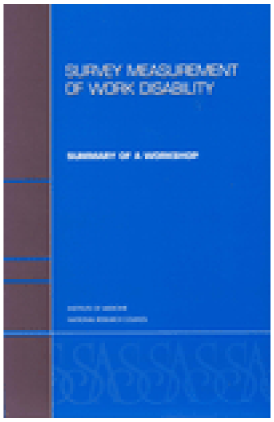

Survey Measurement of Work Disability: Summary of a Workshop

Nancy Mathiowetz and Gooloo S. Wunderlich, editors, Committee to Review the Social Security Administration's Disability Decision Process Research, Committee on National Statistics, National Research Council

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THE NATIONAL ACADEMIES
Advisers to the Nation on Science, Engineering, and Medicine

SURVEY MEASUREMENT OF WORK DISABILITY

Summary of a Workshop

Nancy Mathiowetz and Gooloo S. Wunderlich, *Editors*

Committee to Review the Social Security Administration's
Disability Decision Process Research

Dorothy Rice, *Chair*

Division of Health Care Services
INSTITUTE OF MEDICINE

and

Committee on National Statistics
Commission on Behavioral and Social Sciences and Education
NATIONAL RESEARCH COUNCIL

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We gratefully acknowledge Nancy Mathiowetz of the Joint Program in Survey Methodology, University of Maryland, who served as consultant for planning, organizing, and coediting the summary of the workshop. We acknowledge with gratitude the commitment and support of the committee staff in organizing the workshop and preparing the report. Gooloo Wunderlich, Study Director, and Nancy Mathiowetz not only undertook the major responsibility for the workshop, but also prepared the report. Kathleen Nolan worked closely with the study director and the consultant in organizing the workshop, developing the agenda, and preparing the charts and formatting tables for publication. Rebecca Lucchese, Senior Project Assistant, assisted in the logistical and administrative arrangements of the workshop. Many thanks go to Nicole Amado, Senior Project Assistant for cheerfully and competently reviewing the drafts, and making editorial corrections to the entire report, and preparing it for publication under tight deadlines. The chair thanks the committee members for their time and commitment to the workshop.

REVIEWERS

The report was reviewed by individuals chosen for their diverse perspectives and technical expertise in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments to assist the authors and the National Academy of Sciences in making the published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The content of the review comments and the draft manuscript remain confidential to protect the integrity of the deliberative process.

The committee wishes to thank the following individuals for their participation in the report review process: Edward Brandt, Jr., University of Oklahoma, David Keer, National Institute on Disability and Rehabilitation; Cille Kennedy, National Institute of Mental Health; Mary Grace Kovar, National Opinion Research Center; Janet Norwood, Urban Institute; and Edward Perrin, University of Washington.

While the individuals listed above provided many constructive comments and suggestions, responsibility for the final content of the report rests solely with the authoring committee and the National Academy of Sciences.

Dorothy P. Rice
Chair

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APPENDIXES

SURVEY MEASUREMENT
OF WORK DISABILITY

1

Introduction

The Social Security Administration (SSA) is engaged in redesigning its disability determination process for providing cash benefits and medical assistance to blind and disabled persons under the Social Security Disability Insurance (SSDI) program and the Supplemental Security Income (SSI) program (Title II and Title XVI of the Social Security Act). The agency has undertaken a multiyear research effort to develop and test the feasibility, validity, reliability, and practicality of the redesigned disability determination process before making any decision about its national implementation.

SSA asked the National Academy of Sciences (NAS) to review and provide advice on this research. One of the major areas for review is the ongoing independent, scientific review of the scope of work, design, and content of the Disability Evaluation Study (DES) and the conduct of the study by the chosen survey contractor. NAS has been asked to identify statistical design, methodological, and content concerns and to address other issues as they arise. (See Appendix A for the study mandate.) Consistent with this charge is the need for the committee to ascertain that the methods proposed for measuring disability in the DES, particularly the approach to one of the DES objectives described below, are indeed adequate and correct.

SSA's stated plans regarding ongoing monitoring of the size of the pool of people who might be potentially eligible for benefits under the SSDI and SSI programs are to use existing survey vehicles sponsored by other agencies to supplement a periodic DES. The candidate surveys would be viewed as monitoring tools between periodic comprehensive surveys conducted by SSA. Thus, a partnership between SSA and other federal data collection agencies would be forged to provide ongoing monitoring of this population. Such a plan needs an initial assessment of the current practices and future challenges for measurement of disability by use of household surveys.

Across the various surveys now in place, diversity exists in conceptual definitions of disability, in the nature of reference periods used for recall, in reporting rules for answering disability questions, in modes of data collection, and in levels of thresholds used for construction of disability statistics. Furthermore, many of the measures have not undergone extensive pretesting, such as state-of-the-art cognitive interviewing methods. Too few methodological inquiries have compared alternative measurement approaches.

The interim reports of the Committee to Review the Social Security Administration's Disability Decision Process Research have provided recommendations to SSA on the survey design issues faced by the DES. Although this short-run guidance will be beneficial to the work of SSA, it does not attempt to address medium- and long-term issues in survey measurement of disability.

As a step toward exploring these issues, the Committee to Review the Social Security Administration's Disability Decision Process Research (hereafter referred to as "the committee") convened on May 27–28, 1999, a workshop titled "Survey Measurement of Work Disability: Challenges for Survey Design and Method." The committee believed that a focused discussion among a wide range of disability researchers and survey methodologists could identify unanswered questions about measurement and provide a framework for a long-term research agenda in this area for SSA and others in this field. Such a workshop would be helpful for the committee's review of the design and content of the DES and enhance its ability to make informed recommendations to SSA on the subject. It also could be of great value to SSA in anticipating problems of using data from other agencies' surveys to monitor the size of the pool of eligible people.

Workshop participants included members of the committee, a wide range of researchers in survey design and methods as well as in disability research, and other invited experts. The workshop, though focused on SSA's needs, drew the attention of a large number of disability researchers from other agencies, academia, and members of the public.[1] The workshop agenda and a list of participants are shown in Appendixes B and C, respectively.

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[1] The committee organized the workshop through a planning subcommittee composed of Robert Groves, *Chair*, Monroe Berkowitz, Ronald Brookmeyer, William Kalsbeek, Alan Jette, and Dorothy Rice. Nancy Mathiowetz served as consultant to the Institute of Medicine on the development and organization of the workshop. The full committee reviewed the plans for the workshop and this report, and modifications were made in response to the comments received. Thus, the workshop reflects the collective thinking of the committee regarding the issues discussed.

OBJECTIVES AND FOCUS OF THE WORKSHOP

The objectives of this workshop were to:

1. better understand the conceptual issues related to currently existing measures of work disability, the measurement error properties of these questions, and the essential survey conditions that affect the measurement of disability;
2. aid the committee in advising SSA on methods for measuring work disability in the DES and on ways to facilitate crosswalks between the DES and data collected in other federal household surveys; and
3. identify a research agenda for SSA in survey measurement of work disability.

The workshop opened with a session in which the authors of the two background papers presented a "point-counterpoint" dialog.[2] The remaining sessions for the day focused on measurement and methodological issues within the framework of specific conceptual and programmatic themes. Participants then identified and discussed issues pertaining to:

- translation of various conceptual models of disability and the disablement process to valid and reliable questions in a survey and their ability to address SSA's disability programmatic requirements;
- measurement error properties of existing measures of work disability and the survey conditions that affect these measures;
- the ability to crosswalk among measures of disability collected in a variety of settings, such as the DES, and other ongoing federal data collection efforts; and
- gaps in the current set of disability measures and the inherent problems in attempting to fill those gaps.

In the final session of the workshop, participants identified the key issues that surfaced during the discussions and that could provide a framework for long-term research to address the gaps in survey methods and measurement of work disability.

This report includes the commissioned papers written for the workshop and a summary of the group discussions flowing from the presentations during the subsequent sessions outlined in the agenda (Appendix B). The report concludes with a research agenda identified by the participants during the last day of the workshop. The summary is limited to the views and opinions of those participating in the workshop and reflects the concerns and areas of expertise of the workshop participants. As such, it does not provide a comprehensive review of the research and current status of survey measurement of work disability. The issues and themes of the workshop provided the unifying focus for the various presentations and discussions that flowed over the course of the day-and-a-half workshop.

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[2] The committee commissioned these two papers from Alan M. Jette and Elizabeth Badley and from Nancy A. Mathiowetz. The committee appreciates their contributions. The papers can be found in their entirety in Chapters 2 and 3 of this report, respectively.

2

Conceptual Issues in the Measurement of Work Disability

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The field of disability research is in need of uniform concepts and a common language to guide scholarly discussion, to advance theoretical work on the disablement process, to facilitate future survey and epidemiological research, and to enhance understanding of disability on the part of professionals as well as the general public. A commonly understood language can also influence the development of public policy in the area of work disability, the focus of the Institute of Medicine's workshop titled "Survey Measurement of Work Disability." The current lack of a uniform language and commonly understood definition of the concepts of "disability" and "work disability" is a serious obstacle to all these endeavors.

Conceptual confusion is a particular barrier to the improvement of the Social Security Administration's (SSA) process for determining eligibility for both Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) related to "work disability," as was illustrated in the earlier Institute of Medicine workshop, "Measuring Functional Capacity and Work Requirements." A shared language and conceptual understanding did not emerge from that workshop. If various participants in the disability benefit determination revision process cannot agree on the meaning of the term "work disability," they can hardly be expected to reach agreement on an approach to improving the work disability determination process.

The Social Security Act defines disability as the "inability to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment which can be expected to result in death or can be expected to last for a continuous period of not less than 12 months." As this background paper will illustrate, this definition in the Social Security Act is at odds with most contemporary thought about the concept of disability and is in itself a barrier to the SSA's work disability revision process.

The paper presented in this chapter aims to provide the reader with a conceptual foundation to facilitate discussion at the upcoming workshop titled "Survey Measurement of Work Disability." Our intent is to highlight issues regarding language and concepts directly or indirectly related to the concept of "work disability." To do so, we focus on several activities:

1. present a review of some of the contemporary definitions of disability found in the literature;
2. discuss these definitions in the context of several major disablement frameworks;
3. discuss the concept of "work disability" in the context of these disablement models and relate it to other health-related phenomena;
4. critically review the conceptual basis of frequently used survey items that attempt to assess "work disability"; and
5. highlight some of the pressing research needs in the area of "work disability."

THE CONCEPT OF DISABILITY

A common understanding of the term "disability" is an essential first step to a scholarly exchange about the concept of "work disability" and is the foundation for a fruitful discussion of improving survey research in the general area of disability and, more specifically, in the area of work disability.

Understanding of the source of contemporary conceptual confusion requires a review of the major disability frameworks found in the literature. The goal of bringing together the several different schools of thought on disability and the disablement process remains elusive. Achieving a commonly accepted conceptual language is one of the primary challenges facing the field of disability research.

Major Schools of Thought

Several schools of thought have defined disability and related concepts. We will focus on the Disablement Model developed by Nagi (1965) and the International Classification of Impairments, Disabilities, and Handicaps (ICIDH-1) (WHO, 1980) and the current proposal for its revision, which is referred to in this chapter as ICIDH-2 (WHO, 1997). We will briefly review both of these conceptual frameworks. Both the Nagi Disablement Model and ICIDH frameworks have in common the view that overall disablement represents a series of related concepts that describe the consequences or impact of a health condition on a person's body, on a person's activities, and on the wider participation of that person in society. In the authors' view, the major differences in these frameworks are in the terms used to describe disability and related concepts and the placement of the boundaries between concepts more than differences in their fundamental contents. After reviewing the terms within each framework we will compare and contrast the two major models along with their major derivatives and explore how these relate more generally to the concept of "work disability."

Nagi's Concept of Disability

According to the conceptual framework of disability developed by sociologist Saad Nagi (1965), "*disability is the expression of a physical or a mental limitation in a social context*." In striking contrast to the Social Security Act's definition of work disability as an inability to work due to a physical or mental impairment, Nagi specifically views the concept of disability as representing the gap between a person's capabilities and the demands created by the social and physical environments (Nagi, 1965, 1976, 1991). This is a fundamental distinction of critical importance to scholarly discussion and research related to disability phenomena.

According to Nagi's own words:

> [Disability is a] limitation in performing socially defined roles and tasks expected of an individual within a sociocultural and physical environment. These roles and tasks are organized in spheres of life activities such as those of the family or other interpersonal relations; work, employment, and other economic pursuits; and education, recreation, and self-care. Not all impairments or functional limitations precipitate disability, and similar patterns of disability may result from different types of impairments and limitations in function. Furthermore, identical types of impairments and similar functional limitations may result in different patterns of disability. Several other factors contribute to shaping the dimensions and severity of disability. These include (a) the individual's definition of the situation and reactions, which at times compound the limitations; (b) the definition of the situation by others, and their reactions and expectations—especially those who are significant in the lives of the person with the disabling condition (e.g., family members, friends and associates, employers and co-workers, and organizations and professions that provide services and benefits); and (c) characteristics of the environment and the degree to which it is free from, or encumbered with, physical and sociocultural barriers. (Nagi, 1991, p. 315)

Nagi's definition stipulates that a disability may or may not result from the interaction of an individual's physical or mental limitations with the social and physical factors in the individual's environment. Consistent with Nagi's concept of disability, an individual's physical and mental limitations would not invariably lead to work disability. Not all physical or mental conditions would precipitate a work disability, and similar patterns of work disability may result from different types of health conditions. Furthermore, identical physical and mental limitations may result in different patterns of work disability.

Nagi's Disablement Model has its origins in the early 1960s. As part of a study of decision making in the SSDI program, Nagi (1964) constructed a framework that differentiated disability (as defined and discussed above) from three other distinct yet interrelated concepts: active pathology, impairment, and functional limitation. This conceptual framework has come to be referred to as Nagi's Disablement Model.

For Nagi, *active pathology* involves the interruption of normal cellular processes and the simultaneous homeostatic efforts of the organism to regain a normal state. He notes that active pathology can result from infection, trauma, metabolic imbalance, degenerative disease processes, or other etiology. Examples of active pathology are the cellular disturbances consistent with the onset of disease processes such as osteoarthritis, cardiomyopathy, and cerebrovascular accidents.

For Nagi, *impairment* refers to a loss or abnormality at the tissue, organ, and body system level. Active pathology usually results in some type of impairment, but not all impairments are associated with active pathology (e.g., congenital loss or residual impairments resulting from trauma). Impairments can occur in the primary locale of the underlying pathology (e.g., muscle weakness around an osteoarthritic knee joint), but they may also occur in secondary locales (e.g. cardiopulmonary deconditioning secondary to inactivity).

To describe the distinct consequences of pathology at the level of the individual, Nagi uses the term *functional limitations* to represent restrictions in the basic performance of the person. An example of basic functional limitations that might result from a cerebrovascular accident could include limitations in the performance of locomotor tasks, such as the person's gait and basic mobility, such as transfers, or in nonphysical tasks, such as communication or reasoning. Such functional limitations might or might not be related to specific impairments (secondary to the cerebrovascular accident) and thus are seen as distinct from organ or body system disturbances.

At this point, a "work disability" example will illustrate the distinctions being drawn between the various concepts within Nagi's Disablement Model. Two patients with Parkinson's disease may enter the Social Security work disability benefits determination process with very similar clinical profiles. Both may have moderate impairments such as rigidity and bradykinesia. Their patterns of function may also be similar with a characteristically slow, shuffling gait, and slow deliberate movement patterns. Their work role patterns, however, may be radically different. One individual may have restricted his or her outside activities completely, need help dressing in the morning, spend most of the time indoors watching television, be depressed, and be currently unemployed. The other may be fully engaged in his or her social life, receive assistance from a spouse in performing daily activities, be driven to work, and, through workplace modification, be able to maintain full-time employment. The two patients present very different work disability profiles yet have very similar underlying pathology, impairment, and functional limitation profiles.

Elaboration of Nagi's Disablement Model

In their work on the disablement process, Verbrugge and Jette (1994) maintained the basic concepts of the Nagi Disablement Model and Nagi's original definitions. Within the dimension of disability, however, they categorized subdimensions of social roles that can be considered under Nagi's concept of disability. Some of the most commonly applied dimensions include the following:

- *Activities of daily living (ADL)*—including behaviors such as basic mobility and personal care.
- *Instrumental activities of daily living (IADL)*—including activities such as preparing meals, doing housework, managing finances, using the telephone, and shopping.
- *Paid and unpaid role activities*—including performing one's occupation, parenting, grandparenting, and being a student.
- *Social activities*—including attending church and other group activities and socializing with friends and relatives.
- *Leisure activities*—including participating in sport and physical recreation, reading, or taking distant trips.

Within their framework, "work disability" is clearly delineated as a specific subdimension under the concept of disability.

In their 1994 work, Verbrugge and Jette attempted to extend Nagi's Disablement Model to attain full sociomedical scope. They attempted to clearly differentiate the "main pathways" of the disablement process (i.e., Nagi's original concepts) from factors hypothesized or known to influence the ongoing process of disablement (Figure 2-1).

Viewed from a social epidemiological perspective, Verbrugge and Jette (1994) argued that one might analyze differences in disablement concepts relative to three sets of variables: predisposing risk factors, intraindividual factors, and extraindividual factors. These categories of variables, which are external to the main disablement pathway, can be defined as follows:

- *Risk factors* are predisposing phenomena that are present before the onset of the disabling event and that can affect the presence or severity of the disablement process. Examples include sociodemographic background, lifestyle, and biological factors.
- The next class of variables is *intraindividual factors* (those that operate within a person), such as lifestyle and behavioral changes, psychosocial attributes and coping skills, and activity accommodations made by the individual after the onset of a disabling condition.

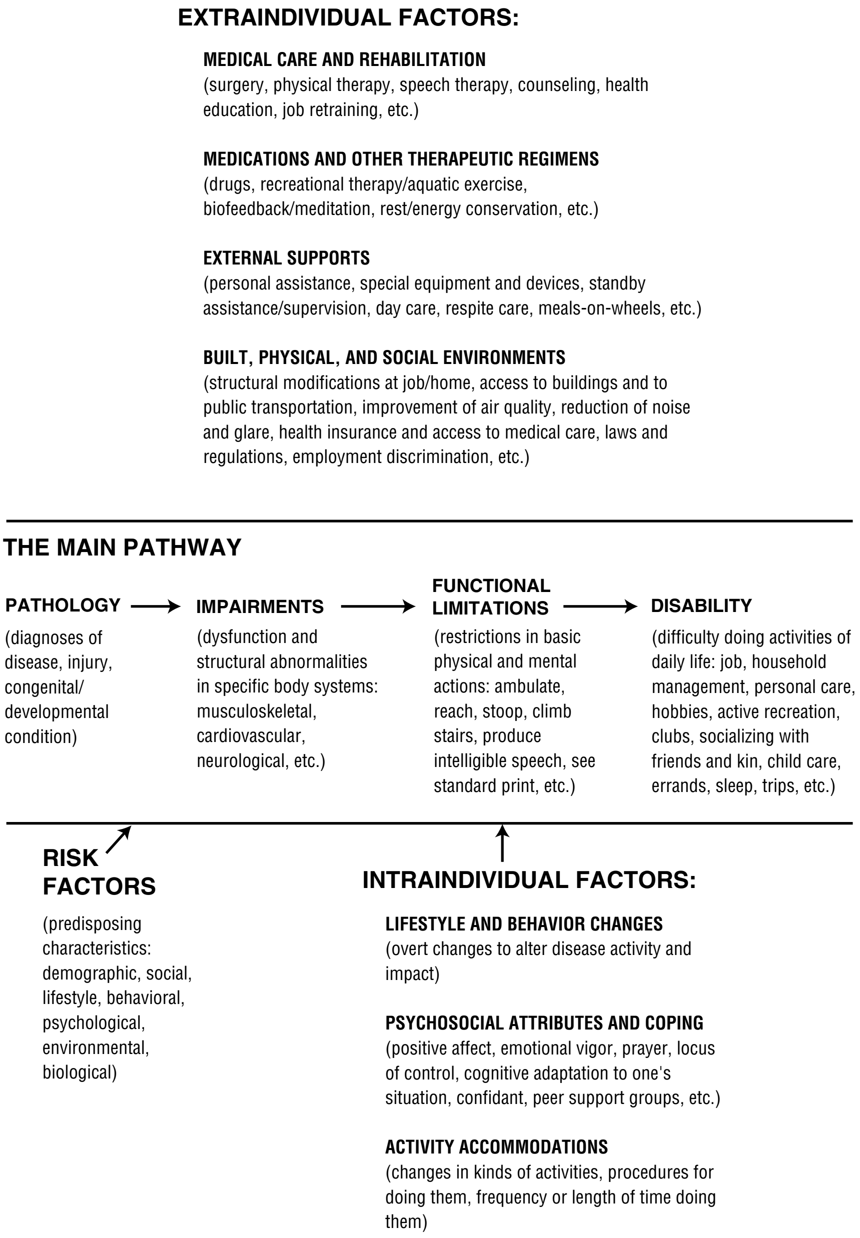


FIGURE 2-1. The disablement process. SOURCE: Adapted from Verbrugge and Jette, 1994.

