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Integrating Measurements of Disability in Federal Surveys: Seminar Proceedings

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention • National Center for Health Statistics

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Integrating Measurements of Disability in Federal Surveys: Seminar Proceedings

Documents and Committee Reports

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics

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Foreword

Background

In November 2000, a statistical policy seminar, “Integrating Federal Statistical Information and Processes,” was convened by the Federal Committee on Statistical Methodology and hosted by the Council of Professional Associations on Federal Statistics. The seminar, which sought to foster interagency integration of Federal statistical information, provided the Federal statistical community with opportunities to learn about and compare Federal agency practices in a dozen important subject areas of general interest. Disability statistics was one of the subject areas highlighted at the seminar. This publication is the proceedings of session four “Integrating Comparable Measures of Disability in Federal Surveys.” Part 1 of this report contains four papers that were presented at session four. These papers describe the ongoing efforts of four different Federal statistical agencies to develop and improve methods for counting people with disabilities in their surveys. “Federal Efforts to Develop an Employment Rate for Adults With Disabilities,” the paper presented Thomas Hale describes research at the Bureau of Labor Statistics to produce labor force statistics by disability status from data collected in the Current Population Survey. “Measures of Disability for the National Study of Health and Activity” presented by Susan Kalasunas describes research at the Social Security Administration (SSA) to measure disability in a survey that is designed to help SSA make informed decisions about the future benefit needs of disabled workers. In “Integrating Comparable Measures of Disability in Federal Surveys: The National Center for Health Statistics,” Gerry Hendershot presents an annotated inventory of disability statistics activities at the Center. “Developing the Capacity to Measure Crime Victimization of People With Disabilities,” presented by Michael Rand describes research at the Bureau of Justice Statistics to produce crime

victimization statistics by disability status from data collected in the National Crime Victimization Survey.

Part 2 of this report contains the remarks of two discussants at session four. The formal discussant was Dr. Katherine D. Seelman, who was then Director of the National Institute on Disability and Rehabilitation Research. I was an informal discussant, who made some remarks during the open discussion period at the conclusion of the session.

Acknowledgments

Many thanks to the authors of the four papers and the discussant for participating in session four, and preparing their presentations for this publication. Three of the four papers appear in Federal Committee Statistical Methodology, Number 32, which contains the proceedings of the Seminar on Integrating Federal Statistical Information and Processes. The paper presented by Thomas Hale and the remarks of the two discussants are published here for the first time.

My special thanks to Gerry Hendershot and Paul Placek. Their help was invaluable in organizing this session. This publication would have been impossible without the support of the National Center for Health Statistics. My thanks to Dr. Edward Sondik for permission to publish these proceedings in the Center’s *Vital and Health Statistics* series of reports. Publication in this series assures wide circulation of these proceedings in the health community. However, the views expressed in this publication are solely those of the authors and do not necessarily represent the official views or positions of the National Center for Health Statistics.

Lastly, a warm thank you to Karen Whitaker for formatting and preparing this report for publication.

Abstract

In November 2000, the Federal Committee on Statistical Methodology (FCSM) convened the seminar “Integrating Federal Statistical Information and Practices” to foster a greater awareness of the importance of integrating statistical information issued by different Federal agencies. Disability statistics was one of a dozen cross-cutting subject matter areas that were discussed at the FCSM seminar. This publication contains the proceedings of the session on “Integrating Comparable Measures of Disability In Federal Surveys.” The first part of this publication describes programs that count people with disabilities in surveys of four Federal statistical agencies: the Bureau of Labor Statistics, the Social Security Administration, the National Center for Health Statistics, and the Bureau of Justice Statistics. The second part of this publication contains the remarks of the sessions’ two discussants. They recognize the significant progress made by the four Federal agencies in developing survey disability measures responsive to their own agency needs but conclude that by mandate or purpose of the data collection, the disability measures differ significantly between agencies and interagency integration of disability statistics will be difficult. The discussants propose research and funding strategies to improve disability measurement integration among Federal statistical agencies.

Keywords: disability measurement • interagency coordination • missions of Federal statistical agencies • survey standards for disability measurement

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Prevention
April 30, 2002

**Part 1. Disability Survey Papers Presented at the Federal Committee on
Statistical Methodology Statistical Policy Seminar**

Federal Efforts to Develop an Employment Rate for Adults With Disabilities

by Thomas Hale, Ph.D., U.S. Bureau of Labor Statistics

Subsequent to signing the Americans With Disabilities Act (ADA), and the publication of the implementing regulations, there has been a strong interest in measuring the labor-force status of people with disabilities. Other protected classes are already identified in labor-force data. This discussion will detail some of the efforts of the Federal Government to meet the need for employment statistics for the disability population.

The official source of labor-force measures such as employment and unemployment is the Current Population Survey (CPS), sponsored by the U.S. Bureau of Labor Statistics (BLS) of the Department of Labor. The CPS is a monthly household survey of 50,000 households or about 100,000 people. BLS maintains tens of thousands of time series based on the CPS, and there are potentially many more estimates that could be created by combining various demographic and labor force variables. While other surveys such as the Survey of Income and Program Participation (SIPP) and the National Health Interview Survey (NHIS) contain employment questions, the CPS is the official source of employment data. The concepts, reference period, and essential survey conditions of the other surveys are sufficiently different from that of the CPS so that the other surveys are not effective substitutes for the CPS. Also, the CPS is the official source of labor-force data for other protected classes (e.g., blacks, Hispanics, women, and people age 40 and over), so it would be desirable to collect labor force data for people with disabilities on the same basis.

In its current form, the CPS contains two sets of questions that

appear to allow it to identify persons with disabilities. The March Work Experience and Income Supplement of the CPS has a question that asks if people have a health problem or disability that makes them unable to work or limits the type or amount of work they can do. It may seem on the face of it, that those who respond positively to this question plus those who report income from a disability program (another set of questions in the March supplement) represent the disability population. The CPS disability question, however, was designed to be a screener for the income questions. The question focuses solely on the work aspect of disability, ignoring all other possible facets, of which there are many. There isn't any evidence it effectively identifies the broader disability population. In the main portion of the CPS, there is also a question on disability, and this question does an even worse job of identifying persons with disabilities, especially if one wants to be able to compute employment and unemployment rates. In the monthly CPS, respondents are asked if they did any work for pay or profit in the preceding week. One of the response categories is "disabled." It is only recorded if the respondent offers it as his/her explanation for NOT working. No one is asked if they have a disability, whether or not they reported working. Also, there are no probes to determine whether this is a long-lasting condition, a temporary one, or merely a bad cold. Indeed, the response category is only provided to help streamline the interview for those who are not working. Also, some respondents may say they have a disability and later in the interview report that they did in fact

work or look for a job during the reference week. In that case, their disability response is edited out of the file—erased—because, in the context of the CPS and data derived from it, labor force activity takes precedence over nonlabor force status and, hence, a response of disabled is viewed as inconsistent with working or looking for work. As a result, the only people for whom the response category "disabled" remains on the file are those who are classified as not in the labor force, that is, persons who neither worked nor looked for work. Hence, the CPS was not designed to measure disability status directly, and there is no accurate way to derive data on the employment status of the disabled from the CPS.

BLS was approached in 1996 by the President's Committee on the Employment of People with Disabilities and several other organizations and asked to collect and publish disability labor force statistics from the CPS. BLS thought the need for disability employment data was quite legitimate and decided to try an experiment to see if it was possible to meet the need, within certain constraints, using the CPS. The chief constraint was that the collection of disability data did not interfere with the primary mission of the CPS—to gather data on the employed, unemployed, and those not in the labor force. Any disability questions would be added to the demographic variables already on the survey, such as sex, age, race, and education. BLS did not think it would be appropriate to define disability in terms of the ability to work, since this might influence the way respondents answered the questions relating to employment status (if the disability questions were to precede the labor force questions). In addition, a work definition of disability is viewed as being overly restrictive, and there is an inherent circularity to defining disability in this way and then cross tabulating disability status with employment status.

BLS planned a test that took the purpose and the time and space constraints of the CPS into account.

Two questions were drafted and a plan was set to place the two questions in the 1996 Wave 4 of the SIPP. They would be administered to the same individuals (or their proxy respondents) who were to be administered a long SIPP disability battery in a later wave. The two questions were:

1. This question concerns common daily activities such as seeing, hearing, walking, climbing stairs, driving a car, or going out to shop for groceries.

Does . . . have a LONG-TERM physical or mental condition that makes it difficult to perform any of these kinds of activities?

Yes

Yes—sometimes

No (go to next section)

The field representative instruction said: By “LONG-TERM” we mean any condition expected to last at least 6 months. Mark the second category if the respondent volunteers that the condition “sometimes” affects activities.

2. Does . . .’s condition SUBSTANTIALLY LIMIT . . .’s ability to perform any common daily activities; again, I am talking about seeing, hearing, walking, climbing stairs, driving, shopping or other everyday activities?

Yes

Yes—sometimes

No

Included was a field representative note which stated: “By ‘SUBSTANTIALLY LIMIT’ we mean the person has great difficulty performing the activity, needs someone’s help to perform the activity, or is unable to perform the activity.”

The limitations cited in the questions correspond well to those in both the SIPP and the ADA. In fact, the SIPP was a particularly appropriate survey in which to conduct the test because several of the terms in these questions were already operationalized

in the SIPP, and the concepts in the two classification schemes (the test questions and the regular SIPP) were parallel. For example, many of the activities that are asked about in the group format of the test questions (i.e., seeing, hearing, walking, climbing stairs, driving, shopping, or other everyday activities) are asked as separate questions in the SIPP disability battery. Many of the SIPP questions have two parts, used in the classification scheme to differentiate between those with moderate and severe disabilities. Once a person says that they have difficulty performing a task, the next question probes if the person is able to perform the task with the assistance of others or unable to perform the task at all. Thus, in SIPP and in the test questions, the algorithm is such that if a person has difficulty with a task, they would be classified as having a moderate disability, and if they needed help or were unable to perform the task, they would be classified as having a severe disability.

As indicated above, the object of the test was to determine if the short questions could identify the same individuals as the longer battery of questions. It would also allow BLS to determine if the test questions could separate disabled individuals into two groups—those with moderate and severe disabilities.

The 1996 Panel, Wave 4 of the SIPP was asked the two short classification questions (above), and then, three months later, the full SIPP was administered to the same individuals. The test results were far from satisfactory.

The table indicates that the test questions identified about 95 percent of

the people that the full SIPP identified as having no limitation, and 63 percent of those that the full SIPP identified as having a severe limitation, but only 8 percent of those with a moderate disability.

At this time, an ad hoc group, consisting of representatives from BLS, the President’s Committee on the Employment of People with Disabilities, the Department of Labor’s Assistant Secretary for Policy, the U.S. Census Bureau, the National Center for Health Statistics, the National Institute on Disability and Rehabilitation Research, and the University of California—San Francisco’s Center for Disability Statistics assembled to analyze the data from the SIPP and the test questions. Several different algorithms were used to define disability to see if that explained the differences between two groups, without success. The data were checked and errors were ruled out.

On March 17, 1998, President Clinton signed Executive Order 13078, which established the Presidential Task Force on the Employment of Adults with Disabilities. The Task Force, chaired by Alexis Herman and Tony Coehlo, with Becky Ogle as Executive Director, is responsible for coordinating several mandates identified in the Executive order. One directs: “The Bureau of Labor Statistics of the Department of Labor and the Census Bureau of the Department of Commerce, in cooperation with the Departments of Education and Health and Human Services, the National Council on Disability, and the President’s Committee on the Employment of People with Disabilities shall design and implement a statistically reliable and

Table 1. Percent comparison of test question responses to Survey of Income and Program Participation responses

Disability type	NHIS	NHANES	LSOA	NNHS	NHHCS	NMFS
Seeing	✓	✓	✓	✓	✓	
Hearing	✓	✓	✓	✓	✓	
Speaking	✓					
Moving/mobility	✓	✓	✓			✓
Body movements	✓	✓	✓	✓	✓	✓
Gripping/holding	✓	✓	✓			
Learning	✓	✓	✓			✓
Behavioral problems	✓	✓	✓			✓
Personal care	✓	✓	✓	✓	✓	✓

accurate method to measure the employment rate of adults with disabilities as soon as possible . . ." In response, the Task Force established the Employment Rate Measurement Methodology (ERMM) Work Group, and appointed Philip Rones, Assistant Commissioner Current Employment Analysis in BLS to its chair.

The Work Group consists of about 17 Federal agencies. The initial meetings took up issues such as the purpose and need for collecting data and the concept of disability given the definitions in the Executive order. The Executive order defines disability in terms of the first prong of the definition in the Americans With Disabilities Act (ADA): "An adult with a disability is a person with a physical or mental impairment that substantially limits at least one major life activity." The Work Group spent some time exploring the implications of various disability definitions and the related need by the agencies for specific types of employment data. The meetings later evolved into discussions of methodological issues.

