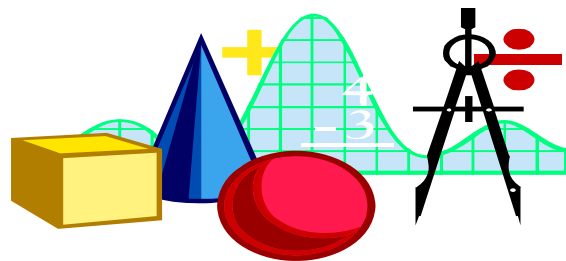


AGENDA FOR ACCESS:
SCIENTISTS AND ENGINEERS
WITH DISABILITIES



October 1991
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**AGENDA FOR ACCESS:
SCIENTISTS AND ENGINEERS WITH DISABILITIES**

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FOREWORD

Barbara Bailar
Executive Director
American Statistical Association

The importance of learning more about occupational access by persons who wish to be or are trained in science, mathematics, and engineering and who have disabilities is crucial to us as a nation. First, there are critical shortages in these fields, and we must make access easier. Second, to improve access, we must learn more about effective strategies to recruit and support students with disabilities who are interested in science, mathematics, and engineering. Cooperating on this study was an opportunity for the American Statistical Association for which we are grateful. Indeed, as an Association with many members with skills in survey procedures, we are eager to take part in the implementation of the recommendations and pledge our strong support for future development.

FORWARD

John M. McNeil
Chief, Poverty and Wealth Statistics Branch
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There are already signs that the workshop described in this report will prove to be a major catalyst in reshaping the views of federal data producers about what is important in measuring the existence and effect of disabilities.

Readers of the report will see citations from a number of federal studies, but they will learn that federal efforts have fallen far short of fully describing the barriers that persons with disabilities have faced and continue to face. Federal efforts have been hindered by a lack of communication and cooperation among agencies, but, more importantly, by a failure to communicate with and learn from those persons who have lived with disabilities.

A major strength of the workshop was the bringing together of data producers and data users and including in the latter group a number of persons with firsthand experience in dealing with an environment that can be hostile to persons with disabilities.

The federal statistical effort in the area of disability has been tied closely to the concept of work disability. The first major disability surveys were sponsored by the Social Security Administration (SSA) and focused on the population in need of income replacement and/or rehabilitation services and the population thought to be at risk for these services. The basic identifying questions in the SSA surveys became "Are you limited in the kind or amount of work you can do?" and "Are you prevented from working?" These questions found their way into many federal survey questionnaires including the long-form questionnaires used in the censuses of 1970, 1980, and 1990.

Questions about work disability status remain a legitimate if incomplete method of identifying persons with income replacement or rehabilitation needs, but there is a growing awareness that a statistical profile of the effects of disability must go well beyond concepts of "work limitations" or "work prevention."

Part of the awareness is based on the need for a more complete description of the nature of the disabilities a person has experienced or is experiencing; part is based on the need to consider the effect of disabilities on all life activities, not just work; and part is based on the growing understanding that disabilities occur when society does not or cannot remove barriers that limit full participation. The description of a person as "limited in the kind or amount of work he or she can do" or "prevented from working" leaves out an enormous amount of information and may depend more on the characteristics of society than on the level of difficulty the person may have in performing particular tasks.

There is no doubt that the workshop has contribute to a new awareness of the need for better data. The signs of the new awareness include the revised disability items that were included in the 1989 National Survey of Natural and Social Scientists and Engineers, and the addition to the 1991 National Health Interview Survey of a set of disability items patterned after the set asked in the 1990 Survey of Income and Program Participation.

Finally, the workshop discussions played a very important role in the serious effort to design and fund a large-scale national survey of persons with disabilities as a follow-on to the 1990 census. At the request of Congress, the Bureau of the Census has developed a plan for such a survey and has circulated initial drafts of questionnaires for comment. As part of this effort, there has been a significant effort to obtain the views of persons with disabilities.

Given the budget situation, it is far from certain that the new survey will be funded. Such a survey is needed because it would provide the in-depth data that cannot be obtained through supplements to ongoing surveys. If such a survey is not funded now, I believe it will be in the near future.

Whatever the outcome of the proposed new survey, the benefits of the workshops are already evident. There is reason for optimism among data producers and data users.

PREFACE

This report summarizes the results of the Workshop on the Demography of Scientists and Engineers with Disabilities which took place in Washington, D.C. on January 29 and 30, 1988, and of the following Census Subgroup meeting which took place on January 31, 1988. Additionally included are three position papers addressing various topics covered in the workshops, as well as an extensive bibliography concerning various aspects of disabilities, demography, and statistics.

This Workshop and Census Subgroup Meeting was supported by the National Science Foundation under Grant BAC-8751914. It was organized under the auspices of the American Association for the Advancement of Science and the American Statistical Association. The three Principal Investigators for this grant were Allan R. Sampson, Chair of the Ad-Hoc Committee on Disability of the American Statistical Association, Virginia Stern, Director of the Project on Science Technology and Disability of the American Association for the Advancement of Science, and Randall Spoeri, Acting Executive Director of the American Statistical Association, currently with Humana Corporation.

The success of both the Workshop and Census Subgroup meeting resulted from the efforts of many individuals from the National Science Foundation, American Association for the Advancement of Science, the American Statistical Association and many of our colleagues and friends. Graham Kalton, Richard Savage, Seymour Sudman, and Irving Zola were instrumental in the organization, preparation and conduct of the Workshop, and in helping to prepare this report. Shirley McBay, Kimiko Bowman and Sally Wood, members of the NSF Committee on Equal Opportunity in Science and Engineering, gave important support and guidance to planning of the Workshop. Mary Clutter, Michael Crowley, Nancy Conlon and Mary Kohlerman of the NSF staff were also extremely helpful.

Significant conceptual and logistic support was given by Shirley Malcom, Head, AAAS Directorate for Education and Human Resources, and other Directorate staff, including Judy Kass, Brenda Files, Michael Oby, Maria Sosa, Laureen Summers and Beth Goodrich. Jack McNeil from the Census Bureau shared many of his insights and we appreciated the support of Barbara Bailar, who then was the Associate Director of the Census. Diane Hall is owed a debt of gratitude for her patience in typing this report multiple times and in multiple forms.

We have deliberately kept this Preface brief. Our expectations for this report's agenda for access are amply stated throughout the text. Our experience in conducting the Workshop and preparing this report are extremely satisfying. However, the value of this Workshop's contribution will be borne out in the increased accessibility to the sciences and engineering for individuals with disabilities.

August 25, 1991
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1. INTRODUCTION

A landmark Workshop on the Demography of Scientists and Engineers with Disabilities took place in Washington, D.C., on January 29 and 30, 1988. Sponsored by the National Science Foundation, the Workshop addressed the pressing need to increase the representation of individuals with disabilities in science and engineering fields. Workshop participants focused on the primary objective of preparing an agenda and strategic plan concerning the required steps to achieve this goal.

The day following the Workshop, a subgroup of Workshop participants met to discuss specific improvements in disability data collected by the U.S. Census Bureau.

In the time since these meetings, efforts by Workshop participants along with many other individuals and organizations have produced significant results.

The two-day Workshop and Census Subgroup meeting were funded by the National Science Foundation and organized by the American Association for the Advancement of Science and the American Statistical Association. The Workshop brought together experts from diverse fields to develop recommendations for surveying scientists and engineers with disabilities. Participants also discussed many issues pertinent to surveying individuals with disabilities and to obtaining reliable demographic information from them.

This report details these groundbreaking meetings and the results. The Workshop's recommendations and the issues discussed are presented in Section 2 of the report. Section 3 describes the Census Subgroup Meeting on January 31, 1988. Section 4 highlights national events and activities that have occurred since the Workshop.

In addition, the Workshop prompted several participants to prepare thought-provoking papers in their areas of expertise. These position papers, published in Part II of this report, explore three topics: the language of disability, perspectives on the sampling of disabled scientists and engineers, and a methodological approach to such sampling.

This introductory section provides an overview of the Workshop's goals and background on the organizations involved and on the meetings themselves. This section concludes with some historical observations motivated, in part, by the Workshop.

1.1 Workshop on the Demography of Scientists and Engineers with disabilities: Overview

The United States is approaching a time of critical shortage of scientist and engineers. All national resources must be tapped to counter-balance this shortage. One talent pool that has not been effectively deployed is that of engineers and scientists who are also disabled. Another relatively untapped pool are children and youths with disabilities who are deflected from science and engineering studies. Moreover, relatively little is understood about the demography of such individuals. A thorough knowledge of this demography is essential both to better utilize scientists and engineers with disabilities and to develop effective recruiting efforts to bring students with disabilities into the sciences and engineering. Moreover, a comprehensive

understanding of ways to involve individuals with disabilities in the mainstream of American life is an important societal goal.

For more than a decade, several national scientific organizations have recognized the need for better demographic information concerning scientists and engineers with disabilities. Beginning with its inception in 1975, the Project on Science, Technology and Disability of the American Association for the Advancement of Science (AAAS) has been in the forefront of efforts to address the problem. The National Science Foundation (NSF), since the early part of the 1980s, also has devoted considerable efforts to understanding this population. And in the middle 1980s, the American Statistical Association (ASA), through its Ad-hoc Committee on the Disabled in Statistics, became active in this enterprise. Together, the AAAS and the ASA coordinated the NSF-sponsored Workshop on the Demography of Scientists and Engineers with Disabilities, held in Washington, D.C. on January 29 and 30, 1988.

1.2 Background

Since its inception in 1975, the AAAS Project on Science, Technology and Disability has sought a better understanding of the demographics of scientists and engineers with disabilities. The Project was an outgrowth of the AAAS Office of Opportunities in Science, expanding the reach of this office beyond its initial focus on women and minorities.

The first efforts of the Project on Science, Technology and Disability supported the civil rights of people with disabilities to enter and advance in science education and careers. One immediate goal was to make professional meetings barrier-free. The Project also served as an information and technical assistance center for scientists and engineers who experienced disabilities during their careers. In the late 1970s federal legislation gradually mandated access of citizens with disabilities to college and pre-college education. Concurrently, institutions began upgrading facilities to insure access to university classrooms, laboratories, and community buildings.

In the 1980s, AAAS continued to work toward the implementation of barrier-free environments at professional meetings and also on campuses. But the focus shifted as the organization confronted the nation's shrinking pool of talent in the technical fields. The AAAS recognized that under-represented groups - people with disabilities as well as women and minorities - must receive motivation and education to remain in the science and engineering pipeline.

Currently, the emphasis is on developing programs to inform, encourage, and technically assist students with disabilities and with interest in mathematics and sciences so that these students can sustain their interest through the educational pathway to professional careers. More than ever, scientists and engineers who have lived with disability are needed to serve as role models to share experiences and coping strategies with students with disabilities and their families, counselors, and colleagues who have recently experienced disability.

In 1982 the NSF, acutely aware of the need to assemble better demographic data on all under-represented groups in science and engineering, added a question on disability to its biennial National Survey of Natural and Social Scientists and Engineers. This survey, based upon a sample of individuals in the science and engineering population at the time of the 1980 census, was and still is conducted for NSF by the Bureau of the Census. Responses to the

disability question, which were first published in the 1984 edition of the NSF "Report on Minorities and Women in Science and Engineering," show that an estimated 90,000 scientists and engineers have a disability. However, a number of scientists and engineers with disabilities have observed that the wording of the Biennial Survey disability question and its placement on the questionnaire might not have provided fully meaningful responses, thus leading to an underestimate of the real numbers. In order to obtain a more accurate estimate, they noted that definitions of disability must be considered both from a physiological and a contextual point of view, and the questionnaire should reflect these definitions. Their comments were corroborated by staff of the AAAS Project on Science, Technology and Disability, members of the AAAS Office on Opportunities in Science, and the NSF Committee on Equal Opportunity in Science and Engineering (CEOSE).