- *Extraindividual factors* (those that perform outside or external to the person) pertain to the physical as well as the social context in which the disablement process occurs. Environmental factors relate to the social as well as the physical environmental factors that bear on the disablement process. These can include medical and rehabilitation services, medications and other therapeutic regimens, external supports available in the person's social network, and the physical environment.

A further elaboration of Nagi's conceptual view of the term disability is contained in *Disability in America* (IOM, 1991) and a more recent Institute of Medicine (IOM) disablement model revision highlighted in a report titled *Enabling America: Assessing the Role of Rehabilitation Science and Engineering* (IOM, 1997).

The 1991 IOM report uses the original main disablement pathways put forth by Nagi with minor modifications of his original definitions. The 1997 IOM report adds two important concepts to the Disablement Model: the concepts of *secondary conditions* and *quality of life*. Both of these concepts are discussed later in this chapter.

In 1997, in an effort to emphasize Nagi's view that disability is not inherent in the individual (as defined by the Social Security Act), but, rather, is a product of the interaction of the individual with the environment, IOM issued *Enabling America*, in which it referred to disablement as "the enabling-disabling process." This effort was an explicit attempt to acknowledge, within the disablement framework itself, that disabling conditions not only develop and progress but can be reversed through the application of rehabilitation and other forms of explicit intervention. Figure 2-2 is an illustration of IOM's 1997 enabling-disabling process.

The IOM report (1997) describes the enabling-disabling process as follows:

> Access to the environment, depicted as a square, represents both physical space and social structures (family, community, society). The person's degree of physical access to and social integration into the generalized environment is shown as the degree of overlap of the symbolic person and the environmental square. A person who does not manifest disability (Figure 2-2a) is fully integrated into society and has full access to both: (1) social opportunities (e.g., employment, education, parenthood, leadership roles) and (2) physical space (e.g., housing, workplaces, transportation). A person with disabling conditions has increased needs (shown as the increased size of the individual) and is dislocated from their prior integration into the environment (Figure 2-2b). The enabling (or rehabilitative) process attempts to rectify this displacement, either by restoring function in the individual (Figure 2-2c) or by expanding access to the environment (Figure 2-2d) (e.g., building ramps). (IOM, 1997, p. 3)

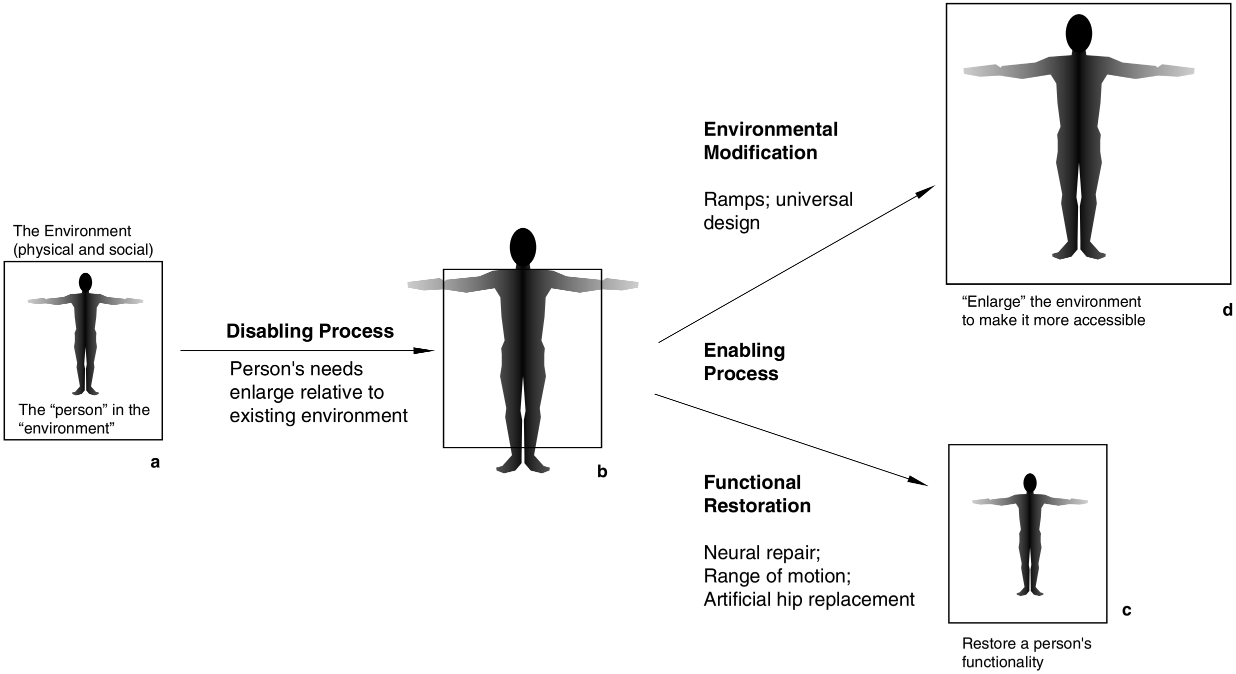


FIGURE 2-2. Conceptual overview of the enabling-disabling process. The environment, depicted as a square, represents both physical space and social structures (family, community, society). A person who does not manifest a disability (a) is fully integrated into society and "fits within the square." A person with potentially disabling conditions has increased needs (expressed by the size of the individual) and is dislocated from his or her prior integration into the environment (b), that is, "doesn't fit in the square." The enabling (or rehabilitative) process attempts to rectify this displacement, either by restoring function in the individual (c) or by expanding access to the environment (d) (e.g., building ramps). SOURCE: Reprinted from IOM, 1997.

International Classification of Impairments, Disabilities, and Handicaps

Independently from the development of the Nagi model, a similar process was also under way in Europe, which led in the early 1970s to the first draft of what later became the World Health Organization (WHO) ICIDH (WHO, 1980). This model also differentiates a series of related concepts: health conditions, impairments, disabilities, and handicaps (WHO, 1980; Badley, 1993). We will refer to these as the ICIDH-1 concepts. ICIDH-1 is not only a conceptual model; it has also associated with it a hierarchical classification of impairment, disability, and handicap (WHO, 1980). We will not review this classification as such, except to note that, in principle, this system provides a scheme for coding and manipulating data on the consequences of health conditions. This classification and the related model of disablement are being revised and have been named ICIDH-2. At the time of this writing (April 1999), a first, beta draft has been circulated for comment (WHO, 1997), and the beta-2 draft is in the final stages of production. The beta-2 draft revised classification will then undergo 2 years of field testing before the final version is prepared for ratification by the WHO. The changes in the definitions and conceptual model that are being recommended in the process of revision to get ICIDH-2 are discussed below. The U.S. National Center for Health Statistics and the Centers for Disease Control and Prevention have served as the lead U.S. agencies in the international ICIDH revision process.

The first component of the ICIDH-1 model is *impairment*, which is defined as follows:

> *In the context of health experience, an impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function.* (WHO, 1980, p. 27)

This definition is similar to Nagi's definition of impairment, but it also includes some of Nagi's notions of pathology. Just as Nagi's impairment is focused on organs or organ systems, impairment as defined here is very much concerned with the function and structure of the body and its components. The ICIDH-2 definition is similar:

> *Impairment is a loss or abnormality of body structure or of a physiological or psychological function.* (WHO, 1997, p. 15)

Huge confusion arises because the ICIDH-1 also uses the word *disability*, but with a slightly different meaning from the Nagi definition of the term. The ICIDH-1 defines *disability* as follows:

> *In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.* (WHO, 1980, p. 28)

The focus of this definition is very much on the activities carried out by the person. Further understanding of what is included in this definition can be gained by inspection of the associated classification (WHO, 1980, 1997). The activities included range from simple functional activities, such as gripping and holding and maintaining and changing body positions, to more complex activities, such as those related to self-care and other ADLs, IADLs, and some of the activity components of other role activities. The latter include, for example, activities that might be carried out in a work environment. Examples from the ICIDH-1 classification include activities such as organizing a daily routine (ICIDH 1980, Code D18.2), use of foot control mechanisms (ICIDH 1980, Code D67), and tolerance of work stress (ICIDH 1980, Code D76). The ICIDH-1 term *disability* then bridges the Nagi concepts of functional limitation and disability. In revision of the ICIDH, the term *disability* has been replaced by the positive term *activity*, which is defined as follows:

> *Activity is the nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality.* (WHO, 1997, p. 14)

To prevent further confusion, the rest of this paper will use the term disability solely in the Nagi sense and use the term *activity limitation* for the ICIDH concept.

In terms of definitions, the construct analogous to the Nagi definition of disability is embodied in the term *handicap*. This is defined as follows:

> *In the context of health experience, a* ***handicap*** *is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.* (WHO, 1980, p. 29)

As is apparent from the definition, *handicap*, like Nagi's *disability*, also embodies the notion of role. However, by referring to disadvantage it goes further than the actual performance of roles to attach a value judgment, that of disadvantage, to restrictions in role performance. The focus of handicap is the person in the society in which he or she lives and reflects cultural norms and expectations for performance.

The term *handicap* did not generally find favor, particularly among people who themselves had disabilities, as it carried within it a history of stigmatization (unrelated to its technical definition). In the ICIDH revision process, this questioning of the term *handicap* spilled over to the whole of the classification and led to the issue of why the emphasis was entirely on the negative. In other words there was a reaction against the whole classification being focused on deficiencies resulting from health conditions. In response to this there has been a switch to neutral terminology, as was illustrated above by the use of the term *activity* instead of the term *disability*. In the proposal for revision of the ICIDH, the concept of handicap, as defined above, has been replaced with the term *participation,* with negative aspects being referred to as *restriction in participation*:

> ***Participation*** *is the nature and extent of a person's involvement in life situations in relation to impairments, activities, health conditions and contextual*

> *factors. Participation may be restricted in nature, duration and quality.* (WHO, 1997, p. 14)

Like Nagi's definition of disability, the ICIDH definitions of handicap and participation are essentially relational concepts. This is made very explicit in the ICIDH-2, which states that:

> Participation is characterized as the outcome or result of a complex relationship between, on the one hand, a person's health condition, and in particular, the impairments or disabilities he or she may have, and on the other, features of the context that represent the circumstances in which the person lives and conducts his or her life . . . different environments may have a different impact on the same person with impairment or disability. Participation is therefore based on an ecological/environmental interaction model. (WHO, 1997, p. 17)

The conceptual model that accompanies the ICIDH-2 shows that the context potentially has an effect on the expression of all levels of the model: impairment, activity limitation, and restriction in participation. The context refers both to external environmental factors and to more personal characteristics of an individual. The latter range from relatively uncontroversial characteristics, such as age and gender, to aspects of the person relating to educational background, race, experiences, personality and character style, aptitudes, other health conditions, fitness, lifestyle, habits, coping styles, social background, profession, and past and current experience (WHO, 1997). ICIDH-2 includes a draft classification of environmental factors that covers components of the natural environment (weather or terrain), the human-made environment (tools, furnishings, the built environment), social attitudes, customs, rules, practices and institutions, and other individuals (WHO, 1997). All of the above contextual factors may be relevant, in connection with the impairments or activity limitations of a person, for determining whether that person experiences disability in working or not.

Finally, the ICIDH-2 concept of participation goes beyond the performance of roles and deals with the wider issues of the effect of barriers and facilitators to overall participation in society. In the context of work disability these barriers and facilitators include discrimination, stigma, legislation around workplace design and participation (including the Americans with Disabilities Act), attitudes of coworkers, and extra-work issues such as mobility in the community. This means that an assessment of restriction of participation does not necessarily need to be on a personal basis and might, in some situations, be predicted by direct assessment of barriers. For example, workplaces that are not accessible to wheelchair users would systematically restrict participation, irrespective of the nature and demands of the actual work tasks.

THE CONCEPT OF SOCIAL ROLES

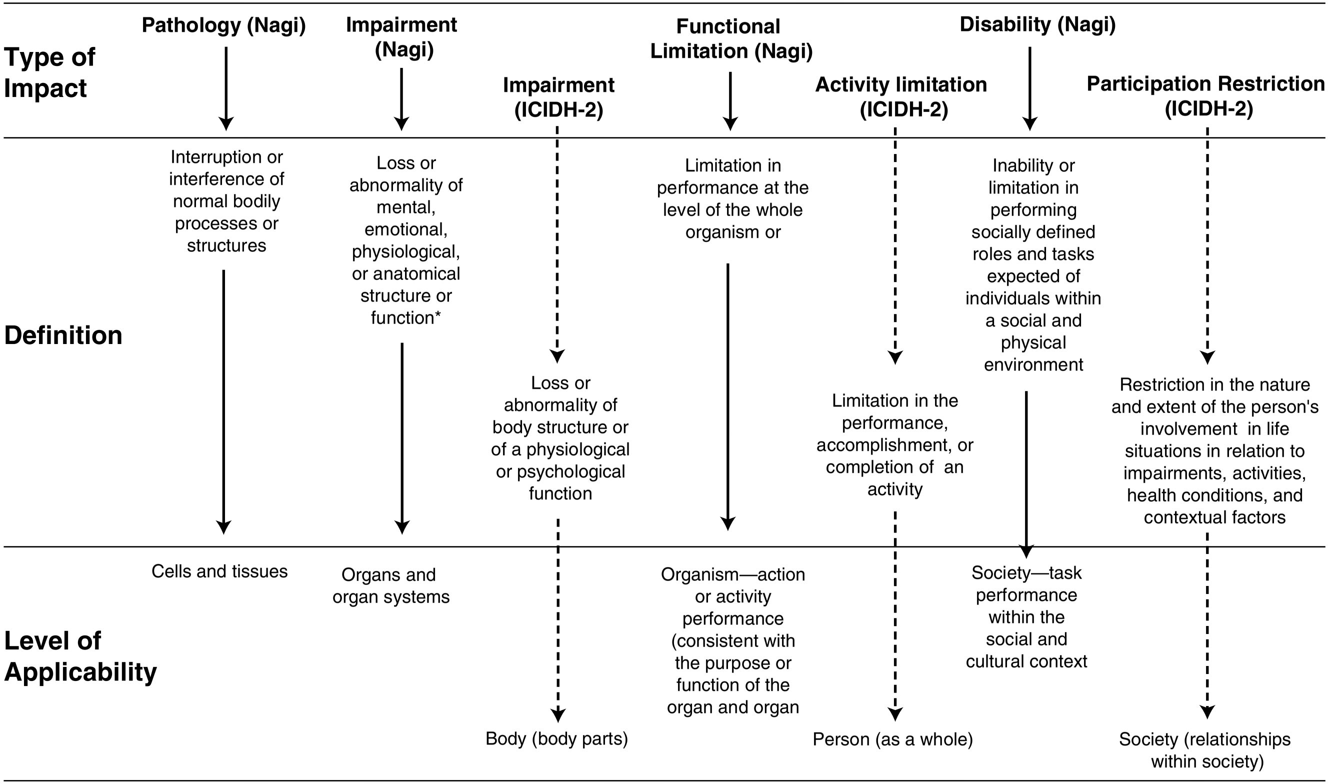
To understand fully how Nagi's definition of disability and the ICIDH definition of handicap can be applied to the area of work disability, one must understand the concept of social role and tasks from a sociological perspective. Social roles, such as being a parent, a construction worker, or a university professor, are basically organized according to how individuals participate in a social system.

According to Parsons (1958), "role is the organized system of participation of an individual in a social system" (p. 316). Tasks are specific activities through which the individual carries out his or her social roles. Social roles are made up of many different tasks, which may be modifiable and interchangeable. For Nagi, the concept of disability is firmly rooted in the context of health. Thus, for Nagi (1991), health-related limitations in the performance of specific social roles are what constitute specific areas of disability, work being one important area of disability. Roles such as work can be disrupted by a variety of factors other than those that are health related. A change in the economic climate or technological changes, for example, may lead to unemployment totally unrelated to health conditions. These would not represent work disability in the way that Nagi defines this term. As Parsons clarifies:

> Roles, looked at that way, constitute the primary focus of the articulation and hence interpretation between personalities and social systems. Tasks on the other hand, are both more differentiated and more highly specified than roles, one role capable of being analyzed into a plurality of different tasks. . . . A task, then, may be regarded as that subsystem of role which is defined by a definite set of physical operations which perform some function or functions in relation to a role. (Parsons, 1958, p. 316)

Are there limits to this concept of disability from the perspective of role performance? Nagi argues that components of roles—expectations or specific tasks that are learned, organized, and purposeful patterns of behavior—are part of the disability concept. They are more than isolated functions or muscle responses (Sarbin and Allen, 1968; Nagi, 1991). Some tasks are role specific, whereas others are common to the enactment of several roles. For Nagi, to the extent that these tasks are learned, organized, and purposeful patterns of behavior, they are part of the disability concept. It is for this reason that Nagi views the concept of disability as ranging from very basic ADLs to the exquisitely complex social roles such as one's occupation. Since activities of daily living (e.g., dressing, bathing, and eating) are part of a set of expectations inherent in a variety of other social roles, Nagi sees deviations or limitations in the performance of even such basic social roles as components of the concept of disability (Nagi, 1991). For Nagi, disability as a heuristic concept is inclusive of all socially defined roles and tasks.

In the ICIDH-2, overall role performance mainly falls into the domain of participation. The boundary between activity limitation and participation is drawn differently from the way in which it is drawn in the Nagi model, in that a person who is unable to perform activities that are the components of roles is considered to have activity limitations (Figure 2-3). These are the roles that Nagi refers to as "basic social roles." In the context of work disability, the distinction is between



Type of Impact	Pathology (Nagi)	Impairment (Nagi)	Impairment (ICIDH-2)	Functional Limitation (Nagi)	Activity limitation (ICIDH-2)	Disability (Nagi)	Participation Restriction (ICIDH-2)
Definition	Interruption or interference of normal bodily processes or structures	Loss or abnormality of mental, emotional, physiological, or anatomical structure or function*	Loss or abnormality of body structure or of a physiological or psychological function	Limitation in performance at the level of the whole organism or	Limitation in the performance, accomplishment, or completion of an activity	Inability or limitation in performing socially defined roles and tasks expected of individuals within a social and physical environment	Restriction in the nature and extent of the person's involvement in life situations in relation to impairments, activities, health conditions, and contextual factors
Level of Applicability	Cells and tissues	Organs and organ systems	Body (body parts)	Organism—action or activity performance (consistent with the purpose or function of the organ and organ	Person (as a whole)	Society—task performance within the social and cultural context	Society (relationships within society)

* Includes all losses and abnormalities, not just those attributable to active pathology; also includes pain.

FIGURE 2-3. Comparison of the Nagi and ICIDH-2 concepts and definitions.

restriction of participation related to work as an overall concept and the carrying out of the activities involved in the work itself. This is discussed in more detail in the section that explores conceptual issues related to work disability.

Fundamental to differentiating the concept of disability from those of pathology, impairment, and functional limitation is the consideration of the difference between concepts of attributes or properties on the one hand and relational concepts on the other (Cohen, 1957).