At this time, confidence in the SIPP was severely shaken when Jack McNeil, the disability expert at the U.S. Census Bureau, indicated that the test questions placed in the SIPP might not be so bad, and that perhaps a large part of the problem lies with the SIPP itself. He soon produced the data to prove his point. **Table 2** shows the percent of people who reported having a severe disability in time 1 (October 1993–January 1994) and still reporting a severe disability a year later, in time 2 (October 1994–January 1995).

Table 2. Percent of individuals who reported having a severe disability in time 1 and time 2

Disability	Percent
Work disability	78.6
Using wheelchair	61.7
Speaking	38.3
Seeing	25.2
Hearing	20.7
Walking	47.6
Handling money	49.1

SOURCE: Survey of Income and Program Participation. U.S. Census Bureau.

Census double-checked the data, and also determined that the reliability problem was not a function of self/proxy responses. No satisfactory explanation for this phenomenon has been advanced. Importantly for our research effort, the SIPP could no longer be considered a gold standard against which we could evaluate other question sets.

The Work Group and BLS have settled on a strategy for generating the disability classification questions. First, an annotated bibliography of disability survey instruments was compiled to determine what survey questions were available, and what research had been conducted on their accuracy and reliability. Specifically, the bibliographer was interested in cognitive interviews and field tests, or data on the properties of the questions generated through other means. This work revealed a paucity of research on existing instruments. We were only able to obtain a report on cognitive work for the Census 2000 questions, and that report indicated that only four of the six questions were tested. The report also indicated that, where problems were found and corrected, the corrected versions were not tested before they were fielded in the dress rehearsal. The Work Group did receive some promising data from the World Health Organization (WHO) on the psychometric properties of its Disability Assessment Schedule (DAS) questions. Also, the definition of disability underlying the WHO questions is consistent with that given in the Executive order.

Originally, the Work Group and BLS planned to identify question sets that were available, and build on whatever existing research had been conducted to the point where the questions would have known reliability and accuracy characteristics. Once satisfied with the characteristics, the questions could be placed in the CPS. Unfortunately, our research indicated the effort would have to start largely from scratch since there appeared to be serious problems with the questions that were currently available.

A good case in point is what happened with the Census 2000 questions from the dress rehearsal,

administered in California and South Carolina. The last two questions inquire if, because of a physical, mental, or emotional condition, the respondent has any difficulty: (1) Going outside to shop or go to a doctor's office, or (2) Working at a job or business. The data show that people who responded "yes" to both of these questions were employed at a higher rate than those who reported having no difficulty. Such a counterintuitive finding indicated the questions failed to do what they were designed to do—identify the disability population.

This caused the Work Group and BLS to reconsider its research plan. The original plan called for testing existing question sets. What was the point of testing question sets that did not work? Besides, any disability questions we selected for further testing would have to be modified to fit the context of the test and the vehicle's essential survey conditions, and eventually, the CPS. Therefore, the research plan evolved to testing individual questions themselves, rather than question sets. This greatly enhanced the flexibility of the research effort in two ways. First, it increased the number and types of questions BLS could test, including modifications to wording for a given question. Second, based on the data, a new question set that had the desirable properties could be constructed from the test questions. The reformulated research plan requires the Work Group to identify a set of questions, conduct cognitive tests, and to test the questions in an existing survey instrument.

The effort to identify disability questions focused on surveys such as the SIPP, NHIS, the National Organization for Disability's NOD/Harris Poll, and others. The object was to identify the minimum set of questions that were responsible for classifying the bulk of the people the survey identified as having a disability. For example, the NOD/Harris Poll had a question "Do you consider yourself to have a disability?" This question was responsible for capturing 87 percent of the individuals that all six of its classification questions identified as having a disability. The SIPP required more than eight questions to identify a

majority of its disability population, and the NHIS had about 80 classification questions to do its job. Both these sets were determined to be too large to be included in the CPS, and thus were excluded from the proposed test.

The importance of Census 2000 in the statistical system led BLS to include them in the test after modifying and testing them as questions, but again, not as a set. It might have been that in a self-administered format as that used in the census, the respondent did not keep the connection with the root of the question—they answered as though they thought the last question was “Do you work at a job or business” rather than “do you have any difficulty working at a job or business.” That hypothesis would be consistent with the high employment rate of people who ostensibly were reporting difficulty working because of a physical or mental condition. A face-to-face or telephone interview with a trained interviewer might correct this problem.

The data reduction method described above delivered about 20 questions for testing. The next two phases of the research plan are to conduct cognitive tests of the questions and to place the questions in an existing survey.

Twenty cognitive interviews are planned for the questions. The interviews are designed to achieve two broad goals. The first is to see what and how respondents think about the question content—if the questions include good examples of activities one might be limited in, if respondents would identify people who they think have disabilities, and if the questions contain language that makes them difficult to understand or otherwise respond to. The second goal is to learn what respondents think of when they hear and use certain terms that are key to the questions. These terms include disability, impairment, conditions, and health problems. The cognitive interviews will be conducted in three waves between October 23 and November 3, 2000. After the first and second wave, researchers will have the opportunity to modify the language and submit the modified question to the next round of cognitive interviews.

Hopefully, by the last round, the questions will be a close-to-finished product.

The next phase is to place the finished product in the National Comorbidity Survey (NCS), which is in the field between February 2001 and October 2001. (One-third of the data will be available in May.) The NCS has several characteristics that make it particularly attractive as a test vehicle. It is an exhaustive instrument for determining the prevalence of mental disorders. These disorders are among the most difficult to identify in a survey. It also has a number of measures for physical disabilities, such as the Global Assessment Schedule. The interviews in the NCS are face to face, but 10 percent of the households will be reinterviewed to determine the relationship between self- and proxy responses.

Six of the candidate questions come from the WHO DAS II; and as it happens, the NCS has 18 questions from the WHO DAS II, including the 6 that were selected for further testing. The NCS is timely as well, and Ron Kessler, the principal investigator in the NCS, has loaned his extensive research experience in this area to the Work Group effort.

The requirement for accurate and reliable statistics means the data must identify the desired population. There is no purpose to providing data on the wrong population. As difficult a task as this has been, many organizations have supported the ERMM efforts with time and money. In particular, we can thank the Presidential Task Force on the Employment of People with Disabilities for providing strong and critical financial and technical support. Other agencies have provided equally important and strong technical expertise. The agencies and individuals involved have appreciated the need for the research effort and continue their support. If it is possible for a scientific approach to generate accurate and reliable questions, the process they put in place will do so.

Measures of Disability for the National Study of Health and Activity

by Susan Kalasunas, Social Security Administration

For purposes of entitlement to disabled worker's benefits under the Social Security Act, disability is defined as: the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. A person must not only be unable to do his or her previous work but cannot, considering age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy.

1. Introduction

The National Study of Health and Activity (NSHA) is a national survey designed to provide the Social Security Administration (SSA) with information critical to making informed decisions about the future of its programs. It will collect health, employment, income, and social/family data on a nationally representative sample of approximately 5,500 individuals through self-reports, medical examinations, and medical records from health care providers.

While NSHA will provide the greater disability research community with a better understanding of the service needs of Americans with disabilities by providing data on the relationship between disability and other aspects of everyday life, it was designed

with a much more focused mission in mind. The NSHA was initiated in response to the rapid growth of SSA's disability programs in the late 1980s and early 1990s. During the 5 years from 1989 through 1994, the number of Social Security Disability Insurance (SSDI) beneficiaries increased 40 percent (from 2.8 million to almost 4 million) and benefit payments increased 65 percent (from \$23 billion to \$38 billion). Dramatic trends in eligibility were also seen for the Supplemental Security Income (SSI) program during that time. The number of disabled SSI recipients rose from 2.1 million in 1989 to 3.2 million in 1994, an increase of 52 percent. In 1994 in response to an imminent shortfall in the DI Trust Fund, Congress amended the statutory formula for allocating FICA tax revenues between the Old-Age and Survivors Insurance (OASI) and DI Trust Funds. While this change proved to be a remedy in the short term, this situation highlighted the critical need for a source to inform SSA of trends and factors affecting the future of SSA programs—especially the SSDI Program. That source will be NSHA.

2. Design

The NSHA sample will be selected using a multistage, stratified probability sample design. At the first stage, a stratified sample of 80 primary sampling units will be selected with probabilities

proportional to size. Within the selected units, households with persons 18 to 69 years of age will be subsampled at rates designed to yield a nationally representative sample of households. Households will be selected using area probability sampling methods. Group homes will be mainly sampled from lists of group homes compiled for selected sampling units.

The second stage involves screening approximately 100,000 households representing the civilian noninstitutionalized population of the United States. Data from this initial screener will be used to classify the respondents into four study groups: persons who receive disability benefits from Social Security, nonbeneficiaries likely to be severely disabled, nonbeneficiaries who are less severely disabled, and nonimpaired/slightly impaired nonbeneficiaries. Following the initial screener, a subsample of screener respondents, 10,000 individuals between the ages of 18 and 69, will be selected to take a comprehensive survey with questions on employment, education, health insurance, income, and program participation.

What makes the NSHA different from most other surveys is that it will not rely solely on self-reports but will provide an opportunity to make direct clinical observations about study participants. From the 10,000 individuals who take the comprehensive survey, 5,500 will be chosen to complete medical examinations. The examinations will take place in a mobile examination center (MEC) specifically constructed for the NSHA and given by an NSHA medical team consisting of a physician, a nurse practitioner, a psychiatric social worker, and a radiological technician. For those who cannot or will not go to the MEC for the examination, at-home examinations will be arranged with a home exam team. The examination has been designed to obtain as much information as possible with the use of a basic examination. In addition, a more detailed examination of a specific system will be completed, if necessary, to address issues identified in the medical history and from the basic exam. The purpose of the exam is to

review reported signs, symptoms, and medical conditions and provide medical observations, tests, and procedures that will document the self-reports of the participants and present some evidence of severity. In addition, participants will be asked to sign consent forms that will allow NSHA to collect 3 years' worth of medical records from all of their health care providers.

The State Disability Determination Services (DDS) examiners make the decision on whether or not an individual meets the disability criteria for the Social Security disability programs. Since NSHA's main purpose is to capture who would or would not qualify for disability benefits under SSA's disability programs, the DDS examiners will be making the determination of disability for NSHA. Information from the comprehensive survey, the results of the NSHA medical examination and the medical records from the participant's health care providers will be compiled into case folders modeled on those developed by the DDS for disability program purposes. The DDS then will make disability determinations based on the Social Security definition in a process that simulates the actual DDS determination process as closely as possible in a research context.

3. The Research Questions

SSA identified four questions with answers critical to the future of the Social Security disability programs:

1. What is the number of people whom, but for work or other reasons, are severely enough impaired to be considered disabled for Social Security purposes?

The primary purpose of NSHA is to examine the population of "eligible nonparticipants." Until the size of this pool of potential eligibles is known, SSA cannot understand the magnitude of possible program growth with which the agency must be prepared to deal. The information that is currently available is based predominantly on

survey data with self-reported health measures. There is no information available in which the Social Security definition of disability has been applied through the current decision process. What is available indicates that at any given time, there are a substantial number of people not on the disability rolls whose impairments are severe enough to meet the SSA definition of disability. If other relevant factors, such as a turndown in the economy or changes in the structure of the labor force, induce these people to apply, the number of applications and awards may surge. The NSHA will provide, through its own, independent medical examination and through application of the SSA disability definition by SSA disability examiners, the numbers and types of people who, but for nonmedical factors, could be eligible for SSA benefits. The key to the future of SSA disability programs lies with those who are severely impaired enough to be eligible for benefits if they lost their jobs or if some other change in their lives occurred. Understanding those individuals will allow SSA to understand the magnitude of and to be prepared to deal with potential program growth. The U.S. economy has been in a sustained period of expansion, and unemployment is at an all-time low. However, should there be a downturn in the economy or changes in the structure of the labor force, the number of applications and awards may very well surge.

In order to determine this pool of potential eligibles, NSHA will combine self-reported information from the comprehensive survey, information from the NSHA medical examination, and medical records from the immediately preceding 3 years to create simulated SSA disability folders for each study subject targeted for the medical evaluation (~ 5,500 people). DDS examiners then will be asked to make disability decisions based on the medical

information in the simulated folders. Those subjects whom the examiners find disabled (disregarding work or other nonmedical reasons for disqualification) for Social Security benefits are those who will be considered disabled for Social Security purposes. These are the individuals who make up the pool of those who are potentially eligible, currently qualified to receive benefits if they lost their jobs, or if some other reason necessitated an application for SSA disability benefits.

Just as important as the number of people currently eligible for Social Security benefits is the number who are "in the pipeline," who might be expected to qualify for disability benefits in the near future due to a progressive condition. These are the people on the cusp of a severe disability who, because they have a progressive degenerative disease or for other reasons, will be eligible for benefits in the foreseeable future. NSHA will estimate the number of these borderline cases by using a prognosis made by the MEC physician, together with an actuarial analysis of the subject's health information. The medical examination also will be used as background for the assessment of the residual functional capacity (RFC). Measures of functional capacity are assessed in the interview section of NSHA prior to being selected to participate in the medical examination. If an individual does not meet the level of disability as defined by the listings for any given condition, the medical information from the examination will be an important consideration in determining the RFC and an important consideration in the process of determining disability classification.

