

PLANS FOR THE 1993-94 NATIONAL HEALTH INTERVIEW SURVEY  
ON DISABILITY

Gloria Simpson, David Keer, and Marcie Cynamon  
Gloria Simpson, National Center for Health Statistics  
6525 East West Highway, Room 850, Hyattsville, Md. 20782

**Key Words:** Disability, Survey methods

Introduction

In the United States there are about 35-43 million people with physical and mental disabilities. The prevalence of disabilities is disproportionately higher among minority, elderly, poor, and rural populations.<sup>1</sup> Disability impacts all aspects of an individual's well-being, and has emotional, social, and financial consequences. From a national perspective, disability exacts enormous economic costs. In 1989 the estimate of economic loss due to disability, including the increased cost of health care and reduced productivity, was \$176.8 billion.<sup>2</sup>

The Americans with Disabilities Act (ADA), which was signed into law in July, 1990, mandates changes in many areas related to disability. The ADA is one of the catalysts prompting legal and policy reforms in the area of disability. However, policy-relevant data on disability needed to understand the many aspects and impacts of disability is either very limited or nonexistent. Currently, we lack the data to provide for a comprehensive assessment of the prevalence and nature of disability in the United States.

Background

In an effort to meet some of these data needs, four federal offices planned national surveys about various aspects of disability in 1993-94.

1. National Survey of Persons with Developmental Disabilities was proposed by the Office of the Assistant Secretary for Planning and Development, Health and Human Services to get data on mentally retarded and developmentally disabled people.

2. The Supplemental Security Low Income Survey was planned by the Office of Supplemental Security Income, Social Security Administration (SSA) to obtain information on low income populations, blind, and disabled adults.

3. National Disability Survey was conceived by the Office of Disability, (SSDI), SSA due to their interest in the severely disabled population.

4. The National Child Health Assessment and Planning Project was proposed by the Bureau of Maternal and Child Health, Health Resources Administration to get information on children with disabilities and special health care needs.

Since many of these topic areas overlap, the agencies decided to merge their interests into one effort utilizing the National Health Interview Survey. As plans

for this survey evolved, other organizations with an interest in disability participated including the U. S. Department of Education, the National Institutes of Health, the Health Resources and Services Administration, the Robert Wood Johnson Foundation, and the Centers for Disease Control.

The National Health Interview Survey (NHIS) is a strong vehicle for fielding this combined effort. It is an annual interview survey of the noninstitutionalized civilian population of the U. S. Personal interviews are used to collect data on socio-demographic and health related variables from approximately 48,000 households including 122,000 individuals each year. Data are collected continuously every year by trained Census interviewers, starting in January and ending in December. Because of its large nationally representative sample size, the NHIS can be used to produce national estimates of persons with specific characteristics or conditions. Data samples from two or more years can be pooled to make estimates for smaller populations.

The NHIS consists of a CORE questionnaire and supplements. The CORE questionnaire is administered each year and collects basic health, socioeconomic and demographic data. Each year one or more supplements are designed to deal with current health issues. The topics of the supplements change in response to public health data needs. In recent years these topics have included issues such as cancer risk factors, youth risk behaviors, knowledge and

attitudes about AIDS, and child health. On the average, the NHIS CORE interview requires about 50 minutes to complete and the supplements run about 35 minutes.

Although the NHIS can be used to produce appropriate prevalence and descriptive statistics about disability, there are limitations that should be mentioned. The NHIS excludes persons who reside in institutions, a population with high rates of disability. Also, it is based on respondent reporting, with no medical verification.<sup>3</sup>

### Survey Goals/Objectives

The 1993-94 NHIS-Disability Survey represents a consensus reached by many researchers and policy makers who use disability data in a variety of ways and for many purposes. One goal was to draft a set of questionnaires that would provide a useful set of measures while maintaining a balance between the social, administrative, and medical considerations involved in disability measurement. The NHIS-Disability is not limited to one definition of disability; therefore, it will allow analysts from varying programs to combine or weight data items in different ways to meet specific agency or program needs. It attempts to collect data that can be used to understand disability, to develop public health policy, to produce simple prevalence estimates of numerous health conditions, and to provide descriptive baseline statistics on the effects of disabilities.

### Survey Plans/Methodology

Given such broad objectives, it was apparent very early in the planning process that it would be impossible to collect all of the data needed about disability in one interview. Previous experience with respondent burden suggests that the household contact should last no longer than one and a half hours. If the household interview is to be kept to a reasonable length, the amount of time available for the disability survey is limited by the time taken to administer the NHIS CORE questionnaire and the other supplements. For the 1993-94 NHIS, there will be supplements on AIDS Knowledge and Attitudes, Immunization, Year 2000 Objectives, and Family Resources. Thus, for the disability survey, it was decided to use a two phase data collection plan with two separate disability questionnaires so that the respondent burden at any one contact would be minimized.

