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DISABILITY STATISTICS: AN ASSESSMENT

Report of a Workshop

Daniel B. Levine, Meyer Zitter, and Linda Ingram,
Editors

Committee on National Statistics
Commission on Behavioral and Social Sciences and Education
National Research Council

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The report was prepared by Meyer Zitter, Daniel Levine, and Linda Ingram, who were responsible for the proceedings of the workshop. Michael Cohen served as consultant to the workshop and contributed significantly to the report. Anu Pemmarazu assisted with the workshop, and Michele Conrad prepared the report for publication. The report also benefited from the thoughtful comments of reviewers and the editorial assistance of Elaine McGarraugh of the Commission on Social and Behavioral Sciences and Education.

Overview

BACKGROUND

Estimates of the number of persons with disabilities in the United States vary significantly, depending upon definition. For example, a person may be disabled with regard to a specific occupation but not with regard to other activities carried out inside or outside of the home. In addition, information on the extent, type, severity, and limitations in activities of disabled persons is difficult to obtain. To illustrate, estimates of the percentage of the working-age population with a work disability range from 17.2 (Social Security Administration, 1982) to 8.5 (1980 census). The range of estimates is equally large when dealing with the elderly, children, and youth. Furthermore, as the aged population of the United States increases, so will the number of persons with disabilities increase, and the implications for policy decisions become more immediate and important. Regardless of the weaknesses of current estimates, it is abundantly clear that effective planning for medical, rehabilitative, and social services will require reliable and consistent estimates of the numbers and characteristics of current and future disabled and chronically ill persons.

Persons with disabilities increasingly regard themselves as an identifiable and significant group that seeks to improve its position in society. There are, for instance, continuing discussions in Congress on legislation specifically extending civil rights protection to persons with disabilities (Americans with Disabilities bill pending in Congress). Without meaningful yardsticks, policy will be based solely on guesswork, with results that are not likely to meet the needs of persons with disabilities or policy makers' objectives.

Statistics on persons with disabilities are produced by many governmental agencies whose needs for information are governed and driven by their respective administrative requirements. These agencies, neither individually nor collectively, provide a consistently applied, widely accepted definition of disability. Similarly, among the general purpose statistical agencies concerned with disability measurement, a generally accepted, consistent definition of disability for planning and evaluation purposes is also lacking. The fragmentation of data on the disabled thus reflects multiple legislative mandates for varying programs with diverse purposes, a lack of consensus on an operational definition (or definitions depending on the purpose), and data needs governing the various data collection efforts.

As a first step in exploring these issues, the Committee on National Statistics convened a workshop in April 1989 to review factors involved in developing a common accepted definition of disability (or alternately several definitions as appropriate), to discuss the broad range of data needs, particularly for policy analysis, and to assess the desirability and feasibility of a panel study. Participants were drawn from the various federal agencies with a policy interest in disability, both those that collect disability statistics in connection with program operation and those that conduct general purpose surveys. Other participants included academic researchers and important users both within and outside the federal establishment and the Congress. A list of participants is shown in Appendix A.

The focus of the workshop was to assess the current state of disability statistics and the feasibility of a panel study to improve the collection and dissemination of disability statistics. Among the topics explored were concepts, definition and measurement problems, data needs and gaps, coordination and communication within and between producer and user groups, data dissemination, the utility of current national data sources, and the integration of various types of data.

This report of the workshop summarizes the discussion and recommendations flowing from the presentations outlined in the agenda (Appendix A). The report begins with an overview and summary of discussion on a variety of the more important topics raised in the workshop, including the workshop recommendations. The body of the report presents a detailed account of the workshop presentations, a section on the group discussions of the issues and recommendations flowing from those discussions, and ends with the concluding thoughts of the chair. A series of appendices providing additional background on a number of the topics is included as an integral part of the report.

Briefly, the workshop began with a summary of a background paper discussing the issues on the definitions of disability and the uses of survey data, prepared for the workshop by Lawrence Haber (Appendix B). This was followed by presentations by representatives of the Bureau of the Census and the National Center for Health Statistics (NCHS), both of which produce broad, general purpose disability statistics. The focus of these presentations was on near term data plans—the 1990 census, including a post-1990 survey of the disabled, and the Survey of Income and Program Participation (SIPP) by the Census Bureau, and the National Health Interview Survey (NHIS) by NCHS. The participants then heard from representatives of federal agencies with disability benefit program responsibilities—Social Security (SSA), Health Care Financing Administration (HCFA), Rehabilitation Services Administration (RSA), Office of Special Education Programs (OSEP), National Institute of Mental Health (NIMH), and the Department of Veterans Affairs. These presentations concentrated on the various systems and data sets generated by these programs, their accessibility, current and potential uses, research applications, and data needs and data gaps.

After the agency presentations the participants discussed a range of issues and concerns from the perspective of age/activity groups, including those related to disability statistics for the working population, the elderly, and for children and youth. For the working-age population, surveys ask about ability to perform usual activity which is paid employment, although they sometimes include homemaking for one's own household. For the aged population, surveys measure ability to perform their usual activities and measures of dependency, such as needing assistance in personal care (ADLs) and household care (IADLs). For children, disability is usually measured in terms of a child's ability to perform social roles: for older children, school attendance represents a generally accepted social role; there is much less agreement about what constitutes an appropriate social role for children of preschool age and social roles are even more difficult to define for infants. The workshop concluded with a discussion led by the chair, Dorothy Rice, that focused on age-related disability issues, definitions, data needs, coordination issues, and finally, on the need for a panel study.

MAJOR ISSUES AND RECOMMENDATIONS

The workshop participants represented different areas of interest related to the production of, need for, and the use of disability data. Reflecting these disparate concerns, there was a wide-ranging discussion on the characteristics, content, and scope of a disability statistics program. However, a number of common and recurring issues emerged:

- concepts, definitions, and measurement problems
- coordination
- the need for longitudinal data
- data needs for policy analysis
- data needs and data gaps
- data linkages and data matching
- data analysis
- information on onset and duration of disability
- sampling
- international comparability

Concepts, Definitions, and Measurements of Disability

The variety of disability concepts and definitions that are currently employed result in a wide range of estimates for the number of disabled persons. The terms impaired, disability, illness, disease, sickness, and handicap are used with a great deal of inconsistency, resulting in differing estimates of prevalence. These disability terms from Rice (1989) are briefly described below. Public programs providing benefits to some persons with disabilities define disability according to their eligibility rules. The prevalence and severity of disability are measured in sample surveys, but questions are worded somewhat differently. Incidence, as opposed to prevalence, raises additional measurement problems (although prevalence was the main focus and concern of the workshop). These differences contribute to variations in estimates of the disabled.

Disability Terms

Disease is defined as any bodily disturbance associated with a characteristic set of signs or symptoms. Signs consist of observable health characteristics such as fever, lumps, elevated blood pressure, and laboratory results. Symptoms, however, are not directly observable but are reported by individuals.

Injury refers to damage inflicted on a body by some traumatic, usually external force.

Illness is the perception of disease or injury by the individual. Illness is a psychological state; a person may feel ill in the absence of a clinically verified disease or injury.

Sickness is the state of being labeled by oneself or others as having a disease or injury.

Impairment is a chronic physiological, psychological, or anatomical abnormality of bodily structure or function caused by disease or injury.

Chronic illness means the presence of long-term disease or disease symptoms.

Chronic condition is a more general term; it includes impairments not due to diseases.

Disability is defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner, or in the range, considered normal" (World Health Organization, 1980). Since human activity is variable, there are many different kinds of disability.

Work disability is a function of the vocation for which a person is trained, which is often selected early in adulthood and may be influenced by impairment existing in youth.

Handicap is the social and economic disadvantage that may result from impairment or disability and may entail loss of income, social status, or social contacts.

Coordination

A common theme was the need for better coordination among data producers, more communication among producers and users, and more communication among the users themselves. However, achieving more networking and communication would be a major undertaking because of the large number of agencies and departments concerned with statistics on the disabled. Several entities that could facilitate coordination, including the Office of Management and Budget, the American Statistical Association, and the National Academy of Sciences were suggested. Coordination or some form of central leadership would lead to improved communications between and among producers and users.

Data Needs for Policy Analysis

The various estimates from different surveys and programs that presently exist confuse users of these statistics, including policy analysts and decision makers. Policy analysts need disaggregated data for population sub-groups, such as age, sex, and ethnicity sub-groups, as well as for sub-national geographic areas with some degree of definitional consistency across areas. A big question is whether there should be one survey or one minimum data set that would provide disability data to the entire disability research and policy community. Although there is support for this idea, there is hesitation about imposing one survey on researchers and policy analysts with varying needs.

Developing a single disability indicator or rate also needs to be considered. This rate, like the infant mortality rate, would be useful and understood in tracking societal well-being. While this would focus policy attention on disability, it would be difficult to obtain agreement on the underlying measures.

Some other questions considered under this rubric include: What kind of topics and new areas of data do policy formulators need? How can two proposed policies be compared for effectiveness? Does the government need attitudinal data? Can we obtain data about persons with disabilities in a timely manner to be responsive to policy formulation?

Other examples of data gaps for policy formulation include information on service needs and barriers to receipt of services, and on costs (emotional, financial, and social) to the disabled and to those who care for persons with disabilities and information on the impact of rehabilitation services.

Another area of concern is the need for *longitudinal studies*. Since disability is best conceived of as a continuum or process, longitudinal data from onset through various levels of deterioration and rehabilitation is required for addressing policy needs. Such studies also could provide important information on access to and use of rehabilitation services and their impact on individual lives, program participation, and program evaluation. To project the medical and social furtherance to meet the needs of the growing number of persons with disabilities, data are required for a relatively long period of changes in the characterization of these persons, their use and cost of services, and the nature of this support system, both formal and informal.

Data Needs and Gaps

In the discussion, much attention was given to the need for new data in areas not sufficiently covered by existing data sets. Specifically, participants emphasized the importance of developing indicators in such areas as epidemiology, demography, health services, health insurance coverage, rehabilitation, employment, earnings, social services, benefits, and quality of life. Much interest also was expressed in reexamining and mining more fully the existing data sets.

Data needs for the growing number of elderly people with disabilities were discussed. The elderly are a very heterogeneous group, physiologically, psychologically, and clinically. It is important to note that the needs of the elderly differ from those of younger individuals, not only from a quantitative perspective, but also qualitatively. Their medical care, social, and rehabilitation needs reflect a complex interaction of the physiologic changes with age, their psychosocial concomitants, and their pathologic changes that occur with advancing frequency. Policy analysts need to be able to detect trends and to forecast changes among the elderly in their health and disability status, use and cost of services, and quality of life. The recent report issued by the Committee on National Statistics, *The Aging Population in the Twenty-First Century: Statistics for Health Policy* (National Research Council, 1988), addresses many of the complex data issues and needs relating to the changing age structure of the population. The workshop participants recognized the major contribution of this report to health statistics needed for an aging population, but felt that specific focus is required on the special data needs of elderly persons with disabilities.

There also was discussion on developing data on children's disabilities as several of the current surveys and censuses exclude children from coverage. Participants noted the special problems of children and thus the importance of including them in longitudinal surveys. Such surveys could measure transitions that occur in the lives of children with a disability and provide needed information on medical care utilization and expenditures over time. The need to sharpen the concepts and tools for measuring children's disabilities has been noted, and the need for more data on children with disabilities emphasized.

Data Linkages and Data Matching

Data linkages can significantly enhance the integrity of existing databases at a marginal cost, but the underlying obstacle, according to the several agencies maintaining large individual record data files, remains the issue of confidentiality. This issue needs to be more fully addressed if access to individual data files and data linkages are to be facilitated for both interagency and academic researchers involved in the collection and analysis of disability statistics. The establishment of "statistical enclaves" as one possible solution was noted, but past efforts in this direction have had only limited success.

Data Analysis

Alternative analytic approaches to utilizing existing data sets could lead to the development of a single "index of disability," one overall (but perhaps very rough) measure of disability that can be compared over time among various areas and different population groups. Mention was also made of the feasibility of developing life tables (from existing data) and using life table methodology to derive "active life" expectancy tables (using the concept of disability-free years). This would be a useful product in the armamentarium of disability measures.

Sampling

Problems in sampling a rare population such as the disabled need methodological consideration and warrant special attention.

International Comparability

It was suggested that more research should be done on the World Health Organization (WHO) classification system *The International Classification of Impairments, Disabilities and Handicaps* (ICIDH) and on comparisons with the U.S. classifications. At present, there are problems with county-to-county comparisons because of the lack of a common concept.

Recommendations

The study of disability statistics is complex and is compounded by the fact that we need to deal with and understand the varied concepts of disability at different stages of the life-cycle, namely, the working-age, the elderly, and children and youth and the methodological and measurement problems associated with each population group. It was clear from the workshop deliberations that although there is much activity and no dearth of statistics on disability, the present system of statistics seems to lack cohesion, coordination and direction. Thus, the workshop participants recommended that a panel be established to study disability statistics and identified a wide range of items as potential topics for in-depth investigation.

A panel would explore in depth the major concerns expressed by the workshop participants as outlined above. It should be emphasized however, that the study would not attempt to design specific survey instruments. The panel would review current data collection systems on disability, identify strengths or weaknesses, and recommend improvements in survey methodology and content. A key objective would be to assess the adequacy of and make improvements in the broad-based, general purpose and program statistics to attempt to answer the questions of the management of the problem and how it is changing over time—whatever the stimulus—with attention to relevant policy formulation, policy analysis, and planning for the future. There was implicit recognition that statistics are needed to study disability under various definitions, to enable the definitions to be compared, to provide data on the effect of disability on the lives of disabled individuals, to study the course of disability longitudinally, to examine the usefulness of rehabilitation services, etc. A panel study could deal with the many conceptual issues involved in defining disability as well as the problem of quantifying the uncertainties of disability measurement. Such information also would provide both demographic and socioeconomic detail to assist the multiple uses and users of disability statistics.

As a final note, the workshop also expressed its support of efforts to conduct a post-1990 census disability survey, which would provide needed disability statistics at the sub-national level.

Workshop Proceedings

INTRODUCTION

The workshop began with Lawrence Haber's summary of the key points in his background paper, "Issues in the Definition of Disability and the Use of Disability Survey Data" (see Appendix B). Haber raised the following issues: (1) alternatives to the present "functional" approach to defining disability; (2) adopting the World Health Organization (WHO) approach to disability research; (3) alternatives to the self-reporting of work disability; (4) the role of administrative records in estimating disability prevalence; and (5) the need to reconcile and/or merge the various administrative data with survey-based results.

Haber noted that despite the 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 varies considerably among these studies. Such variation has little to do with time trends but seems to be more related to the purposes or auspices under which the studies are conducted and particularly to the variation in questionnaire language. Haber also stressed the need to review, analyze, and extend the data that have already been collected and to learn from existing research. He concluded with the following suggestions for prioritizing future data collection activities:

1. a predictable study cycle for disability data;
2. a disability follow-up study to the 1990 census to provide detailed, extensive data at the state level;
3. a mid-decade mini-census, with appropriate attention to disability-related issues; and
4. the reinstatement of a longitudinal disability supplement in SIPP.

DISABILITY STATISTICS BY GOVERNMENT AGENCIES

Bureau of the Census

Jack McNeil discussed the disability items in the various household surveys that are conducted by the Census Bureau, including the 1970, 1980, and 1990 censuses, the 1976 Survey of Income and Education, the 1981-1989 March supplements to the Current Population Survey, and the 1984 panel of the Survey of Income and Program Participation (see Appendix D). He pointed out that the work disability question on the decennial census questionnaire produced reasonably reliable responses, and that work disability correlates negatively with socioeconomic status thus providing good information on the target population for assistance programs. The 1980 census, however, collected no information on children's disabilities, older people who have nonemployment-related functional limitations, or employed disabled people who manage to work despite their disability. Also, the Census Bureau obtains information from a single household respondent in its surveys; thus, many proxies are used to obtain information on those with disabilities. The decennial census, however, is mainly self-enumerated so the individual with the disabling condition would have an opportunity to respond directly.

Some items on children with disabilities and chronic conditions were enclosed in a national content pretest for the 1990 census but were then rejected because the data were considered to lack reliability. Some questions on mobility and self-care limitations have remained, but these are limited to the adult population aged 15 years and over. Neither the 1970 nor the 1980 census included questions about children's disabilities or about nonemployment functional limitations. A pretest for the 1980 census incorporated several questions about various types of activity limitations, but the responses were considered inconsistent and nonresponse was high, so these items were deleted. The 1980 census also contained a question on the use of public transportation, but the question apparently was not perceived as useful and had been dropped for the 1990 census.

McNeil briefly described the pretest for a post-censal disability survey that was planned to be based on the 1990 census. The pretest was conducted in Richmond, Virginia in 1979, on 1,000 households with a disabled person and 1,000 households without disabled persons. A screening questionnaire asked both groups about functional and household limitations, work and transportation, followed by a comprehensive questionnaire administered to those respondents with a disability. The survey did not cover all ages. The pretest provided good information, as measured by reinterview consistency, although there was some variation across items. However, since funds for the survey were denied, the survey did not take place.

The Census Bureau has not proposed to conduct such a survey after the 1990 census. There have been many requests for a disability survey based on the 1990 census, however, and some activity in this direction continues, including preparation of cost estimates by the Census Bureau.

McNeil noted that the 1984 SIPP provides better data on disability than other census data sets because it included several questions on functional limitations. This series of questions was repeated in 1988 and 1989 in different waves of SIPP. However, the sample size is smaller than in 1984: 12,000 households for each wave, which, given the relatively low incidence, makes it difficult to measure the prevalence of some disabilities with adequate precision. The disability questions were not repeated for the same respondent in 1988 and 1989, this is not important since it is thought that there is very little change in disability status over a 2.5-year period. The SIPP was never expected to measure individual changes in disability over time. (The above reflects the status of SIPP as of the date of the workshop, April 1989. Plans may have been affected by budget constraints since this date.)

In a response to several questions concerning perceived omissions in the census questionnaire, it was pointed out that the decennial census is a very specialized and unusual statistical activity. Because of space limitations and self-enumeration, there is great emphasis on brevity and clarity of the questions. The number of questions on disability therefore has to be strictly limited, and the questions have to be straightfoward. Another problem is that disabled people may be reluctant to respond positively to a disability question because they view the disability as a stigma. This reluctance may result in some understatement of the level of disability in the population. To date, the Bureau has not had the resources to permit the testing of alternative questions that would address the stigma effect. Despite the problems with census disability measures, workshop participants agreed that the decennial census must include a disability question in order to give disability estimates for local areas and for small population subgroups.

National Center for Health Statistics

Gerald Hendershot discussed the disability data collected in the National Health Interview Survey (NHIS) (see Appendix C). The NHIS, which has been conducted by the NCHS since 1957, is a continuous, cross-sectional survey of the civilian, noninstitutionalized population of the United States, based on a stratified, clustered area-probability sample. (Another NCHS survey, the Nursing Home Survey, uses an institutional frame.) With its current sample design, introduced in 1982, the NHIS yields information on about 900 families and 2,500 persons per week, or about 45,000 families and 125,000 persons per year.

The NHIS questionnaire has two parts: a core health and demographic questionnaire that is revised about every 10 years; and a special health topics questionnaire that is new in each calendar year. The questionnaires are administered in face-to-face home interviews by specially trained Census Bureau interviewers. All adults present at the interview are invited to respond for themselves to the basic health and demographic questionnaire; an adult proxy informant responds for children and absent adults. For the special health topics questionnaires, a single adult usually is subsampled from the family and self-response is required. Response rates for the basic health and demographic questionnaire average about 95 percent; response rates for the special health topics questionnaires are usually in the range of 85-90 percent.

