

Identifying The Disabled: Concepts and Methods in the Measurement of Disability

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ESTIMATES OF the number of disabled people in the United States vary substantially, according to the particular concept and method used. The terminology used to describe disability is frequently inconsistent, and considerable confusion exists about concepts, criteria, and operational definitions. Different terms are used to designate similar aspects of disability, and the same terms are sometimes used to designate different aspects and levels of limitation.

The methods of measurement common to survey research differ substantially from the disability evaluation procedures used in judicial and administrative decisions in benefit, compensation, and rehabilitation programs. Administrative disability determinations tend to rely primarily on the medical evaluation of impairment—often as the sole criterion for the evaluation of disability.¹ Population estimates based on survey interviews rely primarily on the respondent's evaluation of his limitations in activities such as work, house-keeping, or school.

Literally interpreted, disability refers to "loss or reduction of ability." Definitions in use in clinical studies, survey research, and administrative evaluations commonly accept the loss or reduction of capacity to engage in normative role activities as the central point of reference of disability, with an origin in impairments or functional limitations resulting from disease or injury. The specification of activity requirements and the criteria for determining ability loss are, however, related to the research or administrative objectives.

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¹ American Medical Association, Committee on Medical Rating of Physical Impairment, *Journal of the American Medical Association*, "Guides to the Evaluation of Permanent Impairment(s): The Extremities and Back," Feb. 15, 1958; "The Visual System," Sept. 27, 1958; "The Cardiovascular System," Mar. 5, 1960; "Ear, Nose, Throat, and Related Structures," Aug. 19, 1961; "The Central Nervous System," July 6, 1963; "The Digestive System," Apr. 13, 1964; "The Peripheral Spinal Nerves," July 13, 1964; "The Respiratory System," Nov. 22, 1965; "The Endocrine System," Oct. 10, 1966; "Mental Illness," Dec. 19, 1966.

A national survey of disabled adults has been undertaken by the Social Security Administration to examine the major economic, occupational, and other social consequences of disability and to evaluate the social insurance provisions for disability. In order to provide an adequate conceptual basis for the study and the identification procedures, the definitions and criteria of disability in current use were reexamined. A new survey instrument for identifying the disabled was developed in order to meet the objectives of the study.

This article describes the methods and procedures used to develop and test a survey instrument to identify the disabled adult population. The differences in concept and methods and in the estimated levels of prevalence from other methods for identifying disability are discussed. The purposes of the Social Security Administration disability study are also reviewed.

DISABILITY CONCEPTS

The terminology and criteria of disability in administrative use reflect the objectives of the defining organizations and their social context. Individuals with the same degree of impairment or limitation of functional capacity are not necessarily comparably classified as disabled under different programs, nor would an individual meeting one set of disability criteria necessarily qualify under another evaluation procedure. Organizations with a responsibility for benefit or compensation awards tend to emphasize medical evidence requirements and the restrictiveness of the impairment. Organizations with rehabilitation objectives tend to focus on vocational potential and the "marketability" of the client.²

Program-administering agencies—such as the

² Marvin B. Sussman (editor), *Sociology and Rehabilitation*, American Sociological Association, 1966, page 68, and Saad Z. Nagi, "Some Conceptual Issues in Disability and Rehabilitation," *ibid.*, page 110.

Social Security Administration, the Veterans Administration, the Social and Rehabilitation Service, and the State public assistance and workmen's compensation agencies—define their eligible population in terms of procedures and criteria relevant to their objectives and their statutory authority. In addition to disability criteria, each program may apply criteria unrelated to the disablement itself, such as work experience, financial need, place of injury, local residence, and similar requirements. Where the program is State-administered, as in workmen's compensation and aid to the permanently and totally disabled (APTD), the criteria and procedures may vary from State to State, permitting potentially more than 50 criteria for disability evaluation for each program.³

Disability in the compensation context is often evaluated on the basis of "scheduled impairments," regardless of the capacities involved in specific activities. Where wage loss is a consideration in the award, the economic consequences of an injury may also enter into the evaluation. The extent of the impairment and the causative relationship are usually, however, the key issues in compensation awards.⁴ Programs such as workmen's compensation, for example, have produced a huge literature on medico-legal requirements for evidence of impairments.⁵

This approach is closely related to the primacy

given to impairment evaluation in the American Medical Association guides. Although the distinction between the medical impairment and disability is recognized, the impairment is "in fact the sole or real criterion of permanent disability far more often than is readily acknowledged."⁶

Income-maintenance programs, such as disability insurance under the Social Security Act and the public assistance APTD programs, are concerned with the socio-economic consequences of disability. Their procedures typically require only dichotomous judgments for eligibility requirements. Although consideration is given to vocational factors, such as age, education, training, and work experience, the severity of the impairment and the resulting functional limitations, based on medical evidence, are the primary considerations in the disability evaluation.⁷

Rehabilitation agency definitions also tend to be impairment-oriented but from the viewpoint of adjustment or prevention. The criteria for disability may be more flexible in order to identify populations with greater potential—as, for example, those with chronic diseases or impairments, regardless of the extent of capacity limitation.⁸

The relationship of these aspects of disability may be clarified by a review of essential terms and of the analytical distinctions that appear most useful for research in disability.

Disease and Injury

The origins of disability may be identified with the onset of a *mental or physical disease process or trauma*, involving anatomical or functional abnormalities in bodily and behavioral processes. During the acute stage or active pathology of the disorder, short-term limitations in functional capacities are frequently evident and accepted—such as bedrest, absenteeism, and avoidance of

³ Philip Frolich, *A Summary of APTD Requirements and Comparison with OASDI*, Division of Economic and Social Surveys, Office of Research and Statistics, Social Security Administration; and Bureau of Family Services, *Characteristics of State Public Assistance Plans Under the Social Security Act* (Public Assistance Report No. 50), 1962.

⁴ Wilmer C. Smith, *Principles of Disability Evaluation*, J. B. Lippincott Company, 1959, pages 11, 74, 76, 196.

⁵ See, for example, Earl D. MacBride, *Disability Evaluation*, J. B. Lippincott Company, 1963; Richard T. Hudson, "Disability Evaluation," *American Surgeon*, August 1959; Packard Thurber, "Observations on Disability Evaluation," *Medical Trial Technique Quarterly*, 1960, pages 215-220; Arthur J. Vorwald, E. D. Robin, B. L. Gordon, H. L. Motley, and T. B. Noonan, "Evaluation of Disability," *Archives of Environmental Health*, June 1964; H. H. Kessler, *Accidental Injuries: The Medico-Legal Aspects of Workmen's Compensation and Public Liability*, Lea and Febiger, 1941; Council on Industrial Health, *Medical Relations Under Workmen's Compensation in Illinois* (Illinois State Medical Society), 1953; Don M. Jackson, "Compensation Hearings: Medical Witnesses, Disability, and Medical Impairment," *Journal of the Kansas Medical Society*, October 1964; and Wilmer C. Smith, *op. cit.*

⁶ American Medical Association, "Guides . . ." *op. cit.*

⁷ Social Security Administration, *Disability and Social Security*, March 1965.

