inferences. Using data from the National Health Interview Survey on Disability (NHIS-D), proxy-response biases were modeled by independently collected measures of cognitive inferences. Conditional likelihood judgments about a number of disabilities (e.g. likelihood that a person has a disability given another disability) predicted the conditional disability reports for proxy- but not for self-respondents (e.g. the proportion of respondents who reported difficulty learning after reporting difficulty communicating). A model of self/proxy differences was estimated on data from the 1994 NHIS-D and tested against 1995 data. The correlation between predicted and actual differences was 0.76. The correlation between predicted and actual proxy-reports was 0.95. Such research can be used to estimate and correct for systematic proxy-response biases.

Todorov, Alexander. "The Accessibility and Applicability of Knowledge: Predicting Context Effects in National Surveys." ***Public Opinion Quarterly*****, vol. 64, 2000, pp. 429-451.** ▲ *****

Using data from the National Health Interview Survey on Disability from 1994 and 1995, this research demonstrates that the size of accessibility effects (increased likelihood of using information activated by initial questions in responding to subsequent questions) can be modeled as a function of the applicability of the initial to the subsequent questions. When respondents reported a disability and were asked about the main condition causing the disability, they were more likely to report conditions they had been asked about earlier in the interview than alternative conditions. This accessibility effect was inversely related to the effect on reports of "other" or unclassifiable conditions. The more reports of primed conditions, the fewer reports of unclassifiable conditions. A log-linear model of the accessibility bias fit the data for all disabilities. For reports of specific conditions, a measure of the applicability of context

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accounted for 74.4 percent of the variance of the accessibility bias; for unclassifiable or "other" conditions, it accounted for 61 percent. When limited to "well-defined" disabilities, applicability accounted for 91.9 percent of the variance (a multiple correlation of .96). finally, models of the context effects derived from the 1994 data were tested against the actual effects for the 1995 data. The correlation between predicted and actual effects was .80 across disabilities. The theoretical and the practical implications of the findings are discussed.

Todorov, Alexander, and Corinne Kirchner. "Bias in Proxies' Reports of Disability: Data from the National Health Interview Survey on Disability." ***American Journal of Public Health,*** **vol. 90, 2000, pp. 1248-1253.** ▲

Objectives. These studies examined whether differences between self-reports and proxy reports of disabilities reflect proxy response biases or only respondent selection factors.

Methods. The data were from the National Health Interview Survey on Disability (1994-1995, phases 1 and 2). In study 1, reports of disabilities were regressed on respondent status, self vs proxy, and demographic factors. In study 2, the ratios of the proportions of self-reports and proxy reports of disabilities were regressed on independent lay ratings of observability of these disabilities and their "interactional" nature. In study 3, the disability reports for people who differed in respondent status in one phase but self-reported the same disability in the other phase were compared.

Results. In study 1, proxies underreported disabilities for people aged 18 to 64 years but overreported for people 65 years or older. In study 2, the observability and interactional scores accounted for more than 60% of the variance of self and proxy differences in an inverse relationship study 3 confirmed the basic findings of study 1.

Conclusions. Use of proxies in representative surveys on disability introduces systematic biases, affecting national disability estimates.

Tuffrey-Wijne, Irene, Jane Bernal, Gary Butler, Sheila Hollins, and Leopold Curfs. "Using Nominal Group Technique to Investigate the Views of People with Intellectual Disabilities on End-of-Life Care Provision." ***Journal of Advanced Nursing,*** **vol. 58, no. 1, April 2007, pp. 80-89.** ▲ *****

Title. Using Nominal Group Technique to investigate the views of people with intellectual disabilities on end-of-life care provision

Aim. This paper is a report of a study using the Nominal Group Technique as a method to elicit the views of people with intellectual disabilities on sensitive issues, in this example end-of-life care provision.

Background. Establishing consumer views is essential to providing appropriate end-of-life care, yet people with intellectual disabilities have historically been excluded from giving their opinion and participating in research.

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* New entry.

Methods. Nominal Group Technique was used in three groups, with a total of 14 participants who had mild and moderate intellectual disabilities. This technique involves four steps: (1) silent generation of ideas, (2) round robin recording of ideas, (3) clarification of ideas, and (4) ranking of ideas (voting). Participants were presented with an image of a terminally ill woman (Veronica), and were asked: "What do you think people could do to help Veronica?"

Findings. Participants generated a mean of nine individual responses. The highest rankings were given to issues around involvement in one's own care, presence of family and friends, offering activities to the ill person, and physical comfort measures.

Conclusion. People with mild and moderate intellectual disabilities are capable of expressing their views on end-of-life care provision, and should be asked to do so. The Nominal Group Technique presents and effective and acceptable methodology in enabling people with intellectual disabilities to generate their views.