Although the NHIS is designed primarily as a cross-sectional survey, it can accommodate ad hoc longitudinal data needs: (1) information is collected to identify the death records of sample persons in future years through the National Death Index and for matching to Social Security records; and (2) tracking information is collected so that respondents can be located for reinterview in person or by telephone in future years.

Several measures related to disability are available routinely from the NHIS basic health and demographic questionnaire; other measures have been available from various special topics questionnaires. The measure most closely related to the concept of disability is "limitation of activity," defined as a limitation of normal functioning due to a chronic health condition. Limitation is measured at four levels: unable to perform major activity; limited in major activity; limited in nonmajor activity; and not limited in activity. "Major activity" is defined as play for pre-school children, school for school-age children, work or housework for adults 18-69, and personal care and home management for adults 70 and over. If a person is reported to have a limitation of activity, additional questions determine the chronic health conditions or impairments causing the limitation, which are coded to 4-digit ICD codes.

Another NHIS measure related to disability is the prevalence of certain chronic conditions or impairments often resulting in disability, such as deafness, blindness, loss of limb, arthritis, and so on. Questions are asked about more than 120 specific chronic conditions; however, to minimize respondent burden, the conditions are divided into 6 different lists, and only one randomly selected list is asked in each sample family. This has two important consequences for estimates of disability in the population: (1) the sample size for any given chronic condition is only one-sixth of the total sample, causing sampling errors to be relatively large; (2) the presence of "comorbidity" (more than one chronic condition in the same person) is not detected if the comorbid conditions are on different lists.

A third NHIS measure related to disability is "restricted activity days," on which the sample person stays home from work or school, stays in bed, or otherwise cuts down on his normal activity. Questions about restricted activity days are asked about a specific 2-week reference period before the interview to reduce recall bias. If restricted activity days are reported, additional questions are asked to determine the condition causing the restriction.

These measures have been available, with some changes in procedures, over the 30-year history of the NHIS. Some other measures of disability have been available periodically as part of special health topics questionnaires. The following disability measures have been obtained in the special health topics surveys in recent years: child health (1988), alcohol dependency (1988), work injuries (1988), poliomyelitis (1987), functional limitations (of the elderly, 1986), aging (1984), child health (1981), home care (1979 and 1980), and special aids (for handicapped persons, 1977).

Social Security Administration

Paula Franklin presented information on disability data in the SSA. The disability definition for entitlement of benefits is the same for both the Title II Disability Insurance Program and the Title XVI Supplemental Security Income program, although other requirements differ. Disability is defined under the two programs as "inability to engage in substantial gainful activity because of any medically determinable physical or mental impairment lasting at least twelve months." Because of fiscal constraints in the survey research area, demonstrations addressing issues of beneficiary rehabilitation and return to work have received priority through demonstration projects that have been the main vehicles for data collection. The current demonstrations budget is about $10 million a year.

The central questions have shifted in the past couple of decades from disability prevalence, the socioeconomic conditions linked to disability, and the need to provide new government services to more targeted questions related to interventions aimed at returning persons with disabilities to the mainstream occupations of society: work, occupational training, and independent living supported by community services.

Some of the major categories of SSA disability research are: current estimates and future projections of disability and disease prevalence; the economic and social impact of disability; and detailed, current, and accurate disability program management information. In addition, cost projections and studies on the likely impacts of alternative legislative initiatives are frequently requested.

To meet these research objectives, both survey and administrative records are used. Administrative data are essential to determine the demographic and program characteristics of beneficiaries, both newly awarded and in current benefit payment status. Studies on denials, terminations, and the disability decision-making process also are based on administrative records. Health care use by type of disability can be examined by linking SSA with HCFA files.

Recent SSA surveys include the New Beneficiary Survey (1982), the Retirement History Survey (1969-79), and the Survey of Disability and Work (1978). The follow-up to the New Beneficiary Survey, which will contact the same beneficiaries, has just been contracted. In addition, there has been interagency collaboration in collecting and using survey data. Data from the Census Bureau SIPP Survey are presented in the *Social Security Bulletin Annual Statistical Supplement*, and segments of the SIPP have been linked to SSA administrative records for analysis. Social Security program participation questions have been added to the National Health and Nutrition Examination Survey III (NHANES III). These surveys, in addition to the NHIS and the current National Medical Expenditure Survey (NMES) conducted by the National Center for Health Services Research, are providing information on the general disabled population.

These surveys do not provide large sample sizes of SSA beneficiary populations. Without a large scale, longitudinal survey of disabled awardees, it is impossible to determine changes over time in health status, utilization of medical and rehabilitation services, work attempts, employment opportunities, income, assets, and living arrangements. Beneficiary surveys are also needed to determine the effect of recent work incentive, rehabilitation, and health insurance coverage legislation on beneficiary behavior.

Health Care Financing Administration

Penelope Pine gave a presentation on the Medicare/Medicaid data sets. Medicare, whose population is defined by Congress, has one of the best national data bases available. In addition to the population 65 years and over, some 3 million persons under age 65 are covered by Medicare because of disability and are included in these data sets.

Medicaid, whose population is defined by the state legislatures, has only aggregate data available at the national level. HCFA is currently looking at the disaggregated data bases of 30 states.

Some of the areas now being examined at HCFA using these data bases are:

- service utilization patterns for Medicare/Medicaid program eligibles;
- estimating costs of eliminating the 24-month waiting period before a disabled person can receive Medicare disability benefits;
- severity of disabilities of those who go into intermediate or long-term care; and
- analysis of Mentally Retarded Developmental Disability (MRDD), the most costly population in Medicaid (see Appendix D for a list of some of the research available using the Medicare/Medicaid data bases).

Because of the comprehensiveness of these data bases, it is important for policy research to be able to link them with other complementary data bases. Proposed linkages include:

- Medicare with Medicaid (some of this has been done);
- HCFA data with SSA data (done at one time but cannot be done again because of confidentiality problems);
- HCFA data with the National Medical Expenditure Survey (NMES): confidentiality problems (preclude this linkage in general), although it may be performed through the Office of the Assistant Secretary for Policy and Evaluation); and
- Medicare data with the National Long-Term Care Survey conducted by HCFA and Assistant Secretary for Policy and Evaluation (this linkage has been contacted).

In addition to confidentiality problems, the vast amount of documentation required for successful matching is a major deterrent.

Rehabilitation Services Administration

Larry Mars described the data systems at RSA. RSA has or will have 12 systems or subsystems of data describing the state-federal program of vocational rehabilitation (VR). The two systems of greatest interest to researchers and evaluators are the Case Service Report (RSA-300/911) and the RSA-SSA Data Link.

The Case Service Report contains sixty personal and program-related items of information on each of 600,000 disabled persons whose cases are closed out each year by state VR agencies (whether successful or not). Data gaps are: (1) fringe benefits resulting from employment; (2) work history prior to rehabilitation services; (3) public assistance amounts received by clients before and after rehabilitation services and; (4) primary source of support at closure. A serious problem has been RSA's inability to manage, process, and analyze data from the Case Service Report and the other reporting systems because of inadequate staffing and resources. A proposal has been prepared that, hopefully, will lead to the establishment of a data center in 1990. The Case Service Reports are not available as public use tapes, but can be obtained by special request and all requests are granted.

The RSA-SSA Data Link contains selected Case Service Report items and earnings and beneficiary data on nearly one million clients whose cases were closed out in FY 1975 by state VR agencies. The earnings and beneficiary data are available from Social Security records for 1972 to 1983, or from about 3 years before case closure to 9 years after closure. RSA gave a tape of cases to SSA, and SSA provided 12 years of SSA data on those cases, including before and after the rehabilitation closure. (This tape includes some RSA rejects.) Social Security is currently working to correct errors in the FY 1975 tape now available, update the earnings and beneficiary data to at least 1986, and begin merging records on VR clients whose cases were closed in FY 1980. The entire Data Link process could be improved by the presence of a permanent Data Link unit in both RSA and SSA and by the enhancement of RSA's capacity to use the tape now in its possession to generate its own tabulations of data. A successor cohort is now being attempted so that continuity in data linkage will not be lost.

Mars noted that the Rehabilitation Act requires each state to conduct a statewide study of the handicapped—where they are, what services they need, etc. It would be preferable to conduct a national survey that would provide state estimates because the states clearly do not have the capacity to conduct surveys and many states are making wild estimates.

Office of Special Education Programs

Susan Thompson-Hoffman noted in her presentation that several laws in the special education area require data collection. There is a requirement that disabled students be served in the public schools and they require annual evaluations from birth to age 21 (11 conditions are covered). Data must be collected on the number of children who receive special education and related services, where they are placed (schools or residential facilities), dollars expended, the number and types of personnel, and a description of the services. Data must also be collected on children in state-operated programs who are more severely impaired. Under another law, data must be collected on the provision of services to infants and children aged 0-5. Data are collected on 4.5 million students in 15,000 school districts and are aggregated at the state level and reported annually to Congress. The current philosophy in special education is to serve as many children as possible in the least restrictive environment. For this reason data collection on children with disabilities has been more difficult because such children are not separately identified.

There also have been several legislatively mandated studies, including a recent longitudinal study of 11,000 handicapped students aged 13-26 that focused on demographics and outcomes, such as vocation and independent living.

An important area of interest to OSEP is outcome data, including further education, vocation, and independent living (including data on dropouts from regular schools and institutions). It is useful to have these data by handicap, age, sex, ethnicity, and severity. OSEP currently has no data on sex and ethnicity because the Office of Civil Rights (OCR) has a mandate that does not permit data collection of these items. In addition, OCR does not collect data on all the handicapping conditions; only data on the most litigated types of handicaps are collected due to funding constraints.

Because of legislative requirements, there is an interest in data on health status, children aged 0-5, prenatal care, early intervention, physician and hospital visits, and the presence of a case manager.

There is also a need for basic methodological studies, e.g., on the reliability of parents' reports about children's conditions and about participation in services. Parent reports frequently have been found to be unreliable. There is also a need for a functional limitation/capacity scale for 8 of the 11 handicapping conditions. Three of these conditions are very severe per se, but in the other 8, severity can vary. Finally there is concern about concepts. For example, asking if a child is in a special class or special school may result in an underestimate of special education students because of the recent trend toward mainstreaming disabled children.

The implementation of recent laws concerning those with disabilities has resulted in an increase in the percentage of those with handicaps, especially in the "learning disabled" area, a very ambiguous area with no common definition.

Because counts of children are programmatic, data reflect state and local practices and financial incentives to schools. The visually handicapped, for example, are frequently counted under other headings, such as "multi-handicapped" or "learning disabled." Another administrative problem in data collection is that eligible children are not counted by OSEP if they are in private programs and do not use federal or state money, causing low prevalence estimates.

In regard to related data collections, the Center for Education Statistics (CES) has a new Schools and Staffing Survey, that will report on numbers of persons with disabilities by handicapping condition at the state level. Also, OSEP works with CES to put disability questions on the CES surveys. OSEP has also worked with the National Assessment of Educational Progress (NAEP) on a dropout study.

National Institute of Mental Health

Harold Goldsmith discussed the National Reporting Program for Mental Health Statistics. The Survey and Reports Branch collects national statistics on specialty mental health organizations and the patients they serve, conducts applied demography research, engages in the development and refinement of minimum data sets that serve as standards for the field, and conducts the annual National Conference on Mental Health Statistics. (For representative current projects, see Appendix E.) These projects do not cover statistics collected in grant programs. The unit of analysis usually used is the organization or facility in which patients are aggregated. NIMH data do not capture anyone who is not treated as an inpatient or at a clinic.

In addition to these data collection activities, NIMH has sponsored questions on mental health (self-reports) and on instrumental activities of daily living (in the NHIS pattern) in the National Medical Expenditure Survey.

In regard to the determination of symptoms, NIMH collects data from the five Epidemiological Catchment Areas (ECAs) that cover various sections of the metropolitan United States. Diagnostic Interview Schedules (DSM IIIR) are used, which identify disorders and degree of severity, and some interview schedules include activities of daily living (ADL). NIMH is currently sponsoring a related project in Colorado using the DSM IIIR but are asking more questions on function. There is a cognitive impairment scale in the ECA data that gives symptom patterns for 27 specific diagnoses, allowing crude national estimates of prevalence of mental disorders.

Cooperative agreements between the NIMH and the five ECA sites have ended, decreasing the longitudinal aspects of the data that had been guaranteed by federal involvement. Each site is now independent and the sites are funded for individual projects, e.g., analysis of data collected. The ECAs conducted a large pretest of instruments that has led to a new generation of measurement instruments.

In 1989, NIMH and NCHS cosponsored a survey on chronic mental illness to make national estimates of the prevalence of mental disorders in the general population. Since the diagnoses was obtained from respondent reports, the respondent had to be willing to tell the interviewer that he or she had a symptom and could identify it. Pretests were conducted with mental patients.

Department of Veterans Affairs

Steven Dienstfrey noted that the Veterans Administration (VA) pays compensation to disabled veterans, whether service-connected or not. Eligibility for medical care is determined by a mean test which is waived for certain service-related conditions. The VA commissioned a Louis Harris survey of aging veterans in 1983. This survey produced data on VA-extended care programs, hospitalization of veterans over age 55, current health status, and future demand for health care and social support services. Major surveys with disability components also have been conducted of female veterans and of all veterans. From internally generated data, VA publishes a 4-page fact sheet twice a year on "Disability Compensation, Pension & Death Pension Data" that has aggregate figures on sex, degree of disability, unemployability, type of disability, aid and attendance, housebound, special monthly compensation, and dependency. While these data are not public use, special requests can be handled.

DISABILITY STATISTICS BY AGE/ACTIVITY GROUPS

Disability Statistics on the Working-Age Population

Mitchell LaPlante, Director of the Disability Statistics Program at University of California, San Francisco, discussed disability statistics on the population of working age (see Appendix F for a description of the Disability Statistics Program at University of California, San Francisco). LaPlante defined work disability as "unable to work" or "limited in ability to work." "Unable" is more clear-cut than "limited," which requires more elaboration. For example, has someone changed jobs since the onset of the disability? What is the nature of the work restriction? The magnitude of the disability problem among the working-aged population is indicated by the fact that 40 percent of long-term care services are provided to people under age 65 (this includes institutionalized populations). Also, there is much commonality in the levels of disability between the elderly and nonelderly as measured by ADL (activities of daily living) and IADL (instrumental activities of daily living) correlates.

Looking at just those people who may be in the work force, the "disabled," as defined by the SSA, account for less than half the working population who in the NHIS are reported as having health limitations. Similarly people receiving SSI or SSDI are fewer than a third of those in the NHIS reporting major activity limitations. Clearly, there are many people in the work force with various types of limitations.

LaPlante then noted the major data gaps in several data topics for disability statistics on the working-age population in several areas (Appendix G). These data are not available because they are either not collected, not analyzed, or not disseminated.

LaPlante made the following suggestions for ways to fill some of the data gaps:

- development of a complete, detailed inventory of data systems relevant to disability
- expansion of the NHIS questions on disability; linkage among data sets
- improvement of income data in the NHIS
- oversampling persons with conditions and disability
- more effective use of supplements to the NHIS on disability topics
- greater disability content in the SIPP
- disability minimum data set
- longitudinal data permitting study of transitions

The discussion identified some of the problems in measuring workplace disability accurately. On the one hand, the worker may be observed in the workplace to identify his or her actual limitations, which may be alleviated by environmental accommodation. On the one hand, workplace limitations may not be the place to start since some people "work around" their disability and would not be helped by admitting to it, thus foregoing any accommodations that might be made. Others, including some scientists who have disabilities, are *not* limited in the workplace. In this case, "work potential" rather than "work limit" seems to be a more useful concept. A variety of questions arise: What are the psychosocial aspects of making the decision to work or not work? Why are some people able to work with a disability while others are not? How is early retirement related to disability? More subtle measures than have been previously used may be necessary to truly reflect the extent and nature of disability during the working years.

Disability Statistics on the Elderly

Lois Verbrugge noted that there is a growing recognition of disability as a concept relating to the quality of life. The sociomedical view looks at disability as the endpoint of a complex process. People place buffers in the way of disability if they feel the need, e.g., they use accommodations. If a respondent is asked, "Do you have any difficulty in doing X (activity)?", he or she will say no if enough buffers are in place. Thus, the number of disabled can be construed to be the number of those who do not have enough buffers in place.

Generally, government surveys employ measures of disability that are measures of dependency (needing assistance from another person) in personal care (ADL) and household care (IADL) activities. This is a very narrow perspective of disability as experienced in real life by people with chronic conditions. In real life, difficulty in performing social tasks typically precedes the need for personal assistance. Problems in functioning pervade the broad spectrum of human activities, including hobbies, care of other family members, education, entertainment, civic/religious activities, and sports/active leisure. All of these are valued arenas of social life. These problems are not limited to ADL and IADL. There is a need for disability thinking and research to be broadened to include the true scope and course of chronic disease impact. Chronic conditions make it difficult to conduct life "as usual"—and "usual" changes over the course of a condition.

An epidemiological framework is needed, which follows the course a condition takes, leads to asking about capacity to perform an activity, rather than about dependency. What should be measured is the use of buffers or accommodations in overcoming disability. There should also be questions about all the important domains of life, not just ADL and IADL, in order to identify the changes that come early in regard to hobbies, church activity, driving, playing with grandchildren, and nurturing behavior.

Time budget research shows that chronic disability causes people to change their management of time. The sequence of changes is best seen for chronic conditions that progress slowly, such as osteoarthritis or hearing impairment. There are examples of time expansion and contraction, and of activity addition and deletion, due to arthritis. Examining changes in time spent on all activities provides the means to look at the staging of disability and questions about ADL and IADL do not permit such analysis. A time-use perspective should be incorporated into health survey research along with the more standard measures such as dependency.

The question of how to identify the disabled population has several aspects. An agreed-upon classification technique must be found, from which subgroup profiles could be developed. A broad net of questions must ask about all valued activities. Longitudinal surveys are necessary because disability is dynamic in a way that mortality and prevalent chronic conditions are (usually) not. There is a need to distinguish physical disability from social disability i.e., musculoskeletal dysfunction from social task difficulties. Also, the difference between "limitation rates" (limiting conditions per 1,000 population) and "limiting potential" (the probability that a given condition causes limitation) must be established.

The discussion centered on what types of surveys could most cost-effectively and easily provide these data: one longitudinal survey, many surveys, or ECA data.

Disability Statistics on Children

Paul Newacheck discussed disability statistics on children. Federal legislation now requires that funds for disabled children reach them through the schools. Data that could be used to allocate this money have been routinely collected in NCHS surveys, but data are infrequently used because of concerns about validity and reliability.

In almost all national surveys, disability of children is measured in terms of a child's ability to perform social role activities. For older children, school represents a reasonable social role, but there is much less agreement over what constitutes a valid social role for preschool children. Even when a social role is specified, such as play, it is difficult to determine whether a limitation is the result of the child's developmental stage, parental encouragement of dependence in early childhood, or an underlying physical or mental health problem. Ascertaining disability in infants is especially difficult, because social roles and activities are least well-defined. The lack of respondent agreement on what "disability" is in children is illustrated by a survey that compared parent and teacher ratings of learning disability. While parent-teacher agreement was high in the case of mental retardation, only 57 percent of children identified as having a learning disability by teachers were similarly identified by parents.

The reporting of childhood disability, especially learning disability, is also sensitive to changes in questionnaire wording, leading many observers to question the utility of childhood disability data from national surveys. Newacheck gave an example of a wording change in an NHIS questionnaire that resulted in the estimated number of children aged 6-16 unable to conduct their major activity due to chronic conditions increasing over 400 percent in one year.