One of the provisions of the Ticket-to-Work and Work Incentives Improvement Act of 1999 is an expanded availability of health care services. The law gave States the option to provide Medicaid coverage to more people with

disabilities who work, created a new Medicaid buy-in demonstration project to provide medical assistance to workers with impairments who are not yet too disabled to work, and extended Medicare coverage for people with disabilities who work. All of these initiatives will be supported by information from NSHA.

2. What enables disabled persons to remain in the workforce?

Part of the growth in SSA disability programs in the late 1980s through the early 1990s occurred because few disabled workers left the programs due to resumption of work activity. For fiscal year 1996, only 6,024 workers referred by SSA were rehabilitated by State vocational rehabilitation agencies. This is a major concern, since a 1997 report by the U.S. General Accounting Office shows that the lifetime savings for each 1 percent of the DI and SSI beneficiaries leaving the rolls is \$3 billion.

To increase the number of disabled individuals who rejoin the labor force, improved return-to-work strategies must be developed. On December 17, 1999, the President signed the Ticket-to-Work and Work Incentives Improvement Act of 1999 (PL 106-170), designed to assure that more Americans with disabilities have the opportunity to participate in the workforce and lessen their dependence on public benefits. A major goal of SSA is to develop ways to encourage people with disabilities to remain in the labor force rather than apply for benefits, and to provide the supports necessary for disability beneficiaries to leave the rolls by returning to work. One objective of the Ticket-to-Work and Work Incentives Improvement Act of 1999 was to ensure that more Americans with disabilities have the opportunity to participate in the workforce and lessen their dependence on public benefits. The NSHA plays an important role with respect to SSA's Ticket-to-Work initiatives.

While the current definition of disability is intended to distinguish that part of the population that is too impaired to work, we know that some severely impaired persons nonetheless continue to work despite their impairment. The NSHA will allow SSA to compare persons with similar impairments who are in and out of the labor force, in order to identify the crucial factors that enable some disabled individuals to work while others with the same impairment do not. An understanding of the accommodations, social supports, and other variables that influence this activity will support employment initiatives designed to encourage beneficiaries to return to work.

Most notably, one of the provisions of the Ticket-to-Work legislation, the \$1-for-\$2 Project, will make NSHA data the basis of its analysis of the induced entry effect of the \$1-for-\$2 benefit offset. The serious design issues and measurement problems inherent in undertaking a demonstration project to measure the induced entry effect of altering program provisions to include a benefit offset has led the \$1-for-\$2 Project to consider an alternative to attempts at direct measurement. The alternative would use data on potential eligibility from NSHA to develop estimates of possible induced entry. In order to make estimates of induced entry and the associated program costs, NSHA will provide the information that will help the \$1-for-\$2 evaluation answer the following critical questions: (1) Who is eligible? (2) Who will be better off under the new program and induced to apply? (3) When will they apply? And, (4) how much will they work while on the program (i.e., what is the amount of the reduced benefit)?

NSHA data also will permit comparisons of individuals with similar impairments who are in and out of the workforce, and will help us to understand the crucial factors that enable some disabled

individuals to remain in the labor-force while others, with the same impairments, do not work. These factors include interventions, accommodations, and social supports. An analysis of the responses from the five sections of the NSHA survey instrument (which asks questions about activities of daily living, access to services, functional limitations, social and community living, and economic resources) will provide significant information about persons who continue to work and how they do so. It is anticipated that this is the NSHA research question that will be of most interest to general researchers in the field of disability and work and will be the focus of significant independent research in all disciplines.

3. What are the effects of planned or possible increases in the retirement age on the disability program?

In order to lower the cost of the Social Security retirement program, and thus safeguard the trust fund, the majority of 1994–1996 Social Security Advisory Council members favored accelerating the legislated change in the eligibility for full retirement benefits to age 67, so that the age of eligibility for full retirement benefits increases to 67 by the year 2011. After 2011, the retirement age would continue rising in line with longevity trends. NSHA will determine what effect such a rise in retirement age will have on the disability program by estimating the number and characteristics of people with disabilities between the ages of 62 and 69 who could receive disability benefits should retirement benefits not be available.

4. How can we cost-effectively monitor future changes in disability?

National surveys are expensive, yet in order to make informed decisions on Federal disability programs and policies, it is vital that the flow of information continues beyond the life of individual studies such as

NSHA. Lack of resources and the realities of changing Federal priorities make the possibility of any one permanent longitudinal study an improbability. If the Federal Government is to be a reliable and consistent source of disability information, it is critical that Federal agencies work together to ensure that continuum.

The last national survey by SSA was conducted 20 years ago. Since then, SSA has had limited information on which to base its policy and program decisions. This was most apparent in the disability trust fund crisis of the mid-1990s, which resulted in emergency measures by Congress and negative public perceptions of SSA's program management abilities. In order to avoid such situations in the future, SSA needs a better source of disability information.

SSA cannot afford to run a full-fledged NSHA every few years, but a reasonable alternative would be to have an inexpensive tracking system, which could monitor changes in the prevalence and incidence of disability in the population. During the NSHA analysis, we will identify those survey items that provide the most reliable responses to our key questions. We will then be able to include those items in other disability studies and collect limited but vital and accurate information on an on-going basis, which will enable us to detect change in the prevalence and incidence of disability in the U.S. working-age population.

4. Integrating Comparable Measures of Disability Federal Surveys

As NSHA's fourth research question illustrates, it is sometimes possible and desirable to integrate

comparable measures of disability in Federal surveys. NSHA uses survey questions from a variety of sources, including the census, the National Health Interview Survey, and the Occupational Information Network, and NSHA data will be used for analysis beyond that necessary for Social Security program administration. An obstacle to comparability are the diverse number of definitions of disability used by various Federal agencies. For example, SSA's definition is based on work and the effects of disability on an individual's capacity to work. Although this definition constitutes a difference between SSA and the major foci of other Federal agencies, employment and the effects of disability on employability are of definite concern to the Departments of Labor, Education, Health and Human Services, and the Veterans Administration. The challenge to create effective ways to crosswalk between the surveys specifically designed for various agencies is a considerable one but should be pursued expeditiously. The major question about this endeavor is whether we can attain a meaningful and efficient crosswalk between survey databases while at the same time meet the specific program needs of each Federal program.

The primary purpose of NSHA is to provide the information necessary to make the critical decisions about the future of SSA disability programs, information that is not available anywhere else. Who would apply and receive benefits if the economy changes? Who will be applying for benefits next year, and the following year, and the following year, and why? What will it take to get people with disabilities into the workforce? Through NSHA, SSA will find some answers to these important questions.

The NSHA also will provide information necessary to implement more immediate, legislatively mandated Social Security provisions, such as the Ticket-

to-Work and Work Incentives Improvement Act. This includes the \$1-for-\$2 Demonstration Project, the initiative to expand availability of health care services through Medicaid and Medicare, the Work Incentives Advisory Panel, and the Work Incentives Outreach Program. The researchers of SSA's Disability Research Institute (DRI) will also use the results of NSHA. The mission of the DRI is to plan and conduct a broad range of research that will facilitate development of disability policy information to assist policymakers and the public in understanding disability issues as they relate to programs under the Social Security Act and people with disabilities. The NSHA will provide much of the raw data which will highlight needs for focused research.

Beyond this primary goal to provide data to inform Social Security disability policy, however, NSHA also will provide an extensive database for disability researchers. The disability research community currently has no primary data source on which to base its research. The National Health Interview Survey Supplement on Disability, conducted from 1994 to 1995 by the National Center for Health Statistics, was the last national disability survey and its 5-year-old data are now dated. The NSHA will fill that gap and serve as the definitive source for information on the disabled population of the United States. It will also provide the foundation for disability research for years to come.

While such an effort would be a challenge, attaining some degree of comparability in measures of disability in Federal surveys that examine the needs, services, and outcomes of programs for people with disabilities would be a valuable endeavor. The database derived from such measures would provide a comprehensive repository of data, helping to develop a consistent definition of disability

and the variables associated with it. This database, being national in scope, would provide researchers through the world with the means to develop a multidimensional image of disability.

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Integrating Comparable Measures of Disability in Federal Surveys: The National Center for Health Statistics

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I. Introduction: Elements of a Program for Integrating Disability Measures

This session is a milestone of sorts. Those of us in the disability statistics community have long recognized and worked toward the integration of disability measures. The Interagency Subcommittee on Disability Statistics, for instance, has been meeting monthly for 25 years. That any Government committee should last so long is a bureaucratic miracle of no small magnitude. It is especially miraculous in the case of this committee, which only recently began to receive some paid staff support. It has survived on the determination and dedication of its members, with little recognition from the larger statistical community. In this session, however, we pass a milestone, because the larger Federal statistical community *is* taking note of an important issue in disability statistics—the integration of survey measures of disability. A milestone, however, does not mark the end of the journey, nor does one session yield integrated disability survey measures. To achieve that requires, on a larger scale, the same determination and dedication demonstrated by the Interagency Committee on Disability Statistics. To sustain the effort, a plan or program is required. Toward that end, I would like to suggest some elements that should be included in a program for integrating

disability measures in Federal surveys.

The new paradigm of disability—Efforts to integrate disability measures must be consistent with the new paradigm of disability that is now emerging. In the paradigm of disability that dominated discussion until recently, disability was understood to be like disease, a deficit in the individual person that should be addressed by medical interventions. In the new paradigm, disability is understood to be like discrimination, a deficit in person-community relationships that should be addressed by social interventions. Under the old paradigm, the goal was to prevent, cure, or ameliorate disability. Under the new paradigm, the goal is to facilitate the full participation of persons with disability. Existing survey measures of disability were developed under the old paradigm, so the paradigm shift has major implications for integrating disability measures. This is recognized in the long-range plan of the National Institute for Disability and Rehabilitation Research, which says:

The new paradigm has significant implications for NIDRR's research agenda during the next decade. Examples include . . . new approaches for measuring and counting disability, including changes in the methods for conducting demographic studies and national surveys to reflect new definitions or concepts . . .

A common disability nomenclature—The language used to discuss disability has been various and variable. One person's "impairment" is another person's "disability," and yet another

person's "functional loss." Terms that were once respectable are now forbidden, such as "handicap." In the U.S. it is considered offensive to say "disabled person," but in the U.K., it is *de rigueur*. The resulting Babel has hindered disability research, including integration of survey measures of disability.

Fortunately, there is a developing consensus on some nomenclature, best captured in the new version of the *International Classification of Impairments, Disabilities, and Health* (ICIDH-2) (1). The classification recognizes three constructs: body functions and structure, personal activity, and societal participation. The construct labels are value neutral, but their negative aspects are labeled, respectively, impairments, activity limitations, and participation restrictions. The ICIDH-2 framework also includes a list of environmental factors that facilitate or hinder participation, activity, and function. The ICIDH-2 nomenclature is consistent with the new paradigm and is accompanied by a detailed classification system for the three dimensions of disability. Its early adoption as a standard would facilitate integration of survey measures.

An international outlook—The ICIDH-2 is only one example of international efforts to reconceptualize and harmonize disability measures. Others include the work of the European Health Expectancy Network (Euro-REVES), which has assembled and examined the health and disability questions from many European surveys and made recommendations for standard questions. Also relevant is WHO's development of survey questions on disability that are consistent with ICIDH-2, some of which it proposes be included in standard national health status surveys. Finally, the United Nations Statistical Division is preparing a manual on disability surveys and censuses that recommends disability questions. U.S. efforts at integrating survey measurement of disability should be at least aware of, and preferably consistent with, these international efforts.

Standards for collecting and reporting disability data—The promulgation of official standards for collecting and reporting data by authoritative government agencies or professional associations can be a strong force toward integration. Witness the effects of the Office of Management and Budget's Directive 15 on collecting and reporting data on race and ethnicity. Even when official standards are not backed up by penalties or incentives, they help the consensus-building process move forward. To be effective, of course, proposals for new standards must be supported by research findings and convincing argument. In the field of disability statistics, the time may be right for proposing standards that would require or recommend in all on-going surveys sponsored by the Government (1) the routine collection of simple disability measures, and (2) the adoption of survey procedures that facilitate participation in surveys by respondents with disabilities. With regard to (1), a substantial step forward was made with publication of *Healthy People 2010* (2) in January 2000, because it includes as a national health objective the placement of disability questions in all statistical systems that track progress toward the national health objectives.

An organizational framework—Those who are interested in working toward the integration of survey measures in Federal surveys need an organizational framework within which to work. That framework must, of course, be interdepartmental because many departments of Government conduct surveys that include, or should include, questions on disability. Some elements of an organizational framework exist, including the ad hoc Workgroup on Employment Rates for Persons with Disabilities of the Presidential Task Force on Employment of Adults, and the Interagency Subcommittee on Disability Statistics of the Interdepartmental Committee on Disability Research. Informal links already exist among interested staff at many agencies. Those links need to be extended to other agencies and to be recognized and supported at higher levels of management.