⁸ Hearings before the Subcommittee on Executive Reorganization, *Federal Role in Programs for the Handicapped* (89th Congress), July and August 1966, testimony by Mary E. Switzer, pages 30-40; William M. Urdane, "Introduction," *Sociology and Rehabilitation* (Marvin B. Sussman, editor), American Sociological Association, 1966, pages xiii-xxi.

social contact to limit infections.⁹ Most disease process is of this nature. A 1949 survey found that one-fourth of the adults unable to work because of a sickness or disability on the survey day had been incapacitated for 1 week or less. An average of 3 days a year are lost from work among the employed population of the United States because of acute conditions or because of sickness.¹⁰

Chronic diseases may be of a continuing or recurrent nature or may stabilize after an active stage. As F. C. Shontz has pointed out, acute and chronic disease processes may not be clearly distinguished even in patients with chronic diseases, since both types of disease may be part of the same process.¹¹ The arrested disorder or trauma may, however, produce residual losses and abnormalities as a direct result of the disease process, such as destruction, loss, or injury to body tissues, with a consequent loss of functional capacities. Other effects or extrinsic residuals, such as muscle atrophy, hallucinatory symptoms, bed sores, incontinence, and character and personality disturbances, may result from stimulus deprivation,¹² pain, or anxiety, although they may not be a direct consequence of the mental or physical disorder or injury. Extrinsic residuals are, in a sense, the products of the social management of the disorder.

Residual Impairments

It is useful to characterize the disease and in-

⁹ The exemptions and expectations of the sick role have been discussed in Talcott Parsons, *The Social System*, Free Press, Glencoe, 1951, pages 439-447; G. G. Kasselbaum and B. O. Baumann, "Dimensions of the Sick Role in Chronic Illness," *Journal of Health and Human Behavior*, Spring 1965; and Gerald Gordon, *Role Theory and Illness*, College and University Press, New Haven, 1966.

¹⁰ Marjorie E. Moore and Barkev S. Sanders, "Extent of Total Disability in the United States," *Social Security Bulletin*, November 1950; U. S. Public Health Service, National Center for Health Statistics, *Acute Conditions* (Series 10, No. 26), table 10.

¹¹ F. C. Shontz, "Severe Chronic Illness," *Psychological Practices with the Physically Disabled*, edited by J. F. Garrett and Edna S. Levine, Columbia University Press, 1962, New York, pages 415-416.

¹² Bernard D. Daitz, "The Challenge of Disability," *American Journal of Public Health*, April 1965, and Nagi, *op. cit.*, page 104.

jury residuals as *impairments*, relating primarily to abnormalities in physical and mental structure and functioning and to characterize the activity losses or restrictions as *functional limitations*. Muscle atrophy, for example, might constitute a residual impairment of stroke, but mobility losses are functional limitations. A close correlation between the extent of muscle atrophy and the ability to walk may be expected, most markedly at the extremes, but the intervening variables of personal orientation and environmental expectations will also influence the outcome. As Bert Hanman has observed, similar impairments do not always mean similar activity limitations for everyone nor that everyone has similar remaining abilities.¹³

The distinction, while helpful for some purposes, is not essential to disability conceptualization, since impairments may restrict activity not only through direct functional limitations but also through therapeutic limitations, environmental restrictions, energy reserve losses,¹⁴ and psychological overlays. Of more importance in the consideration of the impairment or functional limitation is the expected duration. Only when the impairment is expected to be of prolonged duration, to aggravate existing conditions, or to stimulate complications of long duration can it be considered an element in the changed pattern of behavior that constitutes disability.

The term *handicapped* has also been used as an expression of disability, in referring to defects and limitations imposed by disease or injury, as well as to social disadvantages. Handicaps are frequently referred to as limitations an individual has or has not overcome. In this sense, handicaps may be considered as competitive disadvantages. The individual may retain or develop the ability to cope with the environment by minimizing the extent of incapacity or, more affirmatively, by optimizing the use of his residual capacities. Handicaps presuppose the existence of an impairment of structure or function but not necessarily of a functional limitation. An individual with a disability or an incapacity for structured role performance would of necessity have a handicap, but an individual with a handicap need not neces-

¹³ Bert Hanman, "Clues in Evaluating Physical Disability," *Journal of Occupational Medicine*, November 1959.

¹⁴ Wilmer C. Smith, *op. cit.*, pages 63 and 137-139.

sarily be disabled.¹⁵ A chronic disease would not necessarily constitute a handicap, unless there were disease residuals with the potential for creating activity limitation. The definition of handicaps given in a recent Danish study represents an interesting ideal-type application of this distinction:

For the purposes of this survey a physical handicap is defined as a protracted physical disease or defect of such a degree that an unskilled unmarried worker without support from his surroundings and with mental reserves and energy a little below average, normally would have difficulty in coping with daily life on an equal footing with others if he were suffering from the disease or defect in question.

In other words, the difficulties caused by the physical handicap need not actually be present for a person to be included in the survey, if they have been compensated by, e.g., favorable social circumstances, particularly high intelligence, or great energy.¹⁶

In terms of prevalence estimates, the number of handicapped people in the population should be greater than the population with activity limitations but less than the number with chronic conditions. It should approximate the number with residual impairments of a nature and extent to be reportable by the individual or observed by others as creating difficulty or requiring special adjustments to participate in normal activity.

Disability is distinguished from functional limitations by its relationship to the *required capacities* for the performance of normal roles and activities. Disability represents a loss or decrease in ability to respond to behavioral expectations as a result of impairments and functional limitations. The nature and extent of the capacity losses, the residual capacities, and the opportunity for using residual capacities defines the severity of the disability. The initiating condition may be relevant to the residual impairments, as active pathology, or may be of interest in the epidemi-

ology of disability. It is not intrinsic to the nature of the disability nor is it necessarily predictive of its severity.¹⁷ Disabilities with different etiologies may have similar capacity restrictions, while similar conditions may produce different patterns of activity limitation.

When physical and mental impairments affect functional ability in intellectual, emotional, social, and economic areas, the affected individual may be defined as disabled or as exhibiting changes in behavior characteristic of disability. The interaction of the individual with the environment structures the nature or perception of disability, as the requirements or behavioral expectations for which his capacity to respond is evaluated. Disability is the result of social and individual processes as well as medical processes. In consequences as in epidemiology, disability is a "social problem with medical aspects."¹⁸

The adaptability of the individual, in terms of his age, education, skills, and temperament may mitigate the capacity-limiting effects of the underlying impairment. The greater his capacity for adaptation, the greater the likelihood of compensation for capacity losses. Performance requirements may be met by different combinations of residual capacities, by changes to an environment with requirements within the scope of his capacities, by acquiring new capacities to offset the incapacity, through retraining, or by changes in the capacity requirements within an environment.

Disability is also distinguished from the limitations of short-term acute conditions or sickness by its duration. The impairment and limitation residuals of disability are of permanent, prolonged, or indefinite duration. They may be irreversible or require extensive or prolonged treatment to restore functional capacity. The behavioral patterns of disability must, therefore, also be of an extended or continuing nature, as adjustments to the loss of capacity for work and social activities and their possible consequences for income support, for family stability, and for social involvement.

¹⁵ It should be recognized that usage on this point is far from uniform. Beatrice Wright, for example, uses *disability* to refer to the medical condition, as deviation from the normal standard, and *handicap* to refer to capacity limitations, in terms of the requirements of the environment (*Physical Disability—A Psychological Approach*, Harper and Row, 1960, pages 7-9). For another approach, see Maya Riviere, *Rehabilitation Codes: 5-Year Progress Report, 1957-62*, Rehabilitation Codes, Inc., pages 1-2 and 60-64.

¹⁶ Bent R. Anderson, *Methods of the Study of the Physically Handicapped in Denmark*, Danish National Institute of Social Research, Copenhagen, 1964, page 6.

¹⁷ James N. Morgan, Martin H. David, Wilbur J. Cohen, and Harvey E. Brazer, *Income and Welfare in the United States*, McGraw-Hill, 1962, pages 222-231.

¹⁸ James F. Garrett and Edna S. Levine, editors, *Psychological Practices with the Physically Disabled*, Columbia University Press, 1962, page ix.

SURVEY OF DISABLED ADULTS

Under the old-age, survivors, and disability insurance (OASDI) program, disability benefits are provided to severely disabled adults with extensive work experience in covered employment and to adults disabled since childhood who are dependents of retired, disabled, or deceased beneficiaries.