In addition to validity, the statistical precision of survey studies of disability for children is a problem. Disability is fortunately a relatively rare event among children requiring large samples to generate accurate prevalence estimates or to conduct epidemiological studies of childhood disability. Even very large surveys, like the NHIS, generate small numbers of disabled sample children. For example, in the 1984 NHIS, that sampled 105,000 persons, 14,571 cases of disability were reported, but only 1,514 were children, and only 123 of these children were severely disabled. Newacheck combined multiple years in order to increase the numbers, but a drawback to this method is that not all the same related characteristics are collected every year, making analysis of these relationships between these characteristics and disability difficult to conduct.

Newacheck's overall conclusions were that current national data on childhood disability are limited by the following factors:

- the questionable validity of existing disability measures for very young children;
- the absence of agreement among different types of informants over whether a disability is present;
- the sensitivity to reporting of minor changes in question wording;
- statistical imprecision associated with the rarity of disability among children; and
- few data on institutionalized children, who make up almost half of the severely disabled in this population group.

Newacheck suggested that the following steps would be useful in improving disability statistics on children:

- a careful study of data collection methods for obtaining data on childhood disability, including studies of the effects of questionnaire wording and studies of the effects of proxy informants and of self-reporting for older children; and
- consideration of ways to expand survey sample sizes to provide more reliable estimates of childhood disability, including the use of network surveys and other nontraditional sampling approaches, and the inclusion of childhood disability measures in the decennial census, or other census surveys.

A brief discussion followed of how children might be interviewed. For child respondents, some rewording of standard disability questions might be necessary. For example, children do not know how to respond to a question on "limitations." Showing pictures is one method, but when this method was used with people limited in English speaking ability, it did not work. The Youth Survey of the National Longitudinal Survey (NLS) tested 5,000 children in their households, using various diagnostic tests, and very usable data were collected. Hendershot noted that the NHIS is moving in the direction of covering both home and school and is planning a population study of adolescent health-related behavior in 1991.

DISCUSSION

This section summarizes additional discussion on selected topics that took place both during the major presentations and afterward. The summaries are grouped by topic without regard to chronological sequence in an attempt to capture the major viewpoints on each topic broadly defined.

The International Classification of Impairments, Disabilties, and Handicaps (ICIDH)—An Alternative Classification Scheme

The Haber paper laid the groundwork for the discussion on the ICIDH classification system. While "functional" limitation is the major concept used in U.S. national surveys, according to Haber, the leading alternative to this approach is the impairment, disability, and handicap classification that has been proposed in the experimental manual of the World Health Organization (WHO). The ICIDH is essentially an extension of the taxonomic approach of the "International Classification of Diseases" (ICD). This alternative classification has stimulated an active and provocative critique of disability concepts and has received both positive and negative reviews in the literature.

Some workshop participants suggested that the ICIDH provides a better framework for looking at the transition from disease to impairment to disability than the functional limitation framework. It was also noted that there is research abroad using this classification system, and the U.S. should not fall behind. Also, the ICIDH gives the international community a common language with which to discuss worldwide problems such as AIDS.

On the negative side, it was suggested that because of the frame of reference of ICIDH, the resulting disease orientation does not adequately reflect the knowledge available about holistic measures. There was also concern that the science underlying the classification is inadequately developed.

It was agreed that the ICIDH should be studied further, if only because of its great popularity abroad. A panel study should contrast the ICIDH approach with the U.S. approach in order to determine what effect the use of a particular model has on data collection and policy analysis.

Types of Data Needed

In the discussion, much attention was given to the need for new data in areas not sufficiently covered by existing data sets, such as the following:

- physical capability (musculo-skeletal) of the elderly
- costs of time management, both social-psychological and monetary, for both the disabled and their caretakers
- personal care, including what types of people with disabilities need what type of care, and the quality and effectiveness of care. (These data are directly policy-related because Medicaid has recently changed its rules on personal care and the states now have more flexibility in providing it.)
- types of rehabilitation and their outcomes, such as adaptive learning, education, work preparation, and independent living (such data have obvious policy uses, for example, at RSA).
- measures of capabilities, as opposed to limitations
- measures that would capture changing and emerging disabilities, such as AIDS
- measure of quality of life
- measures of health and disability transitions over the life course

In addition, it was suggested that different types of data are needed on the same topic for the development, implementation, and evaluation of policy. For example, there are data currently available to show the economic plight of the disabled population, but these data are not sufficient to evaluate the change in economic level that might occur as the result of policy change. Also, we know very little about the "oldest old," i.e., those 85+, and we need to learn more about the risk factors for disability for this group.

It was pointed out however, that while new measures are indeed needed in various areas, certain data sets exist that have been insufficiently analyzed. The 1978 SSA Survey was given as an example.

One Data Set

An issue that arose was whether there should be a single comprehensive survey or a minimum data set that would provide disability data to the entire disability research community. A minimum data set could comprise a basic core set of questions to be used on all surveys involving persons with disabilities. While it was thought that a multipurpose study or a taxonomy of variables from different agencies in one data base seemed rational, there was more agreement on the fact that different needs of different researchers and changes in the disability field itself might preclude the development of a minimum data set for all users. One thought was that the Bureau of the Census and NCHS should produce several types of indicators and researchers can use the indicators they need. There was agreement that there is no "best" measure of many of the concepts in this field. Also, this is a fast-changing area requiring constant reassessment in regard to data needs. For example, there are many more technologies available now to help people with disabilities than there were even a few years ago.

Longitudinal Data

The need for longitudinal studies was widely expressed, especially since disability is best conceived of as a continuum or process. It was agreed that the sequencing and timing of disability from the onset of a condition, to the deterioration in function, to the need for assistance, receipts of different types of assistance or medical care, rehabilitation and accommodations could be best examined through longitudinal data. Also, at-risk rates, the likelihood of various age/population groups becoming disabled, could be developed with such data, as well as reflecting on or distinguishing among incidence, duration, and prevalence. The relationship between death and disability could also be studied, as could the secondary aspects of disability, which were made known recently in a study of the later-life effects of childhood polio. The onset of some conditions, such as dementia or other forms of mental illness is hard to determine and may perhaps only be picked up when life function is affected.

Several existing studies that contain longitudinal data were mentioned, such as follow-ups of the National Nursing Home Survey, the Longitudinal Survey of the Aged, the ECA Survey, and the National Long-Term Care Survey. It was felt, however, that none of these were comprehensive enough or else they needed to begin a new generation of subjects. A proposed Health and Retirement Survey that would bring together health, disability, and retirement data was also mentioned in the context of longitudinal surveys. The view was was expressed that while it may sound rational to have one large multipurpose study, there would have to be more than one study to meet the many specific data needs.

It was suggested that obtaining age of onset retrospectively might be used in lieu of longitudinal data in some cases. Obtaining time of onset, however accomplished, is very important in disability analysis, which now emphasizes the dynamic progression of a condition and the accommodations that are made, in contrast to a more static type of analysis.

Disability Index

A disability benchmark rate index, like the infant mortality rate, which would also be understood to track societal well-being, was suggested. While most participants agreed this could be a good idea, some problems were pointed out. There might be little agreement on the standard underlying the index, so that more than one index, or multidimensional measures, might be necessary. Also, if there were a single index number, people might dismiss the need for any more data, such as social participation rates for the disabled. It was suggested that some measure of independence and productive life expectancy (both paid and unpaid) would best capture this rate.

Coordination

The issue of coordination and the need for better communication between the various players in disability data development were discussed several times. The sharing of administrative data on disability could be valuable but there are serious problems of confidentiality. Reference was made to past efforts to establish "statistical enclaves" to overcome the confidentiality problems, but these had limited success. There was agreement that the panel study should encompass this issue.

There was agreement that there should be more networking and communication among those involved in disability statistics and research. This would be a major task because of the large number of agencies and departments that are concerned with statistics on the disabled. Each group has different interests, based on different legislation. In addition to the government departments and agencies, there are state-level departments, international groups, and private groups. Some of the possible entities that could facilitate coordination include: a committee appointed by the Office of Management and Budget; a special committee within the American Statistical Association; additional workshops under the auspices of the National Research Council; a single government agency, such as the Census Bureau, becoming a lead agency; a special committee in a national organization such as the American Statistical Association or the American Public Health Association; or preparation of white papers under the auspices of the National Research Council. The objective of this facilitation activity would be to assure that the professionals involved in demographics of the disabled are well-informed as to what data are and are not available and what the data mean.

Post-Censal Study

Although the group was wholeheartedly in support of a post-censal activity on the disabled to be conducted by the Bureau of the Census, there was recognition of the sampling problems associated with such a survey. Graham Kalton, in particular, was concerned about the effectiveness of disproportionate stratification to oversample those classified by the census as disabled, given that many truly disabled are likely to be classified as not disabled by the census. The issue of using screening questions on the basis of disproportionate stratified sampling is discussed in the sampling literature (e.g., Kalton and Anderson, 1986).

Concluding Thoughts of the Chair

Disability statistics are of major interest to policy makers, program managers, and researchers. The exact number of persons in the United States with a disability remains elusive, as clearly demonstrated by the workshop discussions. Reliable and accurate data are needed for policy planning to target public and private programs to meet the needs of disabled persons, to estimate future program needs and costs. Researchers are eager to study the multiple facets of disability and its burden on society, but they are frustrated by the lack of consistency in estimates of prevalence and severity of disability from various surveys and by the small sample sizes for analysis of disability among subpopulation groups. Persons with disabilities and their advocacy and service organizations that have grown in recent years also want more detailed and current data on disability. Compounding the picture is the aging of the population in the twenty-first century and the growing number of elderly persons who are at higher risk of chronic illness and disability.

Population surveys, such as the National Health Interview Survey (NHIS), often class disabilities by the degree of disruption of activities. A distinction is made between inability to perform one's major activity and limitations in the kind or amount of activities a person can perform. For example, the NHIS has four levels of limitation relating to activity while other questions are asked of older people relating to functional assistance and in instrumental activities of daily living (IADLs). Which of these activity limitation terms best describe the disabled population? Table 1 compares statistics on the prevalence of disability by age from three sources: the 1985 National Health Interview Survey, the 1985 Survey of Disabled Americans aged 16 years and over conducted by Louis Harris and Associates for the International Center for the Disabled (ICD) in December 1985, and the 1982 Long-Term Care Survey conducted by the Health Care Financing Administration (HCFA). The prevalence of disability from these three data sets differs for the various age groups depending on the questions asked. The NHIS and ICD surveys used similar definitions of disability except for the population group aged 65 years and over. Thus, the two surveys show a 5 percent difference in the number of disabled in the 45-64 years age group. For the elderly, however, there is a 110 percent difference in numbers reported, ranging from 5.1 million from the Long-Term Care Survey to 10.7 million from the NHIS. NHIS and ICD employed the definition of limitation in activity due to chronic conditions and the LTC Survey definition was based entirely on ability to perform daily activities.

Another illustration of differences in the prevalence of disability between surveys is shown in Table 2. This table presents estimates of the percentage of the population with a work disability. The estimates for the total working-age population range from 8.8 percent from the Current Population Survey (CPS) to 12.1 percent from the Survey of Income and Program and Participation (SIPP). The NHIS reports 9.4 percent of the working population with a work disability. The language of the work disability questions in these three surveys is similar but not identical. In addition, definitions of the working-age population differ—NHIS uses those aged 18-64 years, SIPP, 17-64 years, and CPS, 16-64 years.

There was unanimous agreement among the workshop participants that disability concepts are complex and require further study; the present system (or lack thereof) of collection, analysis, and dissemination of disability statistics lacks cohesion, coordination and direction; a variety of methodological and measurement problems exist in the production of disability statistics and these need to be systematically explored. The challenge and opportunity is to improve disability statistics to support policy makers in improving the health, social, and economic status of persons with disabilities in the United States. Accordingly, the workshop unanimously recommended that a panel of experts be established to carry out the necessary studies.

TABLE 1 Prevalence of Disability from Three Surveys by Age, 1985

Age Group	NHIS	ICD	LTC
Number (in thousands)			
Under 18	3,221	—	—
18-44	8,391	8,802	—
45-64	10,405	10,179	—
65 and over	10,709	7,992	5,074
Total	32,726	27,000	—
Percent of Population Group			
Under 18	5.1	—	—
18-44	8.4	8.2	—
45-64	23.4	22.7	—
65 and over	39.6	28.0	19.1
Total	14.0	14.8[a]	—

[a] Persons aged 15 and over.

Notes: NHIS: 1985 National Health Interview Survey; ICD: 1985 International Center for Disabled Survey; and LTC: 1982 Long-Term Care Survey. A dash (—) indicates data not available.

SOURCE: Rice and LaPlante (1988).

TABLE 2 Percent with Work Disability from Three Surveys, by Sex, 1986

Sex	NHIS	SIPP	CPS
Males	10.0	11.7	9.4
Females	8.9	12.4	8.2
Total	9.4	12.1	8.8

Notes: NHIS: 1986 National Health Interview Survey (18-64 years); SIPP: 1984 Survey of Income and Program Participation (17-64 years); and CPS: 1986 Current Population Survey (16-64 years).

SOURCE: Haber (1989).

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Appendices

APPENDIX A
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AGENDA
WORKSHOP ON DISABILITY STATISTICS
April 6-7, 1989

April 6

Opening Remarks	Dorothy Rice Miron Straf
Setting a Framework	Lawrence Haber
Data Plans for the Short Term	
Bureau of the Census	Jack McNeil
National Center for Health Statistics	Gerry Hendershot
Program Agencies: Perspectives on Needs and Gaps	
Social Security Administration	Paula Franklin
Health Care Financing Administration	Penelope Pine
Rehabilitation Services Administration	Larry Mars
Special Education	Susan Thompson-Hoffman
National Institute of Mental Health	Harold Goldsmith
Department of Veterans' Affairs	Steven Dienstfrey
Age/Activity Groups: Issues and Concerns	
The Working Population	Mitchell LaPlante
The Elderly	Lois Verbrugge
Children and Youth	Paul Newacheck

April 7

Focusing the Discussion	Dorothy Rice
Age-Related Disability Issues	
Definitional Issues	
Data Needs for Policy Analysis	
Coordination Issues	
Summary and Recommendations	
Agreement on Major Issues	
Need for a Panel Study	

APPENDIX B

ISSUES IN THE DEFINITION OF DISABILITY AND THE USE OF DISABILITY SURVEY DATA

LAWRENCE D. HABER

Introduction

The level of interest and concern about the availability, consistency, and scope of national data on disabled persons has risen greatly in the past few years. The differences in estimates of prevalence and severity of disabilities from national federal surveys have been a major problem. There has also been dissatisfaction with the uniformity and scope of the definitions of the term "disability" and the methods of identification of disabled people.

These concerns are, in part, based on the need for creditable data for policy planning and for estimating future program needs and costs. The concerns are aggravated by the anticipation of rising disability prevalence rates, reflecting the increase in disability prevalence associated with an aging population. They also reflect the interests of disabled people and their advocacy and service organizations for more involvement in planning and providing services and in the availability of more and better data.

The accumulation of data on the disabled population over the past 25 years has had a major effect on the development of an informed critical analysis of disability research and statistics. A central concern, for example, has been the sensitivity of work-disability prevalence estimates to specific survey conditions. Disability prevalence rates for studies conducted between 1966 and 1986 vary between 8.5 to 17 percent of the population.

This paper focuses on the work needed to improve the quality and consistency of disability surveys and statistics. The body of data is examined to identify measurement problems and to suggest ways of improving methods and standards for identifying the disabled. The major issues considered include:

Disability Concepts: disease, impairment, functional limitations, disability, and handicaps; disability as a social process; U.S. survey concepts and World Health Organization (WHO) classifications.

Operational Definitions of Disability: survey measures of disability and severity; program definitions of disability; the use of survey data with administrative records.

Age and Activity Constraints: measures specific to socially-expected performance for children, working-age adults, and retirement-age persons; other role and "social" limitations.

Descriptive Dimensions: medical diagnoses and disabling conditions or impairments; functional limitations and mobility and self-care measures; duration and age at onset; psychological and psychophysiological measures.

Estimation and Methodological Questions: accounting for estimation differences—wording; questionnaire placement and context; study auspices and focus; interviewer training; proxy and self-respondents; reliability and validity measures from cross-sectional and longitudinal studies.

Improving the Quality of Estimation: approaches to resolving differences in estimation and developing guidelines for standard definitions and methods.

Data Gaps and Needs: for a routine and predictable cycle of disability studies—sub-national data, descriptive detail, longitudinal data collection; a methodological studies program; review of concepts and measurements.

Disability Concepts

The concepts of disability used in most of the major national studies stem from the concepts of activity limitation used in the National Health Interview Survey (National Center for Health Statistics, 1987; Haber, 1967). As defined by NCHS, "disability is a general term that refers to any long- or short-term reduction of a person's activity as a result of an acute or chronic condition." Limitation of activity refers to "a long-term reduction in a person's capacity to perform the average kind or amount of activities associated with his or her age group . . ." resulting from "chronic disease or impairment" (National Center for Health Statistics, 1987:5,141).

In the functional sense, disability represents a loss or reduction in the ability to meet behavioral expectations as a result of impairment and functional capacity limitations. The concept of disability focuses on the outcome of the interaction between impaired abilities and expectations for performance. As elaborated in the literature, disability is differentiated from pathology, impairments and activity or capacity limitations by the focus on behavioral consequences and its relational nature (American Medical Association, 1958, 1967; Daitz, 1965; Burk, 1967; Haber, 1967, 1975, 1985; Haber and Smith, 1971; Nagi, 1965, 1969, 1975; Ruesch and Brodsky, 1968).

Pathology and impairments are concerned with attributes or properties of individuals. The physical properties of impairment, physiological or anatomical loss or abnormality, are usually identified by examination of the individual. Functional limitations refer to individual capability, without reference to situational requirements, as restrictions in abilities resulting from impairment. Functional limitations are frequently characterized in terms of "activities of daily living," mobility and self-care limitations, and assistance needs.

The social expectations involved in the designation of disability refer to a variety of situational and contextual factors, as well as the physical and mental limitations of the individual. Impairment is a necessary but not a sufficient condition for defining disability. The predisposition toward disability associated with an impairment may be enhanced or reduced by other attributes of the individual and are responsive to the conditions of the larger social unit, such as the state of the economy and the labor market.

Taking this orientation a step further, disability may be defined as a social process—the pattern of behavior arising from the loss or reduction of ability to perform expected or specified social role activities of extended duration because of a chronic disease or impairment. From this perspective, disability is a form of adaptive behavior provided for by the norms of social role relationships (Haber and Smith, 1971).

The process of disability designation starts with the recognition of a loss of capacity in the performance of a set of socially structured expectations. The loss of capacity must be attributed to a condition beyond the control of the individual, such as a medically definable impairment. Formal or informal proofs of the validity of the attribution may then be required in order to legitimize an exemption from conventional standards of performance. The disability designation differentiates "incapacity" from "willful" deviance as the basis for social interventions, such as rehabilitation, income maintenance, and other social services.

The expectation that the limitations will be of extended duration justifies behavior adaptations and exemptions. Conditions and limitations expected to be acute or of short duration may have immediate impacts, but would not normally require extended behavioral and social adaptations.