Commitment by individual agencies—Those agencies whose missions include disability statistics as a major component have a responsibility to lead by example in efforts to integrate survey measures of disability. They can do so by participating in those efforts, first with regard to their own surveys and survey-related activities, and second with regard to interagency initiatives in this area. Because the mission of the National Center for Health Statistics (NCHS) does include disability statistics as a major component, it is appropriate to ask what it is doing to further the integration of disability survey measures. This paper is an attempt to answer that question by first reviewing disability statistics activities at NCHS and then presenting an analysis of disability questions in six NCHS data systems to identify opportunities for greater integration of disability statistics.

II. Inventory of Disability Statistics Activities at the National Center for Health Statistics

The following pages comprise a selective inventory of disability statistics activities at the National Center for Health Statistics (NCHS). Two criteria were used to select activities for inclusion. First, the activities selected for this report are those that bear most directly on integrating survey measures of disability, namely, activities that involve setting standards for disability survey data and activities that involve the ongoing or recurring collection of disability survey data. That omits activities in data analysis and dissemination, some of which demonstrate substantial progress in interagency cooperation. For instance, NCHS was a charter member of two interagency forums, the Federal Interagency Forum on Aging Statistics and the Federal Interagency Forum on Child and Family Statistics, both of which have recently published annual

reports that highlight disability survey statistics.

Second, only activities that are ongoing or recurring were included. NCHS was launched in 1960 and some of its data systems began even before that. Over its long history, NCHS has made many contributions to the field of disability statistics. Those activities, however, are either reported elsewhere or not relevant to integrating disability statistics in Federal surveys today. Similarly, NCHS has plans at various stages of development for future activities in disability statistics, some of which may have important implications for integrating disability statistics.

The activities selected for inclusion in the inventory have been arranged in sections by organizational unit within NCHS, with each section introduced by a brief overview of unit functions. This arrangement of the inventory should help readers who want to follow-up on an activity by identifying the staff unit directly involved in that activity. It also reflects the decentralized nature of many disability activities at NCHS. As in many Federal agencies, activities related to emerging issues with crosscutting features sometimes arise in different parts of the organization and only later become integrated.

Office of the Center Director (OCD)

Among the functions of the Office of the Center Director, the top management unit in the Center, are (1) to plan, direct, administer, coordinate and evaluate the vital, health, and health-related statistics programs of the Center; (2) to stimulate basic and applied research and developmental activities; and (3) to provide national and international leadership in vital and health statistics and epidemiology. In exercising those functions, the Office has initiated a program of Centers for Excellence in Health Statistics.

In 1999, three Centers for Excellence in Health Statistics were funded by NCHS for the purpose of improving data collection systems to help develop and evaluate prevention programs. Current projects include

addressing statistical issues aimed at (1) health promotion and disease prevention in high-risk populations; (2) developing methodology that can be applied to issues such as the effects of smoking on public health and on racial disparities in health status and outcomes; and (3) addressing issues central to the field of survey research—cognition, technology, and nonresponse. The last issue is being addressed by the Michigan Center for Excellence in Health Statistics at the University of Michigan's Survey Research Center. James Lepkowski (principal investigator) leads the Center for Excellence, which also includes Robert Groves, Michael Couper, Nancy Mathiowetz, and others.

One project of the new Center, headed by Nancy Mathiowetz, is studying the effect of questionnaire context on responses to disability survey questions. The study was prompted by the observation that different surveys often yield different estimates of disability statistics even when they are based on similar disability questions. While many factors may contribute to such differences, the Michigan researchers hypothesize that differences in the context of disability questions, primarily differences in the questions that precede the key questions, are an important cause of differences in responses. To test and specify that hypothesis, they have designed a study in which key disability questions are asked in different contexts in the same survey, using a split sample technique. The test uses a national random-digit-dial-telephone survey as its vehicle.

The test of context effects is viewed by the research team as one of several survey methodological issues that must be investigated, such as difference in data collection mode and self versus proxy reporting, in the course of developing valid, reliable, and standardized disability modules for use in a wide range of Government surveys.

Cognitive Methods Staff, Office of Research and Methodology (ORM)

The Cognitive Methods Staff conducts basic and applied research on

the cognitive aspects of the survey response process in order to improve the efficiency and quality of the Center's data systems. It also develops and tests survey data collection instruments using cognitive laboratory methods and related questionnaire evaluation methods and conducts a program of reimbursable applied and basic research, technical assistance, and consultation on cognitive aspects of survey methods.

In June 1997, the Cognitive Methods Staff organized the Second Advanced Research Seminar on the Cognitive Aspects of Survey Methodology (CASM II Seminar). The Seminar was sponsored by the National Center for Health Statistics and the National Science Foundation, with support of several Federal statistical agencies. About 50 researchers and survey methodologists representing a broad range of scientific disciplines attended the CASM II Seminar. The Seminar assessed the contributions of the CASM movement since its inception at the CASM I Seminar in June 1984 and sketched a roadmap for fostering interdisciplinary survey methods research into the 21st century.

Among the topics on the agenda of the Seminar was the measurement of disability. A working group on that topic submitted a report identifying several areas for future cognitive research on disability surveys: the wording of disability questions, the effects of the survey context on responses to disability questions, differences in answers given by self- and proxy respondents, and mode of data collection (such telephone, mail, face-to-face). Part of this program of research is being realized at the Michigan Center for Excellence in Health Statistics described in the preceding section.

The Cognitive Methods Staff continues its interest in disability surveys. It has conducted laboratory research on administering disability questions to deaf respondents by means of a Telephone Device for the Deaf (TDD) and on the effects of variations in question wording on reports of vision impairments by persons with vision impairments. It has also performed cognitive testing on disability questions developed by CDC for use in the

Behavioral Risk Factors Surveillance System.

Office of Analysis, Epidemiology, and Health Promotion (OAEHP)

OAEHP has responsibility for a wide range of activities that are perhaps best characterized collectively as analysis of health data from multiple data systems. Each of the Center's main data production divisions—Vital Statistics, Health Interview Statistics, Health Care Statistics, and Health Examination Statistics—operates one or a few data collection systems and analyzes and disseminates data from those systems. In contrast, OAEHP typically uses data from many data systems operated by NCHS and other agencies to analyze and disseminate data on selected topics or for selected purposes.

Some OAEHP activities relate to ongoing or recurring data reports, such as the annual report on Health, United States and the periodic tracking reports on the National Health Objectives, now Healthy People 2010. Other of its activities are more *ad hoc* and topically focused, but involve the linking of data across agencies, such as the Longitudinal Study of Aging. This report focuses on two OAEHP projects that have special importance to the integration of survey measures of disability: Healthy People 2010 and the Longitudinal Study of Aging.

Healthy People 2010—In 1980 and 1990 the Department of Health and Human Services (DHHS) published health promotion and disease prevention objectives for the Nation (*Healthy People 1990* and *Healthy People 2000*). The objectives were developed in consensus processes involving hundreds of organizations and individuals in the Government and private sectors all across the country. In January 2000, DHHS launched the third in this series, *Healthy People 2010*, a comprehensive, nationwide health promotion and disease prevention agenda. *Healthy People 2010* contains nearly 500 specific objectives designed to serve as a road map for

improving the health of all people in the United States during the first decade of the 21st century.

Two overarching goals—increase quality and years of healthy life and eliminate health disparities—served as a guide for developing objectives that will actually measure progress. The objectives are organized in 28 focus areas, each representing an important public health area. Each objective has a statistical target for improvements to be achieved by the year 2010. For most targets, data sources already exist for measuring baseline levels and tracking progress. For some objectives, however, data sources have yet to be developed.

NCHS is responsible for coordinating the effort to monitor the Nation's progress toward the objectives, using data from many data sources. National data are gathered from more than 150 different data sources, including seven Federal Government Departments and voluntary and private organizations. Data are made available through DATA2010, an interactive database system accessible through the NCHS Web site at www.cdc.gov/nchs.

Because these objectives are national, not solely Federal, their achievement is dependent in part on the ability of health agencies at many levels of Government and on nongovernmental organizations to assess objective progress. Therefore, NCHS is preparing a document entitled *Tracking Healthy People 2010* that will be published in November 2000 and that includes technical information on how the data are derived and the major statistical issues.

One of the 28 focus areas in *Healthy People 2010* is Disability and Secondary Conditions, the overall goal for which is to “Promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the U.S. population.” Thirteen specific objectives for 2010 are included in the disability area, the most important of which, for purposes of this report, is the first:

Include in the core of all relevant Healthy People 2010 surveillance instruments a standardized set of

questions that identify ‘people with disabilities.’ ”

In a draft of *Tracking Healthy People 2010*, the NCHS document that specifies measures of objectives, it is proposed that this objective be measured by the percent of all relevant surveillance instruments that have adopted a standardized set of disability questions. The baseline estimate of that measure for 1999 is given as 0 (zero). In a comment on the proposed measure, the document reports:

No standardized set of questions that identify people with disability currently exists. . . . CDC has proposed that a standardized set of questions on disability be developed. As standard questions are adopted by the data systems, the data produced from them will be incorporated into the Healthy People 2010 objectives that specifically identify people with disabilities. This presents the opportunity in the future to have a standard definition of people with disabilities that can be used across data systems and geographic levels.

That a major national program such as Healthy People 2010 should include a proposal to standardize disability questions in many of the data systems it uses to track progress toward scores of its individual objectives is a major step toward standardization of disability measurement in the Federal statistical system. Another aspect of Healthy People 2010 that may also be a major step toward standardization is its overarching goal of increasing the quality and years of healthy life of the American people. Progress toward that goal is to be measured by one or more summary measures of population health.

A summary measure of population health uses one or more measures of population health and the demographic composition of the population to create a composite measure that expresses the health of the national population (or a subpopulation) in a single statistic. For *Healthy People 2000* the summary measure of population health combined data on mortality, activity limitation, and self-assessed health (excellent, very

good, good, fair, and poor) and the demographic composition of the population.

The World Health Organization is now promoting use of a summary measure of population health as an important component of its recommended approach to evaluating health care systems and setting health care policy. Its recommended summary measure of population health is Disability Adjusted Life Expectancy or DALE. This measure uses data on mortality rates and disability prevalence along with valuations of life lived with a disability to calculate a single statistic for a national population (or subpopulation) that expresses its overall health status.

The DALE is one of a set of summary measures of population health that use the “Sullivan method” first developed by Francis Sullivan at NCHS in the 1960s. The measures differ in their conceptual and measurement approaches to disability and in the valuations they assign to life lived with a disability. WHO uses the new version of its International Classification of Impairments, Disabilities, and Handicaps (ICIDH-2) as the conceptual framework and classification scheme for the disability component of the DALE.

In fulfilling its responsibility to track progress toward the Healthy People 2010 objectives, NCHS has adopted a pluralistic and methodological strategy. Rather than select any one of the several currently available summary measures of population health, NCHS will track progress toward the goal of more healthy years of life using several such measures, depending on available data, and evaluate their performance as tracking tools.

This work may narrow the field of choice for concepts and measures of disability. Concepts and measures of disability that are both feasible for ongoing data systems and useful in summary measures of population health will have an advantage. Given the attractiveness of summary measures to health planners, especially to health economists, this narrowing could have a powerful effect on the integration of disability statistics.

Longitudinal Studies of Aging—The Longitudinal Studies of Aging (LSOA) are a collaborative effort of the National Center for Health Statistics (NCHS) and the National Institute on Aging. The study is conducted by NCHS, and the U.S. Bureau of the Census collects the data. Baseline information for the first LSOA came from the Supplement on Aging (SOA), a supplement to the 1984 National Health Interview Survey. The sample for the LSOA came from the 7,527 persons on the SOA who were 70 years of age and over in 1984. Reinterviews were conducted in 1986, 1988, and 1990 using three methods of interviewing: computer-assisted telephone interviewing, telephone interviews using paper questionnaires, and mail questionnaires.

The purpose of LSOA II was to replicate LSOA for elderly persons who were 10 years younger than the population represented in LSOA I, and to determine if certain processes associated with aging in the LSOA were the same or different in a later cohort. Given this purpose LSOA II was designed to be as similar to the LSOA as possible, using the same sampling plan, questionnaires, and field procedures. Baseline information for LSOA II came from interviews conducted at the same time as Phase 2 of the 1994 National Health Interview Survey on Disability (NHIS-D), which was in the field from late 1994 to 1996. The sample for LSOA II came from the 9,447 persons who were 70 years of age and over at the time of the baseline interview. The LSOA II sample was reinterviewed in 1997–98 and 1999–2000 using the same data collection modes used in the LSOA.

LSOA I and LSOA II collected data on limitations of the following activities: seeing, hearing, chewing, walking, climbing, standing, sitting, stooping/crouching/kneeling, reaching, grasping, lifting, bathing, dressing, getting in or out of bed or chair, getting outside, preparing meals, shopping, managing money, using the telephone, doing housework, getting to places outside walking distance, managing medication,

driving a car, and using public transportation.