As part of the Administration's continuing evaluation of program administration and social policy issues, the Office of Research and Statistics conducts a wide variety of studies into areas related to income-maintenance problems. Relatively little information has been available on the social and economic consequences of disability. Most of the research in disability has been local, clinical, or of a limited descriptive nature.

Following a pilot study of OASDI disability insurance beneficiaries conducted in 1960,¹⁹ the Social Security Administration undertook a major national study of disability. The study population includes all disabled adults aged 18-64 in the United States. The study has several objectives:

- to describe the prevalence, nature, and extent of work-limiting disability
- to examine the relationship of antecedent and onset factors to the severity of the disability and the subsequent work experience
- to examine the effect of the severity of the disability on income and income sources, occupation and work adjustments, medical care, rehabilitation, and family relationships and activities
- to examine the relationship of the public income-maintenance programs, in terms of the populations "selected by" or benefiting from the provisions of these programs—including, for example, comparison of the characteristics of disabled OASDI beneficiaries, disabled adults receiving support from other income-maintenance programs, and disabled adults with no income from public income-maintenance programs
- to examine alternative program provisions for disability and work experience requirements.

Study Design

The study is being conducted through two surveys, a household survey for the noninstitutionalized population and an institutional survey. Field work for the survey of the noninstitutional-

¹⁹ Lawrence D. Haber and others, *The Disabled Worker Under OASDI* (Research Report No. 6), Social Security Administration, 1964.

ized adult population was carried out by the Bureau of the Census during the spring of 1966. Field work for the survey of disabled adults in long-stay institutions was conducted during August and September of 1967.

The survey of noninstitutionalized disabled adults is based on a multiframe area probability sample design, selected to be representative of the noninstitutionalized, civilian population of the United States. The survey was conducted in two stages: first, to screen the population aged 18-64 for people with health-related limitations in their ability to work or do housework, whose condition had lasted longer than 3 months; second, to verify the disability statement and to collect extensive data on the nature, severity, onset, and duration of the disability, current and past labor-force status and work experience, medical care, rehabilitation services, income and income sources, assets, family relationships and activities, and demographic characteristics. The first stage was conducted by mail questionnaire. The second stage was conducted by personal interview. The Bureau of the Census was responsible for data collection and processing.

The survey sample was selected from a 243 first-stage area design, combining the Census Bureau's Monthly Labor Survey (MLS) and Current Population Survey (CPS) primary sampling units. Approximately 30,000 households were selected from seven population frames, including 18,000 sample households from the CPS and MLS, 2,000 OASDI disability beneficiaries, 1,700 persons receiving public assistance because of disability,²⁰ and 8,000 persons whose application for OASDI disability benefits had been denied.

The disability identification questionnaires were mailed out during February-March 1966. There were two certified mail follow-ups for nonresponses and personal interview callbacks for a subsample of the remaining nonresponses. A subsample of disabled persons, stratified by extent of limitations was selected for interview. The completed survey sample includes approximately

²⁰ A sample of recipients of aid to the permanently and totally disabled (APTD) and aid to the blind (AB) was obtained from the State and local jurisdictions through the cooperation of the Bureau of Family Services. The assistance of Ellen J. Perkins and Robert H. Mugge, of the Bureau of Family Services, in obtaining this sample is gratefully acknowledged.

8,700 disabled adults who were interviewed by Census enumerators during April-May 1966.

Survey Definition of Disability

Disability is defined in this study as a limitation in the kind or amount of work (or housework) resulting from a chronic health condition or impairment lasting 3 or more months. The extent of incapacity ranges from inability to perform any kind of work to secondary limitations in the kind or amount of work performed. The disability classification is based on the extent of the individual's capacity for work, as reported by the respondent in a set of work-qualification questions. Data on employment and on functional capacities—such as mobility, activities of daily living, personal care needs, and functional activity limitations—were also collected to evaluate further the nature and severity of the disability.

Under the Social Security Act, the social security program is limited to severe disability, that is, disability defined as:

inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months.

The definition of the study population, however, encompasses a broader range of limitations in work activity in order to provide a basis for examining the social policy implications of disability. Although disability can be defined in more general terms than work activity, the work-limitation criteria are more appropriate to the objectives of the study and are also more rigorous than most other role activities. The survey population was limited to adults under age 65, in the major working years during which disability has the most direct bearing on income-maintenance problems. There is also more difficulty, conceptually and methodologically, in separating work limitations from other age-related phenomena among children and among the aged.

DISABILITY PREVALENCE ESTIMATES

Several estimates of disability prevalence were available from sample surveys conducted by per-

sonal interview. The criteria for disability are loss of capacity for normative activity such as work, housekeeping, school, or play because of a health condition of extended duration. As measured in the Current Population Survey and the National Health Interview Survey, the presence or extent of disability of all household members is reported by respondents at home at the time of interview. Proxy respondents are accepted for persons not at home.

The major objective of the CPS is the measurement of labor-force characteristics and participation. There is no express intent to measure the prevalence of disability. The designation of disability is only one of several alternative reasons for not participating in the labor force. Other reasons for not working or looking for work may be "keeping house, going to school, retired, or unable to find work." Only subjects who have been unable to do any kind of work and are "also suffering from a definite illness or disability of long duration and sufficiently serious to prevent him from working," are classified as disabled—and then only if the respondent does not expect the person to be able to return to work within 6 months.²¹

The National Health Interview Survey (NHS) is concerned with a wide variety of health problems, conditions, and services. In the interview, the respondent is asked a number of questions about chronic conditions and impairments, doctor's visits, and medical services utilization.²² If no chronic condition, impairment, or acute condition of more than 3 months' duration is reported, the respondent, who may be answering for other household members, is not asked about the extent of activity limitations. If any member of the household is reported as having a chronic condition or impairment, or a condition that was first noticed more than 3 months ago, the respondent is then asked: "Please look at each statement on this card, then tell me which statement fits you best in terms of health." The statements for work and housework are:

²¹ Bureau of the Census, *Current Population Survey, Interviewer's Reference Manual*, page D-6/12, unpublished.

²² National Center for Health Statistics, *Age Patterns in Medical Care, Illness, and Disability* (Series 10, No. 32) 1966, Appendixes II and III, and *Health Survey Procedures, Concepts, Questionnaire Development, and Definitions in the Health Interview Survey* (Series 1, No. 2), May 1964.

- (1) Not able to work (keep house) at all
- (2) Able to work (keep house) but limited in amount of work or kind of work (housework)
- (3) Able to work (keep house) but limited in kind or amount of other activities
- (4) Not limited in any of these ways.

Other studies have used closely related concepts. Two studies conducted by the Bureau of the Census for the Social Security Administration, in February 1949 and September 1950, defined disabled persons as:

those who, on the day of enumeration, were unable to do their regular work or perform other duties because of disease or injury, as well as those who had a long-term physical or mental condition that allowed them to work only occasionally or not at all.²³

Two questions were asked:

First of all, I'd like to check the persons who aren't able to do their regular work or other duties today because of illness or disability.

Is there anyone else under 65 years of age with a physical or mental condition that allows him to work only occasionally or not at all?

Anyone regularly employed was not defined as disabled. No information on the cause of disability or diagnosis was available from the 1949 and 1950 studies. The information on disability was obtained from a household respondent who was not necessarily the disabled person.