The major alternative to the disability concepts used in U.S. national surveys are the impairment, disability, and handicap classifications (International Classification of Impairments, Disabilities, and Handicapps—ICIDH) proposed in the experimental manual of the World Health Organization (World Health Organization, 1980). The ICIDH is essentially an extension of the taxonomic approach of the *International Classification of Diseases* (ICD). The ICIDH has stimulated an active and provocative critique of disability concepts and has received both positive and negative reviews (Wood, 1985, 1986; 1987a; 1987b; Nordenfelt, 1983). It offers the advantage of international sponsorship by the WHO and the association with an established taxonomy, the ICD. As Wood has pointed out, however, the ICIDH is neither a classification of persons nor a research tool (1987b).

The original intent of the classifications was to provide a framework to organize information about the consequences of disease. There is substantial disagreement on the extent to which the ICIDH has achieved this. The ICIDH has been regarded by some as an intrusion of the medical profession into the social aspects as life, as a "medicalization of disablement" (Badley, 1987). Other reviewers have concluded that, despite its flaws, adoption of the basic ICIDH definitions would enhance understanding of disability definitions (Rehabilitation International and World Rehabilitation Fund, 1986:137-143).

"In the context of health experience," the WHO manual treats impairments as a classifications of "disturbances at the level of the organ;" disabilities as a taxonomy of individual limitations; and handicaps as a classification of circumstances "that place such [disabled] individuals at a disadvantage relative to their peers when viewed from the norms of society" (World Health Organization, 1980:47,143,183).

There is little difference in the concept of impairments between the two sets of definitions, although there are questions about the relationship of specific elements of the impairment and disability listings in the ICIDH (Nordenfelt, 1983:9-20). The major problems relate to the distinctions between disability and handicaps. The term "handicaps" is often used as a synonym for disability in American legislation. Although it appears frequently in federal legislation concerning rehabilitation, education, and discrimination, handicaps have not been consistently or clearly defined (Nagi, 1975; 1979:3).

Many of the elements of what the ICIDH calls "disabilities" we have usually been classified as functional limitations or "activities of daily living." However, the ICIDH classifies some social role limitations under "behavior disabilities," such as family role, occupational role, and other role disturbances (World Health Organization, 1980). The distinction between these "disabilities" and the limitations described as "occupation handicaps" and "social integration handicaps" (World Health Organization, 1980:197-201) is unclear and confusing. It is also not clear why problems in an individual's ability to orient him or herself in relation to surroundings are considered "orientation handicaps" (World Health Organization, 1980:185-187), while "self-awareness," "postural," or "environmental" problems are disabilities. Without attempting an item by item comparison, the distinctions between disabilities and handicaps appear to be poorly drawn and overlapping in many areas.

The distinction between individual attributes and social interaction is important and should be preserved, but the distinctions between disability and handicaps described in the ICIDH descriptions do not appear to accomplish this. Many of these distinctions would be difficult to measure in a survey interview and appear to have limited use for survey data collection or classification. Although there are good reasons for attempting to reconcile these definitions, it is obvious that a great deal of clarification is needed before a useful accommodation can be reached.

Operational Definitions

A variety of studies including measures of disability have been conducted since the mid-1960s. Questions on health-related "limitations in major activity" have been included in the National Health Interview Survey (NHIS), conducted by the National Center for Health Statistics for more than 30 years. The Social Security Administration (SSA) conducted a series of surveys focusing on the social and economic correlates of work disability between 1966 and 1978. The Bureau of the Census included work disability measures in the 1970 and 1980 censuses in the Income Supplement to the Current Population Survey since 1981, and in one topical module of the Survey of Income and Program Participation (SIPP), 1984-85. A disability survey was planned as a follow-up to the 1980 census; a pilot study was conducted in 1981, but the full survey was never implemented.

The language of the work disability questions in all of these surveys is fairly similar, but only occasionally are they identical. Each survey conducted under different auspices has its own purposes and orientation. The language differs, sometimes in what may appear to be trivial or nonsignificant ways, the extent of detail varies, and the positioning and the context of the questions differ. Interviewer training takes place within the context of the survey purposes, and a different emphasis is placed on the disability questions.

The participation of the Bureau of the Census is common to all of these surveys. The Bureau was responsible for sample development and data collection in all of the studies discussed and contributed to the development of the questionnaire.

To illustrate both the degree of commonality and the extent of diversity among these surveys, a list of the questions used is included in Appendix B-1. The following surveys are included:

Social Security Administration: 1966, 1972-1974 and 1978
Survey of Economic Opportunity, 1967
Survey of Income and Education, 1976
Census of Population, 1970, 1980

National Health Interview Survey, 1980 and earlier years
Census Disability (pilot) Survey (Richmond), 1981
March Current Population Survey, 1981-1988
Survey of Income and Program Participation, 1984
Canadian Health and Activity Limitations Survey, 1986-1987.

Questions and problems arising from the differences in disability estimates produced by these studies is discussed in the section on estimation problems. The procedures and questions used in the 1980 census to identify the disabled are discussed below as an example of the general approach.

The 1980 decennial census defined disability as a limitation in the ability to work because of a physical, mental, or other health condition that lasted 6 or more months, as reported by the household member who answered the questionnaire. The universe included the civilian noninstitutionalized population 16-64 years of age. The questions on work disability in the 1980 census were included in the long form questionnaire, answered by over one-sixth of the U.S. population in April 1980.

Although disability can be defined in more general terms than work limitations, work limitations were considered as more important in their social consequences than most other areas of social activity, more rigorous in their external constraints, and of more direct concern to public policy and programs.

The underlying assumption of self-identification of disability is that the individual can make an assessment of his capabilities and limitations in the context of his experience and the socially defined requirements and opportunities. Most public programs depend on the individual to initiate the claim for services and benefits. The cross-sectional studies have shown the reliability and consistency of the work disability relationships. The longitudinal studies found that the work disability measures were reliable predictors of premature death and early retirement (Sheppard, 1977; Andrisani, 1977; Kingsley, 1982).

The alternatives to self-identification discussed by Slater et al. (1972) either have their own limitations or are to some extent included in disability studies. Legal identifications are based on program definitions and determinations. Program beneficiary status is sometimes obtained in surveys and can be validated by comparison to program records, but program determinations include only the "processed" portion of the population. As the level of denials and reversals in the SSA disability insurance program indicates, program determinations are far from infallible. Medical determinations are costly and have only limited applicability; as the American Medical Association (AMA) has pointed out, disability is an administrative, not a medical determination (American Medical Association, 1958, 1967).

Behavioral measures are usually obtained by self-report in surveys. Observational measures would have the same limitations as medical examinations and would also be impractical in terms of survey costs and response problems. Household member reports are sometimes used as proxy respondents; the effects of proxy respondents on disability reporting is a question that needs further study, but there is no reason to assume it would markedly improve reporting. With all its flaws, self-reporting appears to be the most practical, reliable, and valid method of disability identification currently available.

In addition to the general question on disability, data were obtained on severity of disability. This provided three measures of disability: severely disabled (prevented from working); partially disabled (limited in kind or amount of work but not prevented from working altogether); and totally disabled (any limitation in kind or amount of work).

Some criticisms of the work disability measurements have focused on the narrowness of the definition. We agree with the need for disability measures in other areas of social life and in activities appropriate to other age groups. The NHIS has routinely included major activity limitation questions for children and older people in its data collection. The 1990 census includes questions related to mobility and self-care, in addition to the work disability questions used in 1980. These questions provide a measure of disability-related service needs for older persons in the retirement age group, as well as for other adults. Questions on children's activity limitations were tested in the Census Content interviews, but were later dropped because of problems with response reliability.

There are, however, deeper dissatisfactions with the work disability concept. They concern the perception of the limitations of the work disability concept in reflecting the experience of disabled people. This is particularly evident in terms of the failure or inability to deal with discrimination against the disabled or to express or clarify the adaptations required of the environment and of people with impairments in order to function in a work or other environment. One question is frequently asked in discussions of the disability definition: "What if an individual has . . . (a condition, such as epilepsy, or an impairment, such as paralysis of both legs, or a mobility limitation, such as confined to a wheelchair) but isn't limited in his work, is he disabled?" The answer, "Not if he says he isn't," is clearly felt to be unsatisfactory by many members of the disability research and policy community.

From a social insurance or service point of view, this is a correct and appropriate answer; people who don't consider themselves disabled don't apply for benefits and probably don't qualify, regardless of impairments. From the perspective of people with impairments, the answer may fall far short of their experience. A more satisfying answer might be, "Well no, but only if certain conditions have been met" or "Possibly, but not if the right support services are provided."

The distinction is neatly captured in a discussion of the primary criteria for disability pensions as "incapacity", or the specific inability to work, in contrast to benefits provided for "people with disabilities" (Rehabilitation International and World Rehabilitation Fund, 1986:52-53). "Disabilities" is used here in the broad sense of impairments that have a significant effect on the ability of people "to participate in an unreconstructed society, whether or not they can work, or indeed are working" (pp. 52-53). This approach focuses on the effect of impairments as the major variable in social limitations. The recent reports of the National Council on the Handicapped (1986, 1988:27-32) and their legislative proposal, for example, emphasize an impairment approach to disability and handicap.

The available research indicates that equating impairment with disability would substantially increase the proportion of the population identified as limited by an "impairment" rubric. Close to half the population aged 20-64 reported a chronic condition or impairment in 1972; only 29 percent of those reporting an impairment or chronic condition identified themselves as work-disabled (Social Security Administration, 1981:50-52). Of the 36 percent of men aged 18-64 who reported an activity limitation in 1978, three-fifths did not identify themselves as work-disabled (Social Security Administration, 1981:86-87). Approximately 900,000 adults reported that they were confined to a wheelchair; about half of this number said that they were not limited in their ability to work (Social Security Administration, 1982:90-91).

Impairment designations provide little information for estimating the likelihood that an impaired person is or is not working or is able to work. Data from the Framingham heart study, a biennial health examination panel of over 30 years duration, for example, show that many people who met or equaled the Social Security Disability Insurance (SSDI) impairment listings continued to work for a substantial period after onset of impairment (Brehm and Rush, 1988:388-391). The work disability measures, on the other hand, have been highly predictive of later events, such as premature death and early retirement (Sheppard, 1977; Andrisani, 1977; Kingsley, 1982).

There is obviously a major gap in the meaning of disability implied by an impairment or functional limitation compared to a limitation in the kind or amount of work that an individual can engage in. Between the estimate of persons reporting impairments or chronic conditions and the estimate of persons reporting a work disability is a large number of people who say that they are not limited or prevented from working by their impairments or functional limitations.

Many factors affect the extent of the predisposition to disability. In some cases, the conditions may not be seriously limiting. Education, occupation, economic, or family background or support enable some people to cope with functional limitations better than other people. The state of the economy, labor force, and composition of the society also contribute to the likelihood that an individual will or will not be disabled. All of the disability studies have shown similar effects from age, education, occupational background, and marital status on the prevalence of disability. Studies of the economic and social environment of the states have shown the powerful influence of education, employment, and income levels in disability rates (Sheppard, 1977:182-185; Haber, 1987; Howards et al. 1980).

From a conceptual and measurement point of view, there is no conflict between impairment and disability measurement, as long as we remember that they are not the same thing and they don't have the same impact on social and economic consequences. Impairments have received less attention in general population surveys; this is mainly a function of the difficulties in collecting and interpreting impairment data and the interests of the sponsors. The 1972 and 1978 Social Security surveys collected impairment prevalence for both disabled and nondisabled adults.

Impairments represent only one element in the array of medical, social, and economic factors that may condition the likelihood of disability. The distinctions between impairments and disability are essential to understanding the factors that influence the individual's predisposition to disability. Changing the names from impairments to disabilities or handicaps doesn't solve any of the conceptual or analytical problems, but it does help to confuse the issues.

The same distinction should be maintained for instrumental activities and disability. Taking a bus, for example, is not a social role or task performance. The ability to use public transportation may help or hinder the performance of a social role, but is not a general social requirement. Information on mobility limitations, such as transportation problems, are useful for services planning and to understand environmental factors that contribute to disability, but are not necessarily relevant to the estimation of the disabled population.

When data are available from administrative records, questions are sometimes raised about the need for survey data. If the data needed are available in administrative records, then obviously no additional data collection is needed. Administrative records, however, usually include only the information needed for eligibility or qualification and for routine maintenance and operation of the program. When questions beyond the scope of these data are needed, then other data collection approaches, such as surveys, may be necessary. Data about family cohesion or economic resources, coping behavior before or after application, denied claimants, or the potential applicants for a program are not usually available from administrative records.

Surveys are generally intended to supplement or expand the data available from administrative records. Survey and administrative record data can sometimes be combined to provide a more comprehensive data set. Administrative records have been used to expand on data collected in household interviews and to verify information provided by respondents. SSA has, in the past, been able to link data from survey cases with beneficiary and earnings records. Data linkage of rehabilitation records with SSA earnings records have been used to provide a prospective earning history for rehabilitation cases. Cost, confidentiality, or administrative inconvenience, however, often limit access to administrative records. Confidentiality and tax legislation discourage the use of records for data linkage.

Administrative records can also be useful by providing a sampling frame for part or all of a survey sample. Supplemental sampling of program populations that represent "rare" cases in household samples is a particularly effective way of combining program records with surveys.

Few surveys of the disabled population have included the institutionalized population. Administrative records can be particularly helpful in surveys of persons in long-term care or institutional settings as sampling frames and as data sources. In some institutional studies, for example, there may be concern with the competence of the sample person or other reasons for avoiding direct contact. These record data, however, are not used in place of a survey data, but as the survey data. There is however, little uniformity in institutional records. The flexibility required to obtain data from records is at least equal to the effort of personal interviews.

Survey measures of disability are, of course, statistical abstractions, intended to assist us to understand the phenomena of disability rather than to provide entitlements or benefits and services. The legal or program determinations of disability are based on legislative and administrative procedures. The records of disability-related programs provide data on that segment of the population who have applied for and have been found eligible by administrative procedures to receive benefits and services from these programs.

Program definitions vary widely in the extent to which they include or exclude segments of the disabled population. These definitions are based on the legislation that implements the program. The regulations may clarify legislative intent or provide administrative procedures for program operations. Organizations tend to emphasize that aspect of the patient or client that approximates their service objectives. Nondisability criteria, such as insured status or age guidelines, may be administratively convenient or legally required. The particular criteria that evolve reflect the objectives of the program rather than any general or coherent concept of disability. Comparisons of disability insurance programs in several national systems provides specific examples of how their goals effect program procedures and disability definitions (Rehabilitation International and World Rehabilitation Fund, 1986:53-67).

Program definitions are program specific and cannot provide a standardized definition of disability.

The limitations of specific program definitions emphasize the need for reliable estimates of a coherently defined disabled population. These measures can help to examine the effectiveness of the service programs in reaching and serving their target populations, identify the unserved populations, and determine the effect of programmatic restrictions.

Despite the frequency with which the issue is raised, it is not clear what a "universal" definition of disability is expected to be used for or what it is expected to include. To the extent of my understanding, disability definitions and measures are useful when they relate to specific social expectations and performances. Without this restriction, it is doubtful that a "universal definition" is meaningful. The distinctions among impairments, activities of daily living, and capacity for expected social performance are meaningful, however, and should be maintained.

Nevertheless, it should be possible to develop standards that narrow the range of variation in disability estimates by examining the effects of different disability questions and identification methods. Recommendations for disability questions and procedures should be based on the results of this methodological work. Rather than imposing a standard, these guidelines should indicate the kinds of yardstick variations expected to occur with a specific set of questions and what measures to use for comparability of findings. The guidelines would encourage standardization without discouraging innovative ideas or alternative measures designed for specific study purposes.

Guidelines place the burden of proof on the researcher or sponsor to justify the selection of nonstandard measures. Methodological work to explain the effects of variant measures or specific survey conditions should be as routinely expected and reported as the sampling errors are now.

Age and Activity Constraints

Most of the U.S. national surveys on disability examined in this paper have focused on work disability among the civilian adult noninstitutionalized population under age 65. The NHIS, however, has consistently included a more general measure of disability related to age and usual activity. Based on age and major activity, "during the past 12 months," respondents aged 18-69 years were asked about limitations in their ability to work, to do housework, and in other activities.

Sample members aged 70 and over were asked about the need for help from other persons for personal care and for handling "routine" household needs. About one-third of this population reported a limitation in these activities. Information was obtained on play activities for children under age 5 and on school attendance for children aged 5-17. Less than 6 percent of the children under age 18 were reported as limited in these activities. Activity limitation questions from the NHIS are included in Appendix B-2. Questions from other surveys of childrens activity limitations are also included.

Measures of children's activity limitations have had more problems with response reliability than the measures for adults and have shown a considerable differences in reporting between parents and school reports and between parents and children. It is apparent that different aspects of experience are being measured and that better or more intelligible measures are needed if meaningful data are to be collected on disabled children.

The first requirement is agreement on what is intended or acceptable. Parental respondents, the usual source in household surveys, did not necessarily provide answers comparable to those that were obtained from teachers or school records. A 1981 study of school-age children, for example, showed that less than three-fifths of the children identified by teachers as needing special help as slow learners were identified by their parents as having a limiting condition (Zill, 1985:xi, 40-43). Further studies of this type are needed. Although it may not be possible to improve parental reporting, in the absence of improved parental knowledge, it should be possible to have a better understanding of the limits of the data collected.

Another area in which there has been interest from the disability research and policy community is in measures of social integration and independent living. Although these are interesting concepts, it is not clear what is meant, how it would be measured, and what areas of social experience could be used to check on the validity of the responses. Some intervening measures may be needed to express the adaptations required of the environment and of people with impairments in order to function in a work or other social environment. Further development of concepts and definitions is needed in these areas.

Descriptive Dimensions

To understand the causes and consequences of disability, we need descriptive information on the individual, his impairments and activity limitations, when they started, the ways in which these conditions affect his or her independence of movement, and how he or she copes with the problems presented by these limitations.

Data on chronic conditions and impairments have been collected in a variety of ways, both in terms of specificity and in terms of the defined population. Respondents may be shown a list of conditions or may be asked to describe their chronic conditions and impairments. Additional information may be obtained on date of onset, cause of condition, physician's diagnosis or verification, and whether the condition is the major reason for a disability or an activity limitation. Data on sensory and communications limitations may be obtained by extended questioning on the extent of vision, hearing, and speech impairment.

Sets of questions have been developed and extensively used to describe "activities of daily living," such as walking, bending, lifting, reaching and handling, and similar physical activities. Other sets of questions deal with mechanical aids used or needed, mobility and self-care limitations, and care needs. Data have also been collected on age at onset of disability, duration of disability, and the receipt of disability-related income and services.

Current work information data are usually collected as part of the demographic and economic battery of questions. Data on work history, work experience at the onset of disability, and disability-related work history have also been collected.

Questions related to psychophysiological and psychological dimensions of disability are more complex and difficult to frame and have been rarely included in disability surveys. Measures of psychological distress were included in the 1972-1974 SSA surveys. Two working papers that examined the distress measures found a strong relationship between disability and psychological distress symptoms (Briscoe, 1982; Levy, 1979).

In addition to the degree of specificity, there are also questions of population scope. Most of the disability surveys that obtain impairment and activity limitations data restrict these questions to the population identified as disabled. The 1972-1974 and 1978 SSA Disability Surveys are among the few studies that provide comparable data for the nondisabled and disabled population on chronic conditions, impairments, and activity limitations. These data provide some insight into the relationship of specific conditions and limitations to the probability of disablement.