Contemporaneous with discussions on demography at AAAS and NSF, the ASA, an AAAS affiliate society, establish an Ad-hoc Committee on the Disabled in Statistics in 1985. This committee was composed of a number of statisticians who, because of their professional background and their own disabilities, were interested in promoting statistical careers for individuals with disabilities, in making the profession more accessible, and in learning more about other scientists and engineers with disabilities. Additionally, the ASA committee members, as statisticians, had an excellent perspective and background for developing new methodology to study the degree of participation of disabled individuals in science and engineering.

1.3 Workshop Goals and Issues

To begin exploration of this area, the ASA Ad-hoc Committee on the Disabled organized and presented a scientific session concerning the demography of scientists and engineers with disabilities at the ASA's 1987 Annual Meeting in San Francisco, California. Participants included individuals from AAAS, NSF, and other statisticians who had conducted relevant research. At the same time, the AAAS and the ASA developed a joint proposal, subsequently funded by NSF in late 1987, for a Workshop to address in more detail these and other issues. The NSF also additionally funded a post-Workshop subgroup meeting with individuals from the Bureau of the Census to discuss census data on disability in the 1990 Census as well as broader issues of disability data collection in the United States.

The primary goal of the Workshop was to prepare an agenda and strategic plan for developing a methodology to survey scientists and engineers with disabilities. The secondary goal was to prepare, for distribution, a report covering the strategic plan and position papers on topics that need to be addressed in order to develop this methodology.

The collection of quality demographical information concerning individuals with disabilities and their participation in the sciences and engineering promises a number of benefits. Interventions to recruit and support students with disabilities who are interested in careers in mathematics and science demands an increased knowledge of the demographics of individuals with disabilities at the precollege, undergraduate, and graduate education levels, as well as within the scientific work force. Careful demographic study of scientists and engineers with disabilities is critical for evaluating future national programs and policies to increase the number of youth with disabilities in the science and engineering pool. Quality data also are required for programs to develop and test adaptive equipment for scientists and engineers with disabilities. Yet another goal is that this demographic information be used to assess those in the scientific work force who are under-utilized or retire early due to disability, so that future

programs and strategies provide opportunities for these individuals to continue their professional contributions.

The planners and participants of the Workshop confronted specific issues and questions related to scientists with disabilities. How, for example, do we classify scientists or engineers trained in a discipline, such as chemistry or civil engineering, but who for various reasons are not currently employed in their field? While this problem affects surveys of all science and engineering professionals, it is of critical concern in sampling individuals with disabilities whose lack of employment may be directly related to their disability. Another issue in measuring disability is the hesitation of people to identify themselves as disabled. In addition, legal restrictions make it difficult for university administrators and private sector employers to provide information on students or employees with disabilities. Finally, the self-perceptions of individuals with disabilities can affect their answers to questions concerning the nature, extent, and context of their disability. Their responses might well differ from an outsider's observations.

1.4 Workshop and Census Subgroup Meeting

To approach these multifaceted issues and tasks, Workshop planners invited a group of experts with widely varied academic, industrial, and personal experience. The resulting interdisciplinary group included survey statisticians, demographers, sociologists, rehabilitation scientists, health economists, psychologists, educators, lawyers, engineers, and representatives of public and private agencies working in these fields. Noteworthy is that at least fifteen of the forty-eight professionals had disabilities including mobility-impairment, visual impairment, hearing impairment, and health disability. Thus Workshop discussions never evolved solely from the viewpoint of participants looking externally at disability, but also from the viewpoint of those looking from within at disability. Importantly, these participants' perspectives about their disabilities were shaped throughout their educational, professional, and personal lives.

Workshop participants were formally asked to consider three fundamental areas of inquiry: identifying target populations that should be studied; exploring definitional issues in disability, especially in the context of science and engineering; and identifying methodological issues concerning sampling and data bases. To promote discussions, the Workshop program specified two types of subsessions. One type permitted discipline-specific discussions; the other involved cross-sections of disciplines. All Workshop participants attended the concluding Plenary Session, in which they approved six recommendations for a research agenda and strategic plan. These recommendations are discussed in Section 2 of this report. Participants in the Workshop are listed in Appendix I and the Workshop Program is given in Appendix III.

Immediately following the two-day Workshop, a one-day Census Subgroup Meeting took place. The Census Subgroup of fourteen participants met as a whole without a formal program. The Census Subgroup focused on specific concerns about certain data collected by the Census Bureau and on ways to improve this data collection. Section 3 presents a full report of the Subgroup meeting. Appendix II lists participants in this meeting.

The Workshop also generated three position papers presented in Part II. The first paper by Irving Zola is entitled "The Naming Question: Reflections on the Language of Disability"; the second by Graham Kalton and Seymour Sudman is entitled, "The Sampling of Disabled Scientists and Engineers: Perspectives"; and the third by Seymour Sudman is entitled, "The Sampling of Disabled Scientists and Engineers: A Methodological Approach."

1.5 Historical Epilogue

The diversity of gender and age, of discipline and disability among Workshop participants reflects, in part, the historical evolution of public attitudes concerning disability. Some disabled participants had received their professional education at a time when officially sanctioned support services in the regular educational or employment system were extremely rare or non-existent. Through determination, the help of their families, the sometime support of a lone educator or administrator, and perhaps a bit of good luck, they proceeded in the mainstream of higher education. They did so despite the public's largely negative perception of disability—a perception reflected by the names of agencies established in the post-World War II era. For instance, the name adopted by the President's Committee to Employ the Handicapped, inferred that "the handicapped" were not so easy to employ and would not likely possess the necessary professional training in science and engineering.

Others in the Workshop pursued their higher education during years after the passage of the Rehabilitation Act of 1973, which provided access to higher education for all qualified individuals, and the subsequent Independent Living movement. These individuals still faced roadblocks but were supported by legislation guaranteeing their right to an education. The development of organizations such as the American Coalition of Citizens with Disabilities (though it did not continue as an entity) influenced language and, to some degree, changed stereotypical views of individuals with disabilities. Instead of perceiving an individual as disabled, first, and secondly a scientist, people began perceiving the individual or the scientist, first, and less so the disability.

In the intervening years since the passage of the 1973 Rehabilitation Act, increased activism, nationally and locally, by many diverse groups has continued to change the social, professional, and educational climate for individuals with disabilities. Of particular impact in this regard were the efforts of the Independent Living Movement and numerous professional societies and associations. Illustrative of the resultant change in perceptions and language, the President's Committee changed its name by Act of Congress in 1988, to the President's Committee for the Employment of People with Disabilities. The new atmosphere for individuals with disabilities can perhaps best be understood by considering the national progress since the completion of this Workshop. Section 4 provides a partial summary of the recent progress made to protect and improve the social and intellectual rights of individuals with disabilities. Without a doubt, the recently passed Americans with Disabilities Act is the pre-eminent result of the changes since 1973.

2. WORKSHOP ON THE DEMOGRAPHY OF SCIENTISTS AND ENGINEERS WITH DISABILITIES: RECOMMENDATIONS FOR A RESEARCH AGENDA AND STRATEGIC PLAN

Participants of the Workshop held on January 29-30, 1988, met in groups to develop a research agenda and a strategic plan for surveying scientists and engineers with disabilities. The Workshop met as a whole in the concluding plenary session to approve six general recommendations for the overall plan. Recommendation #1 was to evaluatively review all current sources of statistical information on disabilities within the context of sciences and engineering. Recommendation #2 called for a detailed evaluation of the current status of

scientists and engineers with disabilities. Recommendation #3 was to develop models for examining how individuals with disabilities enter and exit both education and employment in the sciences and engineering, with particular emphasis on the educational process. Recommendation #4 amplified the previous recommendations by focusing on individuals with disabilities that occur in mid-career. Recommendation #5 was to examine both philosophically and methodologically the conceptualizations of disability. And Recommendation #6 addressed the need for governmental agencies to collaborate in data collection endeavors that seek to address disability issues.

These six recommendations for the research agenda and strategic plan are discussed in the following.

2.1 Evaluative Review of Current Information

The Workshop considered it important to identify data that has been available to date. One of the major sources of disability data on scientists and engineers is the NSF biennial National Survey of Natural and Social Scientists and Engineers conducted by the Bureau of the Census (see "Women and Minorities in Sciences and Engineering," National Science Foundation (1988)). In addition, discussions revealed that various federal and international databases contain some partial information concerning disability. These latter data concerning disability generally were collected as part of larger surveys, sometimes with no immediate purpose for the use of these disability data. The Workshop briefly reviewed some of these data sources.

In 1970 and 1980, the United States Bureau of the Census collected information on "work disability status" in the decennial census "long-form." In 1980, the long-form was completed by about one-sixth of the U.S. population. In 1984, as part of the third wave supplement of the Survey of Income and Program Participation (SIPP), the Census Bureau collected a fairly comprehensive set of disability information from a sample of about 20,000 households. As noted about the SIPP (U.S. Bureau of the Census (1986)) "a major purpose of the questions was to allow researchers and policy makers to learn more about the relationship between disability and program participation...the data also have a more general interest in that they show the extent of disablement among the noninstitutional population and show how the characteristics of the disabled differ from those of the nondisabled." Additionally, the Bureau of the Census had planned a survey of disabled individuals as a follow-up to the 1980 decennial census. While this follow-up was never implemented, much work went into developing and validating the Census Disability Survey Pretest questionnaire. In particular, a pretest was conducted in early 1980 in the Richmond, Virginia, Standard Metropolitan Statistical Area (SMSA). A brief description of this pretest, including results is available from the U.S. Bureau of the Census (1981). Statistics Canada in developing its 1983-84 survey of Canadians with disabilities later utilized the pretest questionnaire. Statistics Canada (1986) describes the results of this survey.

A number of other surveys conducted by the Census Bureau contain several questions concerning disability. The March Supplement to the Current Population Survey has several questions concerning disability status and the March supplement has served as the data source for Census Bureau reports on persons with work disabilities. Also in the Survey of Work Experience of Young Women (U.S. Bureau of the Census (1988)), at least two multipart questions (#59, #60) deal with physical impairments. The Annual Housing Survey conducted by

the Bureau of the Census for the U.S. Department of Housing and Urban Development (1981-82) included questions on accessible features of housing; and the Consumer Expenditure Surveys conducted by Census for the Bureau of Labor Statistics (1988) contain questions on medical care and purchase of medical equipment for personal use.

The Department of Education, through a number of its offices, collects various data concerning individuals with disabilities. The National Institute of Disability and Rehabilitation Research (NIDRR) publishes general-use reference books such as *The Chartbook on Disability in the United States* (Kraus and Stoddard (1989)) and *Data on Disability from the National Health Interview Survey, 1983-1985* (LaPlante (1988)). The Office of Special Education and Rehabilitative Services (OSERS) publishes an annual report on the implementation of the Education of the Handicapped Act (Tenth Annual Report was issued in 1988), as well as analyses of students with particular disabilities. The Center for Educational Statistics (1987) has completed a study of the 1987 high school transcripts of students served under the Education of the Handicapped Act, as part of the National Assessment of Educational Progress (NAEP) and other studies, such as *Access and Quality: Participation of Handicapped High School Students in Vocational Education* (Hayward (1989)).

The President's Committee on Employment of People with Disabilities (PCEPD) (formerly the President's Committee to Employ the Handicapped) has issued a series of booklets presenting data on Americans with disabilities and on work disability prevalence in minority groups (Bowe (1985)). The HEATH Resource Center (Higher Education and Adult Training for people with Handicaps), a program of the American Council on Education, has collaborated with the President's Committee to publish two books of data on college freshmen with disabilities (PCEH (1978)) and Hippolitus (1987)). HEATH also publishes a regular newsletter column called, "Facts You Can Use" with data on enrollment and attrition of students with disabilities (e.g., information from HEATH (1988)) and occasional research papers on participation of students with disabilities in post secondary education (e.g., Hartman (1985)).