As Nagi describes it:

> Concepts of attributes and properties refer to the individual characteristics of an object or person, such as height, weight, or intelligence. Indicators of these concepts can all be found within the characteristics of the individual. Pathology, impairment, and functional limitations are concepts of attributes or properties. . . . Disability is a relational concept; its indicators include individuals' capacities and limitations, in relation to role and task expectations, and the environmental conditions within which they are to be performed. (Nagi, 1991, p. 317)

Let us take the example of limitation in the performance of one's work role—or work disability. Work disability typically begins with the onset of one or more health conditions that *may* limit the individual's performance of specific tasks through which an individual would typically perform his or her job. The onset of a specific health condition—say, a stroke or a back injury—may or may not lead to actual limitation in performing the work role, a work disability. The development of work disability will depend, in part, on the extent to which the health condition limits the individual's ability to perform specific tasks that are part of one's occupation, and alternatively, degree of work disability may depend on external factors, for example, workplace attitudes—say, flexible working hours—that may restrict employment opportunities for persons with specific health-related limitations. Or work disability might be affected by accessible modes of transportation to the workplace, environmental barriers in the workplace, or the willingness of the employer to modify the individual workstation to accommodate a health condition. Viewed from the perspective of role performance, degree of work disability could be reduced by improving the individual's capacity to accomplish functional activities—a very traditional view of rehabilitation—or by manipulating the physical or social environment in which work occurs. A discussion similar to that given above could be formulated by using the language of the ICIDH.

The fundamental conceptual issue of concern is that a health-related restriction in work participation may not be solely or even primarily related to the health condition itself or its severity. In other words, although the presence of a health condition is a prerequisite, "work disability" may be caused by factors external to the health condition's impact on the structure and functioning of a person's body or the person's accomplishment of a range of activities.

DIRECTIONALITY AND THE DYNAMIC NATURE OF DISABILITY

The earliest disablement models represented by the ICIDH-1 formulation (WHO, 1980) and Nagi's disablement model (Nagi, 1965) presented the disablement process as more or less a simple linear progression of response to illness or consequence of disease. One consequence of this traditional view is that disabling conditions have been viewed as static entities (Marge, 1988). This traditional, early view of disablement failed to recognize that disablement is more often a dynamic process that can fluctuate in breadth and severity across the life course. It is anything but static or unidirectional.

More recent disablement formulations or elaborations of earlier models have explicitly acknowledged that the disablement process is far more complex (IOM, 1991, 1997; Verbrugge and Jette, 1994; WHO, 1997; Fougeyrollas, 1998). These more recent authors all note that a given disablement process may lead to further downward-spiraling consequences. These feedback consequences, which may involve pathology, impairments, and further limitations in function or disability, have been explicitly incorporated into the graphic illustrations of more recent disablement formulations. The 1991 IOM report uses the term *secondary conditions* to describe any type of secondary consequence of a primary disabling condition. Commonly reported secondary conditions include pressure sores, contractures, depression, and urinary tract infections (Marge, 1988); but it should be understood that they can be either a pathology, an impairment, a functional limitation, or an additional disability.

Longitudinal analytic techniques now exist to incorporate secondary conditions into research models and are beginning to be used in disablement epidemiological investigations (Lawrence and Jette, 1996).

HOW DISABLEMENT CONCEPTS DIFFER FROM QUALITY OF LIFE AND SIMILAR CONCEPTS

To compare disablement concepts with the phenomenon of quality of life, one must first consider how quality of life has been defined in the literature. Birren and Dieckermann have provided a useful starting point:

> The concept of quality of life is complex, and it embraces many characteristics of the social and physical environments as well as the health and internal states of individuals. There are two approaches to the measurement of quality of life: One is based upon the subjective or internal self perceptions of the quality of life; the other approach is objective and based upon external judgments of the quality of life. (Birren and Dieckermann, 1991, p. 350)

If we apply Birren and Dieckermann's perspective to work roles and work disability, objective dimensions of quality of life might include whether a person has had to change jobs because of a health problem, whereas the subjective dimension might include the individual's satisfaction with his or her job. Consistent with this objective and subjective view of quality of life, Lawton (1983) has suggested that measures of quality of life should include a multidimensional evaluation of both intrapersonal and social-normative criteria including:

1. psychological well-being,
2. perceived quality of life,
3. behavioral competence in multiple areas (i.e., health, functional health, cognition, time use, and social behavior), and
4. the objective environment itself.

Indicators of quality of life are extremely broad and have included standard of living, economic status, life satisfaction, quality of housing and the neighborhood in which one lives, self-esteem, and job satisfaction. Such a broad concept subsumes many dimensions of personal well-being not directly related to health.

In response to concerns about the breadth of overall quality of life, some health researchers have adopted a narrower concept called "health-related quality of life." Health-related quality of life has been defined in line with WHO's definition of health as a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity (WHO, 1947). Major dimensions in the health-related quality-of-life measures include signs and symptoms of disease, performance of basic physical activities of daily life, performance of social roles, emotional state, intellectual functioning, general satisfaction, and perceived well-being.

Some models of disablement such as the IOM formulation (IOM, 1991, 1997) and Patrick's (1997) conceptual work clearly define quality of life as distinct from the disabling process. As IOM describes it:

> Quality of life affects and is affected by the outcomes of each stage of the disabling process. Within the disabling process, each stage interacts with an individual's quality of life; it is not an endpoint of the model but rather an integral part. (IOM, 1991, p. 8)

This view of quality of life strikes the authors as inconsistent with the definitions of quality of life described previously and may create problems in designing appropriate survey measures. The concepts of quality of life and health-related quality of life, in particular, appear to overlap and include within their boundaries many (yet certainly not all) of the disablement concepts reviewed in this chapter. Like the disablement concept, quality of life includes dimensions at the personal activity and social role levels. Like the disablement concepts, quality of life does direct some attention to the concepts of disease, through an assessment of signs and symptoms. Most quality-of-life measures focus little attention on organ and body system functioning and focus more on the consequences of impairments at the personal activity or social role level. At the level of social roles, quality-of-life dimensions are broader than the disablement concepts that incorporate overall life satisfaction, energy, vitality, and emotional well-being (Levine and Croog, 1984).

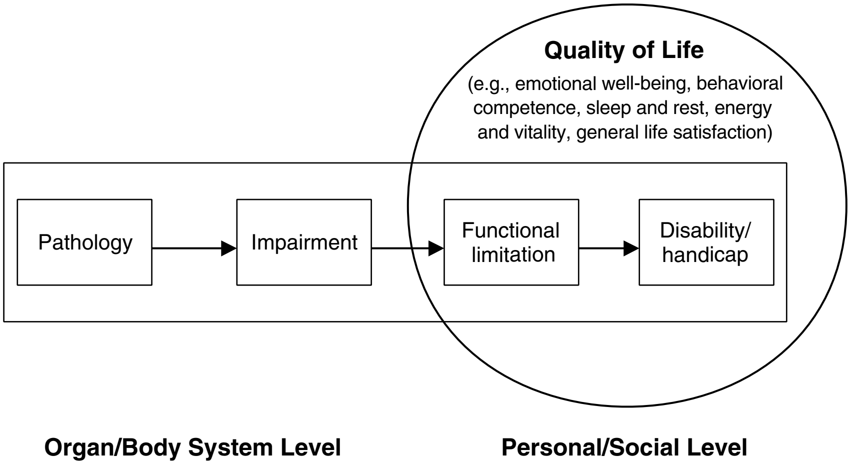


FIGURE 2-4. Relationship of disablement process to quality of life.

Thus, the authors have difficulty viewing the concept of quality of life as entirely distinct from several dimensions in the disablement concepts. For some elements of quality of life, disablement is clearly a precursor, but other elements fall outside the disablement formulation. There appears to be considerable overlap between elements of the two formulations, and a conceptualization that acknowledges this overlap may be a more useful formulation (Figure 2-4).

CONCEPTUAL ISSUES RELATED TO THE MEASUREMENT OF WORK DISABILITY

The underlying structure of models of disablement, as currently conceived, maps a pathway between the health condition and the ensuing "work disability" or other restrictions to social participation. Close inspection of the definitions given above suggests that a number of steps can be identified in the pathway between the health condition and the social consequences described as work disability. At a micro level there are the pathological changes in the body and impairment in the structure and functioning of organs and body systems. There may be an impact on the activity of the person, ranging from simple movements, to basic activities of daily living, to instrumental activities of daily living, and so on. These can then contribute to the performance of more complex social roles, and ultimately, the person's participation in all aspects of society can be adversely affected. Work is one such social role.

Both the Nagi and the ICIDH models cover the spectrum of the consequences of health conditions. As indicated earlier, as well as terminology, a major difference is where these models place the boundaries between the different concepts (see Figure 2-3). In the Nagi model the performance of all activities, except for basic actions or functions of the body, are subsumed into the overall category of disability (Nagi, 1976). In the ICIDH model the concept of activity includes these basic actions as well as ADLs, IADLs, and some other role activities (with the emphasis very much on activity) (WHO, 1980, 1997; Badley, 1993). Participation is reserved to highlight the way in which the performance of activities may be constrained by more than the immediate context of the activity. The juxtaposition of the two models in this way illuminates some nuances in the ways in which the impact of health conditions can been conceptualized as having an impact on the overall functioning of the individual. As indicated earlier, work disability is a function of whether the person can perform specific work-related tasks and of external factors. From the point of view of the measurement of work disability, it may be useful to distinguish between the degree of difficulty that a person may have in carrying out an activity and these other factors (such as barriers in the environment, attitudes of employers or coworkers, and other restrictions) that might prevent the performance of those activities in daily life. In this way, the levels of impact described within the conceptual models are of importance as they allow us to locate where many of the current types of assessment of work disability might fit in.

In the authors' view, in general, no explicit conceptual framework appears to be used in the ascertainment of work disability. A number of implicit conceptual approaches appear to have been used to assess and identify people with possible work disabilities. Each approach can be compared to the different levels of a model of disablement as discussed in the previous sections. We will review these in turn. However, before we do this we need to deal with some more general issues.

Discrete or Continuous Phenomena

Disability is commonly presented as an all-or-nothing phenomenon; either a person has a disability or a person does not. In reality, disability (in particular, roles or activities) is usually encountered in terms of degree of difficulty, limitation, or dependence, ranging from slight to severe. The question then becomes: where on the disability spectrum is that threshold that determines if a person is disabled? This needs to take into account any assistive devices or accommodations that the person may have. In the current context, work participation is often determined as being an endpoint, in that people either have a work disability or they do not. In reality, the situation is likely to be more complex. For example, many people with functional and activity limitations may continue to work, but their labor force participation may be compromised in some way by the condition. To the extent that it is, these people might be said to have some degree of work disability. In measuring work disability, a clear definition of the threshold used needs to be made. Alternatively, a continuous measurement needs to be undertaken.

Duration or Chronicity

There is a pervasive assumption that work disability is a long-term state. Stereotypes about disability are dominated by the archetype of a person who uses a wheelchair. Embedded in this is the notion of some disabling event, a period of adjustment and rehabilitation, and then the resumption of as full a life as possible with the assistance of any necessary assistive devices or accommodations. With many impairments, the reality of disability is somewhat different. The majority of individuals in the working-age population with long-term activity restrictions report that this restriction is due to musculoskeletal, circulatory, or respiratory disorders (LaPlante, 1996). These conditions may also be associated with varying degrees of "illness," so that it is not just an issue of physical performance. There are also considerations of pain, fatigue, and other symptoms. Many of these conditions are episodic in nature and may have trajectories of either deterioration or recovery (the latter being less common). This means that, apart from any environmental barriers or facilitators, the day-to-day or month-to-month experience of disability may be variable. This may need to be taken into account in any measurement scheme.

Examples of Conceptual Approaches to Measuring Work Disability

All disablement concepts appear to have been addressed, at least to some extent, as part of efforts to assess work disability.

Health Condition or Pathology

Under some circumstances knowledge of the health condition or pathology contributes to an assessment of work disability. Medical listings of diagnosis and medical severity have been used by some agencies to identify individuals who would be unlikely to benefit from vocational rehabilitation (Reno, 1999). Such listings have also been applied in the context of Social Security disability determinations. Concern has been expressed because the use of such listings might, on the one hand, deny benefits to individuals who need them and might, on the other, award benefits to those who could still work. Such concerns are a reflection of the many steps in the disablement model between the health condition and work disability.

Impairment

Assessments of work disability, or at least of entitlement to compensation for work injury, are often made at the level of impairment. The classic assessment is perhaps what has been pejoratively referred to as the "meat chart" assessment of the consequences of traumatic injury. An example of this would be the American Medical Association *Guides to the Evaluation of Permanent Impairment* (American Medical Association, 1993), which is a standardized system for translating the extent of an injury of a body part into a percentage of disability of the whole person. This type of system has been used for the assessment of compensation payments, including for workers' compensation.

A number of assessments focus on the functioning of the body, for example, assessments of strength, muscular endurance, body coordination and flexibility, and cognitive and sensory functions (Fleishman, 1972, 1999). The problem with this impairment-focused approach is that even though these assessments may be made in the context of relating functional requirements with the requirements of certain jobs, one needs empirical evidence to support the contention that the degree of impairment is going to have a direct relationship to work disability. Without such evidence, the validity of such an approach is highly suspect.

Functional Limitation

Much of the discussion of assessment of work effectively has been at the level of functional disability. An example would be the assessment of abilities proposed for the Occupational Information Network (O*NET) system (see, for example, IOM, 1999, p. 24). Here abilities such as oral comprehension, memorization, finger dexterity, and depth perception (IOM, 1999, p. 35) will be assessed and compared with the average requirements of particular jobs. Although the intent was that this should be done for all jobs, it has been suggested that this approach could, in principle, provide the basis of an assessment of work disability (IOM, 1999, p. 86). Measures of work-related functional capacity (Lechner et al., 1997) have also been devised to test or ask about activities such as lifting, standing, walking, sitting, and carrying. Although closer in concept to work disability than assessments of pathology and impairment, assessments of capacity to perform work functions are one level removed from the concept of work disability. They look at the specific abilities of the individual for work in standardized ways not directly related to actual work settings. More importantly, they take no account of any environmental barriers or facilitators that might moderate the way in which a person's functional limitations are expressed as disabilities.

Activity Limitation (at Work*)*

A direct way of answering at least part of the question about work disability is to carry out a workplace assessment. This gives information about whether the person can actually carry out the requirements for the major components of the job. This is the kind of assessment that is frequently carried out in the context of vocational rehabilitation. However, factors other than the actual performance of the work tasks likely contribute to work disability as indicated earlier. This is further discussed below.

Work Disability

Having separated out the activity limitation in work tasks, one can look at work disability from the perspective of carrying out a work role. Direct assessment of work disability involves several elements related to the role of work. These include:

- activities within the workplace;
- a range of other aspects including necessary mobility in getting to work;
- interaction with colleagues, superiors, and subordinates; and
- the amount and type of work that can be carried out.

Work disability is most frequently assessed by direct inquiry of the individual. The measurement problems with this kind of approach are reviewed in Chapter 3. In population surveys the two main types of approaches to measurement of work disability are either (1) direct questioning about any limitations in work attributable to a health condition or (2) the independent ascertainment of disability and work status, with some inference of a connection between disability and work status. We will review each of these in turn.

DIRECT ASSESSMENT OF WORK DISABILITY

The most direct approach to ascertainment of work disability is to inquire about working status together with questions as to whether nonparticipation is health related. There are various permutations on these types of questions. Some typical formulations are shown in Figure 2-5.

As Figure 2-5 illustrates, typical survey questions about work disability are asked with a general reference to work, and it is left to the respondent to determine the specific relevant elements to be considered within the work role. If the respondent is currently working or has recently worked, this is presumably taken to mean the most recent working experience. If the person is not working, then this is more problematic. The answer to the question will depend on what type of employment, if any, the individual has in mind when answering the question. If the purpose of the question is to determine incapacity for work, then the nature of the job and any accommodations that have been or might be made is crucial. Few survey research approaches break down work role into its major component parts to determine the perceived degree of disability within each.

Typical survey research questions also leave it to the respondent to attribute not working to an underlying health condition. It may be that the individual answers that he or she cannot work, yet the person may not be given the opportunity to specify the circumstances under which this might be possible. A survey of

1990 Decennial Census: Work Disability

Does this person have a physical, mental or other health condition that lasted for 6 months or more which

(a) limits the kind or amount of work this person can do at a job?
(b) prevents this person from working at a job?

U.S. Census for Year 2000

General question about activity limitations (difficulty in carrying out specific activities) because of a physical, mental, or emotional condition lasting 6 months or more.

March Current Population Surveys, 1981–1988

The CPS has a set of criteria. If one or more of the final four conditions was met, the person was considered to have a severe work disability:

1. Does anyone in the household have a health problem or disability which prevents them from working or which limits the kind or amount of work they can do?

Is there anyone in this household:

2. Who ever retired or left a job for health reasons?
3. Did not work in the survey week because of a long-term physical or mental illness or disability which prevents the performance of any kind of work?
4. Did not work at all in the previous year because ill or disabled?
5. Under 65 years of age and covered by Medicare?
6. Under 65 years of age and a recipient of Supplemental Security Income (SSI)?

Survey of Income and Program Participation (Third Wave Supplement), 1984

Does ______'s health or condition limit the kind or amount of work _____ can do?

National Health Interview Surveys

Phase 1

a. Does ____'s health now keep him from working?
b. Is he limited in the kind of work he could do because of his health?
c. Is he limited in the amount of work he could do because of his health?
d. Is he limited in the kind or amount of other activities because of his health?

Phase 2

a. Does ____ now have a job?
b. In terms of health is ____ now able to work?
c. Is he limited in the kind of work he could do because of his health?
d. Is he limited in the amount of work he could do because of his health?
e. Is he limited in the kind or amount of other activities because of his health?

FIGURE 2-5. Examples of Survey Questions.

working-age people with disabilities in the United States showed that over two-thirds wanted to work (Stoddard et al., 1998, p. 24). In the 1991 Canadian Health and Activity Limitation Survey, 64 percent of respondents with disabilities reported that they were not in the labor force, and over two-thirds of these said that they were completely prevented from working (Statistics Canada, 1993). However, all respondents were given the opportunity to answer questions about needed accommodations in the workplace. Despite reporting that they were prevented from working, 69 percent of these individuals reported needing a variety of workplace accommodations (e.g., job redesign or modified hours) and 76 percent reported needing adaptations (e.g., handrails, elevators, or modified workstations). Whether or not the provision of such accommodations or adaptations would facilitate workplace reintegration is unknown. However, the findings illustrate how changing the framing of a question sheds a different light on what it means to be unable to work. Individuals who were not in the labor force were also asked about barriers to employment. The most frequently mentioned barriers were losing some or all of their current income, feelings that their training was not adequate, no available jobs, and loss of additional supports (e.g., health benefits). Other less frequently mentioned reasons were family responsibilities, having been the victim of discrimination, and not having accessible transportation (Statistics Canada, 1993). In other words, most of the reasons were related not to the nature of the work, but to some of the other circumstances surrounding the issue of work disability.

Furthermore, some individuals will have a choice as to how they describe their working status. For example, a person with a disability who also has small children could variously describe him- or herself as a homemaker or not being in the labor force because of the disability. Or people leaving the workforce in their 50s may describe themselves as having taken an early retirement. Without extra information it may be difficult to tell whether this is indeed the situation or whether the alternative description was seen as a less stigmatizing alternative to describing themselves as having a work disability.

In a survey research situation, if a person is working, the typical approach is to assume that no work disability is present. Nevertheless, the person may be limited in the amount or kind of work done or both. The person may be spending less time working, working at a less skilled job, or earning less money. This information can be obtained from survey questions (see Figure 2-5), but often with relatively little qualifications as to what this means. What is less often addressed is that for many people with disabilities working may mean forgoing opportunities to participate in other areas of life. Just going to work may, for example, exhaust all reserves of energy or require time-consuming preparations. There is a fine line between what might be considered a satisfactory accommodation and an unsatisfactory compromise or necessity, and different people will value this trade-off differently.