U.S. Department of Education. *Workshop on Best Practices for Surveying People with Disabilities.* Washington, DC: ICDR, 2004.

This report presents the proceeding of a two-day conference sponsored by the Interagency Committed on Disability Research's (ICDR) Interagency Subcommittee on Disability Statistics (ISDS) held in Washington, DC, in April 2004. More than 95 people from the federal sector, private organizations, and universities as well as consumers attended this "first of its kind" meeting. A selection process from abstract submissions yielded 26 presenters to share their research about survey design and methodology and to discuss innovative techniques for including respondents with disabilities in national surveys.

Six moderated panels included the following topics: (1) current practices for including people with disabilities in federal surveys; (2) participatory action research and the survey process; (3) methods for improving survey measurement and response; (4) modes of data collection and survey participation; (5) facilitating access through innovation: the role of technology and the Internet; and (6) assuring quality in survey development and implementation. Panel discussions and breakout groups allowed conference participants to share information and to determine a set of best practices for more far-reaching inclusion of respondents with disabilities in national surveys. The event culminated in developing specific recommendations for best practices that will be utilized by the ICDR to promote inclusion of all disability interest groups in data collection, coordinate programs for improved use of disability statistics, and disseminate future survey reference and design.

Valade, Rita Marie. "Participatory Action Research with Adults with Mental Retardation: "Oh My God. Look Out World." *ProQuest DAI (Dissertation Abstracts International),* vol. 65, no. 05A, 2004, p. 1967. ▲ *

This dissertation is a participatory action research project with adults with mental retardation who reside in Louisville, Kentucky. It explores some of the history and ideologies that frequently hindered persons with mental retardation from being regarded by others as unique individuals with various abilities. It investigates dynamics of social ostracism and the resultant

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silence, inclusive of the social work profession's relative absence in the field of mental retardation. Furthermore, it explores various aspects of research with persons with disabilities, and with persons with mental retardation, very few actually include their voices. This dissertation attempts to offer a corrective to this and offers persons with mental retardation a vehicle for their opinions, actions, and voices.

A participatory action research design and methodology is offered involving two phases of the study. The first phase involves interviewing 25 adults relative to their personal concerns of things they would like to see changed in their lives. These interviews reveal that the adults' concerns are as varied as the individuals themselves. The second phase focuses on a ten-month process in which nine persons from the original 25 agree to commit to a group experience in which they decide upon a common issue, their structure, and other group needs. They then work together on how best to address the issue, enact their plan, and communally reflect upon the experience. This group decides to focus on the paratransit system in Louisville and through a process of hard work and commitment, decide to invite the director of the system to attend their group meeting as the focus of their action. The director attends their group, answering their questions and engaging in an extended conversation about their concerns. The dissertation includes a session-by-session reporting on the group gatherings, in addition to insights gained through facilitator's peer supervision experience. It concludes with reflections on the applicability of PAR in social work practice settings and future research needs.

Van Maris, B., L. Soberman, M. Murray, and P.G. Norton. "Satisfaction of Residents and Families in Long-Term Care: II. Lessons Learned." ***Quality Management in Health Care,*** **vol. 4, no. 3, 1996, pp. 47-53.**

The second article of this series describes the construction and use of an instrument to evaluate resident and family satisfaction with care provided in long-term care settings. It addresses operational issues that arose in the application of the instrument and discusses the challenges faced and lessons learned in carrying out the data collection effort. Observations are detailed under four headings:

- Recruiting, Training, and Debriefing the Interviewers
- Success in Interviewing Cognitively Impaired Residents
- Verifying That Residents and Families Are Different Customers
- The Importance of Preparing and Involving Staff

By developing and carrying out this project, the research team gained a better understanding of some potential and real barriers to obtaining satisfaction feedback. They also found that volunteers were eager to participate in new and rewarding endeavors and were ideal for this type of data collection. Furthermore, with training, the volunteers were able to collect valuable data from residents who suffer from cognitive impairments. Project findings also revealed that

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residents and family members were different customers as compared to the institution and to the health care system.

Voelker, S.L., D.L. Shore, C. Brown-More, L.C. Hill, L.T. Miller, and J. Perry. "Validity of Self-Report of Adaptive Behavior Skills by Adults with Mental Retardation." *Mental Retardation*, vol. 28 no. 5, 1990, pp. 305-309. ▲

The validity of self-reports of 48 adults with mental retardation of daily living competency using the recently revised Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984) was investigated. Self-report was compared to standard Vineland interviews of subjects' program counselors and to demonstrated competency in a real-life setting. On domains measuring adaptive skills, the subject and counselor interviews yielded highly consistent results. On the optional Maladaptive Behavior domain, however, the subjects with mental retardation underreported problematic behavior. Response validity and implications for use of self-report for program planning and placement decisions were discussed.