The U.S. Congress, through the Office of Technology Assessment (1982), collected data in 1982, with an update in 1988, on citizens with disabilities and on technology for disability. The data served as background for the 1988 Technology-Related Assistance Act.

Other governmental agencies that collect data concerning disability include the Social Security Administration, the National Center for Health Statistics (NCHS), and the Veteran's Administration. The Social Security Administration sponsored major disability surveys of working-age persons in the 1960's and 1970;s but has not sponsored a major survey since 1978. The NCHS, for instance, sponsors the National Health Interview Survey which provides "estimates on incidence of acute conditions ... limitation of activity." (See Form HIS-1 (1987), U.S. Bureau of the Census (1987a)). Also for NCHS, Westat Inc. conducts the National Medical Expenditure Survey. This survey asks a number of questions concerning physical impairment and disability. The Veterans' Administration, employing the U.S. Census Bureau, conducts an annual survey of veterans that asks multiple questions involving disability (see Form SOV-21, U.S. Bureau of the Census, (1987b)). In addition, the Panel Study on Income Dynamics, in its 1986 survey conducted by the University of Michigan's Survey Research Center, collected some data concerning physical impairment and disability.

The National Research Council recently issued a report on the Scientific and Technical Personnel Data System of the National Science Foundation. (Citro and Kalton (1989b)). This

study points out that a major problem in data collection is the definition of "scientist" and "engineer" and the misinterpretation of data that results from ambiguous definitions.

Other research on disability has involved a synthesis of several databases. Researchers Rice and LaPlant (1988) worked from a variety of sources to consider, among other issues, "comparative data on the magnitude of disability in the United States" and discuss "recent studies of trends ... in disability." Another example of secondary analysis is the paper by Johnson and Lambrinos (1985), who study the effect of disability upon wages.

Internationally, data that are available include the previously noted Statistics Canada (1986) report. Many other countries have important data collection activities in this area and, in fact, the Statistical Office of the United Nations has developed a Disability Statistics Data Base in order to "consolidate the available census and survey statistics...using a common conceptual framework." A 1984 report of the Council of Europe contains policy statements concerning the rehabilitation of disabled individuals along with the specific recommendation "to provide research into the problems posed by impairments, disabilities and handicaps and *to collect the relevant statistics.*"

Some nongovernmental organizations in the U.S. maintain a variety of databases concerning disability. For example, the American Foundation for the Blind maintains a Careers and Technology Information Bank as part of its Technology Information System, which lists currently marketed products for visually impaired individuals as well as the names and occupations of product users. The organization also publishes frequent studies relating to visual that involve secondary analysis of data, (e.g., Kirchner and Peterson (1979)). The Office of Demographic Research of Gallaudet University conducts a survey of educational and rehabilitation programs for deaf and deaf-blind students and adults, and publishes teacher preparation programs annually in the *American Annals of the Deaf*. The National Technical Institute for the Deaf has conducted a study on the earnings of deaf college graduates and non-graduates using data from the Internal Revenue Service (Walter and Welsh (1986)). The Paralyzed Veterans of America (PVA), through its Spinal Cord Research Foundation, is engaged in a long-term study of the economic consequences of spinal cord injury (Berkowitz (1985)). The World Institute of Disability has collected data on the need for personal care attendants used by disabled people in California (WID (1987)).

Louis Harris and Associates, Inc. have conducted at least two sample surveys concerning disability. One Harris survey, for the International Center for the Disabled (ICD) in cooperation with the National Council on the Handicapped, is described as "the first major national study of the attitudes and experiences of disabled persons and the first nationwide survey to ask disabled people about their self-perceptions [and] their experiences ... with employment, education, social life" (Louis Harris and Associates, Inc. (1986)). Harris conducted a second study for the National Organization on Disability. This study examined the participation of disabled Americans in political life and the barriers they encounter. It also examined "what steps are still needed to bring disabled Americans fully into the mainstream of political participation in this country." (Louis Harris and Associates, Inc. (1987)).

Based on the fragmentary nature of the available data on disability, the Workshop recommended that a project be developed to examine and compare both the methodological approaches as well as the results of these numerous surveys. In particular, the project would study the wordings of questionnaires and target populations of these surveys.

Such a project would provide immediate benefits. Demographers and disability researchers could better interpret the NSF Biennial Survey results on disability by comparing the results to general population disability rates, suitably categorized. Also, by examining surveys that collected employment and education information together, it may be possible to derive secondary estimates of the numbers of scientists and engineers with disabilities and to learn more about the characteristics of this population.

Moreover, the Workshop emphasized that a detailed examination of detail these various data bases would benefit disability data collection well beyond the population of scientists and engineers.

2.2 Evaluation of Existing Surveys of Scientists and Engineers with Disabilities

The workshop's second recommendation focused on the need to evaluate and improve the NSF Biennial Survey concerning disabled scientists and engineers. The workshop further recommended that questionnaires be developed and made available to AAAS affiliate societies for surveying their members with disabilities.

The NSF 1986 National Survey of Natural and Social Scientists and Engineers, conducted by the Census Bureau, asked respondents whether they had a physical handicap and, if so, to specify the nature of that handicap (visual, auditory, ambulatory, or other). All data reported by NSF (1988) concerning physically disabled scientists and engineers are based on these two questions. The Workshop pointed out a number of problems with the wording and context of these questions on disability. Due to the phrasing and placement of these questions within the questionnaire, the workshop believed that the observed response rate under counts the actual proportions of scientists and engineers with various disabilities.

To obtain more complete information, it was recommended that *several* differently phrased questions concerning disability be used in the 1989 Survey. This approach should yield more accurate estimates of the proportions of disabled scientists and engineers, especially among variously cross-classifications. (Section 3 of this reports, which describes the Census Subgroup Meeting, further discusses difficulties with current disability questions on the NSF National Survey. Resulting changes in the 1989 National Survey are reported in section 4 on national progress since the workshop.)

The Workshop pointed out that even as revised, the 1989 NSF survey would not obtain data on educational, lifestyle and coping strategies nor on duration of disability. The Workshop stressed that such information is extremely important to realizing its overriding goal: the development of programs to increase the representation of persons with disabilities among scientists and engineers. Thus, the Workshop also recommended that an NSF Follow-up Survey, focusing specifically on broad disability issues, be developed and administered to a subgroup of scientists and engineers who respond affirmatively to the revised disability questions on the 1989 National Survey.

In addition, the Workshop proposed that one or more questionnaires concerning disability be developed for use by AAAS affiliate societies in surveying their membership. Current surveys administered by various societies contain *no* standardized questions, thereby, diminishing the quality of that information and making it impossible to compare and synthesize data results across societies. Moreover, with a prepared and validated questionnaire, individual

scientific and engineering societies would be more likely to survey their memberships about disability.

2.3. Models for Deflections of Individuals with Disabilities from the Science and Engineering Pipeline

The Workshop's third recommendation was that an educational/vocational theoretical model be developed to explain how individuals with disabilities are deflected from the science and engineering pipeline. This recommendation is based on the belief that during the educational process and in the transition to employment, individuals with disabilities are in the pool of future scientists and engineers who are deflected from pursuing this interest and employment possibility. Moreover, a "folklore" assumption maintains that deflections of individuals from the science and engineering pool occur at a higher rate among persons with disabilities than corresponding deflections of individuals with no disabilities. The Workshop explicitly recommended that this folklore assumption be assessed.

As a source for developing a model on deflections, the Workshop considered the National Science Foundation (1987) report "Opportunities for Strategic Investment in K-12 Science Education" which provides a tree-like model for examining how the educational process leads to an occupation in the sciences and engineering or to an occupation outside these fields. A similar model for disabled individuals, however, poses a special challenge. The NSF tree model assumes that *all* individuals start at equal points at the base of the tree. The Workshop recognized that this is not true of people with disabilities. Disability can occur prior to birth or at various times during the educational process. Spina bifida, for example, appears at birth while spinal cord injuries tend to occur more frequently in the late teens and twenties. (The Workshop addressed disabilities occurring later in life in recommendation #4, Section 2.4.)

The Workshop noted that a substantiated educational/vocational model would reveal when deflections occur in the educational process and the cause of these deflections. The Workshop specifically recommended investigating the influence of school guidance counselors and vocational rehabilitation counselors on students with disabilities.

The Workshop also explicitly recommended a detailed examination of individuals with disabilities in the transition from education or training to first job. A first step in developing such a model is a careful examination of any data sources that might provide useful information. Relevant sources include NSF New Entrants Surveys, the NSF Surveys of Doctorate Recipients, and possibly some data bases maintained by the Center for Education Statistics.

Barring the existence of sufficiently informative databases, the Workshop proposed that a prospective longitudinal study be undertaken that follows a cohort of disabled individuals through the educational process. Ideally, the study would include one or more control groups. Such a study could either stand-alone or be part of a larger longitudinal study.

2.4 Evaluation of Science and Engineering Professionals Who Experience Disability in Mid-Career

Because the incidence of disability tends to increase with age, the loss of career scientists and engineers due to newly occurring or age-exacerbated physical and medical disabilities is undoubtedly substantial. The Workshop participants who knew of no studies that

addressed deflections of such individuals, recommended that studies be conducted to determine what factors influence the deflections of career scientists and engineers who develop disabilities in mid-career.

While this recommendation and the proceeding recommendation #3 both address deflections, they approach the topic from different angles. Recommendation #3 focuses on individuals with early-in-life disabilities who must manage the educational process and the scientific work place. Recommendation #4, on the other hand, focuses on accomplished scientists and engineers who must then manage their disability. Clearly, some issues - the need for suitable adaptive equipment, for example - are relevant to both groups.

2.5 Examination of Conceptualizations of Disability

Much has been written on the definitional and conceptual issues surrounding the language used to describe disability. The position paper by Zola in Part II, examines a number of these issues. The Workshop recommended further study of these issues so that the language used in surveys generate precise information.

Survey language, for example, must distinguish between functional disability and work disability. A quadriplegic might be functionally impaired but, as a programmer/analyst, demonstrate essentially no impairment of work productivity. The Workshop specifically recommended an examination of functional and work disability concepts be examined in the context of sciences and engineering. Due to the intellectual nature of scientific endeavor, these concepts may be different for scientists and engineers compared to people in other occupations. The Bureau of the Census also has examined language issues in questionnaire design, as covered in a paper by McNeil (1987), for example. Every effort should be made to build upon the Census research.

Based on the relevant research, survey questions that measure disability concepts, particularly in the context of science and engineering, should be developed and validated. The Workshop pointed out that such questions would be extremely valuable in any follow-up disability study of the NSF National Survey of Natural and Social Scientists and Engineers. Again, this study should build on the Census Bureau's questionnaire design.

2.6 Federal Inter-Agency Cooperation in Data Collection Concerning Disability

The Workshop's sixth recommendation was that a mechanism be established through which the major federal agencies collecting data on disability can formally cooperate in their endeavors. Agencies could then undertake joint projects, for example, and share sets of survey questions. The major federal agencies involved in disability data collection include the National Science Foundation, the Social Security Administration, the Bureau of the Census, and the National Center for Health Statistics. Workshop participants who were present or past employees of these agencies, and who had worked on data collection activities concerning disability reported limited coordination with other agencies working on similar or related disability projects.