Other household surveys have used disability measurements similar to that of the National Health Interview Survey.²⁴

Estimates of disability from the national studies are difficult to compare because of differences in the criteria for disability and the age definition of the population. Considering only the noninstitutionalized severely disabled, unable to work, the NHS reported approximately 1.5 million people aged 17-64 unable to work or keep house, during 1963-65, or 1.4 percent of the 105 million people

in this age group.²⁵ The CPS estimated that there were approximately 2 million aged 20-64 who had not worked all year, in 1965, because of illness or disability.²⁶

On the basis of the 1949-50 surveys, it was estimated that approximately 2.7 million people aged 14-64 were severely disabled in 1965, not including an estimated 700,000 who were institutionalized. As a minimum estimate of the disabled, more than 2 million people aged 14-64 received benefits for long-term severe disability from public income-maintenance programs in December 1965.²⁷

The NHS has also estimated that, in 1963-65, approximately 7.5 million people aged 17-64 were able to work but for health reasons were limited in the kind or amount of work (or housework) they could do.

Chronic conditions have, for some purposes, also been used as a measure of disability. If the presence of a chronic health condition were considered a disability, more than half the noninstitutionalized population aged 18-64, 54 million people, would be defined as disabled.²⁸

IDENTIFICATION METHODS

Early in the study design we recognized that a two-stage screening and interview survey would be the most efficient utilization of field work resources. In cooperation with the Bureau of the

²³ National Center for Health Statistics (Series 10, No. 32), *op. cit.*, and *Chronic Conditions and Activity Limitations* (Series 10, No. 17), May 1965.

²⁴ F. A. Bogan and T. E. Swanstrom, "Work Experience of the Population in 1965," Special Labor Force Report No. 76, reprinted from *Monthly Labor Review*, December 1966, table D-1.

²⁷ Alfred Skolnik, "Persons Receiving Payments from Public Programs for Long-Term Disability, 1939-63," *Social Security Bulletin*, October 1964; and Bureau of the Census, *Statistical Abstract of the U.S., 1967, 1967*, table 417. Skolnik estimated 3.4 million long-term severely disabled aged 14-64. Approximately 700,000 people aged 18-64 were institutionalized, based on estimates from the Bureau of the Census, "Inmates of Institutions," *1960 Census of Population (PC(2)-8A)* and Department of Health, Education, and Welfare, *Health, Education, and Welfare Trends, 1964* (annual supplement to *Indicators*), Part I, pages 5-23 and Part II, pages 5-20.

²⁸ *Ibid.*; and Doris K. Lewis, "Prevalence of Disabilities in the Work Force," *Monthly Labor Review*, September 1964, and *Hearings, op. cit.*, pages 7, 8, 97, 233-237.

²³ Marjorie E. Moore and Barkev S. Sanders, *op. cit.*

²⁴ James N. Morgan, *op. cit.*, and James N. Morgan, I.A. Sirageldin, and Nancy Baerwaldt, *Productive Americans* (Survey Research Center Monograph 43), University of Michigan, 1966; Hyman J. Weiner and Shelley Akabast, "The Impact of Chronic Illness on a Union Population: Implications for Labor-Health Programs," *Journal of Health and Human Behavior*, February 1964, pages 103-107; Warren A. Peterson, *Metropolitan Area Health Survey* (No. 127, Community Studies), Kansas City, 1959.

Census, a series of pretests was conducted during 1965 to develop an effective method of identifying people limited in their ability to work because of a health condition.

The NHS disability classification procedure was used as the starting point in developing an identification instrument suitable to the survey objectives. The work-related disability concept of the NHS was similar to the survey concept. It was also the most extensively used method, and data based on the NHS procedure were available for study planning.

The NHS procedure had several shortcomings for the purposes of this survey. The disability classification of women was based on either work or housework, depending on their "usual activity in the past 12 months." According to this procedure, women who had been disabled for paid employment for more than a year but whose condition did not interfere with their ability to keep house would not be classified as disabled if their usual activity after the onset of disability was keeping house. The disability status of women whose impairment prevented them from entering the labor market was only considered in terms of the limitation on housework if they were usually engaged in keeping house. The procedure for classification of activity limitation for women was therefore changed in order to include both work and housework.²⁹

The length of the interview required for disability classification in the NHS also presented some complications for a screening procedure. The NHS study is primarily concerned with health conditions and medical care utilization. Although both areas are important in the survey of disabled adults, neither aspect appeared necessary to disability identification.

Another problem related to the NHS disability classification was the dependence on condition reporting. Only household members who reported having a chronic condition or impairment were

²⁹ A disability of longer than 12 months' duration may have incapacitated a woman for work activity but not for housekeeping activities. In order to classify women according to work criteria, women were asked the same series of work-activity questions as the men. Women were also asked the housework limitation questions. This seemed a more realistic measure of disability for women, since the requirements of paid employment tend to be more rigorous and less subject to self-definition than housework.

questioned about their disability status.³⁰

The Commission on Chronic Illness concluded, from its studies, that the reporting of chronic conditions and impairments was of low validity and of little value in measuring the prevalence of chronic disease. Only about one-third of the "reportable" conditions found in clinical examination samples were reported in the family interview. The severity of the condition did not have a substantial effect on the level of condition reporting nor did disability status. Completeness of reporting also varied among conditions: some, such as diabetes, show high agreement with the clinical examination; others, such as mental disorders, had very low rates of agreement.³¹

Recent studies by the National Center for Health Statistics show much closer correspondence between physicians' records and interview reports than between clinical examinations and interviews. Even with medical records, however, half the conditions recently diagnosed by the physician were not reported.³²

These data suggest that estimates of disability prevalence that depend on reporting of a chronic condition may be grossly understated. Only respondents who report chronic conditions are asked about disability status; the others can only be classified as "not disabled."

In contrast to the NHS, the Social Security Administration survey of disabled adults focuses on the economic and social consequences of disability and on the developmental processes. The identification of the disabled person was only the first step in the survey data collection. An individual identified as disabled in the screening process was later contacted for an intensive personal interview, which included verification of his activity limitations and further examination of the severity of the disability, primary health conditions,

³⁰ This procedure has been changed for the 1968 interviews. All respondents will be asked the activity-limitation questions, regardless of whether or not a condition or impairment has been mentioned.

³¹ Commission on Chronic Illness, *Chronic Illness in a Large City: The Baltimore Study* (vol. IV), Harvard University Press, 1957, pages 325-328 and pages 299-328; see also Ray E. Trussell and Jack Elinson, *Chronic Illness in a Rural Area* (vol. III), The Commission on Chronic Illness, Harvard University Press, 1959, pages 354-370 and 377-383.

³² National Center for Health Statistics, *Health Interview Responses Compared to Information Derived From Medical Records* (Series 2, No. 23), May 1967.

current work status, and functional limitations and capacities.

All measurement methods have some degree of measurement error. In the identification of the disabled, a screening instrument may underestimate or overestimate the population by identifying people with no meaningful limitation for work as limited or by classifying those with real limitations in working ability as not limited. In the Social Security Administration survey, the risks of overidentification were much less than the risks of underidentification: adults identified as disabled in the first stage would be reexamined in the interview, but those who were incorrectly classified as "not disabled" during the screening stage could not be identified later.

The data available to us on the number of long-term severely disabled adults under age 65 tended to support the conclusion that the NHS procedures understated the prevalence of severe disability in the noninstitutionalized population of the United States. The Current Population Survey had found more working-age adults who were unable to work all year because of their health than the NHS found. The number of people receiving benefits for long-term severe disability was larger than the NHS estimate of adults aged 17-64 who were unable to work.

The receipt of benefits from public income-maintenance programs is based on medical evidence and administrative evaluations of disability. The number of beneficiaries represents a minimum estimate of the long-term disabled, since it does not include those who could have met the medical requirements but not the work experience, financial need, or other requirements of these programs. This number would exclude, for example, disabled nonworking wives of men with adequate incomes and adults disabled since childhood whose parents were neither deceased nor retired for age or disability. In addition, there are disabled people who although limited in work activities do not meet the rigorous medical requirements of the specific program—those, for example, who have applied for and been denied benefits under the OASDI disability provisions.³³

³³ Between 1955 and 1964, approximately 1.5 million applications for worker and childhood disability benefits were denied; 2.1 million benefits were awarded (*Social Security Disability Applicant Statistics, 1964*, Social Security Administration, December 1966).