CONCLUSION

The problem with all the approaches to work disability, as indicated by our discussion of conceptual frameworks, is that there is unlikely to be a one-to-one relationship between the presence of health conditions, impairments, functional limitations, or activity restrictions and disability in employment. There is a pervasive assumption that work disability relates to the person's degree of functional limitation and activity restriction. This is reflected in the concern about assessment, where the focus is very much on the individual's performance. Lip service is paid to the environment, particularly in the context of work disability and vocational rehabilitation. As we have tried to show, a full understanding of work disability needs to take into account the individual's circumstances and the social and physical environments of the workplace.

The research challenge is to apply the insights provided by the models of disablement to come to a common understanding of work disability and to understand the relationships and the dynamics of the pathway between health conditions and work disability. Researchers need to find ways to incorporate an understanding of the external factors that influence the development of work disability into its measurements.

3

Methodological Issues in the Measurement of Work Disability

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The collection of information about persons with disabilities presents a particularly complex measurement issue because of the variety of conceptual paradigms that exist, the complexity of the various paradigms, and the numerous means by which alternative paradigms have been operationalized in different survey instruments (see Chapter 2 by Jette and Badley for a review). For example, disability is often defined in terms of environmental accommodation of an impairment; hence, two individuals with the same impairment may not be similarly disabled or share the same perception of their impairment. For an individual with mobility limitations who lives in an assisted-living environment that accommodates the impairment, the environmental adaptations may result in little or no disability. The same individual living on the second floor of an apartment building with no elevator may have a very different perception of the impairment and may see him- or herself as disabled because of the environmental barriers that exist within his or her immediate environment.

The Social Security Administration (SSA) is currently reengineering its disability claims process for providing benefits to blind and disabled persons under the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs. As part of the effort to redesign the claims process, SSA has initiated a research effort designed to address the growth in disability programs, including the design and conduct of the Disability Evaluation Study (DES). The DES will provide SSA with comprehensive information concerning the number and characteristics of persons with impairments severe enough to meet SSA's statutory definition of disability, as well as the number and characteristics of people who are not currently eligible but who could be eligible as a result of changes in the disability decision process. For those years in which the DES is not conducted, SSA will need to monitor the potential pool of applicants. One means by which SSA can monitor the size and characteristics of potential beneficiaries is through other ongoing federal data collection efforts. For both the conduct of the DES and monitoring of the pool of potential beneficiaries through the use of various data collection efforts, it is critical to understand the measurement error properties associated with the identification of persons with disabilities as a function of the essential survey conditions under which the data have been and will be collected. The extent to which alternative instruments designed to measure persons with disabilities map to various eligibility criteria under consideration by SSA is also important.

BACKGROUND

The collection of disability data is an evolving field. Although a large and growing number of scales attempt to measure functional status and work disability, little is known about the measurement error properties of various questions and composite scales. The empirical literature provides clear evidence of variation in the estimates of the number of persons with disabilities in the United States, depending upon the conceptual paradigm of interest, the analytic objectives of the particular measurement process, and the essential survey conditions under which the information is collected (e.g., Haber, 1990; McNeil, 1993; Sampson, 1997). This literature suggests that estimates of the disabled population not only are related to the conceptual framework underlying the measurement construct but are also a function of the essential survey conditions under which the measurement occurred, including the specific questions used to measure disability, the context of the questions, the source of the information (self- versus proxy response), variations in the mode and method of data collection, and the sponsor of the data collection effort. Furthermore, terms such as *impairment*, *disability*, *functional limitation*, and *participation* are often inconsistently used, resulting in different and conflicting estimates of prevalence. Attempts to measure not only the prevalence but also the severity of an impairment or disability further complicate the measurement process.

Recent shifts in the conceptual paradigm of disability, in which disability is viewed as a dynamic process rather than a static measure and as an interaction between an individual with an impairment and the environment rather than as a characteristic only of the individual, imply that those responsible for the development of disability measures must separate the measurement of the impact of environmental factors in the enablement-disablement process from the measurement of ability. Viewing disability as a dynamic state resulting from an interaction between a person's impairment and a particular environmental context further complicates the assessment of the quality of various survey measures of disability, specifically, the reliability of a measure. As a dynamic characteristic, one would anticipate changes in the reports of disability as a function of changes in the individual as well as changes in the social and environmental contexts. The challenge for the measurement process is to disentangle true change from unreliability.

This workshop comes at a time when the federal government is undertaking several initiatives with respect to the measurement of disability in federal data collection efforts. The Americans with Disability Act of 1990 (ADA) defines disability as (1) a physical or mental impairment that substantially limits one or more of the major life activities of the individual, (2) a record of a substantially limiting impairment, or (3) being regarded as having a substantially limiting impairment. Although the measurement of disability within household surveys is not bound by the ADA definition, the passage of the ADA provides a socio-environmental framework for how society comprehends and uses terms such as *disability* and *impairment* (e.g., the popular press and court rulings on ADA-related litigation). These definitions will evolve as a function of litigation related to ADA legislation and presentation of that litigation in the press. Hence, society is entering a period in which potential dynamic shifts in the comprehension and interpretation of the language associated with the measurement of persons with disabilities can be anticipated.

The paper presented in this chapter is intended to serve as a means of facilitating discussion among individuals from diverse theoretical and empirical disciplines concerning the methodological issues related to the measurement of persons with disabilities. As a first step to achieving this goal, a common language and framework needs to be established for the enumeration and assessment of the various sources of error that affect the survey measurement process. The chapter draws from several empirical investigations to provide evidence as to the extent of knowledge concerning the error properties associated with various approaches to the measurement of functional limitations and work disability.

SOURCES OF ERROR IN THE SURVEY PROCESS: THE SURVEY RESEARCH PERSPECTIVE

For the purpose of defining a framework that can be used to examine error associated with the measurement of persons with disabilities, I draw upon the conceptual structure and language used by Groves (1989), based on earlier work of Kish (1965) and used by Andersen et al. (1979). Suchman and Jordan (1990) have described errors in surveys as the discrepancy between the concept of interest to the researcher and the quantity actually measured in the survey. Bias, according to Kish (1965, p. 509), refers to systematic errors in a statistic that affect any sample taken under a specified survey design with the same constant error or, as stated by Groves (1989), is the type of error that affects the statistic in all implementations of a survey. Variable errors are those errors that are *specific* to a particular implementation of a design, that is, specific to the particular trial.

The concept of variable error requires the possibility of repeating the survey, with changes in the units of replication, that is, the particular set of respondents, interviewers, supervisors, coding, editing, and data entry staff.

Errors of Nonobservation

Within the framework of survey methodology, both variable error and bias are further characterized in terms of errors of nonobservation and errors of observation. As one would expect from the term, errors of nonobservation reflect failure to obtain observations for some segment of the population or for all elements to be measured. Errors of nonobservation are most often classified as arising from three sources: sampling, coverage, and nonresponse.

Sampling Error

Sampling error represents one type of nonobservation variable error; it arises from the fact that measurements (observations) are taken for only a subset of the population. Sampling variance refers to changes in the value of some statistic over possible replications of a survey in which the sample design is fixed but different individuals are selected for the sample. Estimates based on a particular sample will not be identical to estimates based on a different subset of the population (selected in the same manner) or to estimates based on the full population.

Coverage Error

Coverage error defines the failure to include all eligible population members on the list or frame used to identify the population of interest. Those members not identified on the frame have a zero probability of selection and are never measured. For example, in the United States, approximately 5 percent of the population live in households without telephone service; any survey that is conducted by telephone and that attempts to describe the entire household-based population of the United States therefore suffers from coverage error. To the extent that those without telephones differ from those with telephones for the construct of interest, the resulting estimates will be biased.

Nonresponse Error

Nonresponse error can arise from failure to obtain any information from the persons selected to be measured (unit nonresponse) or from failure to obtain complete information from all respondents to a particular question (item nonresponse). The extent to which nonresponse affects survey statistics is a function of both the rate of nonresponse and the difference between respondents and nonrespondents, as illustrated in the following formula:

$$y_r = y_n + \left(\frac{nr}{n}\right)(y_r - y_{nr}),$$

where:

y_r = the statistic estimated from the r respondents,
y_n = the statistic estimated from all n sample cases,
y_{nr} = the statistic estimated from the nr nonrespondents, and
nr = the proportion of nonrespondents.

Knowing the response rate is not sufficient to determine the level of nonresponse bias; studies with both high and low rates of nonresponse can suffer from nonresponse bias.

As noted by Groves and Couper (1998), it is useful to further distinguish among the types of unit nonresponse, each of which may be related to the failure to measure different types of persons. For most household data collection efforts involving interviewers, the final outcome of an interview attempt is often classified into one of the following four categories: completed or partial interview, refusal, noncontact, and other noninterview.[1] Survey design features can affect the distribution of cases across the various categories. Noncontact rates are affected by the length of the field period (in which short field periods result in higher noncontact rates than longer field periods). Surveys that place greater demands on the respondent may suffer from higher refusal rates than less burdensome instruments. The choice of respondent rule affects the rate of nonresponse; designs that permit any knowledgeable adult within the household to serve as the respondent provide an interviewer with some flexibility, should one adult within the household refuse or be unable to participate. Field efforts that fail to accommodate non-English-speaking respondents or that focus their attention on frail subpopulations tend to experience higher rates of other noninterviews.

Errors of Observation

Observational errors can arise from any of the elements directly engaged in the measurement process, including the questionnaire, the respondent, and the interviewer, as well as the characteristics that define the measurement process (e.g., the mode and method of data collection). This section briefly reviews the theoretical framework and empirical findings related to the various sources of measurement error in surveys.

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[1] *Other noninterview* is used to classify cases in which contact was made with the members of the household in which the sample person resides, but for reasons such as physical or mental health, language difficulties, or other reasons not related to reluctance to participate, the interviewer was unable to conduct the interview.

Questionnaire as Source of Measurement Error

Tourangeau (1984) and others (see Sudman et al. [1996] for a review) have categorized the survey question-and-answer process as a four-step process involving comprehension of the question, retrieval of information from memory, assessment of the correspondence between the retrieved information and the requested information, and communication of the response. In addition, the encoding of information, a process outside the control of the survey interview, determines a priori whether the information of interest is available for the respondent to retrieve.

Comprehension of the question involves the assignment of meaning to the question by the respondent. Ideally, the question will convey the meaning of interest to the researcher. However, several linguistic, structural, and environmental factors affect the interpretation of the question by the respondent. These factors include the specific wording of the question, the structure of the question, the order in which the questions are presented, the overall topic of the questionnaire, whether the question is read by the respondent (self-administration) or is presented to the respondent by an interviewer, and the mode of communication used by the interviewer (that is, telephone versus face-to-face presentation). The wording of a question is often seen as one of the major problems in survey research: although one can standardize the language read by the respondent or the interviewer, standardization of the language does not imply standardization of the meaning. For example, "Do you own a car?" appears to be a simple question from the perspective of semantics and structure. However, several of the words in the question are subject to variation in interpretation, including "you" (just the respondent or the respondent and his or her family), "own" (completely paid for, purchased as opposed to rented), and even the word "car" (does this include vans and trucks?). The goal for the questionnaire designer is to develop questions that exhaust the range of possible interpretations, making sure that the particular concept of interest is the concept that the respondent has in mind when responding to the item.

One source of variation in a respondent's comprehension of survey questions is due to differences in the perceived intent or meaning of the question. Perceived intent can be shaped by the sponsorship of the survey, the overall topic of the questionnaire, or the environment more immediate to the question of interest, such as the context of the previous question or set of questions or the specific response options associated with the question.

Respondent as Source of Measurement Error

Once the respondent comprehends the question, he or she must retrieve the relevant information from memory, make a judgment as to whether the retrieved information matches the requested information, and communicate a response.

Much of the measurement error literature has focused on the retrieval stage of the question-answering process, classifying the lack of reporting of an event as retrieval failure on the part of the respondent and comparing the characteristics of events that are reported with those that are not reported. Several factors have been found to be related to the quality of reporting, including the length of the reference period of interest and the salience of the information. For example, the literature suggests that the greater the length of the recall period, the greater the expected bias in the reporting of episodic information (e.g., Cannell et al., 1965; Sudman and Bradburn, 1973). Salience is hypothesized to affect the strength of the memory trace and, subsequently, the effort involved in retrieving the information from long-term memory. The weaker the trace, the greater the effort needed to locate and retrieve the information.

As part of the communication of the response, the respondent must determine whether he or she wishes to reveal the information as part of the survey process. Survey instruments often ask questions about socially and personally sensitive topics. It is widely believed and well documented that such questions elicit patterns of underreporting (for socially undesirable behavior and attitudes), as well as overreporting (for socially desirable behaviors and attitudes). The determination of social desirability is a dynamic process and is a function of the topic of the question, the immediate social context, and the broader social environment at the time the question is asked. Even if the respondent is able to retrieve accurate information, he or she may choose to edit this information at the response formation stage as a means of reducing the costs associated with revealing the information.

The use of proxy reporters, that is, asking individuals within sampled households to provide information about other members of the household, is a design decision that is often framed as a trade-off among costs, sampling errors, and nonsampling errors. The use of proxy informants to collect information about all members of a household can increase the sample size (and hence reduce the sampling error) at a lower marginal data collection cost than increasing the number of households. The use of proxy respondents also facilitates the provision of information for those who would otherwise be lost to nonresponse because of an unwillingness or inability to participate in the survey interview. However, the cost associated with the use of proxy reporting may be an increase in the rate of errors of observation associated with poorer-quality reporting for others compared with the quality that would have been obtained under a rule of all self-response.

Most of the evaluations of the quality of proxy responses compared with the quality of self reports have focused on the reporting of autobiographical information (e.g., Mathiowetz and Groves, 1985; Moore, 1988) with some recent investigations examining the convergence of self and proxy reports of attitudes (Schwarz and Wellens, 1997). The literature is, however, for the most part silent with respect to the quality of proxy reports for personal characteristics, the exception being a small body of literature that addresses self-reporting versus proxy reporting effects in the reporting of race/ethnicity (Hahn et al., 1996) and the reporting of activities of daily living (e.g., Mathiowetz and Lair, 1994; Rodgers and Miller, 1997). The findings suggest that proxy reports of functional limitations tend to be higher than self-reports; the research is inconclusive as to whether the discrepancy is a function of overreporting on the part of proxy informants, underreporting on the part of self-respondents, or both.

Interviewers as Sources of Measurement Error

For interviewer-administered questionnaires, interviewers may affect the measurement processes in one of several ways, including:

- failure to read the question as written;
- variation in interviewer's ability to perform the other tasks associated with interviewing, for example, probing insufficient responses, selecting appropriate respondents, and recording the information provided by the respondent; and
- demographic and socioeconomic characteristics as well as voice characteristics that influence the behavior of the respondent and the responses provided by the respondent.

The first two factors contribute to measurement error from a cognitive or psycholinguistic perspective in that different respondents are exposed to different stimuli; thus, variation in responses is, in part, a function of the variation in stimuli. All three factors suggest that the interviewer effect contributes to an increase in variable error across interviewers. If all interviewers erred in the same direction (or their characteristics resulted in errors of the same direction and magnitude), interviewer bias would result. For the most part, the literature indicates that among well-trained interview staff, interviewer error contributes to the overall variance of estimates as opposed to resulting in biased estimates (Lyberg and Kasprzyk, 1991).

Other Essential Survey Conditions as Sources of Measurement Error

Any data collection effort involves decisions concerning the features that define the overall design of the survey, referred to here as the "essential survey conditions." In addition to the sample design and the wording of individual questions and response options, these decisions include the following:

- whether to use interviewers or to collect information via some form of self-administered questionnaire;
- the means for selecting and training interviewers (if applicable);

- the mode of data collection for interviewer administration (telephone versus face to face);
- the method of data collection (paper and pencil, computer assisted);
- whether to contact respondents for a single interview (cross-sectional design) or follow respondents over time (longitudinal or panel design);
- for longitudinal designs, the frequency and periodicity of measurement;
- the identification of the organization for whom the data are collected; and
- the identification of the data collection organization.

No single design feature is clearly superior with respect to overall data quality. For example, as noted above, interviewer variance is one source of variability that can be eliminated through the use of a self-administered questionnaire. However, the use of an interviewer may aid in the measurement process by providing the respondent with clarifying information or by probing insufficient responses. The use of a panel survey design, with repeated measurements with the same individuals, facilitates more efficient estimation of change over time (compared with the use of multiple cross-sectional samples); however, panel designs may be subject to higher rates of nonresponse (as a result of nonresponse at every round of data collection) or panel conditioning bias, an effect in which respondents alter their reporting behavior as a result of exposure to a set of questions during an earlier interview.

The following scenario is an illustration of statistical measures of error used by survey methodologists. Assume that the measure of interest is personal earnings among all adults in the United States. A "true value" exists if the construct of interest is carefully defined. The data will be collected as part of a household-based health survey being conducted by telephone. The decision to use the telephone for data collection implies that approximately 5 percent of the adults will not be eligible for selection. To the extent that the personal earnings of adults without telephones differ significantly from those with telephones, population-based estimates for the entire adult population will suffer from coverage bias. Similarly, not all eligible sample persons will participate in the interview because of refusal to cooperate, an inability on the part of the survey organization to contact the respondent, or other reasons, such as language barriers or poor health that limits participation. Once again, to the extent that the earnings of those who participate differ significantly from those who do not participate, population-based estimates of earnings will suffer from nonresponse bias.

If all respondents misreport their earnings, underreporting their earnings by 10 percent, and they consistently do so in response to repeated measures, the measure will be reliable but not valid and population estimates based on the question (e.g., population means) would be biased. However, multivariate model-based estimates that examine the relationship between earnings and human capital investment would not be biased, since all respondents erred in the same direction and relative magnitude. Differential response error, for example, the overreporting of earnings by low-income individuals and the underreporting of earnings by high-income individuals, may produce unbiased population estimates (e.g., mean earnings per person) but biased model-based estimates related to individual behavior.

MEASUREMENT ERROR: THE PSYCHOMETRIC PERSPECTIVE

The language and concepts of measurement error in psychometrics are different from the language and concepts used within the fields of survey methodology and statistics. The focus for psychometrics is on variable errors; from the perspective of classical true score theory, all questions produce unbiased estimates, but not necessarily valid estimates, of the construct of interest. The confusion arises in that both statistics and psychometrics use the terms *validity* and *reliability* to sometimes refer to very similar concepts and to sometimes refer to concepts that are quite different. Within psychometrics, the terms *validity* and *reliability* are used to describe two types of variable error. *Validity* refers to "the correlation between the true score and the respondent's answer over trials" (Groves, 1991, p. 8). The validity of a measure can be assessed only for the population, whereas the validity of both population estimates and individuals' responses presented in the survey methodological literature can be assessed.

Reliability refers to the ratio of the true score variance to the observed variance, where *variance* refers to variability over persons in the population and over trials within a person (Bohrnstedt, 1983). Once again, the measurement of reliability from this perspective does not facilitate measurement for a person but produces a measure of reliability specific to the particular set of individuals for whom the measurement was taken.

The psychometric literature identifies several means by which validity can be assessed; the choice of measures is, in part, a function of the purpose of the measurement. These measures of validity include content, construct, concurrent, predictive, and criterion. If one considers that the questions included in a particular instrument represent a sampling of all questions that could have been included to measure the construct of interest, content validity refers to the comprehensiveness as well as the relevance of those questions. Content validity refers to the extent to which the question or questions reflect the domain or domains reflected in the conceptual definition. Face validity refers to the extent to which each item appears to measure that which it purports to measure. Cognitive interviewing techniques that focus on the comprehension of items by respondents is, to some extent, a test of face validity.

Criterion-related validity evaluates the extent to which the measure of interest correlates highly with a "gold standard." The gold standard could consist of a different self-reported measure, a behavioral measure, or an observation or evaluation outside the measurement process (e.g., clinical evaluation). Criterion-related validity is further categorized as concurrent validity or predictive validity. Concurrent validity refers to the correlation between the item of interest and some other item, event, or behavior measured at the same point in time, whereas predictive validity refers to the correlation between an indicator measured at time t and some other measure, event, or behavior measured at time $t + 1$.