As an example of the need for coordination, the Workshop noted that various agencies collect data on college students. The National Science Foundation tracks the numbers of

college graduates in science and engineering; both the American Council on Education and the President's Committee collect data on the number of college freshmen with disabilities; and the Center for Educational Statistics recently has collected data on disabled students receiving financial aid in higher education (Greene and Zimbler (1989)). However, the Workshop knew of no information on how many college freshmen with disabilities continue in their studies, or how many enter and graduate in science or engineering majors, nor how many students with disabilities receiving financial aid are studying or have attempted to study in a science or engineering field.

The benefits of formal cooperation, moreover, extend well beyond the context of sciences and engineering. Federal agencies could share definitions, questionnaires, and validation results to provide a more complete understanding of the American population with disabilities. The result: better resources for formulating the much needed national plans and policies affecting Americans with disabilities.

The Workshop suggested possible formats through which interagency coordination could take place. One suggestion was to establish a Federal Agency-Wide Coordinating Committee. A more far-reaching suggestion was the establishment of a formal Federal Office of Statistics Concerning Disability, which would assume broad responsibilities in this area.

2.7 Summary

The Workshop recognized that some of the six recommendations for a research agenda and strategic plan are more easily accomplished than others due to time and expense. While the Workshop made no attempt to prioritize the recommendations, participants urged that projects addressing the recommendations be initiated as soon as possible. Some of the activities that have resulted from this Workshop are described in Section 4.

3. REPORT OF THE CENSUS SUBGROUP MEETING

3.1 Introduction

The Census Subgroup meeting took place in Washington, D.C. on January 31, 1989 as a follow-on to the two-day Workshop on the Demography of Scientists and Engineers with Disabilities. These meetings were funded by the National Science Foundation (NSF) and convened by the American Association for the Advancement of Science and the American Statistical Association. Participants in the Census Subgroup meeting were a subset of the proceeding days' Workshop participants (see Appendix II). The Census Subgroup focused on three issues: (1) the current status of Census data collection instruments concerning disability; (2) the phrasing of the four disability questions on the 1990 Decennial Census Long Form; and (3) approaches to improving the disability information gathered by the NSF Biennial Survey of Scientists and Engineers, particularly for the 1989 Survey. The group also discussed three related issues: (a) disability data collected by governmental agencies other than the Census; (b) broader perspectives concerning Census disability data collection, including data utilization and history of collection; and (c) the need for high quality and current disability data in order to understand the lifestyle and economic status of individuals with disabilities and to develop strategies for the prevention of disability.

3.2 Background of Census Disability Data Collection Activities

Meeting participants from the Bureau of the Census presented a brief history of Census data collection activities concerning disability. In particular they discussed the questions concerning disability on the 1980 long-form and the disability questions contained in a supplement to the third wave of the 1984 Survey of Income and Program Participation (SIPP). Census speakers noted that in 1980 disability questions were not asked of persons under 15 years; this also is true in 1990. They noted that the SIPP data were a basis for a Census Bureau report on disability and are available on tape from the Census Bureau. The Census Bureau has collected additional but quite limited disability data in the March Current Population Surveys (CPS), since March 1981, and in the 1976 Survey of Income and Education (SIE). Some participants suggested that, should the Census Bureau initiate an ongoing data collection project concerning disability, the CPS might be a suitable vehicle.

In the late 1970s a federal interagency panel met to discuss content and questions for a possible large-scale disability survey to follow the 1980 Census. In preparation for this large survey, the Census Bureau pretested a disability questionnaire in Richmond, Virginia in 1980. Unfortunately, funding was not made available for the full survey, which would have at least produced state level estimates concerning various aspects of disability. Several group members pointed out that Statistics Canada had used the pretest questionnaire in the development of a major disability survey administered in Canada in 1983-84.

Some Subgroup participants expressed concern that the Census Bureau lacked a focused plan for the active utilization of disability data. In part, this is a result of the Census Bureau's concern about the quality and completeness of the data on disability status and the fact that persons with disabilities make up a relatively small proportion of the total population. At present the Census Bureau's only intends to do descriptive tabulations of the disability data collected on the 1990 Decennial Census long-forms, as it did for similar data collected in 1980. There are no formal plans to do any expanded analysis of the data, but there are plans to produce a subject report covering the topics of work disability and mobility, and self-care limitations.

3.3 1990 Decennial Census Long-Form Questions On Disability

The Census Subgroup discussed the following disability questions to be used on the 1990 Census of Population and Housing (Long Forms):

1. Does this person 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 this person can do at a job?
 Yes No
 - b. Prevents this person from working at a job?
 Yes No
2. Because of a health condition that has lasted for 6 or more months, does this person have any difficulty?

- a. Going outside the home alone, for example, to shop or visit a doctor's office?
 Yes No
- b. Taking care of his or her own personal needs, such as bathing, dressing, or getting around inside the home?
 Yes No

Many Subgroup participants stressed that the dichotomous nature of the responses (yes/no) could cause an under-response from disabled individuals. They recommended an ordinal response categorization using, for example, the three categories "frequently," "occasionally," and "never." Discussions revealed that wording changes, especially for item #1, probably were not feasible at this late date. Possibly the item #2 questions concerning mobility limitation and self-care limitation could be modified to provide three responses. While the Census Bureau generally would be reluctant to change questions so late in the planning process, the group nonetheless agreed that, with input from the Subgroup Meeting, as well as possibly the Census Advisory Committee of the ASA and other organizations, it might be feasible to approach senior decision makers at the Census Bureau with recommended changes notwithstanding the late date. One alternative change would be to use the responses "some-none" instead of "yes-no." However, the participants agreed that this minor change was inferior to the recommended ordinal response.

3.4 NSF Biennial Survey of Scientists and Engineers

The Census Subgroup also recommended changes in the NSF Biennial Survey of Scientists and Engineers conducted by the Bureau of the Census under contract. The NSF surveys prior to 1989 contained the following questions concerning disability:
Are you physically handicapped? Yes No

What is the nature of your handicap(s)? (mark as many as apply): visual, auditory, ambulatory, other, please specify _____.

Based on these two questions, the National Science Foundation estimates that there are 94,000 scientists and engineers with disabilities out of approximately 5,000,000 scientists and engineers nationwide. Subgroup participants believed that this estimate of 94,000 might be a low, and hence biased, estimate of the number of persons with disabilities, because individuals may find the term "handicap" ambiguous or even derogatory. Moreover, nonresponse to this survey question was quite high. Additionally, these difficulties make this a poor screening question for a second level survey.

The Subgroup stressed that modifications could be made in the Biennial Survey especially if the AAAS, the ASA, and the NSF Committee on Equal Opportunities in Science (CEOSE) supported these changes. Some speakers, however, raised the issue of whether the historical nature and continuity of the data in the NSF Scientist and Engineer Survey needed preserving. Others acknowledged this concern but believed that historical continuity is not essential. As one participant noted, a National Academy of Sciences panel was already studying the Biennial Survey and the panel's proposed changes could create discontinuity apart from whatever was done to the disability item. Also, since the Biennial Survey is a panel survey,

new information can be fed into the survey instrument at any point without compromising the survey.

In general, the Subgroup recommended that the National Science Foundation modify the Biennial Survey of Scientists and Engineers to: (1) broaden the nature of the disability questions; and (2) ensure commonality and comparability with other data collection activities concerning disability by federal and private organizations. Subgroup participants believed that the Census Bureau could implement proposed changes to the 1989 NSF survey if done prior to May 1988, allowing time for Office of Management and Budget clearance by May 15, 1988. Participants discussed how to meet this deadline so that the scheduled survey could be mailed in January or February 1989.

3.5 Potential Follow-up Disability Questionnaire for the Biennial Survey

To better understand the characteristics of scientists and engineers with disabilities, the Subgroup suggested that a second level questionnaire be administered to a sample of individuals responding positively to the disability questions on the Biennial Survey. Discussions of this second tier questionnaire made it clear that careful design of the screening question and a comprehensive study of the second tier questionnaire would be necessary. The consensus reached was to use the 1989 survey to learn about screening and then use the 1991 survey to collect better data of the sort needed through a second tier questionnaire.

Participants also discussed how similar changes might be extended to the NSF sponsored survey on recent entrants in the sciences and engineering and to the Ph.D. graduate survey. And they considered how to implement these changes with NSF and the Census Bureau.

3.6 Other Issues and Recommendations

The Subgroup expressed concern over the lack of leadership in the federal statistical system regarding disability statistics. So far, no single organization is directing or coordinating such data collection efforts. The Subgroup recommended that planning begin immediately to address this pressing need and to improve disability questions in the Decennial Census for the year 2000. In addition, some Subgroup participants suggested using postcensal surveys as vehicles for gathering better information and data concerning disability.

4. NATIONAL PROGRESS SINCE THE WORKSHOP

In the three years following the Workshop and Census Subgroup meetings, the participants' continuing efforts helped produce a number of significant results. Many individuals, organizations, and governmental groups joined in what has become a national enterprise to understand not only scientists and engineers with disabilities, but all Americans with disabilities. The results of these activities, which are discussed in this section, include changes in surveys conducted by the Census Bureau, the initiation of long-term strategies for improving disability data collection methods, and the formation of a Coalition of Disability Statistics.

Participants in this national effort to upgrade the quality of disability information include the AAAS Project on Science, Technology, and Disability; the ASA Ad-Hoc Committee on

Disability; the NSF Division of Science Resources Studies; the U.S. Bureau of the Census; the NSF CEOSE Committee; the NRC/NAS Committee on National Statistics; individual participants of the NSF workshop; and Principal Investigators of the workshop.

4.1 NSF Biennial Survey Changes

In February and March 1988, the Workshop's Principal Investigators and staff of the NSF Division of Science Resources met individually with Census Bureau staff to discuss changes in the 1989 NSF Biennial Survey of Natural and Social Scientists and Engineers. General discussions also were held concerning changes to related NSF surveys scheduled after the 1990 Decennial Census. The meeting's broad focus was on improving the long term methodology for surveying scientists and engineers with disabilities, but the immediate concern was the 1989 NSF Biennial Survey. Based on these meetings, a draft of new and more extensive questions was developed for the Biennial survey. All participants in the Workshop received this draft of questions concerning disability and their reactions and comments were solicited. In April and May 1988, the Principal Investigators summarized and presented the Workshop members responses to the NSF through the Chair of the CEOSE Subcommittee on Disability. After further refinement, the NSF Division of Science Resources sent a second draft of the new survey questions to AAAS. The AAAS endorsed the changes and the NSF then transmitted the new disability questions to the Census Bureau in July 1988. The Office of Management and Budget approved the 1989 NSF Biennial Survey with the new disability questions. The Census Bureau conducted the survey on February 5, 1989, sending questionnaires to approximately 60,000 scientists and engineers from the original sampling frame of approximately 100,000 identified through the 1980 Decennial Census.

4.2 Post Censal Content Reinterview Survey

Following the Workshop, the Census Bureau considered possible changes to the four disability questions on the 1990 long-form. The Workshop's Principal Investigators discussed the rationale for these changes. Due to the closeness of the 1990 Census, the Census Bureau decided not to make changes in the Long Form Survey. However, Census personnel identified the Post-Censal Content Reinterview Survey as a means of collecting auxiliary information and addressing concerns about the Long Form. The Content Reinterview Survey was to be administered shortly after the 1990 Census to evaluate the reliability and validity of Census Short Form and Long Form.

In 1989, the Census Bureau formally approved a proposal that the Content Reinterview include a number of disability questions that had been used previously on Surveys of Income and Program Participation (SIPP). This change permits the evaluation of responses to the four disability questions on the Long Form and also provides information concerning the construction of disability questions for subsequent Census surveys. Discussions are ongoing to decide the most effective means for analyzing and using this significant new source of information on Americans with disabilities.