Activity limitations—For each reported activity limitation, questions are asked about the severity of the limitation. For most reported activity limitations, questions are asked about the use of assistive devices and personal assistance for those activities. Also, for most reported activity limitations, questions are asked about the duration of the limitation. For selected groups of reported activity limitations (not limitations in specific activities), questions are asked about the medical conditions associated with the limitations.

Assistive devices—In addition to the questions about assistive devices asked in connection with selected reported activity limitations (mentioned above), a question is asked about use for any reason of any of the following devices in the last 12 months: tracheotomy tube, respirator, ostomy bag, catheter, inhaler, nebulizer, hearing aid, crutches, cane, walker, wheelchair, scooter, and feeding tube.

Social participation—Questions are asked about participation in the following social activities: getting together with friends, talking with friends on the telephone, getting together with relatives, talking on the phone with relatives who live outside the household, going to a place of worship, going out to a movie, sports event, etc., and going out to eat at a restaurant. A final question asks about satisfaction with the overall level of social participation.

Medical diagnoses—In addition to the questions about medical diagnoses associated with activity limitations already mentioned, questions are asked about selected medical conditions often associated with activity limitations, such as arthritis, asthma, and stroke. For each reported condition, a question is asked about whether or not it was diagnosed by a doctor. No questions are asked about the possible functional consequences of the conditions reported.

Office of International Statistics (OIS)

The Office of International Statistics (OIS) has an intramural program of cross-national health statistics research and represents NCHS in various international health statistics activities. It also provides funding, planning, and administrative support for collaborative projects on health statistics by staff at NCHS and researchers in other countries. One such activity is Disability International Statistical Tables, or DISTAB. Initial funding for DISTAB was provided by the Office of Disability and Health, National Center for Environmental Health, Centers for Disease Control and Prevention, and OIS has provided additional and continuing support.

DISTAB has five participating countries: the U.S., Canada, the Netherlands, France, and South Africa. Each of the countries has recently conducted a national survey on disability and was able to commit staff time to the project. The project team consists of a representative from each of the surveys, two disability researchers retained through contractual arrangements, a specialist in ICIDH-2 coding, and a consultant from the disability statistics program of the United Nations Statistical Division. Over a 12-month period, the project team met monthly in telephone conference, and three times face to face, twice in Washington, DC and once in Geneva, Switzerland.

The team began with the specifications for standard statistical tables on disability recommended by the United Nations Statistical Division for reporting census and survey results. The team identified variables in those tables that could be constructed from data in at least three of the five national disability surveys. Those variables were then coded to ICIDH-2 categories insofar as possible. Each survey representative then specified how data from their survey could be coded to the ICIDH-2 categories for each variable, noting any details of the survey questions or procedures that might affect international comparability. Each

country then produced the tabulations for the standard tables using data from their national disability survey. Two project reports are planned, one focused on methodological lessons learned from the attempt to produce internationally comparable disability tables based on the UN's recommended standard tables and WHO's recommended classification, and another focused on substantive differences in the disability situations of the five countries.

Data Policy and Standards Staff

Among other functions, this Staff is the organizational home of the World Health Organization Collaborating Center for the Classification of Diseases in North America (or NACC, for North American Collaborating Center), and the Director of the Staff is also the Head of the NACC. The Head of the NACC is the focal point and coordinator of U.S. Government activities related to the International Classification of Diseases (ICD) and the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), and maintains liaison with the World Health Organization (WHO).

The ICIDH is the only official, comprehensive, and worldwide system for classifying disabilities for statistical and other purposes. It was first published by WHO in 1980 "for trial purposes." In 1993 the phrase "for trial purposes" was discontinued, and WHO announced that a revision of the classification would be undertaken to reflect changes in the worldwide disability situation and lessons learned from trial uses. Since then many WHO Collaborating Centers and special International Task Forces have participated in developing and testing the revised classification. WHO staff plans to present the revised classification to the World Health Assembly, the WHO governing body, in May 2001 for its approval. If approved, the ICIDH-2 will become the new worldwide standard for conceptualizing and classifying disability.

The current working title of the draft ICIDH-2 (which could change) is

the International Classification of Functioning and Disability. The classification has three major dimensions, each independent of the others and each classifying a different aspect of disability, corresponding to the body, person, and societal levels of organization. The body dimension is Body Function and Structure; the person dimension is Activity, and the societal dimension is Participation. Also included is a classification of environmental factors that affect disability, especially at the level of societal participation. Using the environmental factors codes to supplement the Participation codes, it is possible to succinctly indicate the level of participation in an aspect of social life and the environmental factors that facilitate or hinder that participation.

The individual numbered classes in each dimension are arranged in logical hierarchies of blocks and chapters, making it easy to find relevant classes and to apply them at different levels of aggregation. The classification is available in a long version (3-digit codes for each class) and a short version (2-digit codes). Also under development by WHO are a four-page checklist for clinical use and two survey questionnaire modules on the Activity dimension, a 36-question version and a 12-question version. Western University of the Health Sciences is developing a Web-based training tool for ICIDH-2 called CODE IDH-2. WHO maintains a Web site (www.who.int/icidh) at which many of these documents can be viewed and downloaded. The Web site includes a searchable hyperlink version of the current ICIDH-2 draft.

The WHO/NCHS Collaborating Center has taken and continues to take an active role in these activities. It has alternated with its Canadian collaborators, initially Statistics Canada and then the Canadian Institute for Health Information, in hosting an annual meeting on the ICIDH revision in which several hundred North Americans have participated. It has sent one or more representatives to the annual international conferences on the ICIDH sponsored by WHO. Through contracts it has funded the development and implementation of ICIDH training

modules, first on paper, then on personal computers, and now on the Web. And it organized and funded testing of the current and earlier drafts of the revised ICIDH-2.

Another function of the Data Policy and Standards Staff is to provide staff support to the National Committee on Vital and Health Statistics (NCVHS). The NCVHS is an independent committee of citizen-experts authorized by law, and appointed by and responsible to the Secretary of Health and Human Services. Through public hearings, commissioned papers, and its own deliberations, the Committee studies current issues in health statistics and advises the Secretary on how to address them. The Committee has no paid staff of its own, but staff support is provided by Federal statistical agencies and coordinated by the Committee's Executive Director, who is the Director of the Data Policy and Standards Staff.

The NCVHS has taken some actions pertinent to the subject of this report. In 1996 the Committee recognized that:

The identification, definition, and implementation of standardized data in the health care and health care information fields are long overdue. The increasing use of electronic data, the evolving managed care field, and the growing requirement for performance monitoring and outcomes research have made it imperative that all health data collection activities, where possible, utilize standardized data elements and definitions.

The committee therefore recommended a set of core health data elements. Among them was functional status, about which the Committee said:

The functional status of a person is an increasingly important health measure that has been shown to be strongly related to medical care utilization rates. A number of scales have been developed that include both a) self-report measures, such as the listings of limitations of Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) and the National

Health Interview Survey age-specific summary evaluation of activity limitations, and b) clinical assessments, such as the International Classification of Impairments, Disabilities and Handicaps (ICIDH) and the Resident Assessment Instrument (RAI) widely used in nursing homes.

The Committee concluded at that time that none of the measures it considered was sufficiently developed to meet its standards for core health data elements. They deferred naming a standard for functional status pending further research.

In 1999 the Populations Subcommittee of the NCVHS returned to the issue of a data standard for functional status, focusing on the feasibility and utility of a functional status item in health administrative records. After hearing from a number of experts, the subcommittee decided to focus its attention on the ICIDH-2 because of the promise it showed as a standard for functional status data. It heard from many researchers, providers, and professional associations, and from officials of WHO. At this time the subcommittee is preparing its report.

Division of Vital Statistics (DVS)

The National Vital Statistics System is responsible for compiling and disseminating the Nation's official vital statistics. The registration of vital events (births, deaths, marriages, divorces, and fetal deaths) is a State function. Standard forms for the collection of the data and model procedures for the uniform registration of the events are developed and recommended for State use through cooperative activities of the States and the National Center for Health Statistics. Additional programs related to the National Vital Statistics System include the Linked Birth and Infant Death Data Set, National Maternal and Infant Health Survey, National Mortality Followback Survey, the National Survey of Family Growth, and the National Death Index. Neither the National Vital Statistics System, the

Linked Birth and Infant Death Data Set, nor the National Death Index have information on disability, but the three national surveys—Maternal and Infant Health, Mortality Followback, and Family Growth—have collected disability data in the past or plan to do so in the near future.

The 1988 National Maternal and Infant Health Survey (NMIHS)—The most recent in the series, was based on a nationally representative sample of certificates for births and perinatal deaths that occurred in 1988. In addition to information from the certificates, the survey obtained questionnaire data from the mothers of the infants, the physicians who signed the certificates, and the hospitals named on the certificates. In 1991 a Longitudinal Followup survey was conducted for the 1988 sample of women with live births, and about 8,000 questionnaires were completed. On the questionnaire completed by sample mothers were questions on developmental delays (the Denver Developmental scale), behavioral problems, and hearing, sight, or speech difficulties.

The 1993 National Mortality Followback Survey (NMFS)—The most recent in the series, is based on a sample of 22,957 death certificates that represent 2,215,000 individuals aged 15 years and over who were residing and died in the United States in 1993. Dates were drawn from two independent sources, the death certificate and a proxy respondent questionnaire. The proxy respondent was someone who knew the deceased, usually the person who provided the personal information about the decedent on the death certificate, often a close relative. Included in the proxy questionnaire were questions on impairments of body function during the last year of life—understanding, remembering, and recognizing—and questions on limitations of activities during the last year of life: lifting/carrying, climbing, walking, doing housework, shopping, going outside the home, preparing meals, managing money, using a telephone, getting around inside the home, walking, getting in or out of a

bed or chair, eating, using the toilet, bathing, and dressing. For each reported activity limitation in the last year of life, a question was asked about the lifetime duration of that limitation.

The National Survey of Family Growth (NSFG)—is a periodic survey on factors related to fertility, such as marriage and cohabitation, sexual intercourse, fertility desires, contraception, and reproductive health. In its first five cycles, the survey included a nationally representative sample of women of reproductive age (15–44 years) living in the community. In Cycle 6, which will be fielded in 2002, the NSFG will again include a sample of women of reproductive age, but it will also include for the first time a sample of men in the age range most likely to be the partners of those women, 15–49 years. The Cycle 6 sample will have an area probability sample with oversampling of persons who are African American, Hispanic American, or aged 15–24 years. The total sample size will be about 19,000. It is planned that the survey will be repeated with the same design in 2005 and 2008.

The version of the Cycle 6 questionnaire current as of this writing includes for the first time a set of questions on disability. They are identical to the questions used in the long form of the 2000 Census of Population that was sent to a randomly selected 15 percent of households. The person completing the form was asked to answer Yes or No to six disability questions about each household member. The questions covered (1) blindness, deafness, or severe vision or hearing impairment; (2) substantial limitations in basic physical activities, such as walking, climbing stairs, reaching, lifting, or carrying; (3) limitations in learning, remembering, or concentrating; (4) limitations in dressing, bathing, or getting around inside the home; (5) limitations in going outside the home; and (6) limitations in working at a job. Items (5) and (6) were only asked about persons 16 years of age or over. With slight modifications to accommodate the face-to-face interview mode of data collection, the NSFG will ask the same questions.

Division of Health Care Statistics (DHCS)

To meet changing health statistics needs, four of the Center's record-based surveys were merged and expanded into one integrated survey of health care providers called the National Health Care Survey (NHCS). New data on alternative health care settings—such as ambulatory surgical centers, hospital outpatient departments, emergency rooms, hospices, and home health agencies—are being provided through this system.

The NHCS is comprised of four National Center for Health Statistics (NCHS) records-based surveys: The National Hospital Discharge Survey, the National Ambulatory Medical Care Survey, the National Nursing Home Survey, and the National Health Provider Inventory (formerly the National Master Facility Inventory). The new surveys include the National Survey of Ambulatory Surgery, the National Hospital Ambulatory Medical Care Survey, and the National Home and Hospice Care Survey. Records-based surveys are so named because they are based on a sample of health or administrative records, not samples of persons, households, or organizations. The National Employer Health Insurance Survey, which is not records based, is also a component of the NHCS.

The two components of the NHCS that provide substantial disability information are the National Nursing Home Survey (NNHS) and the National Home and Hospice Care Survey (NHHCS), each of which will be described here. The two surveys are fielded in alternate years, the NNHS in odd numbered years and the NHHCS in even numbered years. The NNHS was last conducted in 1999 and the NHHCS in 2000.

The sample for the National Nursing Home Survey has a multistage probability design. The elementary sampling unit is the residents served in the facilities, including both current and recently discharged residents. The first stage of selection is a probability sample of the nursing facilities in the universe.