The Phase 1 Disability questionnaire will be administered at the same time as the NHIS CORE, and answered by any available household member who is knowledgeable about the health of the other household members. It will collect basic data on disability and be used as a screening device to determine eligibility for a second phase questionnaire. Eligibility for the second phase will be based on a number of criteria to include individuals experiencing impairments, or those who have made adaptations due to the presence of a health condition. Eligibility for the Phase 2 will be based not only on responses to the Phase 1 Disability Survey, but

also on responses to CORE questions about activity limitation, and questions from the Family Resource Supplement about receipt of disability benefits.

### Questionnaire Development

Questionnaire development for the NHIS-D has involved extensive input from other federal agencies as well as consultants from the research community. Drafts of the questionnaires have been reviewed by an External Panel of Experts from the academic and private research community. Questionnaires continue to be tested in the NCHS Questionnaire Design Research Laboratory where individuals are solicited to test questionnaire drafts.

Although the NHIS-D includes all ages, the federal agency interested in children represented a broader perspective on disability than the other agencies. In addition to impairments, their interest included children with chronic illness or special health needs. These areas are much more difficult to define in children than in adults because developmental milestones are age specific and have a wide range of what can be considered "normal" development. For example, a ten year old child needing assistance with toileting has an impairment, but for a three year old child, assistance with toileting is normal. In order to examine these issues, in the Phase 1 questionnaire, there are three separate sections for children: a section on Special Health Needs of Children, a section on special education services

for children, and a section on Early Childhood Development for children under 5 years of age. The Phase 1 NHIS Disability questionnaire will include the following topic areas:

- Impairments (Sensory, Communication, Mobility)
- List of Conditions
- Activities of Daily Living
- Functional Limitations
- Mental Health
- Services and Benefits
- Special Health Needs of Children
- Early Child Development
- Education/Self-perceived Disability

For the children in Phase 2, additional information was needed on utilization and need for services, functional assessment, including emotional and behavioral development, and the impact of the child's disability on the family. Since this information differs from that which is needed about adults in Phase 2, two separate Phase 2 questionnaires were developed, one for children and one for adults. In the Phase 2 children's questionnaire, the respondent will be the parent or the adult in the household who knows the most about the child's health. For children there is a need to collect normative data for comparison. For this reason the Phase 2 questionnaire will also be administered to a control group of about 5,000 children.

For adults, the Phase 2 questionnaire will obtain more extensive information about the person with disabilities on issues such as employment, use of services and benefits, transportation needs, housing characteristics, environmental

barriers, and participation in social activities. The respondent for the Phase 2 Adult questionnaire will be the individual defined from the Phase 1 interview. If the individual is physically or mentally unable to respond for him/herself, a proxy respondent would be accepted.

#### Sampling

The annual NHIS uses a multi-stage probability design which permits the continuous sampling of households. It includes an oversampling of African-American and Hispanic populations. Because of the low frequency of occurrence of disabilities within the noninstitutionalized civilian population, the NHIS-D will be fielded over a two year period with a sample enhancement of persons with disabilities from the Social Security Beneficiary rosters.

Another special feature of the NHIS-D is that Phase 1 will utilize CAPI, Computer Assisted Personal Interviewing. The Bureau of Census interviewers, who conduct the NHIS, have used CAPI successfully in previous NHIS supplements.<sup>4</sup> The use of CAPI reduces interviewer error, and, for the NHIS-D, it will facilitate the selection of sample persons for the Phase 2 follow-up.

#### Current Status

In September a two phase pretest of several hundred households will be conducted using CAPI in the Washington, D. C. area. With the cooperation of local organizations, we intend to seed the sample with their

members to insure an adequate test of both phases. Once the pretest data are evaluated, modifications will be made to the questionnaires and, if necessary, some ODRL testing will be conducted before the main field survey begins in 1993.

### Analysis Plans

An analytic plan is being developed by NCHS to assist researchers in their use of this complex dataset. Analyses will be done by NCHS staff, as well as by staff in collaborating federal agencies and private research organizations. A public use data tape will be produced one year after data collection is completed.

### Summary

In 1993-94, the National Center for Health Statistics will conduct, as apart of the National Health Interview Survey, a national survey on disability. This survey aims to collect data on a wide range of issues relating to disability from persons of all ages. The National Health Interview Survey on Disability is not limited to any one definition of disability. This will allow for a wider use of the data because researchers

from various programs will be able to select and combine data items to meet their program needs. It is hoped that the NHIS Survey on Disability will make a major contribution towards further understanding disability in the United States.

### References

- <sup>1,2</sup>Institute of Medicine (U. S.) Committee on a National Agenda for Disability. Disability in America: towards a National Agenda for Prevention. Andrew M. Pope and Alvin R. Tarlov (eds.), Chapter 2, National Academy Press, Washington, D. C. 1991.
- <sup>3</sup>Massey, J. T. Moore, T. F., Parsons, V. L., and Tadors, W. "Design and Estimation for the National Health Interview Survey, 1985-1994." National Center for Health Statistics, Vital and Health Statistics, Series 2, Number 110., 1989.
- <sup>4</sup>Rice, Stewart C. Jr., Wright, Robert A., and Rowe, Ben. "Development of Computer Assisted Personal Interview for the National Health Interview Survey." 1988 Proceedings of the American Statistical Association Section on Survey Research Methods, p. 397-400.