4.3 NRC Meetings on Disability Statistics

In May 1988, the Workshop's Principal Investigators presented a brief report of the Workshop at a meeting of the National Research Council (NRC) Committee on National Statistics. In October 1988, members of this Committee and their staff again discussed the issues concerning the national collection of disability statistics. The NRC Committee on National Statistics, stimulated in part by the recommendations of the Workshop, then organized a meeting to consider whether or not the NRC should undertake a panel study concerning disability statistics. This meeting took place in Washington, D.C. on April 6 and 7, 1989. A report on the recommendations of the meeting was released in 1990.

4.4 Coalition on Disability Statistics and Congressional Action

The Workshop also helped to stimulate activities by other organizations concerned with disability issues. Many organizations were aware of the sparsity of appropriate data, but had difficulty conceptualizing how to begin collecting the needed information. The topics and recommendations discussed at the Workshop helped fill that gap.

In the Fall of 1988 a group of disability-related organizations, convened by the American Foundation for the Blind, formed an informal Coalition on Disability Statistics and discussed how to obtain legislative support for improved national data gathering concerning individual with disabilities. The Coalition presented the Workshop's recommendations in its their agenda. The Coalition found that the specific problems in collecting data on scientists and engineers with disabilities (definitions of impairment and function, confidentiality, self-perception, and unwillingness of many individual to self-identify) were some of the same problems confronting disability data collection generally. In November 1988 the Coalition of Disability Statistics and representatives from the Census presented a history and overview of the field at a meeting of the Council of Professional Associations on Federal Statistics (COPAFS) held at the AAAS. Many member organizations of COPAFS expressed interest in pursuing studies in the area if funding is made available.

In a related activity, the AAAS Project on Science, Technology and Disability met with the Consortium of Affiliates on Disability Issues in December 1988. Information about the Workshop was presented to the Consortium, which represented approximately thirty scientific and engineering societies, and discussion concerned the lack of suitable information within all of the societies. Participants specifically noted the almost complete lack of information on society members with disabilities, on membership in student chapters of students with disabilities, on accessibility at professional meetings, and on accommodations for workers with disabilities in laboratories and other worksites. In August 1989 the ASA's Ad Hoc Committee on Disability held a meeting in part to address these issues. The ASA Committee proposed that a transportable methodology be developed that all scientific societies could use to survey members with disabilities. The methodology would be tested on the ASA membership and would then become available to other scientific associations.

Throughout the Spring of 1989, the Coalition on Disability Statistics continued to meet and incorporate points of view from diverse disability-based groups. The Coalition then presented consensus of opinion from all participating groups to members of Congress. The Coalition introduced its case to Congress as follows:

"If our nation has a serious commitment to ensuring full participation of people with disabilities in all aspects of society, it will collect data that permit use to monitor and to enforce the laws and programs which benefit such individuals...Data are a necessary part of the enforcement apparatus but data [for people with disabilities] do not exist."

In July 1989, Congress included \$200,000 in the appropriations bill for the Department of Commerce to develop and pretest a survey instrument to collect information on individuals with disabilities. The Census Bureau was to submit its work by February 1, 1990. The plan included the means for conducting a Post-Censal survey on Americans with disabilities and proposals for sharing the costs among the federal departments and agencies that use the information in their programs.

As this report is being completed, the Congress of the United States has recently passed the Americans with Disabilities Act. It is a propitious time for this Workshop and its effects to have occurred. The continuing results of this Workshop, in a nation committed to develop and guard the intellectual rights of all citizens including those with disabilities, will ultimately help increase the talent pool for American science.

PART II

5. THE NAMING QUESTION: REFLECTIONS ON THE LANGUAGE OF DISABILITY by Irving Kenneth Zola)

"When I use the word, it means just what I choose it to mean--neither more nor less."

Humpty Dumpty

In the early months of 1989 the issue of naming hit the front pages of our newspapers as a political and cultural issue. Jesse Jackson claimed it was time to rethink the usage of the term "Black" and instead use a word more reflective of their roots--"African-American." The heat as well as light that this controversy sheds on the words one uses to describe oneself has particular relevance to such groups as NSF and AAAS as they seek information from scientists, engineers, and other populations about the presence of disability in their lives and its effect on their work and careers. This paper is an attempt to place this issue in historical perspective and thus to aid in the construction of more appropriate instruments.

5.1 The Power of Naming

According to the Old Testament, God's first act after saying, "Let there be light" was to call the light "Day" and the darkness "Night." Moreover, God's first act after the creation of Adam was to bring in every beast of the field so that Adam could give them names; and "whatsoever Adam called every living creature, that was the name thereof" (Genesis 2:20). Thus what one is called tends "to stick" and any unnamings process is not without its difficulties and consequences.

While a name has always connoted some aspect of one's status (e.g., job, location, gender, social class, ethnicity, kinship), the mid-twentieth century seems to be a time when the issue of naming has assumed a certain primacy. In the post-World War II era Erikson (1950) and Wheelis (1958) noted that "Who am I" or the issue of identity had become a major psychological concern of the U.S. population. The writings of C. Wright Mills (1959) as well as the Women's Movement (Boston Women's Health Book Collective 1970), however, called attention to the danger of individualizing any issue as only a "personal problem." The power of naming was thus recognized not only as a personal issue but a political one as well. While social scientists focused more on the general "labeling" process and the measurement of attitudes toward people with various chronic diseases and disabilities, a number of "liberation" or "rights" movements focused on the practical implications. They claimed that language was one of the mechanisms by which dominant groups kept others "in their place." Thus, as minority groups sought to gain more control over their lives, the issue of naming--what they are called--was one of the first battlegrounds. The resolution of this was not always clear-cut. For some, the original stigmata became the banner: Negroes and coloreds become Blacks. For others, only a completely new designation would suffice--'Ms.' has caught on as a form of address but "womyn" and "wimmin" have not been so successful as a way of severing the vocabulary connection to "men." People with disabilities are in the midst of a similar struggle.

The struggle is confounded by some special circumstances, which mitigate against the easy development of either a disability pride or culture. For unlike most minority groups who grow up in a recognized subculture and thus develop certain norms and expectations, people

with chronic diseases and disabilities are not similarly prepared. The nature of their experience has been toward isolation. The vast majority of people who are born with or acquire such conditions do so within families who themselves do not have these conditions nor do they generally associate with others who do. We are socialized into the world of the "normal" with all its values, prejudices, and vocabulary. As one generally attempts to rise out of one status, there is always an attempt to put this status in some perspective. The statements that one is more than just a Black or a woman, etc., are commonplace. On the other hand, where chronic illness and disability are concerned, this negation is almost total and is tantamount to denial. Proof of successful integration is embodied in such statements as "I *never* think of myself as handicapped" or the supreme compliment, "I *never* think of you as handicapped."

A mundane but dramatic way of characterizing this dilemma can be seen by looking at the rallying cries of current liberation movements. As the "melting pot" theory of America was finally buried, people could once again say, even though they were three generations removed from their immigrant ancestors, that they were proud to be Greek, Italian, Hungarian, or Polish. With the rise of black power, a derogatory label became a rallying cry, "Black is beautiful!" And when female liberation saw their strength in numbers, they shouted, "Sisterhood is powerful!" But what about those with a chronic illness or disability. Could we yell, "Long live cancer!" "Up with multiple sclerosis!" "I'm glad I had polio!" "Don't you wish you were blind?" Thus the traditional reversing of the stigmata will not so easily provide a basis for a common positive identity.

5.2 Some Negative Functions of Labeling

The struggle over labels often follows a pattern. It is far easier to agree on terms that should *not* be used than the designations that should replace them. As with the racial, ethnic and gender groups before them, many had begun to note the negative qualities of certain "disability references" (Biklen and Bogdan 1977, Corcoran 1977); and others created quite useful glossaries.

Since as Phillips (1986) notes the names one calls oneself reflect differing political strategies, we must go beyond a list of 'do's' and 'don'ts' to an analysis of the functions of such labeling. There are at least two separate implications of such naming, which have practical and political consequences.

The first is connotational and associational. Being seen as the object of medical treatment evokes the image of many ascribed traits such as weakness, helplessness, dependency, regressiveness, abnormality of appearance, and depreciation of every mode of physical and mental functioning (Longmore 1985; Zola 1982). In the case of a person with a chronic illness and/or a permanent disability, these traits, once perceived to be a temporary accompaniment of an illness, become indelible characteristics. "The individual is trapped in a state of suspended animation socially, is perpetually a patient, is chronically viewed as helpless and dependent, in need of cure but incurable" (Longmore 1985, p. 420).

A second function of labeling is its potential for spread, pervasiveness, and generalization. Peters puts it most concretely: "The label that's used to describe us is often far more important in shaping our view of ourselves--and the way others view us--than whether we sign, use a cane, sit in a wheelchair, or use a communication board" (1986, p. 25). As the social

psychological literature has long noted, this is how stigma comes about--from a process of generalizing from a single experience, people are treated categorically rather than individually and in the process, devalued (Ainlay, Becker, Coleman 1986). As Longmore so eloquently concludes, a "spoiling process" (Goffman 1963) results whereby "they obscure all other characteristics behind that one and swallow up the social identity of the individual within that restrictive category" (Longmore 1985, p. 419). In short, the disability and the person become equated.

While many have offered vocabulary suggestions to combat the above-named connotations and pervasiveness, few have analytically delineated what is at stake in such name changes. The most provocative and historically rooted analysis is an unpublished paper by Phillips (1986). There she delineates four distinct strategies, which underlay the renaming.

"Cripple" and "handicapped," either as nouns or adjectives, she sees as primarily "names of acquiescence and accommodation," reflecting an acceptance of society's oppressive institutions. Terms such as "physically challenged" reflect a "try harder ideology." By making "the challenge" such a personal one, they also run the risk of fostering a "blaming the victim" stance. Such a term, as well as ones like "the Association for Community Living," "physically different," "physically inconvenienced," may not only be so euphemistic as to confound anyone as to who is being referred as well as contribute too strongly to the denial of existing realities. The two remaining strategies represent a more activist philosophy. "Differently-abled" is "a name of reaction and reflection" where the purpose of the creators is in emphasizing "the can-do" aspects of having a disability. Most angry of all, says Phillips, are "names of renegotiation and inversion" where it is the context that sets the meaning. Perhaps the best known examples are when political activists in the privacy of their own circles "talk dirty," referring to themselves as "blinks," "gimps," or telling "crip" jokes and expounding on the intricacies of "crip" time. Far more controversial, however, is when in public people proclaim such terms as a matter of pride. Thus, recently many have written about the positive aspects of "being deaf" (*Disability Rag* 1986, Innerst 1986) or even more dramatically in being a "cripple" (Mairs 1986; Milan 1984). Kriegel (1969, 1981) says that "cripple" describes "an essential reality," a way of keeping what needs to be dealt with socially and politically in full view.

While Phillips' very titles may imply an evaluation of the particular strategies, it is clear from her own caveats that while many may try to impose their terminology as "the correct language," "None feel really right" (Peters 1986, p. 5).

5.3 Recontextualizing Names

The ultimate question, of course, is whether any of these renaming procedures, singularly and alone, can deal with the connotational and generalization issues discussed previously. I would argue that the context of usage (and thus of particular concern when we try to create measures of the presence and complications of "disability") may be every bit as important (as Phillips 1986 implies) as the specific terminology. Thus one of the reasons for all the negative associations to many terms is a result of such contexts.