The primary sampling strata of nursing facilities were defined by bed size and certification status. Certified facilities consisted of facilities certified by either Medicare or Medicaid as a skilled nursing or intermediate care facility. Nursing homes were then selected using systematic sampling with probability proportional to the number of beds in the facility. There were two sampling frames for the within-facility sample: a list of all current residents who were on the rolls of the facility, and a list of residents discharged from care by the nursing home during a designated month prior to the interview. Up to six current residents and six discharged residents were selected. For each selected resident, a staff member familiar with that resident's care and medical records was administered a standardized, fact-to-face interview by a trained interviewer employed by the U.S. Bureau of the Census. In 1999 the sample size was about 1,500 persons.

The questionnaire used for sample nursing home residents (current and recently discharged) obtains information about limitations in the following activities: seeing, hearing, biting or chewing, bathing, dressing, eating, transferring in and out of a bed or chair, walking, going outside the grounds, controlling bladder and bowels, care of personal possessions, managing money, securing personal items, and using a telephone.

In addition to the questions about activity limitations, questions were asked about assistive devices currently used by the sample patient, including glasses, hearing aid, transfer equipment, wheelchair, cane, walker, crutches, brace (any type), oxygen, and commode. The respondent was also asked if the sample patient used any other assistive devices, and if so, the names of those devices were recorded.

The National Home and Hospice Care Survey (NHHCS)—is a survey of patients served by home and hospice care agencies in the United States. Information is collected about agencies that provide home and hospice care and about their current patients and recently discharged patients. The NHHCS is based on a probability sample of home

health agencies and hospices. The survey includes all types of agencies that provide home health and hospice care without regard to whether they are Medicare certified or whether they are licensed.

The sample for the NHHCS has a stratified two-stage probability design. The first stage consists of selecting a stratified sample of agencies. The second stage of sample selection, sampling of six current patients and six discharges within each agency, was done by systematic sampling of current patients and recently discharged patients. The patients and discharges were selected from lists constructed for each agency at the time of the interview. Discharges that occurred because of death were included. Data for the NHHCS are collected through personal interviews with administrators and staff and are administered by interviewers employed by the U.S. Bureau of the Census. In 2000 the sample size was about 1,800.

Limitation of activity—The questionnaire used for sample home and hospice care patients, both current patients and discharged patients, obtains information about limitations in the following activities: seeing, hearing, controlling bladder and bowels, bathing, dressing, eating, transferring in and out of a bed or chair, walking, using the toilet room, doing light housework, managing money, shopping for groceries or clothes, using a telephone, preparing meals, and taking medications.

In addition to the questions about activity limitations, questions were asked about assistive devices currently used by the sample patient, including respiratory therapy equipment, intravenous therapy equipment, ulcer prevention equipment, nutrition equipment, bedside commode, brace (any type), cane, crutches, glasses, hearing aid, hospital bed, orthotics, shower chair, walker, wheel chair-manual, and wheel chair-motorized. The respondent was also asked if the sample patient used any other assistive devices, and if so, the names of those devices were recorded. The assistive devices questions were asked about both current patients and recently discharged patients.

Division of Health Interview Statistics (DHIS)

The National Health Interview Survey (NHIS) is an annual cross-sectional survey of a nationally representative sample of the civilian, noninstitutionalized population of the United States. Standardized interviews are administered face-to-face in sample households by interviewers who are recruited, trained, and supervised by the United States Bureau of the Census. The NHIS began in 1957 and has been in the field nearly continuously ever since. (Interviewing is discontinued for 2 weeks each January for retraining of interviewers, and in a few years interviewing was terminated before the end of the data collection year due to a shortage of funds.) The NHIS sample is redesigned every 10 years, most recently in 1995. The questionnaire has been redesigned periodically, most recently in 1997. In its current design, each year the NHIS samples about 41,000 families with about 107,000 family members.

The NHIS questionnaire is modular, including a basic module that is repeated every year and supplements that are fielded one or more times. The basic module includes a family module that obtains some information on all family members, a sample adult module that obtains more detailed information on one randomly selected adult (18 years of age or over) in the family, and a sample child module that obtains information on one randomly selected child or youth (17 years of age and under). The basic module obtains information on a wide range of measures of health status, health care access and utilization, and health-related behaviors.

Since its beginning, the NHIS has collected some data on disability every year, and periodically it has included special supplemental questionnaires that collected additional data on disability. A major supplement on disability was fielded in 1994 and 1995, and follow-up interviews were conducted in 1994–97 with disabled persons identified in 1994–95. In this report the focus will be on the disability data

currently collected as part of the annual NHIS basic module.

Limitation of activity—As part of the family module, the NHIS collects age-appropriate information for all family members on limitations in these activities: play, bathing, dressing, eating, walking, remembering, getting in and out of bed or chair, using the toilet, getting around inside the home, routine needs (such as household chores, doing necessary business, shopping, or getting around for other purposes), and work. For persons who are not reported to be limited in any of these activities, a question is asked about limitation in any (other) activity, which is not further specified. For persons reported to have any limitation in activity, a question is asked about the medical conditions causing the limitation and the length of time since onset of the condition. In the sample adult and sample child questionnaires, questions are asked about two additional activities, hearing and vision, and the sample child questionnaire includes a set of questions that measure limitations in interpersonal activities of children and youth.

Impairment of body function—The sample adult questionnaire includes questions on pain in the joints, neck, lower back, face or jaw, and severe or migraine headache.

Assistive devices—The sample adult questionnaire asks one question about assistive devices: “Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?”

Division of Health Examination Statistics (DHES)

The National Health and Nutrition Examination Survey (NHANES) has been designed to collect information about the health and diet of people in the United States. NHANES is unique in that it combines a home interview with health tests, which are done in a mobile examination center (MEC). Beginning in 1999, NHANES can be linked to the

National Health Interview Survey (NHIS) at the primary sampling unit (PSU) level (i.e., the same counties, but not necessarily the same individuals, are in both surveys). NHANES is also linked to NHIS with regard to questionnaire content of the household interview for selected topics, including disability.

Also in 1999, NHANES became a continuous survey, that is, it now collects data from a representative sample of the U.S. population, newborns and older, *every year*. The number of people interviewed and examined in a 12-month period will be about the same as in previous NHANES, about 5,000. Data from different survey years can be aggregated to achieve greater reliability for estimates of statistics for small subpopulations and rare events.

Limitation of activity—NHANES collects data on disability by personal interview in sample households and by tests and examinations in mobile examination centers (MECs). The household interview questionnaire asks about limitations in the activities of hearing, seeing, remembering, standing, balancing, stooping/crouching/kneeling, getting up from a sitting or lying posture, reaching, grasping, lifting/carrying, eating, walking, playing, working, doing household chores, managing money, going out of the home, socializing, and relaxing at home. The MEC includes a test for walking limitation: the sample person is asked to walk at a normal pace along a flat, straight, 20-foot course, and the elapsed time is recorded as they reach the 8-foot and 20-foot marks. The 8-foot test for walking limitations is also done at the time of the household interview.

Impairment of body function—The household interview also obtains information about impairments of body function. It has a questionnaire module on pain, and cognitive function is tested for persons 60 years of age and older using the Digit Symbol Substitution Test (DSST), which requires the recording of symbols corresponding to a series of standard symbols within a two-minute period. There are two tests for body function impairments in the MEC. The

first is a test of lower body muscle function in which the sample person is asked to lift and extend the right leg from a sitting position against a steady pressure exerted by a machine, which also measures the strength of the leg muscles. The second is a test of vestibular balance impairment in which the sample person is asked to stand for 30 seconds with feet together, arms folded across the chest, and eyes closed.

Medical diagnoses—A great advantage of NHANES for the study of disability is that it incorporates many standard medical diagnostic tests and examinations. While medical diagnoses are in the realm of disease and disorder and outside the scope of disability, they are often associated with disability either as cause or effect. It is very useful, therefore, to have both medical diagnostics and disability assessments for the same study population.

Among the standard medical diagnostic tests used in NHANES are two for mental health diagnoses, the Diagnostic Interview Schedule for Children (DISC) and the Composite International Diagnostic Interview (CIDI), which is for adults. Selected modules from the DISC are administered in interviews with children and youth and their parents, and selected modules of the CIDI are administered in interviews with adults. In relation to hearing impairments and limitations, two standard diagnostic tests are performed in the Mobile Examination Center, pure tone audiometry and tympanometry. In relation to hearing impairments and limitations, three standard diagnostic tests are performed in the MEC: visual acuity, using an autorefractor; current eyeglass prescription, using a Lensmeter; and near visual acuity, by reading from a standard card at a measured distance.

III. Coverage and Comparability of the National Center for Health Statistics Survey Questions for Selected Disabilities

The United Nations Manual on Censuses and Population Surveys recommends that disability data be reported for selected disabilities, using the disability nomenclature and categories of the International Classification of Impairments, Disabilities, and Handicaps. The disability types recommended by the United Nations for inclusion in reports are listed below with the corresponding code ranges of the ICIDH-2, Beta-2, Short Version, in parentheses.

1. Seeing (b210-b229)
2. Hearing (b230-b249)
3. Speaking (a230-a299)
4. Moving/mobility (a410-a499)
5. Body movements (a310-a399)
6. Gripping/holding (a360)
7. Learning (a110-a199)
8. Behavioral problems (a710-a1729)
9. Personal care (a510-a599)

For each type of disability, the questions in six NCHS surveys were examined and assigned to an ICIDH-2 code category. The following surveys were included: NHIS, NHANES, LSOA, NNHS, NHHCS, and NMFS. Two other surveys that have disability data were not included: the NSFG and the NMIHS. The NSFG was not included because the disability questions it used, the 2000 Census questions, cannot be coded to the ICIDH because they confound more than one type of disability in each question. The NMIHS was not included because it is 10 years old, and there are no plans to repeat it.

For each type of disability, a table was prepared with rows corresponding to ICIDH-2 code categories and

columns corresponding to the six surveys. Questions were entered in the cells corresponding to the column of the survey in which they are used and the row of the ICIDH-2 code that applies. The tables are appendix tables 1–9, with the table numbers corresponding to the list of U.N.-recommended disability types given above.

A summary of the coverage of the U.N. disability types by the six NCHS surveys is given in the table below. A check mark in a cell means that a survey has at least one question about that type of disability, although the questions may differ across surveys and may not have the same ICIDH-2 code. According to type of disability, “Body movements” and “Personal care” are covered best all six surveys have at least one question on those types of disability. “Seeing” and “Hearing” are both covered by six of the seven surveys. The least well-covered type of disability is “Speaking,” for which only the NHIS has a question. According to survey, the NHIS provides the best coverage, with questions for all nine of the disability types. NHANES and LSOA follow closely with coverage of seven of the nine disability types. The other three surveys cover four or five of the nine disability types.

Brief comments will be made on each type of disability with respect to similarities and differences in the questions asked in the six surveys.

Seeing—Most of the surveys ask first about trouble seeing and then about blindness, but the LSOA reverses the order, asking first about blindness and then about other difficulty seeing. Most of the surveys ask about difficulty seeing *even when wearing glasses*, but NHANES omits that qualification. All of the surveys ask questions that allow classification into at least three categories of severity: blind, some difficulty seeing, and no difficulty seeing; however, the NHIS and the LSOA allow classification in *only* those categories, whereas the other surveys allow greater detail in the specification of severity of seeing limitations. LSOA does not define blindness, NHIS and NHANES equate blindness with being “unable to see at all.” NNHS and

NHHCS define severely impaired as “cannot watch TV 8 to 12 feet away, but can recognize the features of familiar persons if they are within 2 to 3 feet,” and blind as “[vision] completely lost.”

Hearing—NHIS and NHANES ask about hearing *without* a hearing aid, whereas NNHS and NHHCS ask about hearing *with* a hearing aid; LSOA does not mention a hearing aid. The LSOA asks first about deafness, then about any other trouble hearing, whereas the other surveys ask one question about hearing with deafness being the last of several degrees of hearing impairment mentioned. NHIS and NHANES do not define “deaf,” but the NNHS and NHHCS define it on a card given to the respondent as “can hear only a few words a person says or loud noises.” All of the surveys except allow for coding several degrees of hearing limitation, but the LSOA allows the fewest number of degrees: deaf, some limitation, and no limitation.

Speaking—Only the NHIS has questions on speaking limitations, and then only for children and youth (17 years of age and under). Two NHIS questions deal with speaking limitations, both rather indirectly. The respondent is asked if the child has had any of a list of conditions and impairments, read by the interviewer, that includes “Stuttering or stammering.” Elsewhere, respondents are asked if a child or youth is limited in activities of play, school, or personal care. If so, the respondent was asked to name the condition or impairment causing the limitations, and the preprinted list of coded response categories included “Speech problem.” The first question codes unambiguously to the ICIDH-2 Body Function code B3300, which specifically names stuttering and stammering as inclusions. “Speech problem,” however, is less specific, and in the absence of other information could be coded to B3300 or Activity code a230. This illustrates a sometimes property of the ICIDH-2, the potential for coding the same information to two different codes, that critics would call confusion and supporters would call flexibility.