Estimation Problems and Methodological Questions

The large scale national surveys conducted over the past 20 years have provided us with a broad array of data on disabled persons. In general, these studies show a similar pattern of demographic and economic composition. The disabled population is disproportionately composed of older people, with less education, and poorer occupational skills. The relationship of disability to major social and economic variables, such as age, race, income, education, labor force participation, and marital status has been consistent over time and across surveys. Disability appears to strike more heavily with increasing age, and more often among Blacks, the unskilled and semi-skilled, those with less than high school education, and among southern and rural populations. Economically, disabled persons have less income than nondisabled persons, partly as a predisposing factor and partly as a consequence of disability. The disabled population is more likely to have incomes at or below the poverty level. Proportionately fewer are employed and fewer work full-time. The average earnings of employed disabled workers are lower than those of the employed nondisabled.

The findings of the cross-sectional studies receive strong support from two major longitudinal surveys: the Longitudinal Retirement History Study (LRHS) conducted during 1969-1979 (Social Security Administration, 1987) and the Parnes manpower studies—the National Longitudinal Surveys (NLS), conducted during 1966-1975 (Center for Human Resources Research, 1977). In addition to their replication of the cross-sectional findings for specific age groups, they also show the predictive power of the work disability questions (Kingsley, 1982; Sheppard, 1977):

> The NLS project and the type of analysis it makes possible has a value not associated with the usual cross-sectional project in that it provides an opportunity to make predictions regarding subsequent work or life status. It is also important to make the point that, despite the criticisms that have been made regarding the utility of self-reported health status, the individual's own judgement of his or her health status or work capacity at one point in time is a useful and reliable predictor of subsequent labor force or life status.
>
> There should be no question about the reliability of using respondent's own ratings as to their health status, as measured by the question in 1966 asking whether or not they were limited in the kinds of work they could do. Among the whites who were "healthy" in 1966, only 11 percent were unable to work or were dead seven years later. For whites who were "not healthy" in 1966, 24 percent were unable to work or dead in 1973. The corresponding figures for blacks were 15 versus 33 percent (Sheppard, 1977:163-164).

In a study of very early retirement (before age 62) among men aged 45-59 in 1966, using the NLS, over 85 percent of the early retirees by 1975 had reported a work disability in 1966; 15 percent had not reported a work disability in 1966. The accumulated mortality among early retirees by 1975 was 33 percent for SSDI beneficiaries and 42 percent for nonbeneficiaries reporting a work disability in 1966, compared to 15 percent of the men who did not report a work limitation in 1966 (Kingsley, 1982).

Other analyses concluded that health status (self-reported work limitations) among middle-aged men is closely linked to premature death. "Men whose health affected their work in 1966 were 2-3 times as likely to die between 1966 and 1971 as men whose health did not effect their work" (Andrisani, 1977:11-12).

Despite the 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 among these studies. These estimates range from a high of 17 percent, for the 1966 and 1978 SSA studies, to a low of 8.5 percent in the 1980 census. The data suggest that these variations had little to do with time trends, but were more closely related to the purposes for which the studies were done or the auspices under which they were conducted.

Table B-1 shows the range of variation in disability rates for 19 studies conducted between 1966 and 1988. These include the 1970 and 1980 Censuses of Population; the eight Annual Income Supplements to the Current Population Surveys (CPS) conducted between 1981-1988; three of the annual National Health Interview Surveys (NHIS) for 1969-1970, 1980 and 1986; three Social Security Administration Disability Surveys (SSA) in 1966, 1972-1974, and 1978; the 1984-1985 disability topical module to the Survey of Income and Program Participation (SIPP), and two other demographic surveys that included disability measures: the 1967 Survey of Economic Opportunity (SEO) and the 1976 Survey of Income and Education (SIE). The questions on which the data are based are summarized in Appendix B-1.

At the low end of the disability prevalence estimates are the 1970 and 1980 censuses and the eight CPS Income Supplements, ranging from 8.5 to 9.4 percent (Table B-1). The NHIS estimates, with more emphasis on health and health limitations, ranged from 9.4 to 13.5 percent in the selected years. The special surveys (the SEO, SIE, and SIPP), which vary in their interests but all of which placed some emphasis on disability effects on work or income, ranged from 12.1 to 14.0 percent. The SSA surveys, which focused on work limitations, ranged from 14.3 to 17.2 percent.

While one would not like to argue that more is better, it is apparent that discussion and explanation of the subject included in the extended questionnaire increases the disability estimates. The data from the Census Reinterview Surveys also indicate that the proportion reporting a disability increases with more information and questioning, as shown in Tables B-2A and B-2B.

One could reason that marginally disabled people are encouraged to identify themselves as disabled by more extensive questioning. In that case we would expect to find a higher ratio of disabled people in the labor force in the studies with high prevalence estimates. While there is some tendency in this direction, the trend appears inconsistent. The low prevalence 1970 census estimates have about the same level of labor force participation rates as the high prevalence 1972 SSA survey. The same observation could be made for the 1978 SSA and the 1976 SIE surveys. The argument for different work force relationships receives weak support from the data, at best.

Despite the high degree of variability in the total disability rates (Table B-1), the severe disability rates (unable to work) were relatively stable over the range of studies, with the exception of the NHIS

TABLE B-1 Prevalence of Work Disability: Selected Surveys, 1966-1988

	Percent Total with a Work Disability			Percent Males with a Work Disability			Percent Females with a Work Disability		
	Total	Severe/ Prevented from Working	Percent of WD in Labor Force	Total	Severe/ Prevented from Working	Percent of WD in Labor Force	Total	Severe/ Prevented from Working	Percent of WD in Labor Force
1966 SSA[1]	17.2	5.9/n.a.	52.1	17.2	4.7/n.a.	73.7	17.2	7.0/n.a.	32.6
1967 SEO[2]	14.0	n.a./5.2	n.a.	14.0	n.a./n.a.	n.a.	14.0	n.a./n.a.	n.a.
1969-70 NHIS[1, 5]	11.9	n.a./2.2	n.a.	13.1	n.a./3.5	n.a.	10.9	n.a./1.0	n.a.
1970 CENSUS[3]	9.4	n.a./3.8	46.2	10.2	n.a./3.2	63.4	8.6	n.a./4.4	27.3
1972 SSA[4]	14.3	7.0/n.a.	47.9	13.6	5.7/n.a.	65.1	15.0	8.3/n.a.	33.8
1976 SIE[1]	13.3	n.a./5.8	43.7	13.3	n.a./5.1	57.0	13.3	n.a./6.4	31.2
1978 SSA[1]	17.2	8.6/5.8	44.2	16.1	7.9/5.1	59.7	18.4	10.0/6.6	30.8
1980 CENSUS[3]	8.5	n.a./4.4	38.1	9.0	n.a./4.0	49.1	8.0	n.a./4.7	26.3
1980 NHIS[1, 5]	13.5	n.a./2.8	n.a.	14.3	n.a./4.7	n.a.	12.8	n.a./1.1	n.a.
1984 SIPP[3]	12.1	n.a./5.3	n.a.	11.7	n.a./4.4	n.a.	12.4	n.a./6.1	n.a.
1986 NHIS[1]	9.4	n.a./4.2	n.a.	10.0	n.a./5.0	n.a.	8.9	n.a./3.4	n.a.
MARCH CPS[3]									
1981	9.0	n.a./4.7	33.0	9.5	n.a./4.8	41.9	8.5	n.a./4.7	23.5
1982	8.9	n.a./4.7	32.8	9.3	n.a./4.6	41.5	8.5	n.a./4.8	23.7
1983	8.7	n.a./4.6	n.a.	9.0	n.a./4.6	41.0	8.3	n.a./4.7	24.4
1984	8.6	n.a./4.6	n.a.	9.2	n.a./4.8	40.3	8.1	n.a./4.4	24.4
1985	8.8	n.a./4.5	n.a.	9.2	n.a./4.7	38.2	8.4	n.a./4.4	25.3
1986	8.8	n.a./4.7	n.a.	9.4	n.a./5.0	38.0	8.2	n.a./4.5	25.2
1987	8.6	n.a./4.7	n.a.	9.1	n.a./4.8	39.7	8.1	n.a./4.6	27.1
1988	8.6	n.a./4.8	31.6	8.7	n.a./4.9	35.7	8.4	n.a./4.6	27.5

Note: n.a. indicates data not available.

[1] Age group included: 18 to 64 years of age.
[2] Age group included: 17 to 64 years of age.
[3] Age group included: 16 to 64 years of age.
[4] Age group included: 20 to 64 years of age.
[5] Major activity for women not usually working in past 12 months is considered to be keeping house.
[6] "Prevented from working" estimate based on unpublished data from SSA.

SOURCE: Updated from Haber and McNeil (1983).

TABLE B-2A Work Disability Status By Age: 1980 Census and the Content Reinterview Survey, Age 16-64 (in percent)

	Age 16–54		Age 55–64		Age 16–64	
	1980 Census	CRS	1980 Census	CRS	1980 Census	CRS
Work Disabled	5.7	8.2	20.5	25.0	8.3	11.1
Prevented (unable)	2.4	3.6	13.3	17.1	4.3	6.0
Partial	3.3	4.5	7.2	7.9	4.0	5.1
Not Work Disabled	94.3	91.3	79.5	75.0	91.7	88.9
Sample Number	(12,601) 76.7		(2,701) 16.4		(15,302) 93.2	

SOURCE: Unpublished data, Bureau of the Census.

TABLE B-2B Disability Rates in Richmond BHSA: 1980 Census and 1980 Census Disability Survey Pretest

	16 to 64 Years of Age			65 Years of Age and Over
Disability Measure	Total	Males	Females	
Percent with a work disability	7.7	8.2	7.2	n.a.
1980 Census	10.8	11.4	10.2	n.a.
1980 Pretest				
Percent prevented from working				
1980 Census	3.9	3.7	4.1	n.a.
1980 Pretest	3.9	3.8	4.0	n.a.

Note: n.a. indicates that data not applicable.

SOURCE: Unpublished data, Bureau of the Census.

estimates. Much of the variation in NHIS severity measures can be accounted for by the changes in the treatment of women's work activity over the period included here. The low estimates of "unable to work," 2.2 and 2.8 percent of the total population, are from the 1969 and 1980 NHIS studies, with the high estimate of 5.8 percent from the 1978 SSA survey and the 1976 SIE survey.

If we use the estimates for men from these studies, the range of estimates for the overall disability rate is about the same, from 9.0 to 17.2 percent, but the range in the percent "unable to work" is much narrower, 3.2 to 5.1 percent.

Not surprisingly, the percent that is partially work-disabled does increase with the increase in overall disability rates. Is this the result of "over-stimulation" of the respondent or a desirable improvement in estimation procedures? Without pursuing this microanalysis further, we can reasonably conclude that there are large variations in disability prevalence rates among the major disability surveys that mainly reflect fluctuations in the percent of people with partial work limitations, but cannot be explained by secular trends, labor force nonparticipation, or sampling error.

Most of these differences appear to be associated with the purpose or auspices under which these surveys were conducted. However, as shown in Appendix B-1, different wordings are used under each of these survey auspices for identifying the disabled. The SSA questions ask "Does your health or condition LIMIT the kind or amount of work . . . ?" or "KEEP you working altogether?" and adds more specific questions about the extent of limitation. The 1980 NHIS study asked questions similar to the basic SSA questions, but treats women differently from men in regard to work activity. The 1986 NHIS asked women about work activity as well as housework, but the form of the questions have changed. The questions in the 1970 and 1980 censuses placed more emphasis on the condition: "Does this person have [a] health or physical condition which limits the kind or amount of work . . . ?" In 1970, this condition can "KEEP him from holding any job at all"; in 1980, it can "PREVENT [him] from working at a job."

We tend to accept these differences in wording as being minor variations that should have little effect on the results. This assumption, however, is pure speculation and not particularly well founded-speculation. The early experimental work on the disability screening questions for the 1966 SSA survey tested several variations in form and wording and found substantial differences between questionnaire approaches (Haber, 1967:Tables 3 and 6). Similar differences in disability rates were found in the comparison of the Longitudinal Retirement History Study and the NHIS among people aged 58-63; the estimates for health measures, such as dental condition and doctors visits, however, were quite close (Social Security Administration, 1987:15-19).

The question of proxy respondents also needs further study. Some studies use proxies routinely, others only allow proxies when an individual is incompetent or unavailable. With mail questionnaires, as in the 1980 census, we don't know if an individual participates in responding or if the answers are provided only by another household member. Most household surveys collect information on whether the responses are provided by a proxy or self-respondent. We should have more information on the effect of proxy and self-respondent survey practices on disability prevalence estimates.

From the perspective of the analyst studying relationships between disability and social and economic factors, the differences in prevalence estimates can be accepted as an annoyance and a problem for trend analysis. The major relationships that have been compared generally appear to be stable and consistent across an array of studies. The data in the major surveys appear to be internally consistent and as reliable as other commonly used survey measures.

The measures of reliability from the 1978 and 1980 disability reinterview surveys show about the same degree of consistency as other social measures, such as years of education and marital status. The consistency measures for disability were considerably better than for the poverty and occupational variables (Haber and McNeil, 1983). Changes in form and language of the disability questions used in the 1976 Content Test substantially improved the consistency levels of the questions included in the 1978 Richmond pretest and the 1980 census.

The distribution of disability rates by states was also highly consistent over time. The correlation coefficients for state disability rates for the 1970 and 1980 censuses and the 1976 SIE ranged from .93 to .95 for the three periods.

For the policy and program user and the disability advocacy groups, the large variations in disability prevalence rates undermine the credibility and usefulness of the data and pose problems of interpretation. Even taking relatively small periods of 3 to 4 years, we find differences among the different data series: 9.4 to 14.3 percent between 1969 to 1972; 8.5 to 17.2 percent between 1976 and 1980; and 9.4 to 12.1 percent between 1984 and 1986. Why do the estimates differ so greatly? Which estimate is best or most appropriate for a particular purpose? If the data are so reliable and so good, how come they vary so much from survey to survey?

Improving the Quality of Estimation

I suggest that our first responsibility is to determine the sources of these variations in the data and to improve both the measures and the consistency of estimates for disability prevalence. This would greatly enhance the usefulness of the disability statistics to policy analysts and the concerned public. It would also provide a useful by-product by increasing our understanding of the effect of language and contextual variation on the robustness and consistency of survey data.

What factors in the survey methodology and interview environment create these variations in numbers and levels of disability? What can be done to improve the consistency of measurement or to understand why measures differ? How can we adjust for or interpret the differences in findings of "comparable" studies? The concern with variations in disability prevalence estimates assumes that we are measuring or attempting to measure the same behavior. The differences in language, questionnaire contexts, and training suggest that in fact we may unintentionally be giving some different messages to respondents.

A program of methodological research and evaluation is needed on the effects of questionnaire language, placement, and context on disability response levels. What difference does the focus of the interview and the interviewer training have on disability levels? How does it accomplish this? Is asking whether "your health limits your work" a substantively different question to respondents from a inquiry about whether you have a "condition which limits your work?" It sounds different. It shows a difference in the focus of interest. It's different to me. Maybe it's different to a few million other people as well (or that fraction of the few million that we sample). If we are going to keep using these data, it would seem appropriate to put some resources into testing these questions rather than into another meeting in which we sit around and complain about the lack of data or its presumed weaknesses.

In all fairness, it should be pointed out that all of the major statistical agencies do conduct a fair amount of methodological work. SSA did an extensive examination of disability alternative questions for the 1966 Disability Survey (Haber, 1967); the data collected in the 1978 survey were evaluated through reinterview and a reconciliation schedule (Social Security Administration, 1982b; Thelan, 1979). The NCHS have done extensive validation of health care and health insurance costs and services. The Census Bureau has been producing and circulating reports, data, and analysis on disability reliability for more than the past decade.

Little attention, however, has been devoted to improving disability reporting and little of that has been publicly accessible. Methodology is not a lively interest for most data users nor for most survey analysts, until a specific problem arises. Questions of meaning and validity, like most areas of data analysis, receive far less attention, support, or resources in the statistical agencies sampling design and reliability.

These problems could be approached through a coordinated effort for methodological work by the major statistical agencies. This should include a central clearing house in which data on methodological efforts can be collected and disseminated, and which can urge, cajole, and persuade agencies to share efforts and resources to fill in data gaps and undertake needed areas of study. The National Research Council's Committee on National Statistics can play a role in urging a coordinated effort for methodological work to the major statistical agencies. The Office of Management and Budget could support such efforts, from a safe distance, so that the activity and its controls remain at the level of the statistical agencies. What is needed is a master jigsaw-puzzle coordinator, with working agency players, not a survey czar.

In general, the methodological work should be undertaken as small-scale efforts, preferably tied-in with the use of larger ongoing samples, such as the CPS, SIPP, and the NHIS. NCHS has been very generous in participating in such efforts in the past through the use of questionnaire supplements on split samples. As better understanding develops about the effects of differences in wording and context of disability questions, guidelines can be developed for improving the uniformity or standardization of questions. At some point, we should be able to arrive at a preferred set of disability identification questions and methods, which one would expect to find included in any disability study with a concern for comparability.

Before we can expect comparability, we should be able to demonstrate what comparability means. It should be common practice to conduct methodological studies of innovative or variant measures and to report the findings in much the same way as sampling errors and methods are now published.

These preferred questions should also be tested in different training and organizational environments through survey supplements and split sampling to determine the effectiveness, training, and auspices on a standard set of questions. The process is one of slow incremental improvement. There are unlikely to be any magic solutions, any silver bullets. It is hoped that we will learn more and the data will get better, until we can concentrate on the questions that the data raise about disability, rather than about disability data.

Data Gaps and Needs

In any examination of issues, the question of data gaps and unmet needs is always relevant. The major data needs require the establishment of a routine and predictable study cycle to provide more extensive disability data at the local level than is now dependably available. The inclusion of disability questions in the decennial censuses provide an important resource for local area estimates of disability prevalence, but more extensive descriptive data are needed.

In addition to the decennial questions, a regular Disability Follow-up Study to the decennial census would provide basic descriptive information, at the state level, on impairments and activity limitations and on the social and the economic aspects of disability. A proposal for such a follow-up study is now being considered by the U.S. Senate; the study proposal is actively supported by a coalition of disability organizations.

Another fundamental data gap is the 10-year gap between censuses or more accurately, between data collections that provide reliable information at a subnational level. The mid-decade mini-census, essentially a large-scale social survey with a common core and a set of nested supplementary surveys, would help meet these needs. These data needs are basic to many areas, aside from disability issues, but disability relationships should be considered in any issue-oriented study focusing on social and economic issues.

As an immediate data gap, a biennial disability supplement should be restored to the SIPP, to provide a resource for a continuing longitudinal analysis of disability.

The classifications of group quarters and institutional housing arrangements used in the census and household surveys is badly in need of review and updating. The treatment of these living arrangements tends to pre-date the development of centers for independent living, halfway houses, and other "board and care" housing and special living arrangements. An interagency working group was examining these questions several years ago, but no changes seem to have taken place since then.

The findings from the National Longitudinal Survey and the Longitudinal Retirement History Study amply demonstrate the value and the need for a longitudinal disability survey. Before such a proposal can be considered, we should first do a thorough job of analyzing, reviewing, and assembling the longitudinal disability data now available. This reinforces the need for a central clearinghouse responsible for cutting across the fields with an interest in disability and providing a regular or annual review and annotated bibliography of disability research. The National Institute for Disability and Rehabilitation Research has made a start in that direction, but the statistical agencies that conduct or sponsor most of the disability studies have not been involved.

Review and Summary

As the first priority in the agenda of disability statistical issues, primary attention should be given to analysis of the methodological data on disability that have been collected by the extensive set of cross-sectional longitudinal surveys. The current work in the longitudinal studies of manpower mobility studies should also be included in this examination. The evaluation should be conducted as a cooperative effort among the statistical agencies through a unit that would undertake a regular review of the status of disability research.