Social scientists, researchers, and clinicians are particularly at fault in their medicalizing of disability (Zola 1972; Illich 1977, Conrad and Schneider 1980). In conversation, but more importantly, in their writings and thus in the transmission of these writings by the popular press and media, people with varying diseases and disabilities are inevitably referred to as "patients,"

a term which describes a role, a relationship, and a location (i.e., in an institution or a hospital) from which many connotations, as previously noted, flow. For the 36 million people now designated as having a physical, mental, or biological disability, only a tiny proportion are continually resident in and under medical supervision and thus truly "a patient." Similarly, the terms "suffering from," "afflicted with," and "victims" are projections and evaluation of an outside world. No person with a disability is automatically "suffering" or "afflicted" except in certain time-bound situations where they do indeed "hurt," are "in pain," or feel "victimized," I am not arguing, however, for the complete elimination of medical or physical terminology. We must seek a change in the connotations and the pervasiveness of our names without denying the essential reality of our conditions. Biology may not determine our destiny; but as with women, our physical, mental, and biological differences are certainly part of that destiny (Fine and Asch 1988). A way of contextualizing our relationship to our bodies and our disabilities may not be in changing terms but in changing grammars.

Our use of nouns and adjectives can only perpetuate the equation of the individual equaling the disability. No matter what noun we use, it substitutes one categorical definition for another. An adjective, while modifying a noun, still colors and thus connotes the essential quality off the noun it modifies. Such adjectives as "misshapen," "deformed," "defective," "invalid" tend to taint the whole person. The same is true with less charged terms. If "a disabled car" is one which has totally broken down. Could "a disabled person" be perceived is anything less?

Prepositions, on the other hand, imply both "a relationship to" and "a separation from." The awkwardness that often results from using prepositions may be all to the good, for it makes the user and the hearer stop and think about what is meant, as in the terms "people *of* color" and "person *with* a disability.

Distance and relationship are also at the heart of some very common verb usages. The first is between the active and the passive tense. According to Webster's dictionary, active means that the subject *performs* the action represented by the verb, whereas passive means that the subject is *affected* by the verb. Thus in describing an individual's relationship to an assistive device such as a wheelchair, the difference between "being confined" to a wheelchair or "using" one is a difference not only in terminology but in control. Medical language has long perpetuated this by its emphasis on what it continually *does to* its "patients" rather than *with* them.

The depth of the issue can be seen in the different use of the verbs "be" and "have." The French language is careful in its distinctions between when to use "etre" (be) and when to use "avoir" (have). English daily usage is blurry but another look at Webster's does show the possibilities.

be = to equal in meaning, to have same connotations as, to have identity with, to constitute the same class as (Webster 1973, p. 96); have = to hold in possession, to hold in one's use, to consist of, to stand in relationship to, to be marked or characterized by, SYN - to keep, control, retain, or experience (Webster 1973, p. 526)

Like the issue of nouns vs. prepositions, verbs can also classify people in terms of categories--x is a redhead--instead of naming attributes--x has red hair. The former allows people to feel that the stigmatized persons are fundamentally different and establish greater psychological and social distance. As between the active and passive tense, both "I am..." and "I have..." specify a difference in distance and control in relation to whatever it is one 'is' or 'has.'

And since grammar tends to be normative, concise, shared and long lasting, it may serve us better than just a name change.

There may be stages in the coping with a particular condition or in a particular "therapy" such as the 12 steps of Alcoholics Anonymous, when 'ownership'--the use of 'I am'--is deemed essential. Those old enough to remember President Kennedy's words at the Berlin Wall, "Ich bin ein Berliner" (I am a Berliner) will recall the power of its message of kinship. When we politically strategize as a minority group and seek a kinship across disease and disability groups, the politically coming-out may require a personal ownership best conveyed in terms of "I am..." For scientists or engineers with disabilities, their professional identity is central to their self image and the disability, even if severe, is secondary. The professional affiliation comes first. "A chemist who uses a wheelchair" gives a different message than a "wheelchair-bound chemist."

On the other hand, there are times when the political goals involve groups where disease and disability is not a permanent or central issue. On my own university campus for many reasons there are almost no people with mobility impairments. Yet gradually we are updating old buildings and guaranteeing accessibility in new ones. The alliance here is with women who are or may become pregnant, parents with small children, people with injuries or time-limited diseases or disabilities, and aging staff or faculty. They rarely see themselves as disabled but often see themselves as having a temporary disability or sharing a part of "the disabled experience," as in "Now I know what it's like to try to climb all those stairs." Thus where coalition politics is needed, the concept of "having" versus "being" may be an easier way of acknowledging multiple identities and kinship, as in our use of hyphenated personal and social lineage such as African-American.

Too often this struggle over names has become divisive. People begin to chastise "non-true believers" and emphasize to others "politically correct" usage. This may damage the unity so necessary to the cause of independent living and disability rights. The reason for our struggle in the first place is because we live in a society, which devalues, discriminates against, and disparages people with a disability. It is not our task to prove that we are worthy of the full resources and full integration of our society. The fault is not in us, not in our diseases and disabilities but in society's denials, social arrangements, political priorities, and prejudices. Here a renaming can be of service but it is not of us but of our oppressors. When we turn the tables and create epithets for our oppressors, this may be a sign of a beginning cohesiveness. Thus the growing popularity of terms like TAB's and MAB's (temporarily or momentarily abled-bodied) to describe the general population eliminate the separateness of an "us" and "them" and emphasize the continuity and inevitability of "the disability experience." Those who have created the terms "handicappism" (Bogdan and Biklen 1977) and "healthism" (Crawford 1980; Zola 1972, 1977) equate these with all the structural "-isms" in a society which operates to continue segregation and discrimination.

Thus the issue of naming is clearly a loaded issue--one we must be particularly cognizant of as we structure questionnaires where we require respondents to identify themselves in terms of their disabilities and their consequences. The words of Philip Dunne provide a final remainder of the choices and consequences of language:

If we hope to survive in this terrifying age, we must choose our words as we choose our actions. We should think how what we say might sound to other ears as well as to our own. Above all, we should strive for clarity...

...if clarity [is] the essence of style, it is also the heart and soul of truth, and it is for want of truth that human freedom could perish." (1986, p. 14)

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6. SAMPLING SCIENTISTS AND ENGINEERS WITH DISABILITIES: PERSPECTIVES (by Graham Kalton and Seymour Sudman)

The task of obtaining at a reasonable cost a probability sample of adequate size of scientists and engineers with disabilities is an extremely challenging one. Depending on the definitions of scientists and engineers and of disability adopted, the percentages of the adult U.S. population may be of the order of 1 or 2 percent for scientists and engineers and 10 percent for persons with disabilities. The intersection of these two groups is very small. The problem of selecting a sample of scientists with disabilities and engineers clearly falls in the generic problem of sampling a rare population (Kalton and Anderson (1986); Sudman and Kalton (1986)).

In sampling a rare population, the first step is to investigate whether there is a special list, or a combination of lists that give a sufficiently high coverage for the rare population and that does not contain too many foreign elements. When such a list exists, sampling the rare population can be fairly straightforward. Lacking such a list, a large-scale screening of the general population is required. This screening operation needs to be conducted in an economic manner. Several procedures may be employed for economic screening, including using an inexpensive data collection procedure for screening (e.g., mail questionnaires or telephone interviewing rather than face-to-face interviewing), screening large clusters, sampling strata with greater prevalence of the rare population at higher rates, using existing large-scale surveys to screen, and using multiplicity sampling methods.

In screening for a very rare population like scientists with disabilities (henceforth the terms 'scientists' and 'science' will be taken to include 'engineers' and 'engineering'), great economies are obtained if the screening, or a substantial part of it, can be accomplished as part of another survey. This paper will consider this approach and the possible surveys that might be used for this purpose. The paper in Section 7 will discuss an approach to sampling scientists with disabilities using multiplicity sampling.

Even more difficult than sampling scientists with disabilities is the task of sampling persons with disabilities who have the potential for careers in science, but who have failed to enter these careers because of difficulties they encountered. After considering surveys that may be useful for screening scientists with disabilities, we will briefly discuss approaches for surveying students with disabilities who have the potential for, but who do not enter, science.

6.1 Using Existing Surveys to Screen for Scientists with Disabilities

Questions that define membership of a rare population may be asked in a large-scale survey. When this occurs, the large-scale survey may be used as a screener to identify rare population members for a follow-up survey. For scientists with disabilities, the ideal would be to find a survey that identified both persons with disabilities and scientists and that was large enough to produce a sufficiently large sample of scientists with disabilities. In lieu of that, surveys that identify either scientists or persons with disabilities could be used. In the former case, the identified scientists would need to be screened to find the persons with disabilities, while in the latter case the identified persons with disabilities would need to be screened to find the scientists.

Before turning to consider some surveys that might be used to help in screening for scientists with disabilities, two general observations on this approach should be made. First, the quality of the sample of scientists with disabilities will depend on the quality of the parent survey. In particular, there is the issue of nonresponse. If the parent survey was subject to a high level of nonresponse, this will seriously jeopardize the quality of the sample of scientists with disabilities. Indeed, even if the survey had a low overall nonresponse rate, careful consideration should be given to the possibility of a high level of nonresponse among scientists with disabilities. For example, a response rate of 95% overall is not inconsistent with a low response rate (e.g., 40%) among the rare population of scientists with disabilities. Such a low response rate could well occur if, say, participation in the parent survey was difficult for persons with disabilities.

The second observation concerns the identification of persons with disabilities and scientists in the parent survey. Consider, for example, a parent survey that asks questions about disability. Ideally all those identified by their answers to these questions as persons with disabilities, and none of those identified as non-disabled, would be classified as individuals with disabilities in the follow-up survey. In practice, this ideal will not be attained, both because the disability questions may not enable the exact definition of disability adopted for the follow-up survey to be applied and because of measurement errors in the responses reported for the parent survey.

Two types of classification error can occur in the parent survey, false positive (persons classified as disabled by the parent survey but not disabled according to the definition used for the follow-up survey), and false negatives (persons classified as nondisabled by the parent survey, but disabled according to the follow-up survey definition). The false positives do not create a serious problem. They can simply be removed from the follow up survey as they are discovered. Provided that they are not too numerous, this involves only a small loss of efficiency.

The false negatives are, however, a more serious concern. Since there are many more negatives than positives in the parent survey, even if only a small proportion of the negatives are false ones, these false negatives may constitute a sizable proportion of the rare population. Suppose for instance, that 10% of the members of the parent survey are classified as disabled, that all of them are disabled according to the follow-up survey definition, and that 12% of the remaining 90% of those classified as non-disabled by the parent survey are disabled according to the follow-up definition. Then more than half of the disabled according to the follow-up survey definition come from the stratum of those classified as non-disabled by the parent survey.

When the number of false negatives is too sizable to be ignored, it becomes necessary to select a sample from those classified as negative as well as those classified as positive by the parent survey. In this circumstance, disproportionate stratified sampling may be used, sampling the stratum of negatives at a lower rate than the stratum of positives. However, sizable gains in precision accrue from such disproportionate allocation only when two conditions apply: first, the concentration of the rare population in the positive stratum needs to be high and, second, that stratum needs to contain a substantial proportion of the rare population. As illustrated by the above example, the second condition may easily fail to be satisfied. In particular, it may well fail when the parent survey asks only a single global question on disability, whereas the follow-up survey defines disability in terms of answers to a range of questions on various functional limitations.

The above illustrations have been expressed in terms of using the parent survey to screen for disability, but the general arguments apply equally to screening for scientists. Consider, for instance, the situation where the parent survey identifies scientists as those engaged in scientific occupations whereas the follow-up survey defines scientists as persons with science degrees. Most of those with scientific occupations have science degrees (i.e., the proportion of false positives is not too great), but a high proportion of those with science degrees do not have scientific occupations (i.e., there are many false negatives).

With this background, we now turn to consider some large-scale surveys that might serve as parent surveys for a follow-up survey of scientists with disabilities.

6.2 NSF Scientific and Technical Personnel Data System

The National Science Foundation is required to provide Congress with a biennial report on the nation's scientists and engineers. To fulfill this requirement, the Foundation's Division of Science Resources Studies operates the Scientific and Technical Personnel Data System (STPDS), a system that includes three large-scale surveys of different sectors of the universe of scientists and engineers.