Moving/mobility—NHIS, LSOA, and NMFS have general questions about walking, which do not specify distance or surface. They code quite reasonably to the general ICIDH-2 code for walking activities. Note that the NHIS and LSOA questions specify an environmental factor in framing the question: “without any special equipment.” A person who walks without difficulty using crutches, for instance, is expected to report a limitation in walking under the conditions the question specifies. NHANES also specifies “without any special equipment” in asking about difficulty in walking from one room to another. The ICIDH-2 code for walking short distances applies, but notice that it defines “short” as any distance up to 1 kilometer (0.66 miles). For that reason, the NHIS and LSOA questions about difficulty in walking a quarter mile, are also coded to the ICIDH-2 code for walking short distances. NHIS, NHANES, and LSOA use very similar questions about climbing, each specifying no use of aids, 10 steps, and no resting. There are minor differences in the questions determining the severity of the limitation. The climbing questions are unambiguously coded to the ICIDH-2 activity code for climbing.

Body movements—NHIS, NHANES, and LSOA have very similar questions about limitations in standing, which clearly matches the ICIDH-2 code for maintaining a standing position. All three survey questions specify that the assessment should be made assuming no personal assistance and no special aids. LSOA alone has a question about sitting limitations, which again clearly matches the ICIDH-2 code for sitting; the question specifies no special aids, but does not specify no personal assistance.

Only the NHIS has *no* question about getting in or out of bed, but there are substantial differences in the way the other surveys ask about this activity limitation. NHANES and LSOA specify no personal assistance and no special aids, but the others do not so specify. NHANES, LSOA, and NMFS ask about difficulty in transferring, while NNHS and NHHCS ask about receiving help to transfer. The questions fit, with varying

precision, the IDICH-2 Activity code for changing body position. Getting in and out of bed or chairs is a relatively complex activity that combines several simpler activities that the ICIDH-2 decomposes into changing body position from sitting, changing body position from lying, and changing body position from standing. It must, therefore, be assigned to the general ICIDH-2 code for limitations in changing body position.

Questions about limitations in the related activities of stooping, bending, crouching, and kneeling are asked in NHIS, NHANES, and LSOA. All three questions specify no personal assistance and no special aids, and all measure several levels of severity. All three limitations can be coded to the ICIDH-2 Activity code for changing body position from standing.

One survey, NHANES, asks question about limitations in getting up from a chair (without personal assistance or special aids), which can be coded to the more specific ICIDH-2 Activity code for changing body position from sitting.

The NHIS alone asks a question about limitations in moving large objects, such as furniture. There is no single ICIDH-2 code to which this activity can be assigned, because it combines pushing and pulling with both the arms and the legs, which the ICIDH-2 assigns two different codes.

Gripping/holding—NHIS, NHANES, and LSOA ask nearly identical questions on grasping and handling small objects, which fits well to the ICIDH-2 code for fine hand use.

Learning—The table for this domain contains a fairly large number of questions, most of which find comfortable assignments in the ICIDH-2 code structure, but there is relatively little comparability between surveys. The exception is the comparability of questions in the NHIS and NHANES on mental retardation, remembering/confusion, and depression/anxiety/emotional problems.

Behavioral problems—Only the NMFS has questions that can be coded to the ICIDH-2 in this domain. The NHIS

child questionnaire has a set of developmental questions that includes behavioral items; however, the set of questions comprises a scale, and the individual items are not considered valid and reliable when used alone.

Personal care—NHANES has a question on limitation of eating, and the other surveys have questions on eating, dressing, bathing, and toileting. For all four of these activities, there are ICIDH-2 codes that match well. The major difference between the questions in the six surveys is the circumstance defining limitations: in NHIS it is needing help from another person, in NNHS and NHHCS it is receiving the help of another person, in LSOA and NMFS it is difficulty, and in NHANES it is difficulty when not receiving personal assistance or using assistive technology.

Reference

1. World Health Organization. International Classification of Impairments, Disabilities, and Handicaps(ICIDH-1). Geneva, Switzerland. 1980.

Developing the Capability to Measure Crime Victimization of People With Disabilities

by Michael R. Rand, U.S. Bureau of Justice Statistics

Background

On October 27, 1998, the President and Congress presented the Bureau of Justice Statistics (BJS) with a tremendous challenge with the signing of PL105-301, the Crime Victims with Disabilities Awareness Act. Section 5 of the Act directed the Department of Justice to include in the National Crime Victimization Survey (NCVS) statistics relating to:

the nature of crimes against individuals with developmental disabilities; and the specific characteristics of these crimes.

This paper reviews the efforts that the Bureau of Justice Statistics has taken to date to implement the Act, and examines a number of the issues and problems that need to be resolved in order to develop a national data collection program that permits accurate estimates of crimes affecting people with disabilities.

The legislation was passed because of a perceived dearth of national statistics relating to the victimization of persons with disabilities. This lack was cited both in the legislation and by researchers and advocates in discussing the issue. More than one advocate in this area has characterized victims of violence who have developmental disabilities as "invisible victims" (1,2).

The studies that have been done have consistently found that people with disabilities are at greater risk of criminal victimization than the general population (1). One study, that incorporated

estimates based upon a review of the existing literature, estimated that people with developmental disabilities are 4 to 10 times more vulnerable to crime victimization than people without disabilities (3).

That many of these studies that are cited on this topic were conducted in other countries, demonstrates the overall insufficiency of information about the victimization experience of people with disabilities in the United States. For example, in the Act, Congress cited studies conducted in Canada, Australia, and Great Britain. Compared to other segments of the population, therefore, the amount of data that can be brought to bear on this issue is extremely thin.

The Australian study cited in P.L.105-301 was a survey administered to a sample of people with cognitive disabilities using a questionnaire modified from the Australian Victims of Crime survey. This study found that for violent crimes, the vulnerability of people with disabilities ranged from about 3 times higher for assault to 13 times higher for robbery (4).

At least one study has found that people with intellectual disabilities are also subject to repeat victimization, often at the hands of care providers or family members. In this study 83 percent of the women in the sample reported being sexually assaulted in their lifetimes; of these nearly half had been sexually assaulted 10 or more times (5).

One can draw a number of conclusions from an examination of the citations of studies examining victimization of people with disabilities,

including developmental disabilities. First, many of the studies still cited are, for the most part dated, having been conducted in the late 1980s or early 1990s. Second, because there are only a few studies on point, these are cited repeatedly. Third, no trend data are available. It is therefore not possible to determine whether persons with disabilities have experienced the same improvements in crime rates as the general population has through the late 1990s. Fourth, because of small sample sizes, these studies could not address such issues as differential vulnerabilities related to various types or degrees of disability.

This combination of a few studies indicating the greater vulnerability of people with disabilities, combined with the lack of sufficient data to drive policy and programmatic decisions and raise the issue to a greater public consciousness led in 1998 to the passage of the Crime Victims with Disabilities Awareness Act.

The provisions of the Act were very specific. It did not call upon the Department of Justice to develop the means to measure victimization of people with disabilities using any appropriate platform. It directed the Department to use the National Crime Victimization Survey (cited in the Act as the "National Crime Victim's Survey") to measure the nature and characteristics of crimes against people with developmental disabilities, that is a subset of the population with disabilities.

The National Crime Victimization Survey

The National Crime Victimization Survey (NCVS), conducted annually since 1972, is the U.S. Department of Justice's primary vehicle for measuring the characteristics of victims of crime, including violent crime. The NCVS is conducted at about 50,000 sample households each 6 months to measure the occurrence of a set of serious crimes; specifically the crimes of rape, robbery, assault, burglary, theft, and motor vehicle theft. The NCVS provides information about the victims, and

characteristics and consequences of the crimes sustained during the 6 months prior to the interview. Because the sample is drawn to represent the national population, the survey can produce national estimates of the amount and types of crime, as well as such rates for various demographic population subgroups.

The survey has two parts: a crime screener and an incident report. The screener is administered to every household member age 12 or older to determine whether they have been the victim of a crime measured by the survey. For any crime identified by the screener, the incident report is used to obtain the details about the victimization. The NCVS incident report contains a broad range of questions to obtain information on the characteristics of victims, incidents, and consequences of crime victimization.

The NCVS has a number of procedural and methodological attributes that may enhance it as a vehicle for obtaining information about crimes against people with disabilities. It was specified by Congress as the vehicle for this effort because it is the Nation's premier source of data on crime victimization. The NCVS can produce national estimates of crime victimization. It is an ongoing survey. It utilizes a large sample. This sample has enabled the survey to detect relatively small changes in crime over time as well as to detect differences in the victimization experience of various subgroups of the American population. As will be discussed later, while estimates of persons with developmental disabilities or disabilities in general have varied, such persons represent a relatively small percentage of the population. Since no comprehensive national listings of people with disabilities exists, any estimates based upon population based surveys require extremely large samples to obtain enough cases in order to make reliable estimates. The challenge of this effort requires that estimates be developed for a fraction of the population about a relatively rare occurrence: crime victimization.

Conversely, there are a number of attributes of the NCVS that impose

difficulties in meeting the requirements of the Crime Victims with Disabilities Awareness Act. The survey is household based and was designed to measure the incidence of crime against the U.S. civilian noninstitutional population. Some of the victimization studies that have been conducted among people with disabilities indicate that people in institutions, usually those with the most profound and severe conditions, are at an even greater risk of victimization than people with disabilities who do not reside in institutions, and that often the perpetrators are care givers and other institutional residents. Therefore, estimates drawn from the NCVS as currently constituted would exclude the experiences of a possibly significant proportion of the population intended to be covered under the Act.

Additionally, survey interviewing mode and methods may not be suited for interviewing people with difficulty communicating, especially communicating by telephone. Currently, about 70 percent of interviewing for the NCVS is conducted by telephone. Some people with disabilities that limit their verbal communication have access to technology which enhances their ability to communicate, but many do not.

Under current procedures, NCVS interviewers are permitted to obtain proxy interviews in a very limited set of circumstances. One circumstance under which proxy interviews are allowed is if the respondent is physically or mentally incapable of responding. The restrictions upon proxy interviews were made so stringent in the recognition that others may not know about the victimization experiences of the respondent, and because the person providing the information for the respondent may, in fact, be a perpetrator of abuse or violence.

At the national level, for the population as a whole, the effects upon the estimates caused by obtaining proxy responses for persons with severe disabilities is probably small. However, when measuring victimization of people with disabilities, the use of proxies becomes much more problematic. To evaluate the types of disabilities for which interviewers accepted proxy interviews, the Census Bureau

conducted a special study in July through December 1999. For this period, interviewers recorded the underlying condition for respondents for whom proxy interviews were obtained. Across the 6-month period, about 1,000 such proxy interviews were conducted; accounting for about 1 percent of all NCVS interviews. The most prevalent types of condition for which proxy interviews were accepted were cognitive disabilities and hearing impairments.

The issues related to proxy interviews are intermeshed with those pertaining to interviewing methodologies. NCVS interviewers are trained to ask questions as worded and to not deviate from the script. When respondents do not understand a question or provide insufficient information in response to a question, interviewers are instructed to develop probes or rephrased questions in carefully constrained ways in order to avoid biasing the responses. Such interviewing methodology may be inadequate to communicate with some people with disabilities affecting their ability to communicate. For example, research conducted by the ARC, formerly the Association of Retarded Citizens, found that some people with cognitive disabilities were better able to provide information by drawing pictures than by conventional interviewing methods. If, as studies indicate, people with more profound disabilities are more vulnerable to crime, these are the people for whom the current procedures are least adequate.

Defining Disability

BJS staff began efforts to meet the mandates of the Crime Victims with Developmental Disabilities Awareness Act by creating a strategic plan. This plan set out a number of key issues that required decisions and laid out a plan of attack. The issues identified were:

- The definition of disability
- How to operationalize the definition
- Whether to administer the questions to all respondents or only those who report a victimization
- Whether there exist alternative strategies to meet the mandates of

- the Act
- What methodological issues needed to be addressed

The first two of these are of most immediate importance, and in many ways the most problematic. The legislation specified that the NCVS should measure victimization of persons not with any disability, but with “developmental disabilities” as defined by 42 U.S. Code 6001, which reads:

The term developmental disability means a severe, chronic disability of an individual 5 years of age or older that: is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in substantial functional limitations in three or more major life activities (self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency); reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

One of the difficulties in operationalizing this definition is that it contains at least one element that is highly subjective. Developmental disability is defined by the presence of *substantial* functional limitations in three or more areas of major life activity. Yet the definition does not define what is meant by “substantial.” Therefore, there can be a great deal of subjectivity in the determination of whether an individual has a developmental disability.

Another difficulty is that the definition is based upon the presence of a number of functional limitations. This adds an additional layer of subjectivity: What constitutes, for example, a functional limitation in mobility? Who determines this, an observer, a physician, or the respondent?