There should be coordinated efforts to conduct a series of controlled variation experiments and to develop guidelines for standardized measures of work and other areas of disability. This could be accomplished through a program of small-scale studies to test methods for improving these measurements. The inclusion of methodological studies in study reports and clearinghouse publications should be as routine as the publication of survey sampling errors.

There are areas in which our basic concepts and definitions should be reevaluated. The substance of children's disabilities or handicaps should be reexamined. What is involved in the concept and measurement of social integration? How should the new forms of group quarters, "minimum care" institutions, and "board and care" homes be appropriately defined and classified.

We must also become more involved in the review and development of the World Health Organization proposals for an ICIDH. Our views and experience and the large body of research associated with this experience should be more adequately represented in the modifications of this system than they have been up to now.

Data needs and gaps are important, but subsidiary to the need to review, analyze, and extend what we have learned from the large body of studies conducted here and in other countries. The first priority in data needs is the establishment of a routine and predictable study cycle for more disability data, including: (1) a disability follow-up study to the 1990 census to provide local area data at the state level; (2) a mid-decade mini-census, with appropriate inclusion of disability-related interests; and (3) the reinstatement of a biennial disability supplement in SIPP to provide regular reporting of disability data and longitudinal measures of change.

As an overall assessment, I think we have done a good job of disability data development over the past quarter of a century. Although there are serious problems of conceptualization and measurement that need to be dealt with, these are normal and even healthy signs of incremental growth and maturity in a relatively neglected field of study. The extensive body of work in disability statistics and the general awareness of its shortcomings also suggests that we have the capacity to deal with these problems.

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APPENDIX B-1: COMPARISON OF DISABILITY IDENTIFICATION QUESTIONS: SELECTED STUDIES, 1966-1988

Social Security Administration

1966, 1972-1974, and 1978 SSA

1. Does your health or condition limit the kind or amount of work you can do?
2. Does your health or condition keep you from working altogether?
3. Are you now able to do the same kind of work you did before your work limitation began?
4. Are you now able to work full time or can you work only part time?
5. Are you now able to work regularly or can you only work occasionally or irregularly?

The classification scheme included the following categories of work disability status:

Severe. Unable to work altogether or unable to work regularly.

Occupational. Able to work regularly but unable to do same work as before onset of limitation or unable to work full time.

Secondary. Limited in the kind or amount of work that can be done, but able to work regularly at full-time job and able to do same work as before.

1967 SEO

1. Does ______ 's health
   a. Limit the kind of work______ can do?
   b. Limit the amount of work______ can do?
   c. Keep______ from working?
2. How long has______ been limited in this way?

1976 SIE

1. Does______ 's health condition—physical, emotional or mental—limit the kind or amount of work can do?
2. Does______ 's health keep______ from working at a job at all?

1970 Census

1. Does this person have a health or physical condition which limits the kind or amount of work he can do at a job?
2. Does this health or physical condition keep him from holding any job at all?

1980 Census

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

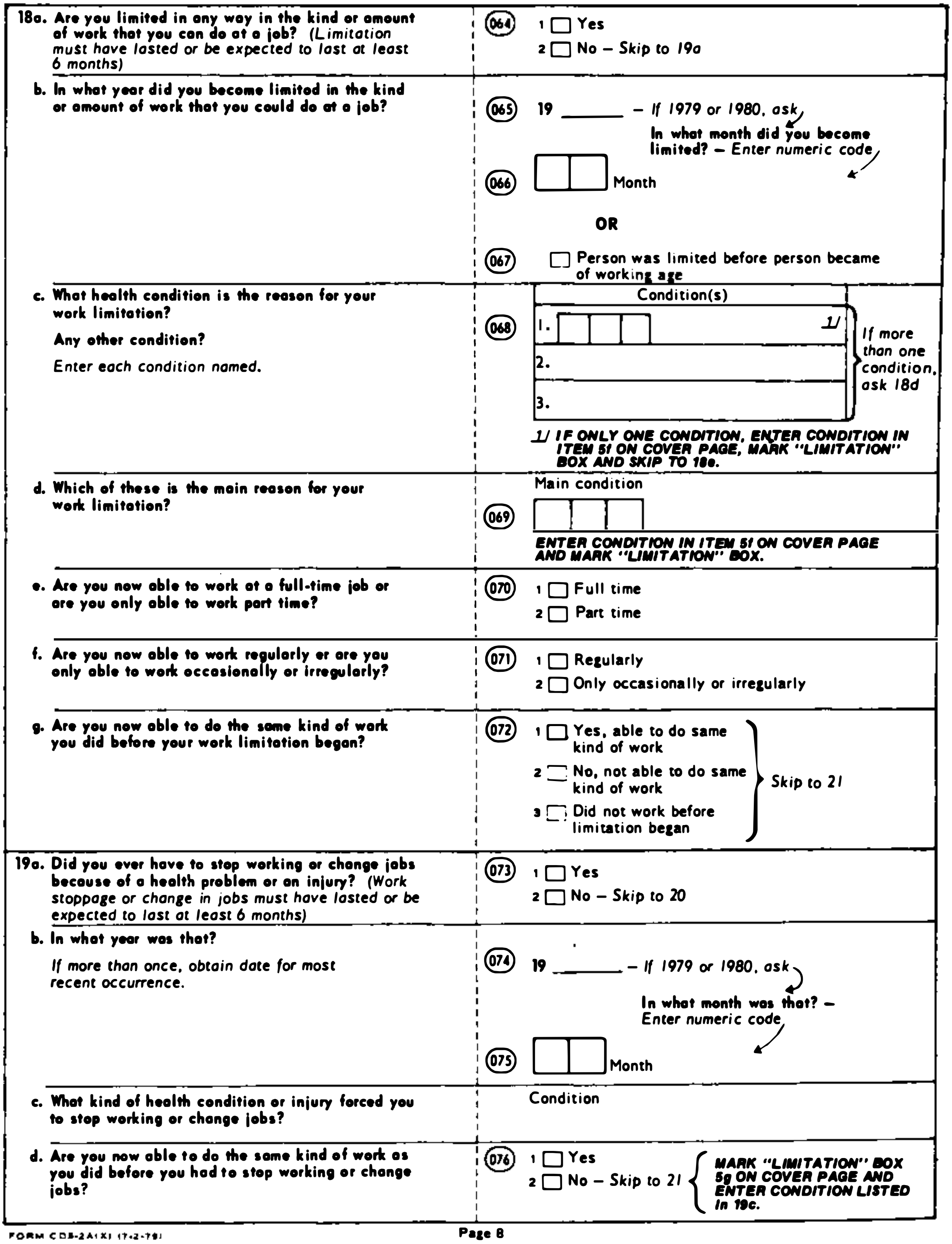
1. Limits the kind or amount of work this person can do at a job?
2. Prevents this person from working at a job?

National Health Interview Survey (1980 and earlier years)

Ages 17+	19a.	What was——— doing MOST OF THE PAST 12 MONTHS
		(For males): working or doing something else? (For females): keeping house, working, or doing something else?
		If "something else," ask:
	b.	What was——— doing?
		If 45+ years and was not "working," "keeping house," or "going to school," ask:
	c.	Is——— retired?
	d.	If "retired," ask: Did he retire because of his health?
	23a.	Does——— 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?
	24a.	Does——— NOW have a job?
	b.	In terms of health, is——— NOW able to (work—keep house) at all?
	c.	Is he limited in the kind of (work—housework) he can do because of his health?
	d.	Is he limited in the amount of (work—housework) he can do because of his health?
	e.	Is he limited in the kind or amount of other activities because of his health?

SOURCE: National Center for Health Statistics (1987).

Census Disability (pilot) Survey (Richmond), 1981



18a. Are you limited in any way in the kind or amount of work that you can do at a job? *(Limitation must have lasted or be expected to last at least 6 months)*	(064)	1 ☐ Yes 2 ☐ No – *Skip to 19a*
b. In what year did you become limited in the kind or amount of work that you could do at a job?	(065)	19 ______ – *If 1979 or 1980, ask* **In what month did you become limited?** – *Enter numeric code*
	(066)	☐☐ Month
		OR
	(067)	☐ Person was limited before person became of working age
c. What health condition is the reason for your work limitation? **Any other condition?** *Enter each condition named.*	(068)	Condition(s) 1. ☐☐☐ 1/ 2. 3. *If more than one condition, ask 18d* 1/ ***IF ONLY ONE CONDITION, ENTER CONDITION IN ITEM 5f ON COVER PAGE, MARK "LIMITATION" BOX AND SKIP TO 18e.***
d. Which of these is the main reason for your work limitation?	(069)	Main condition ☐☐☐ ***ENTER CONDITION IN ITEM 5f ON COVER PAGE AND MARK "LIMITATION" BOX.***
e. Are you now able to work at a full-time job or are you only able to work part time?	(070)	1 ☐ Full time 2 ☐ Part time
f. Are you now able to work regularly or are you only able to work occasionally or irregularly?	(071)	1 ☐ Regularly 2 ☐ Only occasionally or irregularly
g. Are you now able to do the same kind of work you did before your work limitation began?	(072)	1 ☐ Yes, able to do same kind of work 2 ☐ No, not able to do same kind of work 3 ☐ Did not work before limitation began *Skip to 21*
19a. Did you ever have to stop working or change jobs because of a health problem or an injury? *(Work stoppage or change in jobs must have lasted or be expected to last at least 6 months)*	(073)	1 ☐ Yes 2 ☐ No – *Skip to 20*
b. In what year was that? *If more than once, obtain date for most recent occurrence.*	(074)	19 ______ – *If 1979 or 1980, ask* **In what month was that?** – *Enter numeric code*
	(075)	☐☐ Month
c. What kind of health condition or injury forced you to stop working or change jobs?		Condition
d. Are you now able to do the same kind of work as you did before you had to stop working or change jobs?	(076)	1 ☐ Yes 2 ☐ No – *Skip to 21* ***MARK "LIMITATION" BOX 5g ON COVER PAGE AND ENTER CONDITION LISTED in 19c.***

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SOURCE: Bureau of the Census (1979:8).

March Current Population Survey, 1981-1988

Measuring Work Disability Status in the March Current Population Survey (CPS)

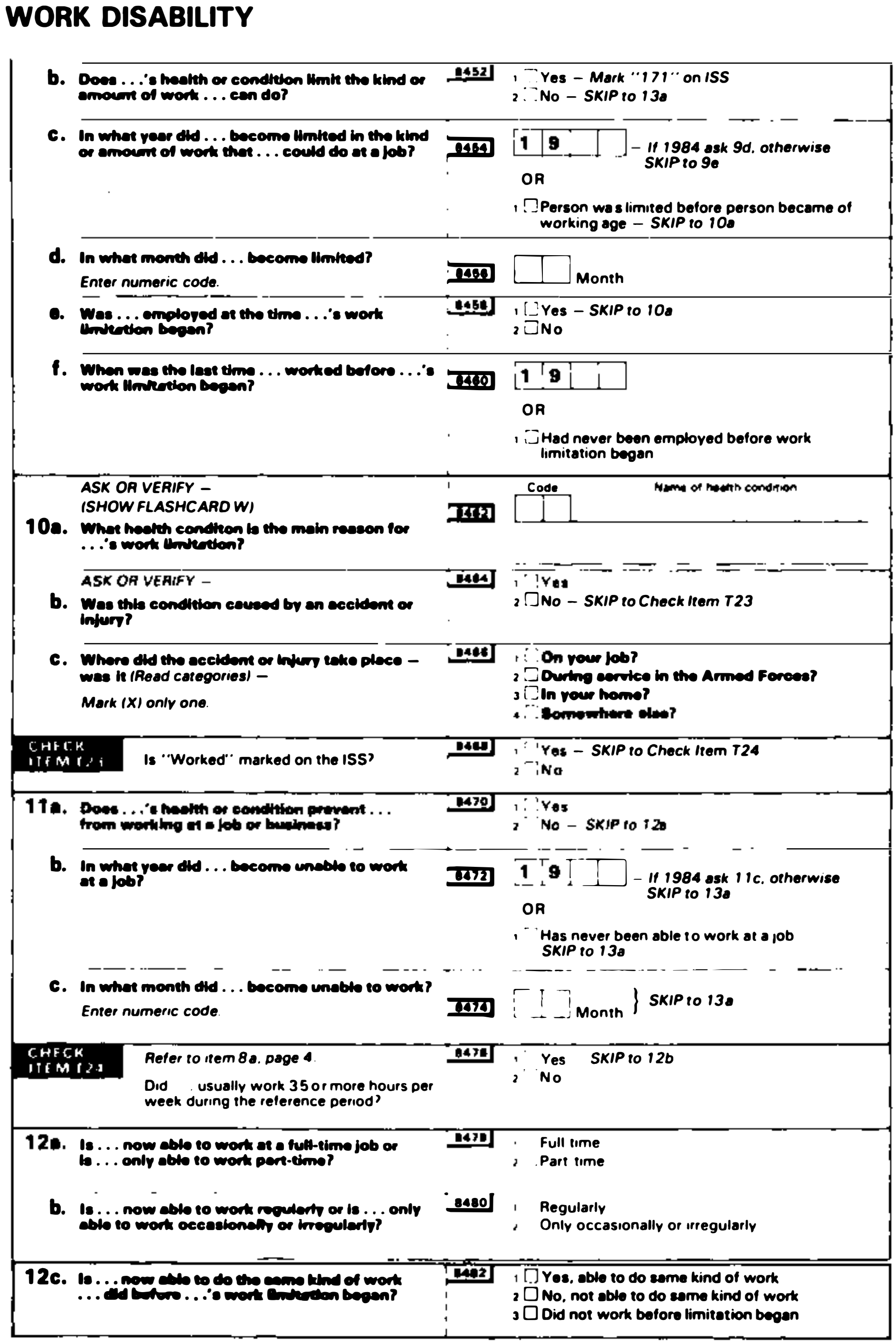
A person is considered to have a work disability if one or more of the following conditions are met:

1. Identified by a question that asks "Does anyone in this household have a health problem or disability which prevents them from working or which limits the kind or amount of work they can do?"
2. Identified by a question that asks "Is there anyone in this household 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 (based on the "main activity last week" question on the basic CPS questionnaire).
4. Did not work at all in previous year because ill or disabled (based on the "reason did not work last year" question on the March CPS supplement).
5. Under 65 years of age and covered by Medicare.
6. Under 65 years of age and a recipient of Supplemental Security Income (SSI).

If one or more of the final four conditions was met, the person was considered to have a severe work disability.

SOURCE: Current Population Reports, Population Characteristic Series P-20. (1981-1988). Bureau of the Census, Washington, D.C.

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



WORK DISABILITY

b.	**Does . . .'s health or condition limit the kind or amount of work . . . can do?**	8452	1 ☐ Yes – *Mark "171" on ISS* 2 ☐ No – *SKIP to 13a*
c.	**In what year did . . . become limited in the kind or amount of work that . . . could do at a job?**	8454	1 9 ☐☐ – *If 1984 ask 9d, otherwise SKIP to 9e* OR 1 ☐ Person was limited before person became of working age – *SKIP to 10a*
d.	**In what month did . . . become limited?** *Enter numeric code.*	8456	☐☐ Month
e.	**Was . . . employed at the time . . .'s work limitation began?**	8458	1 ☐ Yes – *SKIP to 10a* 2 ☐ No
f.	**When was the last time . . . worked before . . .'s work limitation began?**	8460	1 9 ☐☐ OR 1 ☐ Had never been employed before work limitation began
10a.	*ASK OR VERIFY –* *(SHOW FLASHCARD W)* **What health conditon is the main reason for . . .'s work limitation?**	8462	Code ☐☐ Name of health condition
b.	*ASK OR VERIFY –* **Was this condition caused by an accident or injury?**	8464	1 ☐ Yes 2 ☐ No – *SKIP to Check Item T23*
c.	**Where did the accident or injury take place – was it** *(Read categories) –* *Mark (X) only one.*	8466	1 ☐ **On your job?** 2 ☐ **During service in the Armed Forces?** 3 ☐ **In your home?** 4 ☐ **Somewhere else?**
CHECK ITEM T23	Is "Worked" marked on the ISS?	8468	1 ☐ Yes – *SKIP to Check Item T24* 2 ☐ No
11a.	**Does . . .'s health or condition prevent . . . from working at a job or business?**	8470	1 ☐ Yes 2 ☐ No – *SKIP to 12a*
b.	**In what year did . . . become unable to work at a job?**	8472	1 9 ☐☐ – *If 1984 ask 11c, otherwise SKIP to 13a* OR 1 ☐ Has never been able to work at a job *SKIP to 13a*
c.	**In what month did . . . become unable to work?** *Enter numeric code.*	8474	☐☐ Month } *SKIP to 13a*
CHECK ITEM T24	*Refer to item 8a, page 4.* Did . . . usually work 35 or more hours per week during the reference period?	8476	1 ☐ Yes – *SKIP to 12b* 2 ☐ No
12a.	**Is . . . now able to work at a full-time job or is . . . only able to work part-time?**	8478	1 ☐ Full time 2 ☐ Part time
b.	**Is . . . now able to work regularly or is . . . only able to work occasionally or irregularly?**	8480	1 ☐ Regularly 2 ☐ Only occasionally or irregularly
12c.	**Is . . . now able to do the same kind of work . . . did before . . .'s work limitation began?**	8482	1 ☐ **Yes, able to do same kind of work** 2 ☐ **No, not able to do same kind of work** 3 ☐ **Did not work before limitation began**

SOURCE: Bureau of the Census (1986:49).

Canadian Health and Activity Limitations Survey, 1986-1987
(adults aged 15 and over)

20 Because of a long-term physical condition or health problem, that is, one that is expected to last 6 months or more, are you limited in the kind or amount of activity you can do . . .

(i) At home?
Yes, is limited ____________
No ____________
(ii) At school or at work?
Yes, is limited ____________
No ____________
Not applicable ____________
(iii) In other activities such as travel, sports, or leisure?
Yes, is limited ____________
No ____________

20a INTERVIEWER CHECK ITEM

If any "Yes" is checked in 20(i), 20(ii), or 20(iii)
Then 1 ____ Go to 20b
Otherwise 2 ____ Go to 21

20b At what age did you first start having this activity limitation?

Age ____ (if age less than 1 year, enter 00)

20c What is the main condition or health problem which limits you in your activity?

Same condition as question ____ Go to 21
Specify ________________________________

23 Because of a long-term emotional, psychological, nervous, or mental health condition or problem, are you limited in the kind or amount of activity you can do . . .

(i) At home?
Yes, is limited ____________
No ____________
(ii) At school or at work?
Yes, is limited ____________
No ____________
Not applicable ____________
(iii) In other activities such as travel, sports, or leisure?
Yes, is limited ____________
No ____________

23a INTERVIEWER CHECK ITEM

If any "Yes" is checked in 23(i), 23(ii), or 23(iii)
Then 1 ____ Go to 23b
Otherwise 2 ____ Go to 24

23b At what age did you first start having this activity limitation?