The purpose of the survey pretests was to examine the feasibility of using a short, disability-focused screening questionnaire to identify disabled adults. We wanted to compare the effectiveness of mail questionnaires with personal interviews and of schedules with and without health-conditions questions. In the course of the testing, other variations were suggested by the data.

Sample Design Aspects of Screening

The feasibility of mail questionnaire approach was of great importance from a sample design and cost standpoint. To meet the precision requirements of the study, the use of a simple population sample would have required screening more than 250,000 adults to obtain an adequate sample of severely disabled adults with income from disability benefits and of those with no income from any public income maintenance program.³⁴ The sample objectives could be met much more effectively by the use of (1) stratified sampling of special universe frames to supplement the area sample and (2) mail screening to identify the population before the intensive personal interview.

On the basis of the sample requirements, the multiframe sample design was developed, using universe lists of OASDI disability beneficiaries and APTD and AB recipients to provide oversampling for the "unable to work" segment. Denied applicants for OASDI benefits were selected as a source for oversampling of the severely disabled with no income from public income-maintenance programs.³⁵ In addition, the area population samples provided by CPS and MLS rota-

³⁴ Joseph Steinberg, *A Multiple Frame Survey for Rare Population Elements* (paper presented at American Statistical Association meeting, Philadelphia, September 11, 1965); and *1966 Survey of Disabled Adults—Notes on Sample Design*, unpublished, 1965.

³⁵ A pretest was conducted to determine the feasibility of using a subsample of people who had been denied OASDI disability benefits for medical and other reasons to provide a sample of severely disabled people who are not receiving income from any income-maintenance programs. The test data indicated that this sample frame would provide a much higher proportion of severely disabled with no income from public maintenance programs than the general population sample.

tion groups were oversampled for adults "unable to work."³⁶

If the screening stage could be separated from the interview the size of sample identified in each disability category (unable to work and work-limited) could be determined before the interview and subsampled at rates appropriate to survey requirements. Separating the identification screen from the extensive interview would also avoid interviewer bias problems that might be associated with the length of the interview for a disabled person.

Even with the reductions in sample size possible through the use of frames with a high concentration of the severely disabled, the cost of screening by personal interview would have been high relative to the substantive interview costs. Mail screening would cost substantially less than personal interview identification.

Identification Schedules

With the cooperation of the National Center for Health Statistics,³⁷ several identification methods were tested. These included (1) schedules with the disability questions worded as a set of structured simple-choice questions and as a set of multiple-choice statements; (2) schedules with and without a question about chronic conditions and impairments; and (3) personal interviews and mail schedules. Questions about the condition causing the work limitation and its duration followed the work-limitation questions in all forms of the questionnaire.

Several samples were selected for testing the various disability identification screens. These include NHS samples of persons who had previously reported their disability status in an NHS interview and samples of OASDI disability beneficiaries. These samples were not intended to represent the population at large. Although all the

³⁶ The samples obtained from these frames represent overlapping domains. The multiple chances of selection are accounted for by differential optional weighting. See Joseph Steinberg, *op. cit.*

³⁷ We are greatly indebted to Phillip S. Lawrence for his advice and assistance and to Theodore D. Woolsey and the National Center for Health Statistics for their generosity in making available to us the facilities of the National Health Survey.

TABLE 1.—Methods and samples used for each identification screen

Item	Identification schedule					
	A	B	C	D	E	S-47
Question type:						
Multiple choice.....	X	X	X	X		
Dichotomous choice.....					X	X
Conditions question preceding:						
Yes.....		X		X		
No.....	X		X		X	X
Interview procedure:						
Personal interview.....	X	X			X	
Mail questionnaire.....			X	X		X
Samples used:						
OASDI disability beneficiaries.....	X	X				
Expired NHS.....	X	X	X	X		
National probability.....					X	X
Prior screening for disability status:						
Yes.....	X	X	X	X	(1)	
No.....			X	X		X

¹ Followed by NHS disability identification (HIS-1) in the same interview.

samples were based on probability selection, they were selected to oversample for disabled persons.

In addition to samples of persons previously identified by a disability characteristic, three probability samples were selected as representative of the noninstitutionalized population aged 18-64. Personal interviews were conducted with one sample, as a supplement to the Health Interview Survey of May 1965. Two national probability samples were used to test the mail questionnaires.

The schedules were identified as A, B, C, D, E, and S-47 and were constructed and used as shown in table 1.

FINDINGS

Early forms of schedules A and B were used for pretesting the identification schedule with a sample of OASDI disability beneficiaries in two cities—Baltimore and Detroit. These tests showed that the simple disability question could reliably identify proven cases of severe disability with no difficulty (table 2). It also provided a basis for estimating the prevalence of disability among other household members.

Our interviewing experience with this test suggested the need for a question to identify women not in the labor force but with a limitation in housework. This question had not been in the original form of the identification questionnaire but was included in all later variations of the disability screening questionnaire.

TABLE 2.—Work limitation of OASDI disability beneficiaries according to schedules A and B pretest (Baltimore and Detroit)

Disability classification	Total	Schedules	
		A	B
Number in beneficiary sample base.....	115	56	59
Total percent.....	100	100	100
Disabled.....	96	100	92
Unable to work.....	30	86	75
Work limited.....	16	14	17
Not disabled.....	4		8

Personal Interview vs. Mail Questionnaire

The rates of agreement for the A and B forms (personal interview) were compared with the agreement rates for the C and D forms (mail questionnaire), based on the earlier NHS classification. With the exception of the housework questions and the opportunity for all women to answer the work-limitation questions, the questions used in the alternative forms were identical to the questions used in the NHS interview. The respondent could choose among the four possible replies for each person aged 18-64 in the household:

Which statement below fits each person best, IN TERMS OF HEALTH?

- (1) Not able to work at all
- (2) Able to work but limited in amount of work or kind of work
- (3) Able to work but limited in kind or amount of other activities
- (4) Not limited in any of these ways?

For women only:

Does your health limit the amount or kind of housework you can do?

For screening purposes, the primary requirement was that the screening forms should identify as disabled anyone so identified by the NHS, regardless of whether the individual was "unable to work" or "limited in kind or amount of work." An individual was included in the disability universe if he was identified as either "unable" or "limited."

The mail questionnaires were significantly better than the personal interview in their agreement with the disability classifications from the earlier NHS interview. Considering that the NHS cases had been interviewed 6 to 9 months earlier, the rate of agreement was quite high.

The A and B personal interview forms identified only 50 percent of the disabled identified by NHS, compared with 72 percent identified by the C and D mail questionnaires. As shown in table 3, both mail and interview forms were equally successful in identifying those "unable to work," but the mail questionnaires were significantly more reliable in their identification of adults with work limitations.

The high level of agreement of the mail questionnaires with the NHS classifications did, however, have other effects. The proportion identified as "not limited" in the earlier NHS interview who were identified as "disabled" by the screening schedules was considerably higher with the mail questionnaire than with the personal interview—17 percent and 6 percent, respectively. A higher estimate, however, was preferable to a lower estimate, since the other procedures had apparently understated the prevalence of severe disability. Disability status would be verified or changed during the interview with the disabled adult.