When no gold standard exists, validity is evaluated in terms of the correlation between the measure of interest and other measures, according to theory-based hypotheses. As noted by McDowell and Newall (1996), "construct validation begins with a conceptual definition of the topic or construct to be measured, indicating the internal structure of its components and the theoretical relationship of scale scores to external criteria" (p. 33).

Measures of reliability include internal consistency (often referred to as coefficient Alpha or Cronbach's Alpha), test-retest, and interrater reliability. Internal consistency measures the extent to which all items in a scale measure the same underlying concept; it is only applicable for multi-item Likert scales. The reliability coefficient is a function of both the extent to which the items are homogeneous and the number of items in the scale; the coefficient increases with an increase in either the homogeneity of the items or an increase in the number of items. Test-retest reliability involves the measurement of the same person under the same measurement conditions at two points in time and can be used for single-item measures, as well as multi-item scales.[2] Interrater reliability refers to the consistency with which different raters or observers rating the same person agree with one another.

Returning to the example of the measurement of earnings to illustrate the measurement error properties of the construct in terms of psychometrics, assume that the question or questions designed to measure earnings are both comprehensive and relevant. Therefore, the questions would be assessed as having content validity (face validity). If, as noted above, all respondents underreported their earnings by 10 percent, the construct would have a lower score with respect to criterion validity, but since all respondents erred in the same direction and the same magnitude, the indicator would have construct validity. If repeated measurement resulted in consistent reports by all respondents, test-retest measures would indicate a high degree of reliability, not dissimilar to the conclusion drawn by statisticians.

POTENTIAL SOURCES OF MEASUREMENT ERROR SPECIFIC TO PERSONS WITH DISABILITIES

Similar to any other measurement of persons via the survey process, the identification of persons with disabilities is subject to the various sources of error

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[2] Within survey research, the conduct of a reinterview under the same essential survey conditions as the original interview is an example of a test-retest assessment of reliability.

discussed above. The measurement of persons with disabilities raises particular challenges, in light of the complexity of the phenomenon of interest and the demands of the measurement process. Some of the various sources that may be of particular importance are highlighted.

Coverage, Access, and Participation

The interactive nature of the survey interview places great demands on the sensory and physical resources of respondents. A face-to-face interview requires that the respondent have the capacity to hear the questions, respond orally, understand individual questions and response categories, and be able to maintain cognitive focus. In addition, the respondent must tolerate the physical demands of the interview, a task that may take up to an hour or two. Impairments or disabilities may limit a person's ability to participate in the survey process or limit access to the individual. The essential survey design features of a data collection effort can facilitate or limit access and participation of persons with disabilities. This is not unique to the measurement of persons with impairments or disabilities. The use of the telephone for data collection restricts the sample to those households with telephones; if the data collection by telephone does not accommodate the use of TTY technology, hearing-impaired individuals will also not be measured. Similarly, the use of self-administered paper and pencil questionnaires limits participation to those who are literate and whose vision permits the reading of the font size used on the questionnaire. The implementation of a self-response rule eliminates from measurement those for whom gatekeepers deny access and those, although they are willing to participate, who are unable to do so because of physical, mental, or emotional impairments or those for whom the barrier to participation is language, either their use of a different spoken language or their use of sign language.

Cognition and the Measurement of Persons with Disabilities

From a cognitive perspective, the measurement of persons with disabilities offers particular challenges. First, one needs to understand how individuals encode information about impairments and disabilities. In addition, effective questionnaire design requires an understanding of how the encoding of the information varies according to perceptual perspective (self-response versus other response, nature of the relationship between the respondent and the person for whom they are reporting). Second, little is known about how ability (capacity) is measured independent of environmental context (participation).

Many of the questions and sets of questions used to measure impairments and disability are plagued by comprehension problems related to both semantic and lexical complexity. For example, questions concerning work disability are subject to comprehension problems with respect to the shared meaning of "work." As noted earlier, the respondent must infer whether limitations in the kind or amount of work include factors related to transportation and access to the workplace. The desire for parsimonious means by which an individual's status can be assessed with respect to impairments or particular functional limitations has led to the creation of "composite" screening questions that nevertheless represent a single question and that may therefore be cost-effective, even though they press against the limits of working memory.[3]

The response task requires the respondent to retrieve information, determine the relevance of that information to the posed question, and formulate a response. Often the respondent is limited in the form of the response to a simple classification (e.g., yes, limited in the kind or amount of work versus not limited) that fails to capture the full spectrum of the enablement-disablement process and the complexity of the phenomenon of interest. The mapping of this complex phenomenon to a limited number of response categories is most likely fraught with error.

The integration of theories of cognitive psychology with survey methodology has given rise to new methods of questionnaire design and evaluation. Many of the current measures of disability used in federal data collection efforts have not been subjected to testing methods common to new questions and questionnaires, for example, cognitive interviewing and behavior coding. Cognitive interviewing encompasses several techniques designed to elicit information about the respondent's comprehension of the question, the strategies by which the respondent attempts to retrieve information from memory, judgments as to whether the retrieved information meets the perceived goals of the question, and the formulation of responses. These techniques include the use of "think-aloud" protocols, follow-up probes, vignettes, and "sort-order" tasks (Forsyth and Lessler, 1991; Willis et al., 1991).

A small body of literature has attempted to address problems in the comprehension of functional limitation questions in community-based survey interviews through the use of cognitive interviewing techniques (Jobe and Mingay, 1990; Keller et al., 1993). The findings from these investigations of functional limitation questions by use of cognitive interviewing techniques suggest that respondents varied in their interpretation of terms, tended to emphasize capacity rather than actual performance, overlooked qualifying statements within the question, failed to remember the use of human assistance, or failed to remember help with specific activities.[4]

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[3] For example: "Because of a physical, mental or emotional problem does anyone in the family have any difficulty with activities such as bathing, dressing, eating, getting in or out of a chair or bed, or walking across a room?"

[4] See also Beatty and Davis (1998) for a cognitive evaluation of questions from Survey of Income and Program Participation and the National Health Interview Survey concerning discrepancies in print reading disability statistics.

Social Cognition, Self-Concept, and Social Desirability

What is meant when an individual is asked to classify him- or herself or someone else with respect to disability? Although reliable measurement may call for the use of clear, unambiguous, and objective definitions, it is questionable whether these goals are achievable with respect to the measurement of disability. Disability is a dynamic concept related to an underlying interface between an individual, societal accommodations and barriers, cultural norms and expectations, and behavioral norms. The use of "fuzzy logic" in which attributes apply only partially to given individuals may be more appropriate than standard survey techniques for the classification of disability (Hahn et al., 1996).

Although theories from cognitive psychology can provide information about the different cognitive processes by which self and proxy reporters engage in the response formulation process, one can turn to theories from social cognition to understand how individuals classify themselves and each other with respect to social categories. Although social cognition draws heavily from the theory and methods of cognitive psychology, as a subfield its focal point is on social objects, specifically, individuals or groups of individuals.

As noted by Brewer,

> In comparison to object categories, social categories have been postulated to be overlapping rather than hierarchically organized . . ., disjunctively rather than conjunctively defined . . . and more susceptible to accessibility effects. (Brewer, 1988, p. 1)

She further states that "social categories are assumed to be 'fuzzy sets' represented in the form of prototypical images rather than verbal trait lists" (Brewer, 1988, p. 10).

Social cognition also provides a theoretical perspective that provides information about divergent perspectives of actors and observers. The actor-observer difference suggests that actors draw on situational information to explain behavior at any given time, whereas observers use stable disposition properties of the actor to understand behavior (Jones and Nisbett, 1971). To the extent that proxy reporters view disabilities as stable as opposed to dynamic characteristics, one would anticipate discrepancies between self-reports and proxy reports.

Two sets of concepts drawn from social psychology are also useful for consideration with respect to the measurement of disability. The first is the concept of self; from a sociological perspective, self-conceptions involve three components: (1) how an individual sees him- or herself, (2) how other people actually see the individual, and (3) how the individual believes others see him or her (Rosenberg, 1990). The National Health Interview Survey-Disability Supplement (NHIS-D) and the National Organization on Disability/Harris Survey of Americans with Disabilities included questions that asked whether the respondent perceived that he or she had a disability and whether others perceived that the respondent had a disability. The second concept of interest involves the notion of social identity and the groups, statuses, and social categories to which the members of society are recognized as belonging. If the social identity category is ambiguous, the self-concept related to the social identity will also be ambiguous.

As noted by Jette and Badley in Chapter 2, the measurement of disability is often presented in surveys as an "all or nothing phenomenon." This approach to the measurement of disability assumes that (1) the respondent recognizes and identifies with the socially defined label and (2) is willing to reveal membership in the group. If disability were an "all-or-nothing" phenomenon, identification with the classification would be less ambiguous; however, as already noted, the enablement-disablement process is a dynamic one, subject to variation as a function of both self and society. To the extent that identification or affiliation with group membership carries with it any type of social stigma, willingness to reveal membership in the group also carries with it a social cost, not unlike other phenomena subject to social desirability bias.

Ambiguous social classification categories are also more likely to be subject to context effects; respondents use the specific wording of questions, the immediately prior questions, or the overall focus of the question as a means for interpreting questions on disability. From a theoretical perspective, it is not surprising to find that estimates of the number of persons with disabilities vary as a function of differences in the specific wording of the question, the number of questions used to determine the prevalence and severity of impairments and disabilities, the context of the questions immediately proximate to the question of interest, and the overall focus of the questionnaire (health versus employment versus program participation).

EMPIRICAL EVIDENCE CONCERNING MEASUREMENT OF DISABILITY ERROR

To date, most investigations with respect to the error properties associated with the measurement of persons with disabilities or the measurement of persons with work disabilities have focused on errors of observation, ignoring differences in estimates due to coverage error and nonresponse error. This review of the empirical literature is therefore focused on errors of observation. As an illustration of the type of empirical investigations concerning error in the measurement of disability, this section begins by examining the work that has been done to date with respect to measures of activities of daily living (ADL). The intent is to provide an illustration of the type of work that has been done (and not done) with respect to a frequently used measure of functional limitation. The focus is then turned to the measurement of persons with work disabilities.

Measurement of ADLs, Functional Limitations, and Sensory Impairments

Although there are several different measurement methods for the assessment of physical disability, one of the most often used (within the context of survey measurement) is the Index of Activities of Daily Living, often referred to as the Index of ADL (Katz et al., 1963). The index was originally developed to measure the physical functioning of elderly and chronically ill patients, but several national surveys of the general population administer the index to adults of all ages. The index assesses independence in six activities: bathing, dressing, toileting, transferring from a bed or chair, continence, and feeding. Despite its wide acceptance and use, the psychometric properties of the index have not been well documented. Brorsson and Asberg (1984) reported reliability scores of 0.74 to 0.88 (based on 100 patients). Katz et al. (1970) applied the Index of ADLs as well as other indexes to a sample of patients discharged from hospitals for the chronically ill and reported correlations between the index and a mobility scale and between the index and a confinement measure of 0.50 and 0.39, respectively. Most assessments of the Index of ADLs have examined the predictive validity of the index with respect to independent living (e.g., Katz and Akpom, 1976) or the length of hospitalization and discharge to home or death (e.g., Ashberg, 1987). These studies indicate relatively high levels of predictive validity.

Despite the psychometric findings, a growing body of survey literature suggests that the measurement of functional limitations via the use of ADL scales is subject to substantial amounts of measurement error and that measurement error is a significant factor in the apparent improvement or decline in functional health observed in longitudinal data. Jette (1994) found that minor changes in the wording of the questions resulted in significant differences in the percentage of the population identified as being limited. Rodgers and Miller (1997) directly compared responses by the same respondents (or more specifically, for the same target individuals) by using different sets of ADL items and across different modes.[5] They conclude that the measurements of functional limitations with respect to counts of ADLs, indications of the use of assistive devices or personal help, and indications of any difficulty are all subject to large amounts of measurement error, of which a substantial portion is random error. Similar to other empirical work (e.g., Mathiowetz and Lair, 1994), their findings indicate that the use of proxy respondents results in higher levels of reporting, of which only 25 to 33 percent can be explained by demographic characteristics and health variables

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[5] Note, however, that the allocation across modes was not experimentally varied but rather was an artifact in the design in which older respondents (80 years and older) were assigned to the face-to-face mode of data collection and those less than 80 years of age were assigned to the telephone mode of data collection. However, a substantial number of respondents were interviewed in the mode other than that to which they were originally assigned; the crossover permits determination of both main and interaction effects related to the mode of data collection.

TABLE 3-1. Mobility Limitations: Distributions to Census Question 19a and Content Reinterview Survey Question 34a, Persons 16 to 64 Years of Age, United States, 1990

	Content Reinterview Survey: Difficulty Going Outside		
Census Long Form: Difficulty Going Outside	Yes	No	Total
Yes	146	152	298
No	155	14,194	14,346
Total	301	14,346	14,647

NOTE: The prevalence rate based on census: 2.03 percent, of which 49.0 percent were consistent responses. The prevalance rate based on the Content Reinterview Survey: 2.05 percent, of which 48.5 percent were consistent responses.
SOURCE: McNeil, 1993.

of the target individual. The finding suggests that higher levels of functional limitations reported by proxy respondents are not simply a result of selection bias, in which those with the most severe limitations are reported by proxy.[6] Their analyses also suggest that there was no clear effect of mode of data collection on estimates of functional limitations.

As illustrative of the variability and lack of reliability that is evident in survey estimates of functional limitations, Tables 3-1 and 3-2 present findings from the 1990 decennial census and the Content Reinterview Survey (CRS) (U.S. Bureau of the Census, 1993; McNeil, 1993). The CRS was conducted approximately 5 to 9 months following the 1990 decennial census, with a sample of 15,000 housing units selected from among those housing units assigned to complete the long form of the census. With respect to mobility limitations, estimates from the two surveys appear to be similar (e.g., 2.03 versus 2.05 percent), but examination of the responses for individuals indicates a low rate of consistent responses (less than 50 percent) among those who reply affirmatively for either survey. With respect to personal care limitations, once again, a high rate of inconsistency in the responses is seen among individuals who respond affirmatively to the question in either survey. For example, among those 16 to 64 years of age, almost all (83.4 percent) of those who report a self-care limitation at the time of the census fail to report a self-care limitation in the CRS.

Comparison of the percentage of persons with mobility and self-care limitations from the two surveys is confounded by differences in the essential survey conditions under which the data were collected and that most likely contribute to the discrepancies evident in the data. These differences include:

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[6] In comparisons of self-reports and proxy reports with clinical evaluations, Rubenstein et al. (1984) found self response to be more "optimistic" and responses obtained by proxy report to be more pessimistic, findings which suggest that both self and proxy responses are subject to measurement error, albeit in different directions.

TABLE 3-2. Self-Care Limitations: Distributions to Census Question 19b and Content Reinterview Survey Question 34b, Persons 16–64 Years of Age, United States, 1990

Census Long Form: Difficulty Taking Care of Personal Needs	Content Reinterview Survey: Difficulty Taking Care of Personal Needs		
	Yes	No	Total
Yes	69	346	415
No	120	13,856	13,976
Total	189	14,202	14,391

NOTE: The prevalence rate based on census: 2.9 percent, of which 16.6 percent were consistent responses. The prevalance rate based on the Content Reinterview Survey: 1.3 percent, of which 36.5 percent were consistent responses.
SOURCE: McNeil, 1993.

- Differences in the mode of data collection. The decennial census is, for the most part, a self-administered questionnaire, whereas the CRS is interviewer administered and is conducted either by telephone (84 percent) or as a face-to-face interview (16 percent). McHorney et al. (1994) report that telephone administration of the SF-36 led to lower levels of reporting of chronic conditions and self-reports of poor health compared with a self-administered version of the SF-36.
- Differences in the context in which the questions were asked. Although the wording of the specific items is almost the same with respect to mobility limitations or self-care limitations, as can be seen from a comparison of the two questionnaires, the context in which the questions are asked differs in the two instruments. Several additional questions concerning sensory impairments, the use of assistive devices for mobility, mobility limitations related to walking a quarter mile or up a flight of steps, and the ability to lift and carry objects weighing up to 10 pounds precede the items of interest in the CRS. There is a large body of literature that documents the existence of context effects in attitude measurement (e.g., Schuman and Presser, 1981). The asking of additional questions could prime the respondent to think about impairments that he or she did not consider while answering the census questions, thereby resulting in an increase in the reporting of limitations. Alternatively, having just answered questions about a number of sensory impairments and limitations, respondents, when answering the more general questions, assume that the general question is intended to capture information not already reported; in this case one would expect the CRS estimates to be lower than those based on the census form. (See Sudman et al. [1996] for a review of the theoretical underpinning related to context effects and a thorough discussion of addition and subtraction effects.)

- Self-reporting versus proxy reporting. There is little information as to who provided information on either the census form or the CRS. Although the CRS attempts to obtain self-reports from each adult household member, information for approximately 25 percent of the persons was reported by proxy. As noted earlier, proxy respondents tend to report more activity limitations and more severe limitations than self-respondents.

Finally, the possibility that the lack of reliability is indicative of the occurrence of real change between the time of the census and the time of the CRS must also be considered.

Although one can enumerate possible sources that explain the low rate of consistency between the two surveys, the lack of experimental design does not permit the identification of the relative contributions of the various design features to the overall lack of stability of these estimates.

Empirical evidence shows that even when questions are administered under the same essential survey conditions, responses are subject to a high rate of inconsistency. This evidence comes from the administration of the same topical module on functional limitations and disability to respondents in the 1992–1993 panel of the Survey of Income and Program Participation. The module was administered between October 1993 and January 1994 (Time 1) and then again between October 1994 and January 1995 (Time 2). The context of the questionnaire is the same in both waves; the topical module is preceded by the core interview, which focuses on earnings, transfer income, program participation, and other forms of income. Information is collected for all members of the household, usually by having one person report for himself or herself and all other family members. In addition, information as to who served as the respondent is recorded; thus one can examine consistency in the reporting of information across time among all self-responses. Table 3-3 presents selected comparisons of functional limitations and sensory impairments reported at Time 1 with those reported at Time 2. The comparisons clearly reveal high levels of theoretical inconsistency, even among self-respondents. For example, among those who report an inability to walk at Time 1, only 70.3 percent report the same status at Time 2. Limiting the comparison to self-reports only does not greatly improve the consistency. Among self-reporters, 76.7 percent of those reporting inability to walk at Time 1 report the same status in the subsequent interview.

These empirical findings illustrate some of the error properties associated with the measurement of functional limitations and sensory impairments. The research indicates that despite psychometric measures that indicate a relatively high degree of reliability, survey applications offer several examples of low levels of reliability, even under conditions in which the essential survey conditions are held constant. Subtle changes in the wording of questions, the order of questions, or the immediate prior context offer further illustration of the lack of

TABLE 3-3. Selected Panel Survey of Income and Program Participation Data: Time 1 (October 1993–January 1994) and Time 2 (October 1994–January 1995) Comparisons, United States

	All Cases		Self-Respondents both Times	
Status at Time 1	No. of Persons	Percentage at Time 2 with Disability	No. of Persons	Percentage at Time 2 with Disability
Uses cane, crutches, walker	508	45.5	286	50.0
Uses a wheelchair	175	61.7	83	68.7
Unable to see	159	49.1	87	49.4
Unable to hear	121	50.4	41	48.8
Unable to speak	47	68.1	5	80.0
Unable to walk	1,045	70.3	587	76.7
Unable to lift/carry	975	61.2	566	65.6
Unable to climb stairs	1,132	68.3	658	72.3
Needs help outside	699	53.5	302	57.3
Needs help bathing	271	52.0	114	54.4
Needs help dressing	237	49.8	80	55.0

SOURCE: McNeil, 1998.

robustness of these items. Although one can enumerate all of the factors that *may* contribute to this volatility, the relative contributions of the various factors have not been experimentally determined.