Age ____ (if age less than 1 year, enter 00)

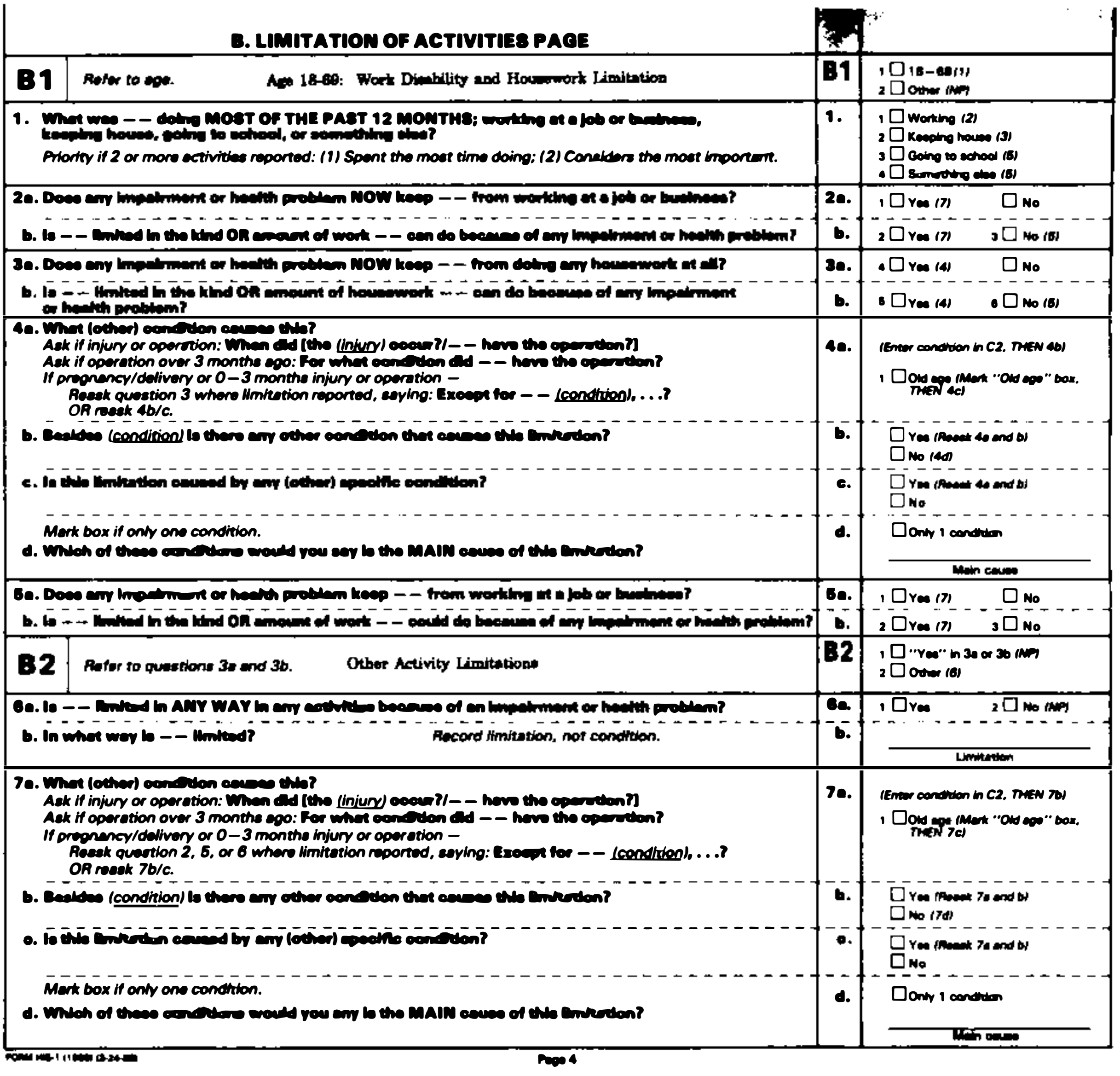
23c What is the main condition or health problem which limits you in your activity?

Same condition as question ____
Specify ________________________________

SOURCE: Statistics Canada (1988:12-14).

APPENDIX B-2: MAJOR ACTIVITY LIMITATIONS AND CHILDREN'S ACTIVITY LIMITATIONS

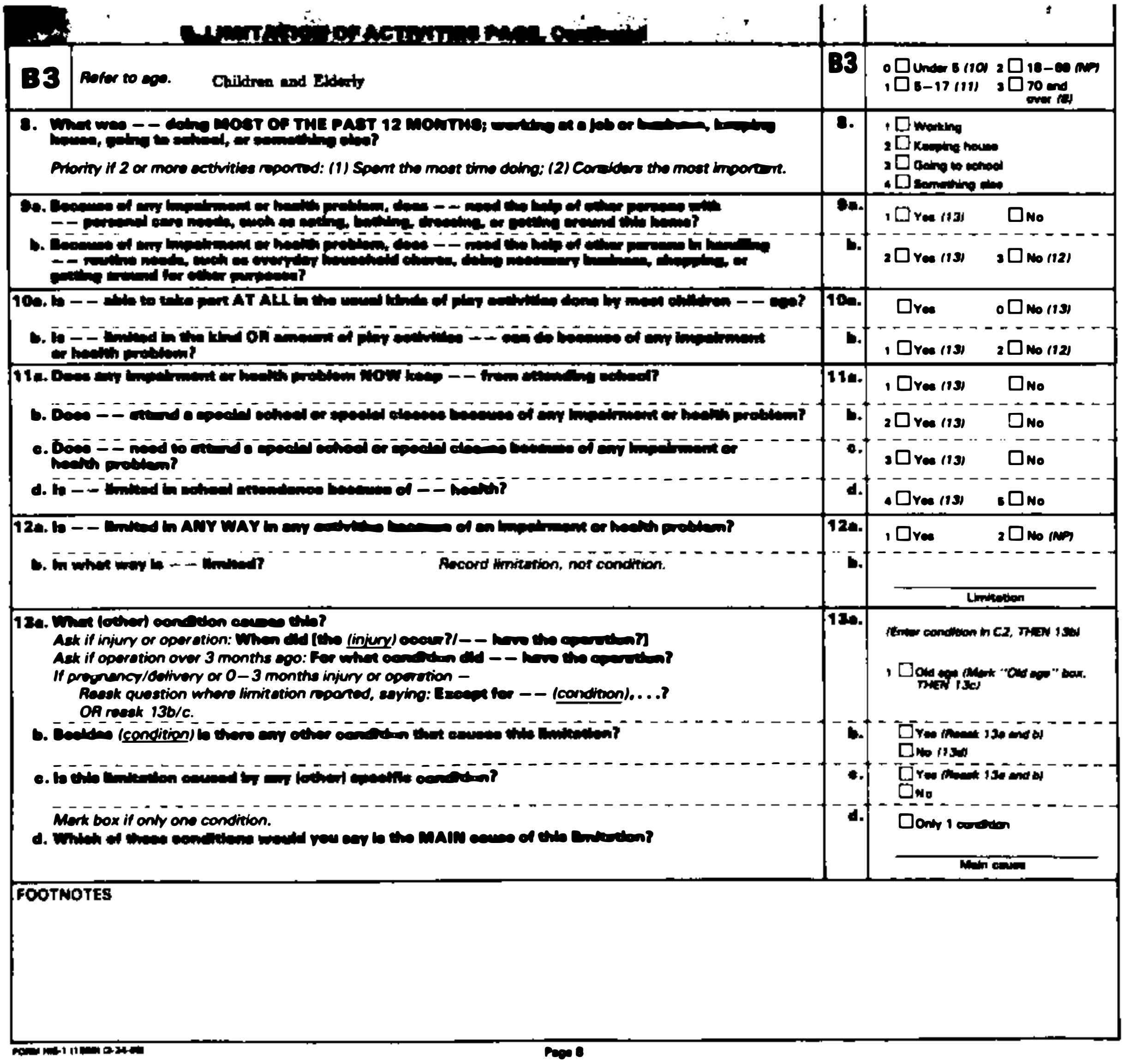
National Health Interview Survey: Major Activities, 1986



B. LIMITATION OF ACTIVITIES PAGE		
B1 *Refer to age.* Age 18-69: Work Disability and Housework Limitation	**B1**	1 ☐ 18–69 *(1)* 2 ☐ Other *(NP)*
1. What was — — doing MOST OF THE PAST 12 MONTHS; working at a job or business, keeping house, going to school, or something else? *Priority if 2 or more activities reported: (1) Spent the most time doing; (2) Considers the most important.*	**1.**	1 ☐ Working *(2)* 2 ☐ Keeping house *(3)* 3 ☐ Going to school *(5)* 4 ☐ Something else *(5)*
2a. Does any impairment or health problem NOW keep — — from working at a job or business?	**2a.**	1 ☐ Yes *(7)* ☐ No
b. Is — — limited in the kind OR amount of work — — can do because of any impairment or health problem?	**b.**	2 ☐ Yes *(7)* 3 ☐ No *(5)*
3a. Does any impairment or health problem NOW keep — — from doing any housework at all?	**3a.**	4 ☐ Yes *(4)* ☐ No
b. Is — — limited in the kind OR amount of housework — — can do because of any impairment or health problem?	**b.**	5 ☐ Yes *(4)* 6 ☐ No *(5)*
4a. What (other) condition causes this? *Ask if injury or operation:* **When did [the** *(injury)* **occur?/— — have the operation?]** *Ask if operation over 3 months ago:* **For what condition did — — have the operation?** *If pregnancy/delivery or 0–3 months injury or operation –* *Reask question 3 where limitation reported, saying:* **Except for — —** *(condition)*, . . .? *OR reask 4b/c.*	**4a.**	*(Enter condition in C2, THEN 4b)* 1 ☐ Old age *(Mark "Old age" box, THEN 4c)*
b. Besides *(condition)* **is there any other condition that causes this limitation?**	**b.**	☐ Yes *(Reask 4a and b)* ☐ No *(4d)*
c. Is this limitation caused by any (other) specific condition?	**c.**	☐ Yes *(Reask 4a and b)* ☐ No
Mark box if only one condition. **d. Which of these conditions would you say is the MAIN cause of this limitation?**	**d.**	☐ Only 1 condition ____________ Main cause
5a. Does any impairment or health problem keep — — from working at a job or business?	**5a.**	1 ☐ Yes *(7)* ☐ No
b. Is — — limited in the kind OR amount of work — — could do because of any impairment or health problem?	**b.**	2 ☐ Yes *(7)* 3 ☐ No
B2 *Refer to questions 3a and 3b.* Other Activity Limitations	**B2**	1 ☐ "Yes" in 3a or 3b *(NP)* 2 ☐ Other *(6)*
6a. Is — — limited in ANY WAY in any activities because of an impairment or health problem?	**6a.**	1 ☐ Yes 2 ☐ No *(NP)*
b. In what way is — — limited? *Record limitation, not condition.*	**b.**	____________ Limitation
7a. What (other) condition causes this? *Ask if injury or operation:* **When did [the** *(injury)* **occur?/— — have the operation?]** *Ask if operation over 3 months ago:* **For what condition did — — have the operation?** *If pregnancy/delivery or 0–3 months injury or operation –* *Reask question 2, 5, or 6 where limitation reported, saying:* **Except for — —** *(condition)*, . . .? *OR reask 7b/c.*	**7a.**	*(Enter condition in C2, THEN 7b)* 1 ☐ Old age *(Mark "Old age" box, THEN 7c)*
b. Besides *(condition)* **is there any other condition that causes this limitation?**	**b.**	☐ Yes *(Reask 7a and b)* ☐ No *(7d)*
c. Is this limitation caused by any (other) specific condition?	**c.**	☐ Yes *(Reask 7a and b)* ☐ No
Mark box if only one condition. **d. Which of these conditions would you any is the MAIN cause of this limitation?**	**d.**	☐ Only 1 condition ____________ Main cause

FORM HIS-1 (1986) (3-24-86) Page 4

SOURCE: Bureau of the Census (1988).



B. LIMITATION OF ACTIVITIES PAGE, Continued

B3 *Refer to age.* Children and Elderly	**B3**	0 ☐ Under 5 *(10)* 2 ☐ 18–69 *(NP)* 1 ☐ 5–17 *(11)* 3 ☐ 70 and over *(8)*
8. What was -- doing MOST OF THE PAST 12 MONTHS; working at a job or business, keeping house, going to school, or something else? *Priority if 2 or more activities reported: (1) Spent the most time doing; (2) Considers the most important.*	**8.**	1 ☐ Working 2 ☐ Keeping house 3 ☐ Going to school 4 ☐ Something else
9a. Because of any impairment or health problem, does -- need the help of other persons with -- personal care needs, such as eating, bathing, dressing, or getting around this home?	**9a.**	1 ☐ Yes *(13)* ☐ No
b. Because of any impairment or health problem, does -- need the help of other persons in handling -- routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?	**b.**	2 ☐ Yes *(13)* 3 ☐ No *(12)*
10a. Is -- able to take part AT ALL in the usual kinds of play activities done by most children -- age?	**10a.**	☐ Yes 0 ☐ No *(13)*
b. Is -- limited in the kind OR amount of play activities -- can do because of any impairment or health problem?	**b.**	1 ☐ Yes *(13)* 2 ☐ No *(12)*
11a. Does any impairment or health problem NOW keep -- from attending school?	**11a.**	1 ☐ Yes *(13)* ☐ No
b. Does -- attend a special school or special classes because of any impairment or health problem?	**b.**	2 ☐ Yes *(13)* ☐ No
c. Does -- need to attend a special school or special classes because of any impairment or health problem?	**c.**	3 ☐ Yes *(13)* ☐ No
d. Is -- limited in school attendance because of -- health?	**d.**	4 ☐ Yes *(13)* 5 ☐ No
12a. Is -- limited in ANY WAY in any activities because of an impairment or health problem?	**12a.**	1 ☐ Yes 2 ☐ No *(NP)*
b. In what way is -- limited? *Record limitation, not condition.*	**b.**	______ Limitation
13a. What (other) condition causes this? *Ask if injury or operation:* **When did [the** *(injury)* **occur?/-- have the operation?]** *Ask if operation over 3 months ago:* **For what condition did -- have the operation?** *If pregnancy/delivery or 0–3 months injury or operation –* *Reask question where limitation reported, saying:* **Except for --** *(condition)*, . . .? *OR reask 13b/c.*	**13a.**	*(Enter condition in C2, THEN 13b)* 1 ☐ Old age *(Mark "Old age" box, THEN 13c)*
b. Besides *(condition)* **is there any other condition that causes this limitation?**	**b.**	☐ Yes *(Reask 13a and b)* ☐ No *(13d)*
c. Is this limitation caused by any (other) specific condition?	**c.**	☐ Yes *(Reask 13a and b)* ☐ No
Mark box if only one condition. **d. Which of these conditions would you say is the MAIN cause of this limitation?**	**d.**	☐ Only 1 condition ______ Main cause

FOOTNOTES

FORM HIS-1 (1988) (3-24-88)

Page 8

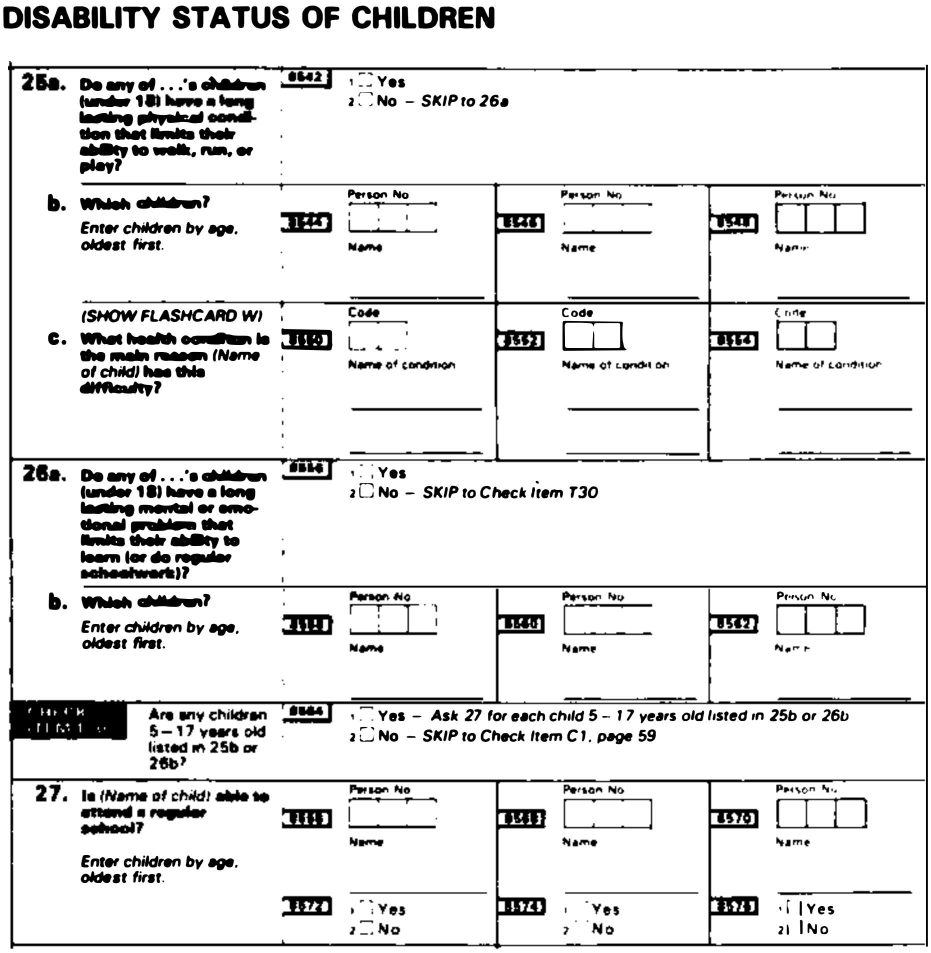
B. LIMITATION OF ACTIVITIES PAGE, Continued

B4	*Refer to age.* Self Care Assistance Needs	**B4** 0 ☐ Under 5 *(NP)* 1 ☐ 5–59 *(B5)* 2 ☐ 60–69 *(14)* 3 ☐ 70 and over *(NP)*
B5	*Refer to "Old age" and "LA" boxes. Mark first appropriate box.*	**B5** ☐ "Old age" box marked *(14)* ☐ Entry in "LA" box *(14)* ☐ Other *(NP)*
14a.	**Because of any impairment or health problem, does –– need the help of other persons with –– personal care needs, such as eating, bathing, dressing, or getting around this home?**	**14a.** 1 ☐ Yes *(15)* ☐ No
b.	*If under 18, skip to next person; otherwise ask:* **Because of any impairment or health problem, does –– need the help of other persons in handling –– routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?**	**b.** 2 ☐ Yes 3 ☐ No *(NP)*
15a.	**What (other) condition causes this?** *Ask if injury or operation:* **When did [the *(injury)* occur?/–– have the operation?]** *Ask if operation over 3 months ago:* **For what condition did –– have the operation?** *If pregnancy/delivery or 0–3 months injury or operation –* *Reask question 14 where limitation reported, saying:* **Except for –– *(condition)*, . . .?** *OR reask 15b/c.*	**15a.** *(Enter condition in C2, THEN 15b)* 1 ☐ Old age *(Mark "Old age" box, THEN 15c)*
b.	**Besides *(condition)* is there any other condition that causes this limitation?**	**b.** ☐ Yes *(Reask 15a and b)* ☐ No *(15d)*
c.	**Is this limitation caused by any (other) specific condition?**	**c.** ☐ Yes *(Reask 15a and b)* ☐ No
d.	*Mark box if only one condition.* **Which of these conditions would you say is the MAIN cause of this limitation?**	**d.** ☐ Only 1 condition ____________ Main cause

FOOTNOTES

FORM HIS-1 [illegible] Page 8

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



DISABILITY STATUS OF CHILDREN

25a.	**Do any of . . .'s children (under 18) have a long lasting physical condition that limits their ability to walk, run, or play?**	8542	1 ☐ Yes 2 ☐ No – *SKIP to 26a*				
b.	**Which children?** *Enter children by age, oldest first.*	8544	Person No ☐☐☐ Name ____	8546	Person No ☐☐☐ Name ____	8548	Person No ☐☐☐ Name ____
c.	*(SHOW FLASHCARD W)* **What health condition is the main reason** *(Name of child)* **has this difficulty?**	8550	Code ☐☐ Name of condition ____	8552	Code ☐☐ Name of condition ____	8554	Code ☐☐ Name of condition ____
26a.	**Do any of . . .'s children (under 18) have a long lasting mental or emotional problem that limits their ability to learn (or do regular schoolwork)?**	8556	1 ☐ Yes 2 ☐ No – *SKIP to Check Item T30*				
b.	**Which children?** *Enter children by age, oldest first.*	8558	Person No ☐☐☐ Name ____	8560	Person No ☐☐☐ Name ____	8562	Person No ☐☐☐ Name ____
CHECK ITEM T30	Are any children 5 – 17 years old listed in 25b or 26b?	8564	1 ☐ Yes – *Ask 27 for each child 5 – 17 years old listed in 25b or 26b* 2 ☐ No – *SKIP to Check Item C1, page 59*				
27.	**Is** *(Name of child)* **able to attend a regular school?** *Enter children by age, oldest first.*	8566	Person No ☐☐☐ Name ____	8568	Person No ☐☐☐ Name ____	8570	Person No ☐☐☐ Name ____
		8572	1 ☐ Yes 2 ☐ No	8574	1 ☐ Yes 2 ☐ No	8576	1 ☐ Yes 2 ☐ No

SOURCE: Bureau of the Census (1986:50).