The core of the STPDS for the 1980s has been a panel survey of individuals sampled from the 1980 Census, known as the National Survey of Natural and Social Scientists and Engineers. The initial wave of data collection, the Postcensal Survey, took place in 1982, when questionnaires were mailed to 138,080 persons selected from households completing the census long-form questionnaire. The sample was drawn from persons aged 16 and over with four or more years of college education (two or more years for those in engineering occupations), and higher sampling fractions were employed for those in science and engineering occupations. Usable returns were received from 97,580 of the sampled persons, representing a 71 percent response rate. The second wave of the panel occurred in 1984 -- the 1984 Experienced Sample Survey -- with mail questionnaires being sent to 87,228 of the 1982 respondents; 64,035 usable questionnaires were returned. The third wave occurred in 1986, when all the 1984 respondents were resurveyed by mail. On this occasion, 54,719 usable questionnaires were returned. It should of course be noted that many of the respondents would not be classified as scientists or engineers whatever the definitions of scientist and engineer adopted (e.g., whether the definition be based on occupation, education, self-identification, or, as in the NSF case, on a combination of the three).

Another series of STPDS surveys is the Surveys of Science, Social Science and Engineering Graduates (also known as the New Entrants Surveys) that survey new science and engineering graduates. In the 1980s, these surveys have been conducted in 1982, 1984, 1986 and 1988. They are cross-sectional mail surveys that sample science and engineering graduates from lists of certain graduating classes in a sample of schools selected from the universe of institutions granting degrees in science and engineering. Thus, for instance, the 1986 New Entrants Survey sampled about 50,000 graduates from the classes of 1982, 1984 and 1985. The response rates for the New Entrants Surveys have been low; that for the 1986 Survey was 48 percent.

The third survey component of the STPDS is the Survey of Doctorate Recipients. This survey is a panel survey in which sampled recipients of research doctorates in science and engineering are surveyed by mail questionnaire every two years. At each wave of data

collection, a sample of doctorate recipients who received their degrees in the past two years is added to the panel, and panel members who received their doctorate more than 42 years earlier are dropped. The 1985 wave of the survey yielded 36,300 usable questionnaires, with a response rate of 63 percent.

Although the STPDS surveys include a question about handicaps, they do not collect the more detailed data needed to describe the working lives of scientists with disabilities. One might consider expanding the range of data relating to the disabilities collected in these surveys, but that does not appear to be a promising approach. Since the surveys are all conducted by mail, there are strong pressures to keep their questionnaires as short as possible. It therefore appears extremely unlikely that the disability sections of the questionnaires could be expanded to a significant degree.

There are, however, two other approaches for enhancing the values of the STPDS for studying scientists with disabilities (Crowley (1987)):

1. Prior to 1989, the STPDS surveys asked a single question about handicaps. That question could be replaced by some questions asking about physical disabilities so that a better classification of the disabled could be made. As discussed in Section 7 of this monograph, this change has in fact been incorporated into the 1989 Experienced Sample Survey. In that survey respondents were asked: What is the usual degree of difficulty you have with -
 - (a) Seeing the words and letters in ordinary newspaper print (while wearing glasses or contact lenses if you usually wear them). .
 - (b) Hearing what is said in a normal conversation with another person (while wearing a hearing aid if you usually wear one).
 - (c) Walking without assistance (human or mechanical) or using stairs. .
 - (d) Lifting/carrying objects associated with your normal occupational duties.

In each case respondents were asked to choose between response categories of no difficulty, some difficulty, and great difficulty or unable to do. Excluding those who answered "No difficulty" to all the above questions, respondents were then asked:

To what extent has your physical condition affected -

- (a) Completing your education
- (b) Finding employment
- (c) Advancement in your career

For each of these questions respondents were provided with response alternatives of: caused no problem, caused some problem, and caused severe problem.

2. With more effective disability questions replacing the handicap question, future STPDS surveys could be employed as screener surveys. These surveys could thus be used to identify scientists with disabilities for more extensive follow-up surveys that collect data about the onset of disability and about the effects of disability on the working lives of

scientists with disabilities. As discussed earlier, the extent and nature of the classification errors needs to be carefully considered with a screening procedure. If screening questions that yield a very low rate of false negatives and not too many false positives can be devised, this approach may be a very efficient way to obtain a sample of disabled scientists. The current handicap question identifies only about 2 percent of scientists as having a handicap, but classifying a person as disabled on the basis of a positive answer to any one of the disability questions given above is likely to yield an appreciably higher percentage of scientists with disabilities, perhaps 5 to 10 percent. With the large samples in the STPDS surveys, a prevalence of even 5 percent should produce a sizable sample of scientists with disabilities. The sample should at least be large enough for analyzing broad subgroups of scientists with disabilities, even if it would not permit analysis of minor subgroups such as organic chemists who are visually impaired.

A panel of the National Academy of Sciences has recently completed a review of the STPDS, and has made a number of recommendations for significant changes in the system and its component surveys for the 1990s (Citro and Kalton (1989 a,b)). NSF has accepted the majority of the recommendations, and the Foundation's plans for the 1990s are described in the report of the Scientific and Technical Personnel Characteristics Studies Group (1989). The plans call for a continuation of the three surveys described above but with some major design modifications. In particular, it is planned that the New Entrants Surveys will become a panel survey. The STPDS surveys of the 1990s will remain an attractive potential means of studying scientists with disabilities, and the value of these surveys will be enhanced if their quality can be improved and if higher response rates can be achieved.

The scientists and engineers surveyed in the STPDS in the 1990s will include only those with at least a bachelor's degree. Within that restriction, however, the system allows for alternative definitions of scientists and engineers. The system could provide a sample of persons with disabilities with science or engineering degrees, or of persons with disabilities working in science or engineering occupations. Thus, for example, it would be possible to sample disabled persons with science or engineering degrees who do not pursue science or engineering occupations to find out why they are not working in science (however, it needs to be noted that a substantial proportion of all science and engineering graduates do not work in science and engineering occupations). The longitudinal nature of the STPDS surveys also has the potential to enable analyses of changes in occupations of scientists with disabilities over time.

6.3 Other Surveys

As noted with the STPDS Postcensal Survey, the Decennial Census collects information on education, occupation and disability. The major limitations to census data are that they are gathered only at ten-year intervals and that the amount of detail is very restricted. Nevertheless, census data might be used in two ways:

1. To estimate the size and demographic characteristics of scientists with disabilities. For this use, the definitions of scientist and disabled adopted will have to reflect the data collected in the census. (The 1990 Census will not, for instance, collect information on field of degree.)

2. To provide a sampling frame for follow-up surveys of scientists with disabilities (as with the STPDS Postcensal Survey). For this use, the follow-up survey will need to be conducted by the Bureau of the Census in order to avoid violating the confidentiality requirements of the census.

The possibility of using other large-scale surveys also exists. The obvious contenders are:

The National Health Interview Survey (NHIS). The NHIS is a continuous survey that has a sample of 42,000 households per year, or roughly 60,000 persons in the labor force. The number of scientists and engineers might be around 3000, of whom perhaps 150-300 might be disabled. It would be necessary to combine NHIS samples over several years to produce a sizable sample of scientists with disabilities.

The Current Population Survey (CPS). The CPS collects labor force data about the U.S. population on a monthly basis. The survey employs a rotating sample design, with sampled households being interviewed for four consecutive months, then dropping out for eight months, and returning for another set of four consecutive months. The CPS interviews around 57,000 households each month.

The Survey of Income and Program Participation (SIPP). The SIPP is a panel survey that follows sample persons at four-monthly intervals for a period of 32 months. A new panel is introduced each year. The first SIPP panel, the 1984 panel, started with about 20,000 households, but subsequent panels have been reduced to about 12,000 households because of budget constraints. The size of the 1990 panel is planned to be increased to about 20,500 interviewed households. Members of the 1984 panel were asked to respond to a module of questions on disability, and disability questions will be in Wave 3 of the 1990 panel.

As a result of the rarity of the population of scientists with disabilities, even these large-scale surveys can produce only small samples of this population. While data from these surveys may provide some broad impressions of the working lives of scientists with disabilities, they cannot do more than that.

6.4 Diversion from Science

Another population of interest comprises students with disabilities with the potential to enter science and engineering but who do not do so, perhaps because they are discouraged by teachers, classmates, family or the physical constraints they face at school. The study of deflection from science is clearly a far more difficult task than studying the career paths of scientists with disabilities.

One approach would be to take a sample of children with disabilities and to follow them in a panel study, collecting data at regular intervals on their career plans, their perceptions of the advice they are given by teachers, counselors, parents, and others, and on their academic performance. In addition, data might be collected directly from teachers, counselors and parents. The sample of students with disabilities would need to be very large, since only a small proportion of the population takes science or engineering degrees and enters science or engineering occupations. In addition, a control group of students without disabilities would be needed for comparison purposes. Although some data for older students might be collected by means of mail or self-administered questionnaires, it is likely that some more personal data and all data for younger students would need to be collected in face-to-face interviews; while data on

school performance might best be obtained from school records. It is clear that such a study would be an extremely challenging one to design, and an expensive one to conduct.

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7. THE SAMPLING OF SCIENTISTS AND ENGINEERS WITH DISABILITIES: A METHODOLOGICAL APPROACH (by Seymour Sudman)

In addition to the use for screening of the existing lists noted in the previous paper, the use of network sampling procedures would also increase the number of scientists with disabilities located as well as locating some scientists who might be missed from the other sampling frames. The method would require two or three additional questions be added to ongoing surveys of scientists conducted by NSF. The added costs would be small. In this paper we briefly describe how the method would be used, give the theoretical and practical justifications for the procedure, as well as possible limitations.

7.1 Method

As part of the survey of scientists, the following questions would be added:

- 1) The total number of scientists in the department or group in which the scientist works.
- 2) Whether any of these are disabled, and, if yes, who? Disabled scientists identified by this procedure would then be added to the sample and, after appropriate weighing, be included in what are called multiplicity estimates.

7.2 Weights

It is obvious that if one uses network procedures not all scientists with disabilities have equal probabilities of selection. The selection probability for any scientist with a disability is directly proportional to the number of scientists in the department or group since any of these could nominate a scientist with a disability. Thus, for an unbiased estimate, the sample would need to be weighted inversely by the probabilities of selection.

The major practical questions that arise when one is using this procedure are whether informants are aware of the disability and whether it is possible to obtain accurate estimates of the work group size so that accurate weights can be applied. On the face of it, it would be likely that scientists working together would be aware of visible disabilities such as blindness, deafness, and a missing or paralyzed limb. Minor disabilities such as a missing finger or toe or non-visible disabilities might well not be reported, either because they were not known to the informant or had been forgotten. It might also be that some scientists would be reluctant to provide information about others, but it is possible to reduce this reluctance by explaining the purposes of the study.

It is not self-evident that scientific respondents will be able to report with reasonable accuracy the number of other scientist with whom they work. This would appear to be easy if there are very few others, but would seem to become more difficult as the number increases. There is some recent research, however, that indicates that some estimates are reasonably satisfactory.

As all sampling statisticians know, weighing a sample increases the sampling variability of the estimates. Thus, the real comparison is not between the sample sizes of scientists with

disabilities that one can obtain by direct and network methods. The comparison should be between the sampling variances of the alternative methods. For network samples using relatives, the increased sampling variability caused by the weights is small relative to the reduction in variability caused by using network methods. The same effect would be expected with network samples of work groups, but there are no data on this.