Empirical Evidence Concerning Error in the Measurement of Work Disability

The assessment of work disability in federal surveys has focused on variants of a limited number of questions, most of which concern whether the individual is limited in the kind or amount of work he or she is able to do or is unable to work at all because of a physical, mental, or emotional problem. Not dissimilar to the assessment of functional limitations, work disability is measured in data collection efforts that vary with respect to the essential survey conditions, the specific wording of questions, the number of questions asked, and the determination of severity, duration, and the use of assistive devices or environmental barriers. As McNeil (1993) points out, one of the problems with the current set of indicators designed to measure work disability is that many fail to acknowledge the role of environmental barriers and accommodations. He states:

> Questions can be raised about the validity of data on persons who are "limited in kind or amount of work they can do" or are "prevented from working." The work disability questions make no mention of environmental factors, even though it is obvious that a person's ability to work cannot be meaningfully

> separated from his or her environment. Work may be difficult or impossible under one set of environmental factors but productive and rewarding under another. It would certainly be logical for a respondent to answer "no" to the question, "Do you have a condition that prevents you from working?" if the real reason he or she is not working is the inaccessibility of the transportation system or the lack of accommodations at the workplace. (pp. 3–4)

As noted in Chapter 2, the "fundamental conceptual issue of concern is that health-related restriction in work participation may not be solely or even primarily related to the health condition. . . ." One of the challenges facing questionnaire designers is the development of questions that match the conceptual framework of interest with respect to work disability, specifically, whether the focus is on the health condition that limits the individual's ability to perform specific tasks related to a specific job, the external factors related to the performance of work, other factors that affect participation in the work environment (e.g., transportation), or all three sets of factors.

Although McNeil (1993) raises questions concerning the validity of the work disability measures currently in use, several empirical investigations raise questions about the reliability of these measures, not unlike the findings with respect to the measurement of functional limitations and sensory impairments. Once again, it can be seen that differences in the wording of the questions, the context in which they are asked, the nature of the respondent, and other essential survey conditions, including the data collection organization and the sponsorship of the survey, may contribute to differences in estimates of the working-age disabled population.

Haber (1990, as revised from Haber and McNeil [1983]) examined work disability from selected surveys between 1966 and 1988. He notes that "despite a high degree of consistency in the social and economic composition of the disabled population over a variety of studies, the overall level of disability prevalence has varied considerably" (p. 43). Haber's findings are reproduced in Table 3-4. The estimates from the various surveys represent differences in the year of administration, the wording of the questions, the overall content of the survey, the mode of administration, the organization collecting the information, and the organization sponsoring the study. Although the wording of the questions is quite similar across the various surveys, there are some minor differences in specific wording (e.g., differences with respect to the emphasis on a health condition) and the order of the questions (e.g., whether the questions begin, as in the NHIS, by asking about whether a health condition keeps the person from working or begin, as in the SSA surveys, by asking whether the person's health limits the kind or amount of work that the person can do). As is evident from Table 3-4, the survey's content appears to be related to the overall estimate; the lowest rates of work disability prevalence come from the Census and the March Supplement to the Current Population Survey (8.5 to 9.4 percent), and the highest rates come from the surveys sponsored by SSA (14.3 to 17.2 percent).

TABLE 3-4. Prevalence of Work Disability Across Various Surveys, United States, 1966–1988

Data Source (age range [years] for estimate)	Percentage Classified with a Work Disability		
	Total	Males	Females
1966 SSA (18–64)	17.2	17.2	17.2
1967 SEO (17–64)	14.0	14.0	14.0
1969 NHIS (17–64)	11.9	13.1	10.9
1970 Census (16–64)	9.4	10.2	8.6
1972 SSA (20–64)	14.3	13.6	15.0
1976 SIE (18–64)	13.3	13.3	13.3
1978 SSA (18–64)	17.2	16.1	18.4
1980 Census (16–64)	8.5	9.0	8.0
1980 NHIS (17–64)	13.5	14.3	12.8
March, 1981 CPS (16–64)	9.0	9.5	8.5
March, 1982 CPS (16–64)	8.9	9.3	8.5
March, 1983 CPS (16–64)	8.7	9.0	8.3
March, 1984 CPS (16–64)	8.6	9.2	8.1
1984 SIPP (16–64)	12.1	11.7	12.4
March, 1985 CPS (16–64)	8.8	9.2	8.4
March, 1986 CPS (16–64)	8.8	9.4	8.2
1986 NHIS (18–64)	13.5	14.3	12.8

NOTE: SSA = Social Security Administration Disability Survey; SEO = Survey of Economic Opportunity; NHIS = National Health Interview Survey; SIE = Survey of Income and Education; March CPS = Annual March Supplement (Income Supplement) to the Current Population Survey; SIPP = Survey of Income and Program Participation.

SOURCE: Haber, 1990.

The lack of stability that was evident for estimates of mobility and self-care limitations between the 1990 census and the CRS is also evident for estimates of work disability. Table 3-5 presents the comparison of responses between the 1990 census and the CRS with respect to whether the person is limited in the kind of work, or the amount of work, or is prevented from working at a job because of physical, mental, or other health conditions. Once again, it can be seen that between one-third and almost one-half of the respondents are inconsistent in their responses.

More recent investigations have used the extensive data from NHIS-D to investigate alternative estimates of the population with work disabilities. The data also provide an opportunity to examine inconsistencies in the reporting of work disability and receipt of SSI or SSDI benefits. For example, LaPlante (1999) found that, based on the data from the NHIS-D, 9.5 million adults 18 to 64 years of age report being unable to work because of a health problem. Among these 9.5 million adults, 5.3 million (or 56 percent) do not report receipt of SSI or SSDI

TABLE 3-5. Work Disability: Distributions to Census Questions 18a and 18b and Content Reinterview Survey Questions 33a and 33b for Persons 16–64 years of age, United States, 1990

Census Long Form: Limited in Kind or Amount of Work or Prevented from Working	Content Reinterview Survey: Limited in Kind or Amount of Work or Prevented from Working		
	Yes	No	Total
Yes	778	366	1,144
No	650	12,988	13,638
Total	1,428	13,354	14,782

NOTE: The prevalence rate based on census: 7.7 percent, of which 68 percent were consistent responses. The prevalance rate based on the Content Reinterview Survey: 9.7 percent, of which 54.5 percent were consistent responses.

SOURCE: McNeil, 1993.

benefits. If one looks at those who report receiving SSI or SSDI benefits, 75 percent report that they are unable to work and 13 percent report that they are limited in the kind or amount of work that they can perform, but 12.3 percent who report receipt of benefits do not report any limitation with respect to work.

Although these variations in estimates derived from different surveys suggest instability in the estimates of the proportion of persons with work disabilities as a function of the wording of the question, the nature of the respondent, and the essential survey conditions under which the measurement was taken, they provide little information about measurement error within the framework of either survey statistics or psychometrics. Little is known about the validity of these items or the reliability of these items, whether one views validity from the perspective of survey statistics as deviations from the true value or from the perspective of psychometrics as criterion-related or construct validity. The relative contributions of various sources of error are, for the most part, unknown; it is only known that various combinations of design features produce different estimates. None of the studies address errors of nonobservation.

QUESTION WORDING ISSUES RELATED TO SELECTED MEASURES OF WORK DISABILITY

Jette and Badley point out in Chapter 2 the conceptual problems inherent in many questions designed to measure persons with work disabilities, including the failure of most questions to enumerate the separate elements related to the role of work. That failure is evident in most work disability screening questions designed to be administered to the general adult population. The gap between the conceptual framework and the questions used to screen for work disability, is illustrated by using questions from several federal data collection efforts.

The long form of the decennial census for the year 2000 includes the following questions:

> Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: . . .
>
> d. (Answer if this person is 16 years old or over.) Working at a job or business?

The respondent is to check a box corresponding to "Yes" or "No."

The question is complex for several reasons:

- The respondent must consider multiple dimensions of health (physical, mental, and emotional) and attribute difficulty working at a job or business to one or more of these health problems. The explicit enumeration of physical, mental, or emotional conditions serves as a means of clarifying for the respondent the fact that the question is intended to cover all three dimensions of health, but at the cost of additional cognitive processing by the respondent.
- The respondent must also assess the duration of the condition and determine the degree to which the 6 months is intended to convey 6 months *specifically* or a more general concept of a "long-term" condition.
- The term "difficulty" is subject to interpretation. Cognitive evaluation of the term "difficulty" suggests that for some respondents the term implies capacity or ability to perform the activity but does not infer actual participation in the activity.
- What is or is not included in the concept of working is further subject to interpretation by the respondent (e.g., inclusion or exclusion of sheltered workshops).

As with many single screening items, the question fails to address accommodations that facilitate participation or barriers that prohibit participation. For example, if an individual is currently employed in an environment that accommodates a health condition, the respondent must determine whether the person should be considered as having difficulty working, even though the present employment situation presents no difficulty to the person.

The NHIS asks two questions concerning work limitations:

> Does any impairment or health problem NOW keep _______ from working at a job or business?
>
> Is _______ limited in the kind OR amount of work _______ can do because of any impairment or health problem?

In contrast to the questions in the census long form, the NHIS questions do not enumerate the various areas of health for consideration, nor does either question include a qualifying statement with respect to duration. The two questions are more specific in addressing the impact on working; compared with the term "difficulty" used in the census questionnaire, the NHIS probes whether a condition prevents the person from working or limits the kind or amount of work. Once again, note the lack of distinction between the ability to perform the activities associated with the actual performance of the job and those activities related to the role of work. For those who retire early because of a health condition or impairment, would the respondent consider that health problem as keeping the person from working?

IMPLICATIONS FOR METHODOLOGICAL RESEARCH

The point of the examples presented above is not to criticize the questionnaires in which they appear but rather to illustrate the problem of attempting to measure a complex, multidimensional, dynamic construct with a single question or a set of two questions. No one or even two questions can possibly tap into the various components of work disabilities. Clearly the first step toward a robust set of screening items is the acceptance of a shared conceptual framework and understanding of the dimensions of the construct of interest. That framework must consider the social environment in which the measurement of interest will be taken, understanding that the comprehension of the question is shaped not only by the specific words used in the question and the context of the question, but by the perceived intent of the question. The use of cognitive laboratory techniques can aid in the identification of problems of comprehension due to the use of inherently vague terms and differential perceptions of the intent of the question. Such techniques will aid in the understanding of the validity of the questions and, through the refinement of the wording of questions, hopefully improve the reliability of the items.

Simply documenting that variation in the essential survey conditions of the measurement process contributes to different estimates of persons with work disabilities is not sufficient; the marginal effects of various factors need to be measured and the impact needs to be reduced through the use of alternative design features. Both of these can be accomplished only through a program of experimentation. Similarly, the psychometric properties of these measures need to be assessed. Without undertaking a thorough program of development and evaluation, the discrepant estimates evident in the empirical literature will persist.

4

Summary of Workshop Discussions

The workshop sessions were designed to discuss issues relating to:

- the implications of different concepts for survey measurement problems;
- sampling, accessing, and measuring people with disabilities;
- questionnaire development issues for measures of work disabilities; and
- the role of environment in survey measurement of disability.

This chapter summarizes the workshop participants' discussions that flowed from the presentations of the two papers presented in Chapters 2 and 3. Participants identified many unanswered questions about measurement that need to be researched. Some of the key issues that surfaced during the discussions are summarized in this chapter.

METHODOLOGICAL RESEARCH ON SURVEY MEASUREMENT OF DISABILITY

One of the major challenges related to the measurement of persons with disabilities and persons with work disabilities concerns the translation of the various complex conceptual models into questions that can be comprehended by the general public and that produce both valid and reliable measures. The Social Security Act defines disability (for adults) as ". . . inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. . ." (Section 223 [d][1]). As stated, the definition appears to presuppose a simple relationship between a medical condition and the ability to work and one that is amenable to measurement via the survey process. In contrast, most contemporary theory concerning disability focuses on the complex nature of the relationship between medical conditions and disability and the importance of environmental factors, including the physical and social environments, in mediating the relationship between a medical condition and work. The first session of the workshop focused on a review of the two background papers, addressing the various conceptual frameworks, the complexity inherent in the measurement of disability, and the empirical evidence of measurement error associated with instruments that have been used to measure disability and work disability.

As discussed by Jette and Badley (see Chapter 2) both the Nagi model of disability and the model proposed in the second revision of the International Classification of Impairments, Activities, and Participation (ICIDH-2) emphasize that the accomplishment of particular social roles, such as work, involves not only the accomplishment of the particular activities related to the work task but also the ability to perform with respect to several other activity domains. For example, participation in work activities may also involve the ability to use transportation systems to get to and from work. Therefore, the inability to find accommodating transportation may result in a "work disability," even though the individual is quite capable of performing the tasks associated with his or her occupation.

Both the Nagi and ICIDH-2 conceptual models view the disablement process as a function of the physical and social environments, accommodations and barriers within those environments, and personal attributes and resources. Work disability therefore is unlikely to be related either directly or only to a health condition or impairment. Rather, from the perspective of these conceptual models, work disability (or any other social role) is a function of the interaction of the physical and social environments, accommodations and barriers within those environments, together with the psychosocial and other attributes of the person. Therefore, the measurement of work disability should take into account personal attributes, as well as the social and physical environments in which the person operates.

The complexities of the conceptual models of disability lead to tension in the measurement of disability. The measurement of disability is further complicated by the often ambiguous and varying uses of the terms used in conceptual models and measurement instruments both within and outside the field. In addition, in light of the passage of the American with Disabilities Act, the language is evolving. These factors suggest the use of a survey instrument in which multiple questions concerning disability are asked to set the context for the measurement process, clarify terminology, and tap the multiple domains of interest. This conflicts with the desire of the Social Security Administration, as well as numerous other federal agencies, to identify a short battery of questionnaire items that can identify persons with disabilities and work disabilities through the survey process. Of primary concern is the fact that the questions used to identify persons with disabilities should be both valid and reliable and should be robust when used under varying survey design features.

The empirical literature addressing the measurement error properties of disability and work disability, albeit limited, provides evidence of low reliability and questionable validity. For example, questions concerning disability were asked in the 1991 Canadian census; individuals were sampled on the basis of their responses to the census and administered the Health and Activity Limitation Survey (HALS). The sample included both individuals who indicated a disability and those who did not in response to the census questions. Of the 35,000 persons classified as disabled on the basis of answers to the census questions, 20 percent were classified as not disabled on the basis of responses to HALS. Among the 113,000 persons classified as not disabled on the basis of the census data, 5 percent were classified as disabled on the basis of the data from HALS. Similar examples of an apparent low reliability are evident in the 1990 U.S. census and the CRS (see examples provided in Chapter 3, p. 51). Factors such as the wording of the question, the context of the question, the mode of data collection, the nature of the respondent (self-response versus proxy response), and the sponsorship of the survey all appear to affect estimates of disability.

Even if it is well measured, work disability is a matter of degree, suggesting that the measurement of work disability should be on a continuum as opposed to the dichotomous measurement currently used in most surveys. The categorization of an individual as "work disabled" or not could then be based on clearly defined and established thresholds.

The survey challenges associated with the measurement of persons with disabilities are not limited to measurement error but must also address errors of nonobservation. Particular physical or cognitive disabilities may affect an individual's likelihood of inclusion in the sample or participation in the process if sampled. For example, the use of telephone for data collection limits participation among deaf persons.

Several key issues were identified during the discussion, including the following:

- Work disability is a multidimensional, complex concept that investigators do not know how to define well. Nor is the relationship among an individual's characteristics, the environmental characteristics, and the phenomena of disability understood. Disability or limitations in participation are a result of a complex interaction among an individual and his or her attributes, the physical and social environments, and the accommodations and barriers to participation. The measurement of disability is further confounded by the fact that all characteristics, whether intrinsic individual characteristics or characteristics of the environment, change with time.

- The measurement of the environment is not limited to the physical, tangible elements but includes all aspects outside the individual, including the social environment. Attitudes held by other individuals, discrimination, and laws all affect the environment and determine the extent to which the environment accommodates or hinders participation.
- There is a significant gap between the theoretical concepts and the current set of measures that are being used. In addition, there is little information about the measurement error properties of the survey measures currently being used to enumerate persons with work disabilities.
- A meta-analysis of variations in estimates of the prevalence of disability and work disability as a function of various survey design features would be informative about the relative effects of various features on survey estimates. The meta-analysis must include studies from outside the United States. Similarly, further exploratory analyses of the data that currently exist may provide additional insight as to the mechanism(s) that leads to variability in survey estimates of disability.
- In addition to the meta-analysis and further analyses using existing data, workshop participants noted the need for a program of experimentation to identify the relative contributions of various survey design features to variability among surveys and variabilities in repeated measurements of the same individual.

IMPLICATIONS OF DIFFERENT CONCEPTS FOR SURVEY MEASUREMENT

The development of valid and reliable measures of persons with work disabilities requires that one identify differences in the various conceptual models and the implications of those differences for survey measurement. Workshop participants were asked to consider the following questions:

- What are the key differences among the concepts that have implications for survey measurement? How would one go about assessing, for example, the practical import of the conceptual differences in a survey measurement environment?
- For the purposes of measuring work disability, what components must or should be measured? What research should be conducted to eliminate gaps in the knowledge needed to answer that question?
- Do any of the measures presently being used represent a "gold standard?" What research should be conducted to eliminate gaps in the knowledge needed to answer questions concerning a gold standard?
- What is known about the use of terminology related to disability by lay people, and do any of the conceptual models provide a framework that relates better or worse to the terminology used by the lay public? What

research needs to be done on translating the concepts to the terminology used by the lay population? Does the use of a particular terminology vary across subgroups?

Despite apparent differences between the conceptual models, workshop participants noted that there is, in fact, a lot of commonality among the models. Of critical importance with respect to the operationalization of the various conceptual models is a clear distinction between the measurement of capacity and participation. Both need to be measured, as do the factors that illuminate the relationship between capacity and participation. Further research is needed on the development of measures of capacity and participation.

One of the gaps identified by workshop participants is the lack of research addressing the relationship between measures of quality of life and general health status and measures of disability and work disability. One means by which the relationship between measures of health status and measures of disability can be addressed and the measurement of capacity can be disentangled from performance within health status measures is to foster cross-disciplinary research between the health status research community and the disability research community.

The disablement process is described in the conceptual models as a continuous, dynamic, interactive process, implying that longitudinal measurement is imperative to understanding the relationship among the individual's characteristics, the environment, and participation in the workforce.

Participants stressed the need to develop valid, reliable measures of workforce participation, regardless of the number of questions required to do so. Once a gold standard is developed, the predictive reliability of any subset of those questions could be established.

In summary, the sessions identified the following key issues:

- The various conceptual models have commonalities that, for survey measurement, imply little or no difference in what needs to be measured.
- Regardless of the conceptual model of interest, there is a need to understand and measure both capacity and performance, contrasting self-reports of capacity and performance with objective performance measures. Many of the current health status measures sets confuse capacity for work with actual work performance. Further research is needed to better understand the relationship between more general health status measures and measures of disability.
- The conceptual models imply that a dynamic relationship between a person, a set of environmental factors, and participation exists. Such models beg for longitudinal measurement to further understand the dynamic nature of disability.
- Central to the measurement of disability or work disability is the issue of duration. Even in cross-sectional data collection efforts, the goal is to characterize an individual not simply with respect to impairments, limita-

tions, or disabilities on the day of the measurement but rather with respect to some notion of duration. Duration has been measured in terms of time since initial onset, time since most recent episode, and even expected duration. Further research is needed on the best means by which disability should be defined with respect to the dimension of duration.

- The participants called for the development of a set of valid, reliable measures of work disability, regardless of the number of question items necessary to capture the multiple dimensions of disability and the various domains outlined in the theoretical concepts. Once such a set of measures is established and the relationship between self-reports and unbiased observation or performance is documented, research could address the reliability and validity of a short form of the gold standard.