Health-Conditions Question

The rates of agreement for the A and C forms (without a health-conditions question) was compared with the agreement rates for the B and D forms (with the health-conditions question). There was no significant difference between the

TABLE 3.—Percent of each work-limitation category reported as disabled by OASDI disability identification forms, based on earlier National Health Survey disability classification

Disability identification schedules	Pretest sample base	NHS disability classification				
		Percent disabled			Percent not disabled	
		Total	Unable to work	Work limited	Activity limited	Not limited
Interview schedule:						
A (no conditions question).....	664	49	81	41	36	7
B (conditions question).....	612	52	87	40	16	5
Mail schedule:						
C (no conditions question).....	207	73	88	66	39	16
D (conditions question).....	214	71	85	68	56	18
Simple-choice questions:						
E (interview supplement).....	5,793	80	96	77	47	3
Interview versus mail:						
A & B (interview).....	1,276	50	85	41	27	6
C & D (mail).....	421	72	87	66	49	17
Health-conditions questions:						
A & C (no conditions question).....	671	60	83	53	37	9
B & D (conditions question).....	826	60	86	63	33	7

two sets of forms in the rate of agreement. Although the lists were felt to be useful in helping the respondent describe his condition, the question did not affect the reporting of disability.

Overall, the screening forms identified 60 percent of the previously designated disabled regardless of whether or not the health-conditions question was used.

Dichotomous Choice Questions

Another test was conducted simultaneously with the interview for the May 1965 NHS sample. A disability supplement, the E form, was added at the beginning of the interview. The major differences between the E form and the NHS disability questions were that:

- (a) the disability questions preceded the conditions questions and were independent of condition reporting;
- (b) three of the alternatives previously shown were set out as independent questions requiring "yes" or "no" answers. This is in contrast to the selection of one possibility among four choices in the A to D pretest series and in the NHS;
- (c) one choice, "able to work, but limited in . . . other activities," was eliminated.

As shown in table 3, the agreement on disability identification was highest in each disability category for the E form—80 percent of those identified as disabled by NHS were classified as disabled by the "E" schedule. Only 3 percent of those not "limited" were classified as "disabled."

In addition, the measurement included a different treatment of work limitations for women.

All women were asked about work limitations, instead of only those who had worked during the past year. All women were asked about limitations in housekeeping, not only those who were usually keeping house, as in the NHS interview. The basis for disability classification of women was therefore somewhat different for the two methods. This change should affect the classification of women who were not disabled for housework but who were unable to work or were limited in kind or amount of work. It would also change some women classified as "limited" to "unable to work."

Differences in reporting disability between the two procedures for men could only be attributed to the condition-reporting requirements and to the context and wording of the questions.

As table 4 shows, the level of disability reported by men is very close for the two methods, but more men reported a disability on the Social Security Administration form than on the NHS schedule.

The differences between the two disability estimates represent minimum differences, since both were administered in the same interview, with the same interviewer and respondent. The double series of questions—the Social Security Administration disability supplement, followed in the interview by the NHS questions—may have influenced the respondent's later disability evaluation or condition reporting or may have affected the administration of the interview. The findings on reliability from the E form, as reported in table 3, should therefore be regarded with caution. It should also be noted that the proportion shown as disabled in the NHS for May 1965 is higher than the average for 1961-63. These findings indicate, however, that the two approaches are measuring essentially the same phenomena and that the disability-focused identification screen could identify as disabled people who were not classified as disabled by a condition-centered approach.

Since the disability criteria for women were different in the two studies, it was expected that more women would be classified as disabled according to the SSA identification form than by the NHS interview. As tables 4 and 5 show, there are obvious differences between the two methods. The SSA disability screen classified as "unable to work" about one-third of the women previously identified as "limited." It also identified as disabled 6.5 percent of the women who were "not

TABLE 4.—Extent of disability by SSA and NHS classifications and sex, May 1965, Health Interview Survey Sample

Disability classification	Total		Men		Women	
	Classification		Classification		Classification	
	SSA ¹	NHS	SSA ¹	NHS	SSA ¹	NHS
Number in sample base.....	5,793	5,793	2,759	2,759	3,034	3,034
Total percent.....	100.0	100.0	100.0	100.0	100.0	100.0
Disabled.....	12.7	9.9	12.1	10.9	13.3	9.1
Unable to work.....	4.6	1.7	3.2	2.3	5.9	.7
Work limited.....	8.2	8.3	9.0	8.1	7.4	8.4
Not disabled.....	87.3	90.1	87.9	89.1	86.7	90.9

¹ E schedule disability supplement.

² Includes 19 with disability classification unknown.

TABLE 5.—SSA disability classification (F schedule) by NHS disability classification by sex: May 1965, Health Interview Survey

Disability classification	NHS classification				
	Total	Disabled			Not Disabled
		Total	Unable	Work limited	
	Total				
Number in sample base.....	5,798	576	96	480	5,217
Total percent.....	100.0	100.0	100.0	100.0	100.0
Disabled.....	12.7	79.9	95.8	76.7	5.2
Unable to work.....	4.6	32.5	81.2	22.7	1.3
Work limited.....	8.2	47.4	14.6	54.0	3.8
Not disabled.....	87.3	20.1	4.2	23.3	94.7
	Men				
Number in sample base.....	2,759	300	76	224	2,459
Total percent.....	100.0	100.0	100.0	100.0	100.0
Disabled.....	12.1	79.0	96.1	73.3	4.0
Unable to work.....	3.2	27.7	81.6	9.4	1.2
Work limited.....	9.0	51.3	14.5	63.9	3.5
Not disabled.....	87.9	21.0	3.9	26.7	95.0
	Women				
Number in sample base.....	3,034	276	20	256	2,758
Total percent.....	100.0	100.0	100.0	100.0	100.0
Disabled.....	13.3	80.8	95.0	79.7	6.5
Unable to work.....	5.0	37.7	80.0	34.4	2.7
Work limited.....	7.4	43.1	15.0	45.3	3.8
Disability in work, but not in housework.....	3.2	11.2	5.0	11.7	2.6
Not disabled.....	86.7	19.2	5.0	20.3	93.5

disabled" according to the NHS interview. In comparison, only 4 percent of the men "not disabled" in the NHS interview were classified as disabled by the SSA screening.

Looked at another way, the SSA disability supplement was able to identify 80 percent of those reported disabled by the NHS procedure; the NHS interview identified only 62 percent of those who earlier in the interview had been identified as disabled by the SSA schedule. Among the men, where the disability criteria were the same, 79 percent of those reported as disabled by the NHS were identified as disabled by the SSA schedule, but only 71 percent of the men identified by the SSA were identified as disabled by the NHS procedure. The discrepancy between the two procedures was greater for women, where the criteria were different; 81 percent of the women identified as disabled by NHS were also identified by SSA but only 55 percent of the women identified by the SSA form, were also identified by NHS.

Estimating the Prevalence of Disability

Two further tests were conducted, to provide an estimate of the proportion of people who would be identified as disabled by a mail questionnaire. Probability samples, designed to be representative of the noninstitutionalized United States population were used for the mailing. These tests used the C and D forms and the S-47 form. The S-47 form included essentially the same set of "yes-no" choice questions as the E form adapted for use as a mail questionnaire. The questions on the conditions causing the work limitation and on the duration of the condition followed the work-limitation questions. As in the other tests, the questions were to be completed for everyone in the household aged 18-64. The work-limitation questions in the S-47 form were:

- (1) Does your health limit the kind of work you can do?
- (2) Does your health limit the amount of work you can do?
- (3) Does your health keep you from working altogether?
- (4) (For women only) Does your health limit the amount or kind of housework you can do?

Several problems were found in the coding and editing of the C and D mail forms. Some respondents were confused by the statements on these forms and incorrectly or incompetently filled out the questionnaire. Women, for example, tended to leave blank the statements on work limitations and to answer only the questions on housework. Some respondents were confused by the multiple-choice question and checked more than one box; entries of "yes" or "no" were written in the boxes. On the form with the health-condition question a number of respondents answered "no" to the health condition questions and left the work-limitations question blank.

The S-47 form incorporated features of the C and D forms and the E form to simplify the questionnaire and to reduce the confusion arising from the multiple-choice questions. Relatively few of the S-47 schedules were incompletely or incorrectly filled out.