Westby, Carol E. "Ethnographic Interviewing: Asking the Right Questions to the Right People in the Right Ways." *Journal of Childhood Communication Disorders*, vol. 13, no. 1, 1990, pp. 101-111. ▲ *

Current philosophy in early childhood education advocates family-centered intervention goals for handicapped children. To develop appropriate goals for children from diverse cultures, professionals must understand parents' beliefs and values regarding the family's and child's resources and needs; and they must adopt an ecological framework that considers children's functioning within the broader aspects of their environment. Interviewing provides a means of obtaining the information necessary to develop culturally appropriate, family-centered intervention goals. This paper describes the influence of culture on the interview process and describes an approach to ethnographic interviewing of families of handicapped children that enables professionals to ask the right questions to the right people in the right ways so they can assist families in meeting the needs of their children.

Williams, Arthur Joel. "The Predictive Power of Selected Interviewer and Respondent Characteristics on a Developmental Disabilities Survey." *ProQuest DAI (Dissertation Abstracts International)*, vol. 41, no. 03A, 1980, p. 1025. ▲ *

This study was designed to determine the predictive power of selected demographic characteristics of both interviewers and respondents on a survey to collect data on developmental disabilities (DD). Data on the characteristics of interviewers were added to data on household respondents and other household members collected in a house-to-house survey by the Tennessee Association for Retarded Citizens. The 141-item questionnaire collected data on identified DD, suspected DD, and services delivered or needed by the persons with DD. The demographic characteristics used as independent variables included the age, sex, race, education, and occupation of the interviewers and respondents, and the neighborhood and proximity of the interviewers to persons with DD. The sample included 7,889 cases (individuals) from 2,664 households from 12 counties (4 in East Tennessee, 4 in West Tennessee, and 4 in Middle

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Tennessee). To identify possible predictors for a contingency model the sample from East Tennessee was analyzed on the Automatic Interaction Detection system (AID). The dependent variables included: (1) evidence of a completed questionnaire, (2) reported identified DD, (3) reported evidence to cause DD to be suspected, (4) evidence that either 2 or 3 were reported (combined DD). The predictors selected were sex of the interviewer (females) and female interviewers interacting with female respondents and race (white interviewer interviewing white respondents). The predictors were tested by analyzing the data from Middle and West Tennessee to see if the predictors were consistent across the subsections and the total sample. Analysis of the data provided support for the following conclusions: (1) Female interviewers consistently collected a higher percentage of completed questionnaires and evidence of DD. (2) female interviewers consistently collected more data when interviewing females than males when completed questionnaire was the dependent variable. (3) White interviewers collected more data from white respondents than black interviewers. Therefore: this study indicated that a higher rate of data was collected when females of the same race were assigned to collect data in house-to-house surveys, particularly from female respondents.

Wilson, Barbara Foley, Senda Benaissa, Karen Whitaker, Paul Beatty, and Gerry Hendershot. "Improving the Feasibility of Including Deaf Respondents in Telephone Surveys." Paper presented at the Annual Conference of the American Association for Public Opinion Research, St. Louis, MO, May 1998. ▲

These researchers conducted interviews with deaf participants about the communicative, social, and practical aspects of administering survey questions via TTY machines. The three purposes of the interview were: (1) to evaluate the feasibility of using the TTY to administer a health survey; (2) to evaluate whether or not the mechanical limitations of the TTY (e.g., narrow screen size, slow speed) affect the survey process; and (3) to evaluate whether questions designed for oral administration to a hearing sample would be as understandable as written English questions for deaf subjects whose primary language is ASL. American Sign Language has a different syntax than English.

Findings:

1. Equipment: For long questions, only portions of a question could be viewed at any one time on the TTY screen. Questions and response alternatives were transmitted as a continuous stream of text, which was difficult to read. Words were split onto new lines (after 24 words), making some questions confusing. Finally, the equipment had occasional malfunctions.

2. Methodology: Recruiting this population was difficult—many deaf people were reluctant to participate because of their lack of English skills or lack of survey experience. Participants were reluctant to participate unless they were convinced survey was being conducted by a credible organization for worthy reasons, and that it was important to the deaf community.

3. Questions: Questions which asked about symptoms or limited activity in the past 30 days were difficult for participants to answer (in terms of number of days). Deaf

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participants did not believe that their deafness was an impairment, limitation, or a disability (e.g., be careful with language that is used). A TTY survey should include a straightforward question asking whether the respondent is deaf. Numerous requests were made for definitions of health-related vocabulary; thus, interviewers should have a manual of standard definitions on hand.