SAMPLING, ACCESSING, AND MEASURING PEOPLE WITH DISABILITIES

Errors of nonobservation are of potential concern for any data collection effort. Of particular interest with respect to the sampling and measurement of persons with disabilities are issues related to coverage error (i.e., the exclusion of persons with disabilities from the frame used for sampling) and nonresponse error (i.e., the extent to which those who do not participate—because of an inability to be contacted, an inability to participate, or an unwillingness to participate—differ with respect to disabilities from those sampled individuals who agree to be interviewed). Design decisions related to the mode and method of data collection, usually viewed as decisions that affect measurement error, also potentially affect both coverage error and nonresponse error.

Obtaining estimates of the population of persons with disabilities raises particularly challenging issues with respect to the development of a frame from which individuals can be sampled for inclusion in a study. The workshop participants noted that persons with disabilities are probably more likely to live in institutions or in group quarters or to be homeless; hence, reliance on a sample frame consisting of households will result in noncoverage of the population of interest.

Design decisions concerning mode of data collection, sample frame, and nonresponse are closely interconnected, perhaps more so for the measurement of persons with disabilities than for other measures. For example, if one is interested in conducting a telephone survey, then the sampling frame is not all households but rather households with telephones. Persons living in households without telephones will have a zero probability of selection. To the extent that individuals who live in households without telephones differ from those who live in households with telephones, the resulting estimates will suffer from coverage error. However, the choice of the telephone as the mode of data collection further assumes that within the households with telephones there is at least one person who can hear well enough to participate.

Findings from the National Comorbidity Study were discussed as illustrative of the interplay among decisions concerning mode of data collection and potential nonresponse error. This study was designed to measure the prevalence of disabling psychotic disorders. The survey was conducted as a household-based face-to-face survey, viewed as the best mode of data collection. The survey achieved a respectable response rate of 85 percent. That meant, however, that 15 percent of the sample selected for participation did not participate, and the prevalence of this type of disability is estimated to be about 1 percent. To address this issue, the investigators surveyed 20 percent of the nonrespondents. They were offered incentives, alternative modes of data collection (e.g., telephone), or alternative locations for data collection (e.g., public place). The nonresponse study found relatively high rates of anxiety disorders among those respondents who were willing to complete the nonresponse interview but who were not willing to have a stranger in their homes. The findings suggest that, for this particular study, the choice of mode of data collection was related to the nonresponse error. Permitting flexible modes of data collection may have resulted in a reduction of the nonresponse rate and a reduction of the nonresponse error.

Workshop participants also discussed the following topics:

- The critical issue that has not been addressed in the research literature is the relationship between the measure of interest, persons with disability, and either coverage error or nonresponse error. The phenomena that investigators are interested in measuring will, in some cases, determine noncoverage for particular types of sampling frames and nonresponse for particular modes of data collection. To successfully sample and include the population of interest, one must consider multiple frames for sampling and multiple modes for data collection.
- Because the phenomenon of interest is a dynamic rather than static state, it is important that the design of any study in which a questionnaire is used to screen or identify the population of interest include in the second stage some portion of the respondents who were not classified as impaired or disabled.
- One dimension to be considered in the sample design is time; for example, homeless individuals are not necessarily homeless all of the time.
- The assessment of disability relies on the willingness of respondents to reveal the information. Hence, one focus for research is to address the motivation of respondents to accurately report the presence of a disability.
- Disability cannot be defined as an attribute of the person apart from the environment in which he or she resides; hence, attempts to measure the person outside the context of that environment are not relevant.

QUESTIONNAIRE DEVELOPMENT ISSUES FOR MEASURES OF WORK DISABILITY

Cognitive psychology provides a theoretical framework for addressing the processes involved in the question-answer interchange between an interviewer and a respondent. This framework is informative with respect to where the process may be problematic for the measurement of persons with disabilities. The question-answer process is most often categorized as a four-stage process involving comprehending the question, retrieving the information, making a judgment concerning whether the retrieved information is relevant, and formulating a response. Given the complexity of the concept of interest, workshop participants indicated that comprehension represented the largest challenge in the development of effective questions to measure disability and work disability. Survey questions are probably most effective in screening out the large number of persons without disabilities as well as identifying persons who are current beneficiaries of Supplemental Security Income or Social Security Disability Insurance. Questionnaires were viewed as most problematic in identifying disabled persons who currently received no benefits and who may or may not be employed.

Potential comprehension problems associated with the measurement of persons with work disabilities were illustrated by using questions scheduled to be included in the long form of the decennial census for the year 2000. The proposed question is “Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities? Working at a job or business?” The response categories are yes or no. The question includes at least three distinct elements: (1) a causal connection between the disability and an underlying medical or psychological condition; (2) the condition is enduring; and (3) the condition results in an inability to do something, in this specific case, the inability to work. To answer the question the respondent must determine what is meant by work, must determine whether the inability to work meets the criteria related to the time element, and must attribute the inability to work to an underlying condition. In addition, the question involves an implicit comparison to a standard, for example, the ability or inability to perform some set of tasks associated with a particular job.

The complexity of the question contributes to problems of comprehension. The empirical literature indicates that many of the questions designed to measure disability are subject to context effects, providing evidence of comprehension problems. Workshop participants called for research in which the reliability of complex multidimensional questions designed to measure persons with disabilities is compared with the reliability of a series of shorter items. The hypothesis is that the use of several less complex questions may improve comprehension with little or no additional administration time for the interview.

Many survey questions that attempt to measure disability include a dimension of duration (e.g., “lasting six months or more”). For some questions, duration is expressed in the past tense; other items express duration either in the past tense or as a duration that is expected to continue for a specific time period into the future. Although the intention of including a dimension of duration is to eliminate short-term disabilities (e.g., a broken leg that will limit the respondent for the next 6 weeks), workshop participants expressed concerns as to respondents' understanding of the dimension of duration as well as concern with the determination of an appropriate duration interval. This was of particular importance for the measurement of persons with intermittent disabilities. Given the dynamic nature of disability, what is the appropriate time period to be used in the survey question? Workshop participants reiterated the need for research related to respondents' comprehension of the questions designed to measure work disability. For example, among persons with episodic mental disabilities, questions of duration become quite difficult to answer. Should the respondent report with respect to date of first onset, total duration of episodes, or duration of most recent episode?

What information concerning disability can and cannot be retrieved during the course of an interview? For many kinds of questions dealing with autobiographical memory, retrieval of the information is the most difficult task facing the respondent. This is most likely not the case with respect to work disabilities. Persons with disabilities and their immediate families are very likely to be aware of a disability if there is one and to be able to retrieve it from memory with little difficulty, if the respondent understands what is being asked. Similarly, the process of making a judgment concerning the retrieved information or formulating a response does not present the respondent with cognitively difficult tasks, but, rather, presents the respondent with tasks that may have implications with respect to issues of social desirability. For example, in a setting in which a respondent is applying for disability benefits, there may be a strong motivation to edit responses toward disability. In household interviews, on the other hand, individuals may wish to deny or minimize their disabilities. Workshop participants suggested the need to conduct research on how to reduce question threat through the use of self-administered modes of data collection, including the use of audio computer-assisted self-interviewing procedures.

The nature of the phenomena of interest implies that information often will be obtained from proxy respondents, that is, one person reporting for another individual. Although there is a small body of empirical literature indicating that responses concerning functional assessments or disabilities obtained by proxy differ from those obtained from a respondent reporting for him- or herself, the direction and magnitude of the response error are not well understood. For items perceived to be threatening, responses obtained by proxy may be subject to lower levels of response error than responses obtained from the target individual.

The discussion resulted in the identification of several additional research activities related to questionnaire development. These include the following:

- A program of research to address the extent to which change over time reflects real change as opposed to measurement error. Although several data files that include repeated measures of disability exist, the time between the first and subsequent interviews is often 6 months or more, a period during which it is quite conceivable that, in fact, some change has occurred. A reinterview program in which respondents are reasked the critical questions of interest within a relatively short time frame would permit estimation of simple response variance. Resolution of discrepancies between reports for the two time periods would permit the separation of true change from response variance.
- An experiment or series of experiments to examine differences in comprehension and response distributions associated with a single, multidimensional disability question (e.g., the ones proposed for the decennial census) compared with those associated with a questionnaire in which a single question is decomposed into a series of shorter items.
- A research program to address the contextual factors that affect responses to questions on disability. Context would include the questions immediately before the disability items, the overall content of the questionnaire (including the sponsorship of the survey), and the environmental context (e.g., the unemployment rate or the weather).

ROLE OF ENVIRONMENT IN SURVEY MEASUREMENT OF DISABILITY

The literature offers at least two frameworks for the measurement of the impact of environment on participation among persons with disabilities. The Quebec model (Fougeyrollas, 1998) focuses on obtaining ratings of the individual's life habits, for example, determining the level of accomplishment for a certain activity (from no difficulty to not performed) or ascertaining the type of assistance that a person uses, including assistive technology, environmental modification, and personal assistance. Respondents are also asked to rate the environment, where environment includes such factors as the physical environment, social attitudes, and rules related to the workplace.

An alternative framework is offered by the ICIDH-2, which can be used to classify the environment on several levels, including the personal level (e.g., the immediate environment of the person including, but not limited to, the home, school, and workplace), the community level (including economic and social institutions), the broader cultural and social customs and structures, the physical, human-made environment, and the natural environment.

To measure environment, researchers need to have a shared understanding of activities and participation, using the ICIDH-2 vernacular. Activity, sometimes referred to as "naked capacity," is the ability to perform an activity without any kind of technology or personal assistance. In measuring activity, one could consider a continuum ranging from "extremely well" to "not at all." Performance could then be defined as performance of activities with all types of assistance. Respondents could be asked whether they do the activity with any type of assistance and, if yes, what kind of assistance. This type of question sequence would allow researchers to understand the types of assistance or environmental accommodation that facilitates the performance of an activity. Such an approach allows people an opportunity to express their views of their level of performance using available assistance and technology.

Environment also alters an individual's perception of disability. For example, the number of applications for SSI and SSDI benefits often varies as a function of the economy, suggesting that individual perceptions may, in part, be a function of the labor force options available. The passage of the Americans with Disabilities Act most likely will change the social climate concerning disabilities and entitlements of persons with disabilities; hence, over time, there may be an increase in the number of individuals who classify themselves as disabled.

Workshop participants expressed concern about the validity of the perspective of the respondent as reporter of the environment, as well as the validity of reports of the environment provided by proxy respondents. To alleviate these concerns, participants recommended comparison of both self-reports and proxy reports of the environment with unbiased measures of the environment to provide empirical data on the validity of the reports by the two types of respondents. For example, work environments could be sampled by trained observers who rate the environment and by comparisons of those ratings with reports obtained from self-reporters and proxy respondents.

- To understand the tasks associated with a particular occupation, rather than looking only at how able-bodied people perform the task, the manner in which people with disabilities perform the task should be examined. Such information could be incorporated into the Occupational Information Network (O*NET) to determine whether other individuals with similar scores are participating in a particular occupation.
- The presence of others during a survey changes the environment of the measurement, and may affect the reporting of disabilities.

5

An Agenda for Research in Survey Measurement of Work Disability

The committee's mandate includes advising the Social Security Administration (SSA) on the design, methods, and content of the Disability Evaluation Study (DES). The purpose of this workshop was to bring together disability researchers and experts in survey methods to discuss conceptual and survey design and measurement issues and to identify unanswered questions of measurement of persons with work disabilities. During the workshop sessions participants presented and discussed many issues and offered suggestions for further research. In the final session of the workshop, participants identified the gaps in survey methods and measurement of work disability and suggested a framework for long-term research for SSA and others in the field.

The measurement of the number of people with work disabilities is complex. The complexity stems, in part, from differences in the various conceptual models of the enablement-disablement process and alternative interpretations of the models. The measurement of persons eligible for disability benefits from the Social Security Administration (SSA) is made additionally complex by the incongruity between the various conceptual models and SSA's model based on its statutory definition of work disability. The various constructs do not necessarily identify the same population. Hence, throughout the workshop participants struggled with how to measure people with work disabilities—people who would apply for SSA benefits—and those who would be classified as persons with work disabilities as a result of the SSA benefits decision process.

In addition, examination of the empirical literature reveals significant voids in the field's knowledge of the error properties associated with the measurement of persons with disabilities or work disabilities. The limited empirical literature raises questions about both the validity and the reliability of various disability measures currently in use in household-based surveys. Among the goals of the workshop was the identification by participants of gaps in knowledge about the error properties associated with the measurement of people with disabilities and the development of a research framework to address those gaps.

The framework outlined by the participants encompasses four broad areas of research:

- **Coverage Error.** To address the serious shortage of research on the effects of coverage error on estimates of the population of persons with work disabilities or potential SSA applicants and beneficiaries, research is needed on the assessment and reduction of errors related to the choice of sampling frame and screening instruments.
- **Measurement Error.** In light of the volatility evident in the limited empirical literature investigating the error properties associated with measures of disability and work disability, research is needed on the assessment and reduction of measurement error.
- **Nonresponse Error.** To address the paucity of research on the effects of nonresponse error, research should be directed toward understanding the correlates of nonresponse and the impact of differential nonresponse on estimates of the population of persons with work disabilities or potential SSA applicants and beneficiaries.
- **Environment.** To address the void between conceptual models of disability that identify the role of the environment in disability and the current set of measures used in surveys of persons with disabilities, research is needed on the development and assessment of effective measures of the environment.

COVERAGE ERROR

Coverage error defines the failure to include all eligible people on the list or frame used to identify and sample the population of interest. The use of screening questions to identify the population of interest leads to an additional source of coverage error—the exclusion of persons because of inaccurate classification at the time of the screening.

Adequacy of Household-Based Surveys

Household-based data collection efforts, by definition, eliminate from the sampling frame those members of the population who are homeless, as well as those who are living in institutions. Those residing in group homes, assisted-living facilities, and other new types of living arrangements may or may not be included in the frame, depending on how the distinction between institutional and noninstitutional residence is made. The extent of this coverage error when attempting to describe the entire U.S. population with disabilities is unknown and is likely to be a function of the type of disability, with estimates of the population with mental retardation or mental health problems most likely subject to the highest rates of coverage error. Empirical data are needed to estimate the differences in the rate of disabilities and the characteristics of the population with disabilities on the basis of household surveys compared with the rate and characteristics on the basis of data for the entire population.

Effects of Alternative Approaches to Screening

The use of a screening instrument to identify the population of interest affects coverage error. Three areas of research were enumerated as being particularly important with respect to the use of screening instruments:

- The effect of alternative wording of questions on the identification of the population. Given the discrepancies in the rates of disability reported in the literature, establishing the reliability of screening items is particularly important.
- Comparisons of estimates based on simultaneous screening and interviewing with those based on separate screening operations. Participants cited empirical evidence that the use of simultaneous screening and interviewing operations (compared with separate field operations to conduct only the screening) may result in a lower incidence of the characteristic of interest. This research should also focus on understanding the mechanism by which the two operations result in different estimates.
- The effect on estimates when a subsample of cases classified as negative according to screening questions are included and rescreened as part of the extended interview. (Statistics Canada in its Health and Limitations Survey takes this approach.)

MEASUREMENT ERROR

Estimates of the population with disabilities appear to vary as a function of the essential survey conditions under which the data are collected, specifically, the mode of data collection, the wording of the specific question, the context of the question, the overall content of the survey as well as the survey's sponsorship, and the nature of the respondent providing the information (self-response versus proxy response). However, the confounding of various design features prevents researchers from identifying the marginal impact of each.

Valid and reliable measures of participation by people with disabilities in the social and economic environments are needed, regardless of the number of questions required to do so. Valid questions must address the conceptual models that view work disability as a matter of degree, suggesting that the measurement of disability be on a continuum as opposed to the dichotomous measures used in many surveys. Participants acknowledged that, regardless of the type of impairment, the development of valid and reliable measures of disability, and especially work disability, is a challenging undertaking. Participants stressed that the episodic nature of mental disabilities, as well as perceptions of social stigma, make the measurement of mental disabilities all the more difficult. The episodic nature of mental disabilities suggests that the reporting of a mental disability may be subjected to greater variability than is true with physical disabilities. Hence the reliability of such measures may be low, even though respondents are reporting quite accurately about their disabilities over time. Perceptions of social stigma most likely will affect the validity of reports of mental disabilities. Respondents tend to err on the side of not reporting such disabilities, especially in face-to-face interviews.

Workshop participants identified three areas of research for developing valid and reliable measures of work disability:

1. Assessment of the effects of specific wording and context of question. In the discussion of question wording, structure, and context, workshop participants identified a number of potential research topics.

- *Research directed toward understanding respondents' comprehension of the key concepts within the question.* Participants suggested that investigations be targeted at understanding respondents' comprehension of the concept of disability as well as their comprehension of specific words used in the measurement of persons with disabilities, such as "difficulty," "work," "performance," and "ability."
- *Decomposing long questions used to screen for persons with disabilities.* In light of the apparent discrepancies in the reports of disability obtained with complex screening items, participants suggested that investigators conduct experiments in which they decompose long, complex single questions into multiple items and make comparisons between the two approaches with respect to reliability, validity, and length of administration.
- *Assessment of context on estimates of the population with disabilities.* Workshop participants called for experimentation to identify the role of context on estimates, where context is broadly defined, ranging from subjective factors such as mood to objective factors such as the survey sponsor, the questions immediately preceding the disability measures, and even such factors as the weather.

2. Assessment of the effects of self-reporting and proxy reporting. A limited empirical literature on the effects of self-reporting and proxy reporting of functional limitations suggests that the direction and the magnitude of response error are, in part, related to whether the report is provided by the individual or by proxy. Among proxy reporters, it is also a function of the relationship between the target individual and the reporter. Participants

identified the need for further evaluation of the validity and reliability of both self-responses and proxy responses, including, but not limited to, comparison of both self-reports and proxy reports with performance indicators for key impairment or disability measures and further empirical studies that address the direction and the magnitude of response error as a function of the relationship between the proxy reporter and the target person of interest (e.g., caregiver or noncaregiver spouse), especially proxy reports obtained for persons with mental retardation and mental health impairments.

3. Assessment of the effects of essential survey design features. The background papers (see Chapters 2 and 3) provided illustrative examples of how estimates of persons with disabilities or persons with work disabilities vary as a function of essential survey design features. A meta-analytic study that would establish significant design predictors of prevalence was discussed as a first step toward disentangling the marginal effects of various design features.

Participants also suggested a number of experiments designed to provide an understanding of the marginal impacts of these various design features. These experiments focused on the need to: (a) understand how the sponsorship of the survey affects both the properties of nonresponse (motivation to respond or not respond) and the measurement process (response editing and formation); (b) measure and examine the effects of the presence of others during survey administration, especially in the measurement of mental illness; (c) understand the effects of mode of interview, incorporating a design that is sensitive to the different issues associated with the measurement of those with physical, sensory, mental, and emotional impairments; and (d) investigate the incorporation of new technology (e.g., audio computer-assisted interviewing) to enhance participation and privacy among persons with disabilities.

Given that conceptual models of disablement view the process as a continuous, dynamic, interactive process, participants indicated that longitudinal measurement of disablement was imperative to understanding the relationship among individual characteristics, the environment, and work participation. Estimates based on longitudinal designs need to be compared with those based on cross-sectional data collection efforts.

NONRESPONSE

Impact of Nonresponse Error on Estimates of Persons with Disabilities

Although no empirical data exist that address the impact of nonresponse on estimates of persons with disabilities, workshop participants speculated that the nature of a person's impairments or disabilities may result in differential nonresponse among members of the population with disabilities. This void in the literature suggests that a priority with respect to nonresponse research is the assessment of differential nonresponse among persons with disabilities due to various physical, cognitive, and mental impairments. One approach could be the use of two-phase sampling of nonrespondents, that is, select a sample among those persons who were nonrespondents and then, using extraordinary methods, attempt to measure these individuals. The methods could include a significantly reduced questionnaire (for example, one that simply attempts to measure impairments and disabilities), the offering of incentives, or the collection of data via an alternative mode (e.g., from face-to-face interviews to telephone interviews). Such an approach would allow researchers to quantify the differences between respondents and nonrespondents as to the rates and characteristics of impairments and disabilities.