The response rate for both pretests was approximately 75 percent of the sample mailed, after two mail follow-ups. The data include nonresponse bias, since there was no further attempt to

interview nonrespondents. With telephone and interviewer callbacks for nonresponse, the completion rate for the mail questionnaire and follow-up procedures would be as high as personal interview screening, at a fraction of the cost. The results of the mail questionnaire tests are shown in table 6. Disability classifications for the May 1965 SSA schedule and NHS interview and the 1961-63 NHS are also shown for comparison.

In both pretests, the proportion of the population identified as disabled was higher than in NHS interviews. The proportion "unable to work" was relatively constant across all tests, as table 6 shows, but was higher than the NHS estimates. The proportion "limited in the kind or amount of work" was considerably higher in the S-47 schedule test than in the NHS interviews or in the interviews with the E form.

The relevant comparisons are in the disability classifications for men, where the criteria are the

same for the SSA and NHS measures. In all tests, the proportion of disabled identified by the SSA measures were higher than the proportion identified by the NHS methods. It should also be noted that the mail questionnaires produced more disability reporting than personal interviews, including the E form. This finding is consistent with the findings of the A-B and C-D schedule tests reported earlier.

In all the SSA identification forms, the proportion of women "unable to work" is substantially higher than the proportion identified as "unable" by NHS. This is a product of the difference in screening criteria for women as well as the differences in identification methods to which both men and women respondents were exposed. About two-thirds of the difference in the proportion of the women who are disabled may be attributed to the difference in methods and about one-third to the change in criteria; about one-third of the difference in the proportion "unable to work" may be attributed to the difference in forms and methods and two-thirds to the change in concept.

On the basis of these test results we decided to use the S-47 form as the identification schedule for the household screening stage of the survey.

The identification schedules from one segment of the multiframe sample, the MLS sample frame, were analyzed to provide another estimate of the level of disability in the noninstitutionalized population aged 18-64 of the United States. As the first column of table 6 shows, 18.1 percent of the population were disabled, 3.2 percent were unable to work, and 14.8 percent were limited in the kind or amount of work or housework they could do. These data are consistent with the results of the earlier test of the S-47.

Verification and Reclassification

In the follow-up interview for the survey of disabled adults, the person identified as disabled in the screening stage was asked to verify the screen disability statement. If the respondent indicated that the classification was not correct, he was asked the same series of disability questions again and his disability status was determined from these answers. If he had recovered from a disability before 1966 or had never been disabled, he was not in the study universe and the interview

TABLE 6.—Disability classification by sex and SSA and NHS disability identification procedures

Disability classification	MLS pilot study S-47	Pretest samples		May 1965 NHS		NHS 1961-63
		S-47	C & D	E	HIS-1	
Total						
Number in sample base	12,431	1,375	1,454	5,796	5,796	(¹)
Total percent	100.0	100.0	100.0	100.0	100.0	100.0
Disabled	18.1	17.5	12.5	12.7	9.9	8.6
Unable to work	3.2	2.8	2.7	4.6	1.7	1.4
Work limited	14.8	14.7	9.8	8.2	8.3	7.1
Not disabled	81.9	82.5	87.5	87.3	90.1	91.4
Activity limited			4.3		4.4	4.2
Not limited			83.1		85.7	87.3
Men						
Number in sample base	5,961	687	725	2,759	2,759	(¹)
Total percent	100.0	100.0	100.0	100.0	100.0	100.0
Disabled	17.9	16.5	12.4	12.1	10.9	9.4
Unable to work	3.0	2.9	2.1	3.2	2.8	2.2
Work limited	14.3	13.5	10.3	9.0	8.1	7.2
Not disabled	82.7	83.5	87.5	87.9	89.1	90.6
Activity limited			3.9		3.2	3.3
Not limited			83.7		86.0	87.3
Women						
Number in sample base	6,470	718	729	3,034	3,034	(¹)
Total percent	100.0	100.0	100.0	100.0	100.0	100.0
Disabled	18.3	18.4	12.6	13.3	9.1	7.8
Unable to work	3.4	2.6	2.5	5.9	.7	.6
Work limited	15.4	15.0	9.3	7.4	8.4	7.0
Not disabled	81.2	81.4	87.4	86.7	90.9	92.2
Activity limited			4.8		5.3	4.9
Not limited			82.6		85.4	87.3

¹ See National Center for Health Statistics, *Chronic Conditions and Activity and Limitation: United States, July 1961-June 1963, Appendix I (Series 10, No. 17), May 1965.*

was closed after a few background questions. If he classified himself as unable to work or limited in the kind or amount of work, the interview was continued, using his revised disability status. Proxy respondents were not accepted, except for the disabled unable to answer for themselves. Preliminary tallies of a subsample of the survey sample indicated that about 1 in 20 disabled adults was reclassified as "not disabled" during the follow-up interview.

Severity of Disability

The extent and nature of the work limitation was further examined in the interview. Responses to a series of questions on the respondent's ability to work regularly, full time and at the same work as before the limitation began, were used to classify the disabled as having a "severe disability," an "occupational disability," or a "secondary work limitation." Disabled adults unable to work regularly or at all were classified as severely disabled; those limited to part-time work or not able to perform the same work as before their limitation began were classified as occupationally disabled.

Respondents limited in the kind or amount of work they could do, who were able to work regularly, full-time, and at the same work (or who had not been employed before their disability began), were classified as having a secondary work limitation. The apparent interpretation of limitations for this group is related to the "amount of work on the job," in contrast to the "amount of time worked," and in the "kind of work which can be done on the job," in contrast to the "kind of job at which he can work."³⁸

The severity of the disability reported in the interview will be examined further by comparing

³⁸ The experience of industrial medical departments provides some insight for the interpretation of secondary work limitations. Among the alternatives available in the disposition of disability cases are retirement and separation, physically restricted duty, and return to full duty, either in the same job or in a different job, with or without restrictions on full performance of the job. See for example, S. C. Franco, "Disability Evaluation: A Function of the Industrial Medical Department," *Journal of Occupational Medicine*, September 1963. The extent to which an impairment may be disabling will also depend on the employment situation, the number and kinds of jobs available as alternatives, the job requirements, and the flexibility of the requirements.

the impairment and limitation attributes of OASDI disability beneficiaries, for whom there has been an administrative evaluation of disability, to the limitations of severely disabled adults who are not beneficiaries of these programs. Through the use of multivariate techniques, a system of values may be developed and ratings assigned to combinations or configurations of variables. The likelihood that a nonbeneficiary meets the same criteria of disability as an OASDI disability beneficiary may then be evaluated by comparison of the distribution of ratings.

At the other extreme of secondary work limitations or moderate disability, it is difficult to say what would constitute meaningful validation. That these people consider themselves limited in a major area of social and economic activity is itself an aspect of capacity limitation. Although many of the disabled with secondary work limitations have lesser degrees of impairment, others with severe impairments may have made greater adjustments to their capacity losses or may work in more flexible or less demanding environments or conditions of employment. The data should provide a basis for understanding the characteristics of disabilities of differing severity and the effects on economic and social activity. From a preventive care point of view, the less severely disabled groups should provide more insight into successful adjustments and adaptations to disability.

Summary of Pretest Findings

The major findings of the series of identification schedule pretests were that:

1. Mail questionnaires were more effective than personal interviews in identifying adults classified as disabled in the NHS interview. Mail questionnaires also identified more people previously classified as not disabled by NHS than personal interviews.
2. The health-conditions question did not effect the level of agreement with the NHS classification but did create editing and coding problems—an indication that the question was confusing to respondents.
3. The change in operational definition of disability for women substantially increased the number of women identified as disabled.
4. Short, directly disability-focused mail questionnaires had relatively high reliability in identifying the disabled; three-fourths of those identified as disabled by NHS were classified as disabled by the SSA mail schedules.