7.3 Previous Experience with Household Network Samples

Most of the work that has been done with network samples has involved household networks, primarily of relatives, but more recently also of neighbors. The idea of network sampling and the theoretical foundations were given in a paper by Birnbaum and Sirken (1965) and in later papers by Sirken and his colleagues (Sirken (1970a), (1972), (1974), (1975); Casady and Sirken (1978); Casady, Nathan, and Sirken (1985); Sirken and Levy (1972), (1974)).

Network samples have been used for surveys of rare illnesses such as cancer (Czaja, Snowden and Casady (1986)) and diabetes (Sirken, Graubard and McDaniel (1978)); to improve birth and death estimates (Nathan (1976); Sirken (1970b), (1973); Sirken, Royston and Bridges (1977)); for a survey of Vietnam era veterans (Rothbart, Fine and Sudman, (1982)); and to estimate the number of missing children (Sudman et. al., (1987)).

Linkages to neighbors have been used in network surveys of ethnic minorities (Brown and Ritchie (1981); Snow, Hutcheson and Prather (1981)) and in a survey of home vegetable gardeners (Bergsten and Pierson (1982)).

7.4 Experience with Work Groups

Networks can exist in many forms. In addition to relatives and neighbors, researchers have studied networks of students in colleagues and using only citations have studied who cites whom in a given discipline. In 1985, we published some results of experiments in measuring the size of church, social group, and work networks (Sudman (1985)). This work, supported by the National Science Foundation, demonstrated that most respondents could give accurate information about the size of their work groups. Indeed, the information on work groups was better than that on other social groups because most people see their fellow employees more often and interact more frequently with them than they do with members of church or social groups.

For this experiment there were five work groups selected, all from the State of Illinois. In selecting them, the joint criteria were (1) their size and (2) the willingness of management to have the study conducted and to provide a list of all employees in a specified department. The types of departments ultimately included were in retailing, wholesaling, and a large office setting. Although these are certainly not a representative selection of work sites, they are three distinctly different types of settings.

There was also a deliberate effort to vary the size of the departments in the main study. The sizes varied from 18 in the smallest group to 52 in the largest. Larger work groups certainly exist. (We had tried and failed to obtain a group with 85 employees.) Most of the groups that we contacted, however, whether they ultimately cooperated or not, had fewer than 100 employees.

Three methods of obtaining the size of the work group were tested: a numerical estimate, one based on recognition and the third on recall. Because we only used groups where employers cooperated, we also had a list of all employees that could be used for the recognition procedure where employees were based if they knew a named person.

Table 1 gives the comparison of estimates based on recognition and the numerical estimates. The recall estimates, which are substantially below both the numerical and recognition estimates, are excluded. It may be seen that there is very good agreement in the mean values of the numerical estimates and the recognition method that was considered the most accurate when the study was designed. Note that the largest work group was approximately fifty employees. Numerical estimates might be poorer for larger work groups, but it is unlikely that many scientific groups would have more than this number.

We obtained information separately for acquaintances, friends and close friends. Initially we had expected that comparisons between alternative methods (recognition, recall and numerical estimates) would differ by the closeness of the relationship, but this did not turn out to be the case. The same methods results were seen whether we looked at acquaintances, friends or close friends.

For purposes of identifying scientists with disabilities, the acquaintanceship relation is the most appropriate since it provides the most information and a closer relationship is not needed to identify a disability. We noted in our study that many respondents were acquainted with *everyone* in their work group, but this was not universally the case. Members of the work group who had been away from the site because of being on a special assignment or because of illness were frequently omitted. In any event, it is not the actual number on a company list, but the number known to the respondent that determines the probability of selection and the weight in network sampling.

Table 1
Mean estimates of network size for acquaintances, friends,
and close friends by group and method

Group	Recognition Treatments		Numerical Treatments
		<i>Acquaintances</i>	
Work group 1 ^b – 50 employees	34.0 (11)*		37.5 (11)
2 ^b – 50 employees	46.2 (11)		37.5 (11)
3 – 52 employees	46.7 (35)		41.8 (35)
4 – 30 employees	22.4 (24)		31.5 (24)
5 – 18 employees	13.1 (13)		12.1 (13)
Average work groups	34.3 (94)		34.1 (94)
		<i>Friends</i>	
Work group 1 ^b	16.2 (11)		20.6 (11)
2 ^b	32.8 (11)		26.9 (11)
3	20.5 (35)		22.6 (35)
4	14.4 (24)		19.4 (24)
5	6.0 (13)		7.4 (13)
Average work groups	17.9 (94)		20.3 (13)
		<i>Close Friends</i>	
Work group 1 ^b	9.0 (6)		7.7 (11)
2 ^b	3.1 (7)		6.8 (11)
3	11.4 (15)		7.6 (35)
4	4.5 (14)		4.4 (24)
5	3.0 (5)		2.2 (13)
Average work groups	6.9 (47)		6.0 (94)

Table 2
Variances for estimates in Table 1

Group	Recognition		Numerical
		<i>Acquaintances</i>	
Work group 1	17.5		44.5
2	11.9		192.8
3	23.9		230.4
4	15.4		384.0
5	6.4		35.4
		<i>Friends</i>	
Work group 1	333.9		164.5
2	113.7		408.5
3	353.2		223.2
4	54.6		426.3
5	20.6		52.7
		<i>Close Friends</i>	
Work group 1	166.0		141.6
2	7.0		210.3
3	227.3		353.3
4	18.7		12.2
5	6.0		13.7

The results of Table 1 suggest that the net biases of numerical estimates are small, but Table 2 indicates that there is substantial individual variability. To put this into words, many respondents substantially over or under-estimate the size of their networks, relative to recognition, but these estimation errors seem to be randomly distributed. As a result of this, the weights applied in the multiplicity estimate would themselves be subject to measurement error and could contribute to an increase in sampling variability, but the estimates would be unbiased. Note that the variability is greater from the larger estimates indicating that the variability of numerical estimates is directly related to the size of the estimate.

7.5 Reports of Disability

In only one of the five work groups was there anyone who reported having a disability. This person was also reported as having a disability by virtually everyone in the work group who knew this person. This is limited, but encouraging evidence that it would be possible to obtain information on disabilities in a sample of scientists.

7.6 Possible Design Problems

Some of the issues facing a network sampling study are identical to those of a regular study while others are unique. We shall discuss three that might be problems. Others may surface when a pilot study is conducted.

7.7 Defining the Department

In the experimental work we reported above, the definition of the department was not a problem since we started with a specified department and used its name with all respondents. Even in this case, some respondents interpreted the work department to mean a sub-group within the larger department (the payroll group within the accounting department).

On a large mail survey it will not be possible to name the department. Rather this will need to be defined by the respondent. This definition is important because most scientists will know others in the organization, but not be able to estimate well the total number of people they know. It is especially likely that a scientist with a disability might be known by others in the organization but outside that scientist's department.

There might be a temptation to ask, "do you know any scientist with a disability in this organization?" While such a question might yield somewhat higher numbers of scientists with disabilities, the weights used for multiplicity estimation would be much less satisfactory since it is much more difficult to estimate the total number of persons known in an organization, especially a large one, than to estimate the number known in one's own department. That is, one wishes to use a procedure that provides reliable network weights rather than simply maximizing the sample size.

Another reason for getting the respondent to define the department is that it may then be possible for the respondent to use organization charts or directories of employees as a memory aid both for estimating department size and for remembering specifically who is in the

department. In the experimental study of work groups those respondents who used some form of employee lists did much better on the memory asks, as would be expected.

7.8 Defining a Scientist

Studies of scientists with disabilities would presumably exclude some categories of workers in an organization such as secretaries and possibly technicians. This differs from our experimental studies that asked for information about everyone in the department and makes the respondents' task more difficult. A respondent may err not only by misremembering the number in the department, but by misclassifying co-workers into or out of the designated group. There is no perfect solution, but the more explicit the definitions given the respondent, the better the replies.

7.9 Defining Disabilities

The term disability is a complex one whose definition can never be left to respondents. The term must be defined in specific detail for the respondent, but this would be the case whether a standard or multiplicity sample is used.

7.10 Unemployed Scientists with Disabilities

For some purposes it may be important to have a sample of unemployed scientists with disabilities. The methods proposed here do not help in the process, but only expand the sample of employed scientists. On the other hand, the network sampling methods do not hurt the location of unemployed scientists with disabilities. These may still be found from the direct sample mailing, although the screening costs for this special group would be very large, indeed.

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APPENDIX I

WORKSHOP ON THE DEMOGRAPHY OF SCIENTISTS AND ENGINEERS WITH DISABILITIES (January 29 and 30, 1988)

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**APPENDIX II
SUBGROUP MEETING WITH CENSUS BUREAU**

(January 31, 1988)

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**APPENDIX III
WORKSHOP PROGRAM ON THE DEMOGRAPHY OF
SCIENTISTS AND ENGINEERS WITH DISABILITIES**

**AMERICAN ASSOCIATION FOR THE ADVANCEMENT OF SCIENCE (AAAS)
with
AMERICAN STATISTICAL ASSOCIATION (ASA)
FUNDED BY THE NATIONAL SCIENCE FOUNDATION (NSF) .
29 - 30 January, 1988**

FRIDAY, 29 JANUARY

AAAS 1333 H Street, NW, Washington, DC, First Floor Conference Room

8:30 AM - 9:00 AM Continental Breakfast

9:00 AM - 10:15 AM

Welcome and Introductions:

Virginia Stern, Director
Project on Science, Technology and Disability
AAAS

J. Thomas Rathchford
Associate Executive Director
AAAS

Randall Spoeri
Associate Executive Director
American Statistical Association

Presenters:

Mary Clutter, Director, Division of Cellular Bioscience, NSF and
Member of the Federal Wide Task Force on Women, Minorities
and the Handicapped in Science and Technology

Michael F. Crowley, Study Director, Scientific and Technical
Personnel Studies National Science Foundation
Virginia Stern, Director, Project on Science, Technology and
Disability AAAS

Workshop Overview:

Allan Sampson
Department of Mathematics and Statistics
University of Pittsburgh
and Chair, ASA Committee on Disability

10:30 AM - 12 Noon **Group Discussions**

(During this session specialized interest groups will meet to pool information. Note: these groups are not strictly defined as people have overlapping interests.)

1. Statisticians, Demographers
(9th floor conference room)
2. Applied Researchers
(8th floor conference room)
3. Specialists in Disability Issues
(1st floor conference room)

12 Noon - 12:30 PM **Reports on Area Discussions**

(1st floor conference room)

12:30 PM - 1:30 PM **Lunch** (1st floor conference room)

1:30 PM - 4:15 PM **Group Discussions**

(These groups are composed of a cross section of participants. The purpose of this session is to provide time for brainstorming and to begin to synthesize the material.)

1. Working Group I
(1st floor conference room)
2. Working Group II
(8th floor conference room)
3. Working Group III
(9th floor conference room)

4:15 PM - 4:30 PM **Points of Information**

(1st floor conference room)

4:30 PM - 5:30 PM **Reception**

(1st floor Atrium)

SATURDAY, 30 JANUARY

(Ramada Renaissance Hotel, 1143 New Hampshire Avenue, NW, Washington, DC)

8:15 AM - 8:45 AM **Continental Breakfast**

(conference room A)

8:45 AM - 9:45 AM **Panel Discussion of Working Groups:**

Preliminary Findings

9:45 AM - 12:00 AM **Group Discussions**

1. Working Group I
2. Working Group II
3. Working Group III
(same groups as Friday afternoon)

12:00 PM - 1:30 PM **Lunch (La Cloche Room)**

1:30 PM - 4:00 PM **Plenary Session to Formulate Future
Agenda and Strategic Plan Recommendations**
(conference room A)

Chairs: Allan Sampson
Virginia Stern

APPENDIX IV

BIBLIOGRAPHY

This bibliography includes all bibliographic citations from Section 1 through Section 7, as well as a number of additional citations pertinent to these topics.

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