"Gatekeepers" and Interviewers

"Gatekeepers" (household members who may limit access to the sampled person) and survey interviewers may represent sources of nonresponse error unique to the measurement of persons with disabilities. Gatekeepers may limit access to persons with disabilities who, if provided with the opportunity, might be quite willing to serve as respondents. The contribution of gatekeepers to nonresponse, and the differential impacts of gatekeepers for telephone surveys compared with face-to-face interviews have never been addressed in the literature. Similarly, interviewers may classify sampled persons as incapable of serving as a respondent, because of cognitive capabilities, sensory impairments, or other impairments. Research is needed to address the extent to which such judgments by an interviewer result in nonresponse among the population of primary interest.

MEASURES OF THE ENVIRONMENT

One of the major voids between conceptual models of impairment and disability and the measurement of impairments and disabilities in surveys is the inadequacy of survey questions to measure the environment. Current data collection efforts, for the most part, fail to measure the environment and its impact either as a means of facilitating participation or as a barrier to participation in the social and economic environments.

Objective Measures

Workshop participants underscored the need for the development of standardized objective measures of both the physical and social environments. Participants stressed that the measurement of environmental context should examine both factors that accommodate impairments and those that serve as barriers. The development of objective measures of the physical environment may be facilitated by fostering collaboration with those in ergonomics and human factors engineering, fields in which a primary focus is the measurement of the environment. Some also noted that the classification of environmental features enumerated in the second revision of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH-2) provides a well-defined architecture for the development of questionnaire items designed to capture environmental factors that affect the disablement process.

To aid in the development of objective measures of the social environment, some participants noted the need to develop and test questions concerning social climate, barriers, and stigma. These questions are especially important for those with mental illness, but they are relevant for and should be asked of all persons with disabilities. To aid in this development of objective measures of the social environment, some participants suggested collaboration with researchers who have developed measures of racial and ethnic discrimination.

One of the challenges related to the development of objective measures of the environment is the identification of a set of questions that can be asked of the general population. This objective contradicts the fact that barriers as well as accommodations in the work environment are a function of the person's impairment and the occupation in which he or she is employed. To fully understand either barriers to employment or factors that facilitate employment, questions need to be tailored so that they are relevant to the individual's situation. Ethnographic exploratory studies of workplace environments are one means by which to inform household measurement of accommodation and barriers. For those who are no longer working, questions that enumerate what accommodations would be necessary to facilitate, or barriers that prevent, participation in the workforce need to be designed and subjected to evaluation.

Subjective Measures

Similar to the discussion concerning objective measures of environment, workshop participants identified the need to develop subjective measures of both the physical and social environments that either facilitate or limit participation.

In addition to research to develop such measures, the discussion concerning the collection of subjective measures of the environment elicited two additional research topics: (1) assessment of systematic differences in evaluating the environment among those for whom the environment is benign versus those for whom the environment is hostile and (2) assessment of the difference between self-reports and proxy reports of subjective environmental conditions.

SUMMARY

Workshop participants expressed strong sentiment that SSA and other federal agencies should undertake a systematic approach to addressing the research agenda identified during the workshop discussions. The approaches currently used in surveys to measure people with disabilities are incongruous with modern theoretical models. The empirical literature examining measurement error associated with specific questions, albeit limited, suggests that items currently used to screen or measure persons with disability are subject to low levels of reliability and are of questionable validity, especially for people with mental illness. The impacts of both coverage error and survey nonresponse on estimates of the population with disabilities and work disabilities have not been addressed in the literature. In light of these points, workshop participants indicated that the measurement of people with disabilities and work disabilities could be greatly improved with research directed toward one or more of these agenda topics.

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APPENDIX A

Review of the Social Security Administration's Disability Decision Process Research

STUDY MANDATE

The study will review and provide advice on the scope of work, design, content of the survey, and the approach and scientific methods of completed and planned research as the Social Security Administration (SSA) develops the new disability decision process. The study will focus on the population 18–69 years of age. Although the committee is given latitude in setting its own agenda and designing its plan of work, the topics it explores will include:

- Review of the research plan and timeline for developing a new decision process for disability;
- Review of the preliminary design of the Disability Evaluation Study (DES) research efforts, the scope of work for the DES, and the design and content of the survey, as proposed by the survey contractor, as well as SSA's plans to integrate the decision method and DES research effort, identifying statistical design, methodological and content concerns, and other outstanding issues;
- Examine the results of completed research including research into existing functional assessment instruments and subsequently identified research for SSA's redesign efforts, and provide advice for adopting or developing functional assessment instruments or protocols for the redesigned disability process and the DES in particular; and
- Assess the results and findings of the research undertaken by SSA, comment on future research proposals, and offer advice on the analysis of the consequences of alternative disability determination processes. Some of the topic areas that might be considered include functional assessment of work-related limitations of physical and mental impairments; disability decision processes (including screening mechanisms); testing and validating decision processes for determining disability; and age, education, and work experience.

APPENDIX B
Workshop on Survey Measurement of Work Disability: Challenges for Survey Design and Method

Committee to Review SSA's Disability Decision Process Research
National Academy of Sciences/Institute of Medicine
Holiday Inn Georgetown, Mirage I
2101 Wisconsin Avenue, N.W., Washington, D.C.
May 27–28, 1999

WORKSHOP AGENDA

Thursday, May 27

9:00–9:15 a.m.	Welcome and Introduction Dorothy Rice, *Chair*
9:15–9:30 a.m.	Welcoming Remarks Jane Ross, *Deputy Commissioner, SSA*

SESSION ONE

9:30–10:30 a.m.	**Overview of the Two Background Papers: Opportunities for Methodological Research on Survey Measures Related to Disability** Elizabeth Badley, Alan Jette, and Nancy Mathiowetz ***Contributor:*** Allan Sampson An examination of the various conceptual models of disability and the disablement process and their ability to address SSA's disability program requirements. • The challenges related to the translation of conceptual models to valid and reliable questions which can be administered to the general population. • The identification of the coverage, nonresponse, and measurement error properties of current measures of work disability. • Potential problems in cross-walking among measures of disability collected in a variety of settings and under varying survey conditions.

SESSION TWO

10:45 a.m.–12:00 p.m. **Implications of Different Concepts for Survey Measurement Problems**

Discussion Leader: Robert Groves

Contributors: Ellen MacKenzie and Allan Hunt

- How do the various conceptual models address the dynamic nature of disability and how do these models address SSA's disability program requirements?
- How do the various conceptual models address the role of environment, adaptation, expectations, and perceptions?
- What measurement gaps exist between the various conceptual models of disability and the current set of disability measures used in federal surveys?

SESSION THREE

1:00–2:00 p.m. **Sampling, Accessing, and Measuring People with Disabilities**

Discussion Leader: Colm O'Muircheartaigh

Contributors: Lawrence Branch and Ronald Kessler

- To what extent do varying modes and methods of data collection facilitate participation among persons with disabilities?
- If access to a person with a work disability is limited (due to the interface between the survey design and the nature of the disability), how is the measurement of disability affected by the role of the proxy respondent—caregiver as respondent, other proxy respondent? Can tradeoffs be assessed between nonresponse and measurement errors?
- What gaps exist in our knowledge of the relative impact of coverage, nonresponse, and measurement error on estimates of disability?

SESSION FOUR

2:00–3:00 p.m. **Questionnaire Development Issues for Measures of Work Disability**

Discussion Leader: Seymour Sudman

Contributors: Roger Tourangeau and Jack McNeil

- In light of developments related to the integration of cognitive theory and survey methodology, how should measures of work disability be evaluated?

- How does the dynamic nature of disability and the disablement process impact the measurement of work disability?
- How is measurement affected by the role of the person providing the information—self-respondent, caregiver as respondent, or other proxy reporters?
- To what extent should we look to statistical modeling related to scale reduction as a means for reducing the effects of measurement error?
- How will the measurement of work disability in a variety of settings (the DES and other ongoing federal data collection efforts) impact SSA's ability to monitor the pool of people potentially eligible for disability benefits?
- What research needs to be conducted to develop robust measures of work disability, and to address the gaps in our knowledge about the measurement error properties of current measures?

SESSION FIVE

3:30–5:00 p.m. **Role of Environment in Survey Measurement of Disability**

Discussion Leader: David Gray

Contributors: Sandra Berry and Lois Verbrugge

- How is the measurement of work disability affected by environment, perceptions, and expectations?
- Is there a differential impact of environment on the reporting of disability as a function of the role of the person providing the information—self-respondent, caregiver, or other proxy respondent?
- What do we know about the measurement of the role of environment, expectations, and perceptions with respect to the various sources of survey error, specifically, nonresponse and measurement error?
- What gaps exist in our knowledge of how to adequately measure environment and its impact on the measurement of work disability? What research needs to be conducted to address these gaps?

5:00–5:30 p.m.	General Discussion
5:40–6:40 p.m.	Adjourn—*Reception for all attendees*

Friday, May 28

SESSION SIX

9:00–10:30 a.m.	**Defining a Research Agenda** ***Discussion Chair:*** Dorothy Rice • What are the criteria for a “successful” measurement of functional capacity to work? • Feasibility and practicality of designing and administering (i.e., safety, cost, etc.) measures of functional capacity to work. • Technical issues of incorporating reliability, validity, sensitivity, and specificity in the context of SSA’s disability decision process. • How can these measurement approaches be linked to work requirements in the context of SSA’s disability decision process?
10:45 a.m.–12:00 p.m.	General Discussion ***Moderator:*** Robert Groves
12:00–12:15 p.m.	Concluding Remarks Dorothy Rice
12:15 p.m.	Adjourn

APPENDIX C
Workshop on Survey Measurement of Work Disability: Challenges for Survey Design and Method

May 27–28, 1999

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Acronyms and Abbreviations

ADA	Americans with Disabilities Act
ADL	activities of daily living
CRS	Content Reinterview Survey
DES	Disability Evaluation Study
HALS	Health and Activity Limitation Survey
ICIDH	The International Classification of Impairments, Disabilities, and Handicaps
IOM	Institute of Medicine
NAS	National Academy of Sciences
NHIS	National Health Interview Survey
NHIS-D	National Health Interview Survey-Disability Supplement
O*NET	The Occupational Information Network
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
WHO	World Health Organization

Biographical Sketches of Committee Members

DOROTHY P. RICE, Ph.D. (*Chair*) is Professor Emeritus of Social and Behavioral Sciences at the School of Nursing, University of California at San Francisco (UCSF) and holds joint appointments at the Institute for Health and Aging and the Institute for Health Policy Studies at UCSF. From 1983 to 1994, she was Professor-in-Residence at UCSF. Previously she served as Director of the National Center for Health Statistics and was Deputy Assistant Commissioner for Research and Statistics at the Social Security Administration. Professor Rice's major research interests and expertise include health statistics; survey research, design, and methods; disability; chronic illness; and the economics of medical care. She has achieved national and international renown for her leadership role, extensive research, and scholarly publications. Professor Rice has received numerous awards including an honorary Doctor of Science from the College of Medicine and Dentistry of New Jersey. She is a Fellow of the American Public Health Association and the American Statistical Association, and a member of the Institute of Medicine.

MONROE BERKOWITZ, Ph.D., is Professor Emeritus of Economics and Director of Disability and Health Economics in the Bureau of Economic Research at Rutgers University. He has served as a consultant to various government agencies including the Social Security Administration, the World Health Organization, and the American Association for the Advancement of Science. Dr. Berkowitz is a leading authority on the economics of disability and rehabilitation in public programs (SSA disability insurance and worker's compensation), private disability insurance, and public and private rehabilitation systems; and has conducted extensive comparative analysis of foreign systems. He is a member of the National Academy of Arbitrators, the National Academy of Social Insurance, the American Economic Association, and the Industrial Relations Research Association.

RONALD S. BROOKMEYER, Ph.D., is Professor of Biostatistics and Epidemiology at the Johns Hopkins University School of Hygiene and Public Health. He has been a Visiting Biostatistician at the National Cancer Institute and the International Agency for Research on Cancer in Lyon, France. Dr. Brookmeyer's research interests and expertise are in statistical modeling and methodology, biometrics, and epidemiology. He is the recipient of the Spiegelman Gold Medal awarded by the American Public Health Association for contributions to health statistics. He is a Fellow of the American Statistical Association and the American Association for the Advancement of Science, and a member of the Biometrics Society and the Society for Epidemiological Research.

GERBEN DEJONG, Ph.D., is Director of the National Rehabilitation Hospital Research Center and Professor of Family Medicine and Adjunct Professor at the Georgetown University Institute of Public Policy. Prior to coming to Washington, D.C., he served as Associate Professor in Rehabilitation Medicine at the Tufts University School of Medicine. Dr. DeJong has a special interest in managed care's impact on medical rehabilitation—people with disabilities and other vulnerable populations; health outcomes measurement, and medical ethics. He is probably best known for his seminal work on disability and health policy and the independent living movement. Dr. DeJong was a Fulbright Scholar in the Netherlands on the research staff of the Social Security Council. He is a member of the American Congress of Rehabilitation Medicine, the Association for Health Services Research, and the National Academy of Social Insurance.

MARSHAL F. FOLSTEIN, M.D., is Chair and Professor of Psychiatry at Tufts University School of Medicine and Psychiatrist-in-Chief at the New England Medical Center (NEMC). Prior to joining NEMC, he was Eugene Meyer III Professor of Psychiatry and Medicine at the Johns Hopkins Medical Institutions. His expertise and research interests are in neuropsychiatry, disability research, and Alzheimer's disease. Dr. Folstein created the Mini-Mental State Examination, widely used for assessing cognitive mental status in medical patients and in population surveys. He is a Fellow of the American College of Physicians, the American Psychiatric Association, and the Gerontological Society; and a member of the American Neurological Association and the Society for Epidemiological Research.

ROBERT M. GROVES, Ph.D., is a Professor of Sociology and Research Scientist at the Institute for Social Research at the University of Michigan, and is Director of the Joint Program in Survey Methodology, based at the University of

Maryland, a National Science Foundation-sponsored consortium of the University of Maryland, University of Michigan, and Westat, Inc. From 1990 to 1992, Dr. Groves was an Associate Director of the U.S. Census Bureau, on loan from Michigan. He has over 25 years of experience with large-scale surveys, and has investigated the impact of alternative telephone sample designs on precision, the effect of data collection mode on the quality of survey reports, causes and remedies for nonresponse errors in surveys, estimation and explanation of interviewer variance in survey responses, and other topics in survey methods. His current research interests focus on theory-building in survey participation and models of nonresponse reduction and adjustment. He is a fellow of the American Statistical Association, an elected member of the International Statistical Institute, former President of the American Association for Public Opinion Research, and currently Chair of the Survey Research Methods Section of the American Statistical Association.

ALAN M. JETTE, Ph.D., is Professor and Dean of Boston University's Sargent College of Health and Rehabilitation Sciences, and Professor of Social and Behavioral Sciences at the Boston University School of Public Health. His previous appointments have included: Chief Research Scientist, New England Research Institute; Associate Professor, Massachusetts General's Institute of Health Professions; and Assistant Professor, Division on Aging, Harvard Medical School. Dr. Jette's research interests include measurement, epidemiology, and prevention of disability and the critical evaluation of treatment outcomes in the medical and rehabilitation fields. He has developed several disability outcome instruments, widely used in health services research in the United States and abroad. Dr. Jette recently directed several health services research projects focusing on disability prevention, home care, and geriatric rehabilitation.

WILLIAM D. KALSBEEK, Ph.D., is Professor of Biostatistics and Director of the Survey Research Unit at the University of North Carolina-Chapel Hill. His prior experience includes statistical research with the Office of Research and Methodology at the National Center for Health Statistics and at the Sampling Research and Design Center at the Research Triangle Institute in North Carolina. Dr. Kalsbeek's research interests and areas of expertise are in biostatistics, survey design and research, spinal cord injuries, and assessment; and he is well known for his work in survey methods. He is a Fellow of the American Statistical Association, and a member of the Biometrics Society and the American Public Health Association.

JERRY L. MASHAW, LL.B., Ph.D., is Sterling Professor of Law and Management and Professor at the Institute of Social and Policy Studies at Yale University. He is a leading scholar in administrative law and has written widely on social insurance, social welfare issues, and disability policy. Dr. Mashaw recently chaired the National Academy of Social Insurance's Disability Policy Panel. He is a Fellow of the National Academy of Arts and Sciences and founding co-editor of the Journal of Law Economics and Organization.

CATHARINE C. (KATIE) MASLOW, M.S.W., is Director of the Initiative on Alzheimer's and Managed Care at the Alzheimer's Association. Prior to this, she was at the U.S. Office of Technology Assessment (OTA), and has experience in public welfare, mental health, and nursing home settings. Her research and consumer interests include aging, disability, criteria for long-term care, client assessment, and Alzheimer's disease. Ms. Maslow is a member of the National Association of Social Workers, the American Public Health Association, the Gerontological Society of America, and the American Society on Aging.

DONALD L. PATRICK, Ph.D., M.S.P.H., is Professor of Health Services and Director of the Social and Behavioral Sciences Program at the University of Washington School of Public Health. He holds adjunct appointments in epidemiology, sociology, and rehabilitation medicine and is a senior investigator at the University's Center for Disability Policy and Research and the Northwest Prevention Effectiveness Center. He is also Director of the U.S. Field Centre for the World Health Organization quality-of-life measures. Dr. Patrick's research interests and expertise are in health services, public health policy for people with disabilities and older adults, and quality-of-life assessment. He is a Fellow of the Association of Health Services Research, and a member of the American Public Health Association, the British Society of Social Medicine, and the Society for Disability Studies. He was the inaugural president of the International Society for Quality of Life Research and is a member of the Institute of Medicine.

HAROLD A. PINCUS, M.D., serves as a senior scientific consultant for the Robert Wood Johnson Foundation, the John D. and Catherine T. MacArthur Foundation and the RAND Corporation. Dr. Pincus was the Deputy Medical Director of the American Psychiatric Association (APA) and founding director of the APA's Office of Research. He is Adjunct Professor of Psychiatry and Behavioral Sciences at Duke University Medical Center, a Clinical Professor of Psychiatry and Behavioral Sciences at George Washington University, and a Clinical Professor of Psychiatry at the Uniformed Services University of Health Sciences, F. Edward Hébert School of Medicine. He has led major health policy and services research and training projects, and co-directs the Practice Research Network, a practice-based psychiatric research network. His research interests are in the relationships between mental health and general medical care; the diagnosis, classification, and treatment of mental disorders; and functional assessment and rehabilitation. Dr. Pincus is the 1997 recipient of the William C. Menninger Memorial Award of the American College of Physicians for distinguished contributions to the science of mental health.

JOHN A. SWETS, Ph.D., is Chief Scientist for Information Sciences at BBN Technologies in Cambridge, Massachusetts, a lecturer at Harvard Medical School on health care policy, and Senior Research Associate in Radiology at the Brigham and Women's Hospital. His research interests are behavioral modeling and analysis, specifically in applied signal detection theory to human perception and decision-making. Dr. Swets' theory created a new paradigm for the study of human sensory systems and addressed new areas in psychology and medicine. He is a member of The National Academies (NAS); the National Research Council's Board on Behavioral, Cognitive, and Sensory Sciences; and the immediate past chair of the NAS Commission on Behavioral and Social Sciences and Education. Dr. Swets is a Fellow of the American Association for the Advancement of Science, the American Psychological Association, and the American Psychological Society.

EDWARD H. YELIN, Ph.D., is Professor of Medicine and Health Policy at the University of California, San Francisco, where he has primary academic appointments in the Department of Medicine and Institute for Health Policy Studies. He is also the Director of the Arthritis Research Group at UCSF. Dr. Yelin's research interests concern the impact of managed care on persons with chronic conditions and disability and employment problems among persons with disabilities. He has over 80 publications in these areas, including *Disability and the Displaced Worker* (Rutgers University Press). Dr. Yelin is a member of the American Public Health Association and American College of Rheumatology. He has received many academic awards, including the Distinguished Scholar Award from the Association of Rheumatology Health Professionals.