5. Simple-choice "yes-no" questions were able to identify 80 percent of the disabled later identified in the same interview by NHS procedures and also identified as disabled 5 percent of those classified as not disabled by NHS. The simple-choice questions were easy to administer and made the mail questionnaire easier to answer.

6. All of the SSA mail identification questionnaires used with national population samples had higher rates of disability identification than the NHS interviews. The S-47 questionnaire, which applied the results of the test, provided a short, simple-choice, disability-focused, mail schedule with more inclusive disability criteria for women. It produced a disability estimate approximately double that reported by the NHS.

7. The SSA estimate for the severely disabled is more consistent with data from disability benefit and compensation programs and other sources than the NHS estimates.

EVALUATION OF IDENTIFICATION METHODS

The primary purpose of the disability identification screen was to provide a relatively inexpensive, simple, reliable means of identifying disabled people. The available data suggested that identification procedure should focus directly on the work-related disability status, without reference to the underlying medical condition. It was felt that this approach would produce a higher level of reporting of severe disability than the NHS interview but the effect on the estimate of adults with partial limitations (in kind or amount of work) or on the total disability estimate was not known. Since essentially the same work-limitation questions were used, differences found between the NHS estimates and the SSA disability survey estimates for men should be attributable to the changes in methods and not to changes in the criteria for disability. The SSA screening procedure included a change in the disability criteria for women.

The series of pretests conducted in examining the feasibility of a disability-focused, condition-free, mail questionnaire provided proof of the effectiveness of this approach. The high rates of agreement of the SSA schedules in identifying people classified as disabled by the NHS procedures demonstrate that the SSA measurement includes the aspect of disability measured by NHS. Changes in the form led to an increase in the proportion of the population classified as disabled. The changes in the disability criteria for women

also produced a substantial change in the proportion of women classified as disabled and as unable to work.

The estimate of the prevalence of disability in the population aged 18-64 produced by the SSA screening procedures is approximately twice as large as disability prevalence reported by the NHS studies.

Since these findings have important implications for the development of social policy in income-maintenance, rehabilitation, and preventive action programs for the disabled, the basis for the differences in disability estimates should be examined and, where possible, explained. The conclusions drawn from this examination are, of course, to some extent speculative.

First, the requirement of prior condition or impairment reporting tends to understate disability. Clinical evidence shows that less than one-third of reportable diagnosed conditions are reported in survey interviews and that these vary considerably by types of diagnosis.³⁹ Some disorders are stigmatized in the sense that they are much less likely to be reported than others—mental illness and mental retardation, for example.

After a condition has been denied, the respondent is unlikely to report a disability, particularly if the question sequence is such as to exclude him from the disability sequence unless he has reported a chronic condition or impairment. The Minnesota studies have also shown the weakness of impairment listing in identifying disabled people.⁴⁰

Second, there are differences between mail and personal interview situations. Each data collection method has certain advantages. The mail questionnaire provides an opportunity for the respondent to consider his reply and to examine the context to which the question refers without interviewer prompting. When data on the other household members are also collected, the respondent

³⁹ Commission on Chronic Illness, *op. cit.*, pages 299-328, and Rene V. Dawis, David T. Hakes, George W. England, and Lloyd H. Lofquist, "Methodological Problems in Rehabilitation Research," *Minnesota Studies in Vocational Rehabilitation*, No. V, University of Minnesota, December 1958, pages 1-27. The Dawis study showed that the proportion of disabled people identified varied significantly by diagnosis, with neurological and respiratory diseases easiest to identify and mental disorders and cardiovascular diagnoses lowest in disability identifications, based on a sample of people who had received vocational rehabilitation counseling (page 15).

⁴⁰ Rene V. Dawis, *op. cit.*, page 4.

may consult them or they may answer for themselves.

The interview is a "time-bound" situation in which both the interviewer and the respondent are under pressure to respond and to maintain the interaction. There is usually little opportunity to consult with absent household members or to check the accuracy of a response.⁴¹ The interviewer may also represent a social presence that discourages the respondent from stigmatizing responses or answers that tend to place him in an unfavorable light.

In the course of the field work, the interviewer is exposed to an expectation or "frequency" bias. Typical or modal characteristics may become expected responses; some responses are relatively rare events in his interviewing experience. The interviewer is also measured by the thoroughness with which questionnaires are completed and, in general, is expected to press the respondent for an approximate answer when there is hesitation.

Severe disability is a relatively rare event in the population. Respondent hesitation or uncertainty about disability status may prompt the interviewer to guide the respondent to an answer, particularly in the absence of the individual about whom the data is being collected. When uncertainty exists, the "usual" response, "not disabled," may become the expected response and the interviewer may tend to push the respondent in the direction of the expected response.⁴²

A third factor is the change in the structure of the questions from a multiple choice to a series of simple "yes-no" questions. The language is closer to conversational usage. The internal evidence from the pretests suggests that the multiple-choice questions did cause some confusion. The simple-choice question should act in the direction of reducing errors in either direction. If this error had been in the direction of overstatement, the level of the disability estimates should have been reduced. The increase of the estimates would indi-

cate that the confusion more often lay in the direction of understating the extent of disability.

It is also possible that eliminating the response category on "limitations in other activities" forced some people to choose the work-limitation response when they might otherwise have indicated a limitation that did not affect their work activity.

In total the SSA estimate provides a more reasonable prevalence estimate for long-term disability. For example, if we take the NHS estimate of one and a half million people "unable to work," there are more people receiving long-term disability benefits, usually based on total disability, than there are individuals "unable to work" in the population. This makes no allowances for other severely disabled people who are not qualified under the nonmedical provisions of these programs or whose disability does not meet the program medical requirements. On the other hand, beneficiaries of these disability programs would comprise one-half to two-thirds of the estimated 3 to 4 million disabled adults who are "unable to work."

The logic of the measurement situation and the weight of the test data strongly suggest that the SSA measurement procedures do identify work limitations that are in part concealed by the requirements of other disability reporting procedures.

Differences between the SSA and NHS estimates of partial disability are more difficult to evaluate than the estimates for severe disability. There are no data for partial disability comparable to the benefit and compensation statistics. Partial disabilities are much more subject to change in respondent evaluation than severe disability, as the lower degree of matching in all tests indicates. It is possible that the nature and extent of partial work limitations is more responsive to changes in work, labor market, and other environmental conditions, to changes in the respondent's health condition, and to self-and-proxy-respondent differences in evaluation. Partial limitations are less likely to be clearly visibly to others than complete work limitations. There is more likely to be error and ambiguity in the reporting of partial disabilities, particularly with a proxy respondent.

These aspects of partial disability would appear to be more aptly handled through a questionnaire or interview situation that focuses directly on the

⁴¹ In the Minnesota studies, for example, reporting differences in disability classifications from agency record criteria occurred only when the informant was not the handicapped person, *ibid.*, page 19. Morgan, David, Cohen, and Brazer also found that proxy respondents tended to understate disability, *op. cit.*, pages 220-221.

⁴² For a discussion of the biasing effects of probability expectations of interviewers see Herbert H. Hyman, *Interviewing In Social Research*. University of Chicago Press, 1954, pages 120-126.

disability rather than on the condition and in which the individual about whom the data is collected answers for himself.

Although the SSA and NHS methods result in sizable differences in the estimates of severe and partial disability, they do not represent contradictory or diverse approaches to disability. The SSA methodological developments are rather an extension of the same general line of reasoning

about disability. We believe these methods represent an improvement in survey measurement techniques for the estimation of disability prevalence. The analysis of the survey data should provide further clarification of the extent of the limitations included under severe and partial disabilities, the patterns of development, and the nature of the social and economic consequences of disability.