Worth, Allison, and Alison Tierney. "Conducting Research Interviews with Elderly People by Telephone." ***Journal of Advanced Nursing*****, vol. 18, no. 7, July 1993, pp. 1077-1084.** ▲

Telephone interviews were employed by nurse researchers as a means of collecting data from elderly people following their discharge from hospital. The paper reviews the literature concerning interviews with elderly patients by telephone and recounts first-hand experience of the method on the basis of over 500 telephone interviews. Although some difficulties were encountered in conducting interviews with the hearing impaired and the unwell, the method was found to be a cost-effective and useful means of obtaining follow-up data for research purposes. The prime factor in ensuring successful use of the method was recruitment of subjects via personal interview prior to telephone contact.

Wright, Allison M., and Robyn E. Holliday. "Interviewing Cognitively Impaired Older Adults: How Useful Is a Cognitive Interview?" ***Memory*****, vol. 15, no. 1, 2007, pp. 17-33.** ▲ *****

This research examined whether an Enhanced Cognitive Interview (ECI) and a Modified Cognitive Interview (MCI) improved 75- to 96-year-old adults' recall for a videotaped event. Specifically, we examined the effectiveness of these interviews in relation to a Structured Interview (control), and compared the performance of older adults who scored high or low on the Mini-Mental State Examination (MMSE), which is a test to assess cognitive functioning. Participants with low MMSE scores recalled fewer correct details, and were less accurate than those with high scores. Nevertheless, both high and low MMSE groups reported substantially more correct information about Action, Person, Object, and Surrounding details with the MCI and ECI than with the SI. No corresponding increase in the amount of incorrect and confabulated information was found. Furthermore, recall accuracy for both groups was greater with the ECI and MCI than with the Structured Interview. Overall, findings suggest that older individuals, including those with reduced cognitive ability *can* benefit from the use of Cognitive Interview protocols.

▲ The abstract was written by the author(s) or publisher.
* New entry.

III. SUBJECT INDEX

AGED/ELDERLY

AGED/ELDERLY

Ball, Annie E., Elizabeth M. Russell, D. Gwyn Seymour, William R. Primrose, and Andrew M. Garratt. "Problems in Using Health Survey Questionnaires in Older Patients with Physical Disabilities." *Gerontology*, vol. 47, no. 6, 2001, pp. 334-340.

Bassett, Susan Spear, Jay Magaziner, and J. Richard Hebel. "Reliability of Proxy Response on Mental Health Indices for Aged, Community-Dwelling Women." *Psychology and Aging*, vol. 5, no. 1, 1990, pp. 127-132. *

Bland, Roger C., and Stephen C. Newman. "Mild Dementia or Cognitive Impairment: The Modified Mini-Mental State Examination (3MS) As a Screen for Dementia." *Canadian Journal of Psychiatry*, vol. 46, August 2001, pp. 506-510. *

Cheston, Rik, Mike Bender, and Sue Byatt. "Involving People Who Have Dementia in the Evaluation of Services: A Review." *Journal of Mental Health*, vol. 9, no. 5, 2000, pp. 471-479. *

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Moore, David J., David Sitzer, Colin A. Depp, Lori P. Montross, Jennifer Reichstadt, Barry D. Lebowitz, and Dilip V. Jeste. "Self-Administered Cognitive Screening for a Study of Successful Aging Among Community-Dwelling Seniors: A Preliminary Study." *International Journal of Geriatric Psychiatry*, vol. 22, no. 4, April 2007, pp. 327-331. *

Parker, M.G., M. Gatz, and M. Thorslund. "Brief Cognitive Screening in a Field Survey of the Oldest Old." *Aging (Milano)*, vol. 8, no. 5, October 1996, pp. 354-359. *

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*New entry

Wright, Allison M., and Robyn E. Holliday. "Interviewing Cognitively Impaired Older Adults: How Useful Is a Cognitive Interview?" *Memory*, vol. 15, no. 1, 2007, pp. 17-33. *

*New entry

COGNITIVE DISABILITIES
(Including Mental Retardation, Development Disabilities, and Learning Disabilities)

COGNITIVE DISABILITIES
(Including Mental Retardation, Developmental Disabilities, and Learning Disabilities)

Agnew, Sarah E., Martine B. Powell, and Pamela C. Snow. "An Examination of the Questioning Styles of Police Officers and Caregivers When Interviewing Children with Intellectual Disabilities." *Legal and Criminological Psychology,* vol. 11, 2006, pp. 35-53. *

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Ciemnecki, Anne B., Kirsten Barrett, Karen A. CyBulski, Jason A. Markesich, Matt Sloan, and Debra L. Wright. "Comparison of Two Methods for Proxy Respondent Decision." Paper presented at the Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC) 2006 State-of-the-Science Conference, Arlington, VA, 2006. *

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