Canadian Health and Activity Limitation Survey, 1986-1987
(children under age 15)

3. Does _____ have any long-term condition or health problem which prevents or limits his/her participation in school, at play, or any other activity normal for a child of his/her age?

   Yes ________________
   No ________________

4. Does _____ attend a special school or special classes at school because of a long-term condition or health problem?

   Yes ________________
   No ________________

12. From time to time, children may experience the occasional emotional or nervous problem, however, does _____ have a long-term emotional, psychological, nervous, or mental health condition or problem which limits the kind or amount of activity that he/she can do at home, at school, or at play?

   Yes, is limited ________________
   No ________________

12a. At what age did _____ first start having this activity limitation at home, at school, or at play?

   Age ________ (if age less than 1 year, enter 00)

12b. What is the MAIN condition or health problem which limits _____ in his/her activity at home, at work, or at play?

   Same as question ________________
   Specify ________________

13. Does _____ have any other long-term condition or health problem not previously mentioned, which is expected to last six months or more?

   Yes ________________
   No ________________

SOURCE: Statistics Canada (1988:2-7).

APPENDIX C
HOUSEHOLD SURVEY QUESTIONS ON DISABILITY STATUS
Bureau of the Census

(Note: the questions on disability which follow are illustrative of those asked in some household surveys for which field work was conducted by the Census Bureau.)

1970 Census

1. Does person 15 and over have a work disability (limited in kind or amount of work he or she can do)?
2. Does condition keep person from holding any job at all?
3. For how long has person been limited in ability to work?

Data published in state reports and a Subject Report.

1976 Survey of Income and Education

1. Does child 3 to 13 have a condition that limits play or sports?
2. Does child 5 to 17 have a condition that limits ability to do regular school work? If so, is child usually able to attend school?
3. Does person 18 to 64 have a work disability?
4. Does condition keep person from working at a job at all?
5. Is person able to work regularly (asked for persons with a work disability who were able to work at a job)?
6. Does person 65 and over have a condition that limits work around the house?
7. Does person need help from others in looking after personal needs (asked for persons 5 to 17 with a school work disability, person 18 to 64 with a work disability, and persons 65 and over with a house work disability)?
8. Does person need help from others to go outdoors or get around outside the home (asked for same group as above)?
9. Name(s) of condition(s) that limit activities (selected from a flash card).
10. Identity of person who diagnosed condition and duration of limitation (asked for persons 14 to 25).

Unpublished data are available. Some data were published in disability data books issued by organizations other than the Census Bureau.

1980 Census

1. Does person 15 and over have a work disability?
2. Does condition prevent person from working at a job?
3. Is person 15 and over limited or prevented from using public transportation?

Data published in state reports and Supplementary Report

1981–1989 March supplements to the Current Population Survey (CPS)

1. Does person 15 and over have a work disability? Status is based on six criteria:
   a. Identified by screening question as prevented from working or limited in kind or amount of work that can be done.
   b. Identified by screening question as having left a job or retired for health reasons.
   c. Main activity last week reported as ill or disabled and unable to work.
   d. Did not work at all in previous year because ill or disabled.

   e. Under 65 and covered by Medicare
   f. Under 65 and received SSI

Data published in Current Population Reports (P - 23).

1984 Panel of the Survey of Income and Program Participation (SIPP)

1. Does child under 18 have condition that limits the ability to walk, run, or play?
2. Does child under 18 have condition that limits ability to learn or do regular school work?
3. Is child 5 to 17 able to attend a regular school (asked for children with limitation described above)?
4. Does person 15 and over have difficulty performing specified functional activities? If so, is person able to perform activity at all?
   a. Seeing words and letters in ordinary newspaper print.
   b. Hearing what is said in a normal conversation with another person.
   c. Having speech understood.
   d. Lifting and carrying full bag of groceries.
   e. Walking a quarter of a mile
   f. Walking up a flight of stairs without resting.
   g. Getting around outside the house by one's self.
   h. Getting around inside the house by one's self.
   i. Getting in and out of bed by one's self.
5. Does person need help to do light housework or prepare meals for one's self?
6. Does person need help for personal needs such as dressing; eating, or personal hygiene?
7. Identity of helper(s) if person needs help with getting around, housework, preparing meals, or looking after personal needs.
8. Does person 15 and over have a work disability?
9. Does condition prevent person from working at a job or business? If not, is person able to work at a full-time job? Is person able to work regularly?
10. Length of time person has had a work disability and length of time person has been unable to work.
11. Health condition that is main reason for mobility limitation; health condition that is main reason for need for assistance with housework and meal preparation; health condition that is main reason for work disability (health condition selected from a flash card).
12. For children under 18 with limitation in ability to walk, run, or play; health condition that is main reason.
13. For children under 18 with limitation in ability to walk, run or play or limitation in ability to learn or do regular school work; ability to attend a regular school.

Data published in P-70 report.

1990 Census

1. Does ____ have a physical, mental, or other health condition that has lasted for 6 or more months and which:
   a. Limits the kind or amount of work ____ can do at a job?
   b. Prevents ____ from working at a job?
2. Because of a health condition that has lasted for 6 or more months, does ____ have any difficulty:
   a. Going outside the home alone, for example, to shop or visit a doctor's office?
   b. Taking care of his or her own personal needs, such as bathing, dressing, or getting around inside the home?

National Center for Health Statistics

1982-1988 National Health Interview Survey (Some data available back to 1958)

1. Is child under 5 limited in kind or amount of play activities (is child able to take part at all in usual play activities)?
2. Is child 5 to 17 limited in school attendance (does child attend special school or special classes or does health or impairment keep child from attending school)?
3. Is person 18 to 69 limited in the kind or amount of work he or she can do (is person prevented from working)?
4. Is person 18 to 69 whose main activity during previous 12 months was keeping house limited in the kind or amount of housework he or she can do (does health or impairment now keep person from doing any housework at all)?
5. Does person 70 and over or persons 5 to 69 with an activity limitation need the help of other persons with personal care needs such as eating, bathing, dressing, or getting around this home? If not, does person need the help of other persons in handling routine needs, such as every day household chores, doing necessary business, shopping, or getting around for other purposes?
6. Is person with no limitation in his or her major activity limited in any way in any activities because of an impairment or health problem (types of activities are not specified; according to interviewer's manual, they include those that are normal for most persons of that age)?
7. What condition causes the limitation of activity (up to two conditions can be listed and the main one is identified)?

1984 Supplement on Aging to the NHIS

1. Does person 65 and over have any difficulty:
    a. Bathing or showering?
    b. Dressing?
    c. Eating?
    d. Getting in and out of bed or chairs?
    e. Walking?
    f. Getting outside?
    g. Using the toilet, including getting to the toilet?
2. For each activity that involved some difficulty, information was obtained on the degree of difficulty, the type of assistance used (person or equipment), and the condition(s) causing the difficulty.
3. Does person have difficulty controlling bowels or urination?
4. Does person stay in bed or in a chair all or most of the time?
5. Does person have any difficulty:
    a. Preparing his or her own meals?
    b. Shopping for personal items such as toilet items or medicines?
    c. Managing his or her money (such as keeping track of expenses or paying bills)?
    d. Using the telephone?
    e. Doing heavy housework like scrubbing floors or washing windows?
    f. Doing light housework like doing dishes, straightening up, or light cleaning?
6. For each activity that involved some difficulty, information was obtained on the degree of difficulty, whether personal help was received, and the condition(s) causing the difficulty.

APPENDIX D
CURRENT OR PLANNED DISABILITY RESEARCH ACTIVITIES IN THE HEALTH CARE FINANCING ADMINISTRATION

Medicare

Health Care Use by Medicare's Disabled Enrollees—Three million persons under age 65 are entitled to Medicare because of disability. This study examines their Medicare use and mortality. Disabled enrollees had higher health-care use and mortality than comparison groups of Medicare's aged enrollees or of the general population under age 65. One type of disabled enrollee, adults disabled as children (over one-half of whom are mentally retarded) show lower use rates than the other types of enrollees—workers and widows. High mortality of the disabled during the 2-year waiting period for Medicare suggests the need to investigate how they pay for care during this period. This report was published in the Health Care Financing Review/Summer 1986/Volume 7/Number 4.

Medicare Utilization by Disabled-Worker Beneficiaries: A Longitudinal Analysis—This article describes Medicare utilization and reimbursement amounts for 1974-81 for a cohort of disabled-worker beneficiaries under age 62 and first entitled to cash benefits in 1972. The data come from a first-time linkage of disability insurance program data with data on Medicare utilization. This report was published in the Social Security Bulletin/December 1987/Volume 50/Number 12.

Estimated Costs of Eliminating the 2-Year Waiting Period for Medicare Entitlement for Disabled Beneficiaries—This study estimates the cost to Medicare of shortening or eliminating the waiting period, based on the Medicare experience of a cohort of persons first entitled to disability benefits in 1972. Health-care costs incurred during the 2-year waiting period are estimated separately for beneficiaries who die, recover, and remain on the rolls, controlling for a variety of individual characteristics, including reason for disability, former occupation, and former earnings. The estimates are conservative in that they do not include an adjustment for the costs associated with AIDS patients who are expected to enter the disability rolls in increasing numbers. The study found that estimated health-care costs during the 2-year waiting period are higher than post-waiting period costs because of high death rates during the waiting period. This is an ongoing study by SSA and HCFA analysts.

Medicaid

Medicaid Expenditures for Care of the Chronically Mentally Ill—This paper reports on the provision of Medicaid-financed mental health care in the state of Michigan. The purpose is to identify some of the basic patient characteristics which are associated with substantial variations in the utilization and cost of care and use this information to estimate statistical functions that predict mental health expenditures. Since there are well-known arguments for financing mental health care through capitation or prospective budgets, the paper experiments with the feasibility of establishing appropriate allocations among 13 regions in Michigan. This report is in preparation for the Tape-to-Tape contract.

Medicaid Expenditures for the Disabled Under a Work Incentive Program—Congress enacted Section 1619 of the Social Security Act to enable the disabled receiving Supplemental Security Income (SSI) to obtain jobs and still retain Medicaid health benefits. Congress intended this work incentive to remove the fear of the severely disabled that by obtaining employment they would lose Medicaid benefits. Based on data from 11 states, this analysis found that Medicaid expenditures for Section 1619 enrollees were relatively small and only one-half the average Medicaid expenditure for the disabled. Retaining Medicaid appears to provide a significant work incentive because Medicaid expenditures represent 13 percent of Section 1619 enrollees' earnings. This report was published in the Health Care Financing Review/Spring 1988/Volume 9/Number 3.

Medicaid Recipients in Intermediate Care Facilities for the Mentally Retarded—This study examines Medicaid utilization and expenditure patterns of Medicaid recipients in intermediate care facilities for the mentally retarded (ICFs/MR) in three states: California, Georgia, and Michigan. Data were obtained from uniform Medicaid data files (Tape-to-Tape project). Most recipients in ICFs/MR were nonelderly adults with severe or profound mental retardation who were in an ICF/MR for the entire year. The average annual cost of care ranged from $26,617 per recipient in Georgia to $36,128 per recipient in Michigan. The vast majority of recipients were low utilizers of other Medicaid services. Approximately one-third of the recipients were also covered by Medicare. This report was published in the Health Care Financing Review/Spring 1987/Volume 8/Number 3.

Medicaid: Use and Cost of Medical Care by Institutionalized Recipients, New York and Michigan, 1982—This Note presents data on the use and costs of medical care of aged and disabled institutionalized Medicaid recipients in New York during fiscal year 1982 and Michigan during calendar year 1982. This report uses three items to measure use and expenditure rates. The first measures use of Medicaid services; the other two measure average expenditures. This report was published as a Health Care Financing Note/ December 1987/Number 7/HCFA Pub. No. 03246.

Patterns of Medicaid Utilization and Expenditures in Selected States: 1980–1984—This paper studies the utilization and expenditures of the disabled in four state Medicaid programs (California, Georgia, Michigan and Tennessee) who received cash assistance through the Supplemental Security Income (SSI) program, for the calendar year 1984. This report is in draft status.

APPENDIX E
NATIONAL REPORTING PROGRAM FOR MENTAL HEALTH STATISTICS

The Survey and Reports Branch (NIMH) collects national statistics on specialty mental health organizations and the patients they serve; conducts applied demography research; engages in the development and refinement of minimum data sets that serve as standards for the field; and operates the annual National Conference on Mental Health Statistics. Representative current projects include:

- *The 1988 Inventory of Mental Health Organizations and General Hospital Mental Health Services*—A periodic, complete enumeration survey of specialty mental health organizations designed to collect information on organizational characteristics, programs offered, aggregate patient characteristics, patient movement statistics, staffing, revenues, and expenditures.

In 1988, the Inventory has been expanded to cover community residential organizations, and questions have been added on case management services. This Inventory was sent to the field prior to November 15, 1988.

- *The 1990 Longitudinal Client Sample Survey of Outpatient, Mental Health Programs*—A sample survey designed to collect longitudinal clinical and service information on admissions and persons continuing care. This represents the first longitudinal survey conducted by the program.

In 1988, a field test was being conducted to examine the feasibility of the full-scale, national longitudinal survey conducted by the program. Survey items included level of functioning, as well as detailed information on service use, provider, and cost. The full-scale survey is scheduled for 1990.

- *Longitudinal Patient Data for State Mental Hospital Inpatient Services*—A full enumeration survey of all episodes of care in state mental hospital inpatient services in 11 pilot states for the period between 1984 and 1987. The data base permits longitudinal analysis of care patterns for individual patients.
- *The Inventory of State and Prison Mental Health Services*—A complete enumeration survey designed to collect information parallel to that of the Inventory of Mental Health Organizations and General Hospital Mental Health Services. This survey was implemented in 1988.
- *Health Demographic Profile System*—A series of mental illness risk indicators derived from the decennial U.S. census available for different geographical aggregations from census tracts to states.
- *The 1989 National Conference on Mental Health Statistics*—The 38th annual conference for state mental health statisticians designed to address statistical, research, and policy issues of current interest. Meeting was held in San Diego, California on May 30-June 2, 1989.

APPENDIX F
DISABILITY STATISTICS PROGRAM DESCRIPTION

The Disability Statistics Program is a 3-year project funded by the National Institute for Disability and Rehabilitation Research (NIDRR) (Cooperative Agreement number G0087C2014) to develop and disseminate statistical information on disability in the United States. The program is directed by Mitchell P. LaPlante, Ph.D. and Professor Dorothy P. Rice of the Institute for Health and Aging, University of California, San Francisco. Collaborating on project planning and dissemination activities is the firm InfoUse, Susan Stoddard, Ph.D., President.

Through statistical analyses of national survey and program databases (primary databases are the Survey of Income and Program Participation and the National Health Interview Survey), the Disability Statistics Program is developing and updating data on major aspects of disability in the United States, including

- demography
- epidemiology and health status
- health care use, costs, and coverage
- employment and earnings
- social services, benefits, and activity

Research results are disseminated through reports, chart books, and journal articles. Two reports are currently available and several others are planned:

Mitchell P. LaPlante (January, 1989) Disability in basic life activities across the life span. *Disability Statistics Report,* No. 1. San Francisco: University of California, Institute for Health and Aging.

Mitchell P. LaPlante (November, 1989) Disability risks of chronic illnesses and impairments. *Disability Statistics Report,* No. 2. San Francisco: University of California, Institute for Health and Aging.

Information about program activities, highlights of research findings, and announcements of publications are disseminated to a wide audience through semiannual issues of the *Disability Statistics Bulletin*, a newsletter mailed to several thousand readers including consumer and advocacy groups, researchers, policymakers, and vocational rehabilitation, special education, and other service providers. The program also serves as a resource center for statistical data on disability and operates a phone inquiry service to disseminate existing statistical information (415) 644-9904. The program is interested in receiving statistical information on disability in the United States for dissemination purposes. Correspondence should be directed to Dr. Mitchell P. LaPlante, Director, Disability Statistics Program, Institute for Health and Aging, University of California, San Francisco, California 94143-0646.

APPENDIX G
DATA GAPS FOR DISABILITY STATISTICS ON THE WORKING AGES[1]

Epidemiology

- prevalence data on chronic conditions need evaluation
- checklists utilized in Health Interview Survey contain many insignificant conditions but omit other important conditions
- prevalence of multiple conditions is a problem with stratified checklist approach
- lack of adequate prevalence data on impairment
- staging of illness
- relationship of disability to conditions: disability risks
- epidemiologic risk factors in disability (nutrition, stress) and secondary conditions
- prevention of disability: primary, secondary, and tertiary

Demography

- continued clarification of concepts of functional limitation, disability, and handicap
- definitions have implications for prevalence and policy
- new mental retardation/development and disability (MR/DD)
- questions of identification and measurement of disability in surveys
- statistical relationships among measures to refine conceptualization
- improvement of measures of disability included in surveys
- onset and duration of limitation: necessary for incidence, no longer included in NHIS
- local area estimates
- time series
- changing demographics and projections
- measures of the environment, i.e., accommodations
- perceived health, morale, social integration, and their relationship to different conditions and types of disability

Health Services Use, Costs, and Coverage

- acute health services by type of disability
- long term health and health related social services by type of disability
- relationships among acute and long term services
- access to services and payment
    - access to insurance coverage
    - adequacy of insurance coverage
    - out-of-pocket costs
    - access to and adequacy of Medicare and Medicaid
- attendant care

Employment and Earnings

- labor force participation
    - employment, unemployment, discouraged worker rates
- hours worked
- occupation and industry
- income—earned and from other sources
- savings and assets—pre- and post-onset of disability
- career development
- early retirement
- work accommodations
- work history
- vocational services

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[1] Prepared by Mitch LaPlante for presentation at the Workshop on Disability Statistics, April 6–7, 1989.

Social Services, Benefits, and Quality of life

- **knowledge and use of information and referral services**
- **knowledge and use of personal attendant services**
- **knowledge and receipt of SSI and SSDI benefits**
- **receipt of other benefits (pension, short-term disability)**
- **quality of life: life satisfaction, service satisfaction**
- **living arrangements**
- **caregivers**
- **measuring handicap and discrimination**