One way to address these difficulties is to ask a large number of questions, addressing different aspects of disability, and triangulating the responses to achieve an operational definition. This approach is used by the National Health Interview Survey. A Disability Supplement (NHIS-DS), which was administered for a 2-year period in 1994–95 utilized a multistage process to identify individuals with developmental disabilities. The process involved creating a set of questions to address each of the seven areas of functional limitation in the Federal definition.

Unfortunately, this strategy involving a large number of questions is not possible for incorporation into the NCVS. One constraint in creating a set of disability questions for the NCVS is respondent burden. Because the main purpose of the NCVS is to measure crime victimization, it is not possible to add a long series of questions on disability. The set of disability questions added cannot jeopardize the overall survey goals of measuring crime victimization. Any set of questions designed to obtain information about disability must, therefore, not add substantially to the respondent burdens already imposed by the survey, or reduce respondent participation.

Other issues related to definition of disability and the operationalization of the definition that BJS had to confront were:

- Should the survey identify all disabilities or restrict the focus to developmental disabilities?
- Is it sufficient to determine whether people are disabled, or must specific types of disabilities be identified?
- If specific types of disabilities must be identified, which specific types?
- Is it necessary to identify in some way degrees of severity of disability?

In resolving these issues, BJS has made a decision to be as comprehensive as possible, and work to the goals of the Act rather than the letter of its requirements. Therefore, BJS, after a substantial study and review process, has decided that the survey will work to identify all persons with disabilities, as well as identify those disabilities that meet the definition of developmental disabilities as required by the legislation. The survey will also have questions to identify types and degrees of disability to the extent possible.

As stated above, the goal in making these decisions was to be as comprehensive as possible. While it is necessary to be able to identify people with developmental disabilities to meet the requirements of the law, the distinction between developmental and other disabilities is not pertinent to the evaluation of risks of victimization.

Similarly, BJS decided that it would not be sufficient to create a module that only differentiated people with disabilities from persons without disabilities. Such a dichotomy ignores the differences in vulnerability to victimization associated with different types of disability or severity of disability. There is no reason to believe that, say people with profound mental retardation and people with hearing impairments would necessarily have similar susceptibilities to victimization. The necessity of producing estimates of victimization for people with specific types and degrees of disability is limited by the numbers of sample cases available for analysis. Therefore, even if it is possible to identify with great exactness the specific types and degrees of disability for every person in the sample, at least some aggregation will be required to produce reliable estimates.

Developing a Plan

The early efforts on the project were primarily involved in gaining an understanding of the nature of disability, the problems associated with measuring it and developing a network of people to draw on in future work. BJS staff initiated a broad range of activities after the bill's enactment, including

commissioning a review of existing literature on disability statistics, meeting with national and State officials working in the area of disability, and becoming active participants in working groups dealing with disability statistics.

A number of Federal agencies are currently grappling with the design of survey questions to identify persons with disabilities. Some agencies, such as the Bureau of Labor Statistics have requirements similar to that in PL 105-301. Other agencies are attempting to identify populations of people with disabilities to address their particular programmatic concerns. A Government-wide group, the Federal Interagency Subcommittee on Disability Statistics (ISDS), has been meeting on a monthly basis for some time to discuss the issues related to identifying people with disabilities and coordinate research in this area.

BJS also found that the Bureau of Labor Statistics had convened a research group to help design questions related to disability on the Current Population Survey (CPS). BJS began to attend meetings of both of these groups and has continued to use them to critique proposals and the strategy it is pursuing in this area.

At the same time, BJS began to establish working relationships with people in the research and disability advocacy communities. A key reason the Crime Victims with Disabilities Awareness Act was passed was the concerted effort by the disability advocacy community to raise awareness of the extent to which people with disabilities become crime victims. BJS recognized that for the estimates eventually achieved through our efforts to be accepted as true reflections of the experiences of people with disabilities, it was necessary to involve knowledgeable researchers and advocates of disabled people into the planning process.

In August 1999, BJS convened a group of experts from within and outside the Federal Government to begin the coordination process, obtain information about other disability-related surveys, and brainstorm on the issues and possible strategies.

In October 1999, BJS participated in a Workshop on Victims with Disabilities sponsored by the National Institute of Justice and conducted by the National Academy of Sciences. This workshop, convened to meet another requirement of the Crime Victims with Disabilities Awareness Act, brought together officials from a number of Federal, State, and local agencies, researchers from academia, and advocates from a variety of organizations involved in programs for persons with disabilities. At the workshop, a number of commissioned background papers were presented and discussed, focusing on both conceptual and programmatic issues related to victimization of people with disabilities, especially developmental disabilities.

Throughout this project, BJS has relied on the considerable resources afforded by the Census Bureau. Since Census fields the NCVS for the Bureau of Justice Statistics, it was important that they be involved in the planning. More than that, however, they have the resources to test and evaluate prospective methodologies and help determine the best strategies to pursue.

Implementing a Strategy

Building upon the information received through the review of the literature, discussions with all of the groups and individuals referenced above, as well as a review of the survey attributes related to producing measures of victimization against people with disabilities, BJS staff began to construct a strategy to address the mandate with which it had been presented.

The basic components of the strategy BJS developed are as follows:

- Adding questions to the existing NCVS to determine whether the person has a disability.
- Developing modifications to question wordings, proxy respondent rules, interview procedures, and interviewer training to improve the information gathering process within the context of the NCVS interview.
- Explore the enhancement of the NCVS sampling frame to oversample people with disabilities.

- Explore enhancement of the NCVS sampling frame to contain an institutional component.

Given the complexities involved in operationalizing this strategy, it is being implemented in phases. The first two items comprise the first phase, and are the focus of current efforts. The last two items have been discussed, but are presently tabled as future activities once the first phase is completed.

Adding Questions on Disability

Building upon the early work, BJS and the Census Bureau drafted a set of questions designed to identify people with disabilities to be added to the ongoing NCVS. One component of the question set also enabled identification of developmental disabilities. The draft questions were a synthesis of questions currently being administered in a number of other Federal surveys such as the National Health Interview Survey, the Survey of Income and Program Participation, and the American Community Survey. Other surveys, identified by the literature search by the Census Bureau, were also reviewed in the process of developing the questions.

The question strategy adopted was one that utilized a short series of questions to determine respondents' disability status based upon their ability to perform specific activities of daily living. This strategy was adopted because of a requirement to minimize respondent burden on a survey whose real purpose is to measure crime victimization, not disability. Rejected therefore was a more comprehensive set of questions closer to that used by most health-related surveys that asks respondents first about the presence of a set of specific health conditions, impairments, and disabilities, the severity of these conditions, and their abilities to perform major life functions.

BJS and Census then submitted the draft questions to a series of reviews. In early 2000, the questions were presented both to the Census Center for Survey Methods Research and to the Interagency Subcommittee on Disability Statistics. Based upon the critiques from

these groups, some modifications were made to the questions. In July 2000, BJS added the questions to the NCVS on a test basis. These questions are presented in [appendix A](#). Because this is the first implementation of these questions, BJS limited their inclusion. Every household in the NCVS sample is interviewed 7 times over a 3-year period. Between July and December 2000, only "outgoing rotation group" households, those being interviewed for the seventh and last time were eligible for the disability questions. Within these households the questions were only administered to people reporting crime incidents. This was done to minimize respondent burden while evaluating the questions, and at the same time obtain an initial reading of the number of respondents with disabilities who would report crime victimization.

Census is reviewing all responses to these questions to determine how well respondents understand the concepts and how well the questions obtain information about any health conditions or disabilities people may have. Preliminary conclusions are that the questions require some modification, but that the NCVS as the sample is currently constituted will probably not accumulate enough cases to allow for more than very broad annual estimates of victimization of people with disabilities.

In order to obtain a wider review, in early 2000 BJS solicited comments on the draft disability questions from more than 150 individuals from academia, national, State and local government agencies, and public and private practitioners as part of a periodic renewal of the survey's Office of Management and Budget approval. The solicitation was also published on the BJS Web page for increased public exposure. The comments and suggestions resulting from this solicitation contributed to subsequent revisions to the questions.

At the same time, the Census Bureau also continued to evaluate the questions. During the spring and summer of 2000, two rounds of cognitive testing were conducted. Respondents with a broad range of disabilities were recruited and

administered the questions utilizing a procedure developed to access respondents' interpretation of the survey questions and concepts.

This testing identified a number of problems with the draft question set, including sequencing and wording of some concepts. Additionally, the question concerning activity limitations failed to elicit some actual impairments. Based upon this test, the questions were revised and a second phase of cognitive testing conducted. The results of this round of testing were evaluated and some additional changes were incorporated. This set of questions is presented in [appendix B](#).

This aspect of the testing and evaluation of questions to identify disabilities was limited by the small numbers of cases available for consideration. Therefore, BJS is developing another research activity to help develop a set of questions. In the spring of 2001, BJS plans to interview a sample of 200 people with developmental disabilities drawn from California's Client Development Evaluation Report (CDER) program. The goals of this project are twofold:

- Determine how well the draft disability questions identify persons known to be receiving services for cognitive and other disabilities
- Evaluate modifications to standard NCVS victimization questions and survey procedures that may enhance the quality of information obtained from people with intellectual and other disabilities

While the CDER file includes people with severe and profound intellectual disabilities, this study will be restricted to individuals who have, at most, moderate retardation, since those with more severe intellectual disabilities are more likely to reside in institutions, which are outside the current NCVS sampling frame.

Plans call for the sample to be divided into two groups. One group will be administered the current NCVS instrument, plus the most current draft disability questions. This will be the control group. The study group will be administered instruments that have been modified to simplify the language. In

addition, the sample will include a small number of people without identified disabilities (not drawn from the CDER list) to act as additional controls.

Interviewers will complete diaries recording problems and other pertinent information about every interview and interviewer debriefing sessions will be held to further evaluate the results of the study.

To assist in developing this study, BJS has contracted with a consultant with extensive experience in interviewing people with developmental disabilities. The consultant will also assist in training interviewers and reviewing the results of the study.

The results of the California pretest will be evaluated to further revise and improve the set of disability questions. The resulting questions will be incorporated into the NCVS interview. It is likely, however, that further revisions will be made as the first data are analyzed. Therefore, those expecting data in the near future are likely to be disappointed.

In addition to the question development, in the coming years, BJS and the Census Bureau will undertake several long-term initiatives to further implement its strategy to create a viable, reliable measure of victimization against people with disabilities. Experience with initiatives to develop measures of victimization in other areas, such as violence against women, teaches that the development of viable measures is an iterative process. Each step produces some improvements. Ultimately, this is a complex problem that will require a series of refinements in order to meet the overall goal of achieving a measure of victimization of persons with disabilities.

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Appendix A

Questions Administered During the Round 1 Cognitive Interviews

<p>1. The next questions ask about any health conditions, impairments, or disabilities you may have.</p> <p>Due to a health condition, impairment, or disability, are you limited in any of the following major life activities? (Read answer categories)</p> <p>(Mark X all that apply)</p>			
a. Self-care, such as bathing, dressing, or feeding yourself?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
b Communicating, such as talking with or listening to other people?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
c Learning any new skills or activities?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
d Mobility, such as bending, walking, climbing stairs, or carrying something weighing 10 pounds?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
e Self-direction, such as making important decisions concerning your health care, education, or career?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
f. Living independently, such as preparing meals, shopping for groceries and personal items, and doing housework?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
g Managing finances, such as keeping track of your money and paying bills?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know

CHECK ITEM A	
Look at 1. Is "Yes" or "Don't Know" marked for any Items a-g?	<input type="checkbox"/> Yes - Ask Question 2 <input type="checkbox"/> No - End Interview
2. What specific health conditions, impairments, or disabilities do you have which limit your ability to [fill with 'Yes' responses from Question 1]?	0 <input type="checkbox"/> _____ 1 <input type="checkbox"/> _____ 2 <input type="checkbox"/> _____ 3 <input type="checkbox"/> _____
FIELD REPRESENTATIVES - List first 3 conditions reported by respondents	
CHECK ITEM B	
Look at 2 Is only one health condition, impairment, or disability reported?	<input type="checkbox"/> Yes - Ask Question 3a <input type="checkbox"/> No - Ask Question 3b
3a. You just reported that [fill with health condition from Question 16] limits you major life activities. Has this condition lasted longer than six months?	1 <input type="checkbox"/> Yes - SKIP to Check Item C 2 <input type="checkbox"/> No - SKIP to Check Item C
3b. You just reported that [fill with health conditions from Question 2] limits your major life activities. Which of these conditions lasted longer than six months?	0 <input type="checkbox"/> None - SKIP to Check Item C 1 <input type="checkbox"/> _____ 2 <input type="checkbox"/> _____ 3 <input type="checkbox"/> _____
CHECK ITEM C	
Look at 2. Is only one health condition, impairment, or disability reported?	<input type="checkbox"/> Yes - Ask Question 4a <input type="checkbox"/> No - Ask Question 4b

<p>4a. Do you consider your [fill with health condition from Question 2] to be mild, moderate, or severe?</p>	<p>1□ Mild 2□ Moderate 3□ Severe 4□ Don't know</p>
<p>4b. Do you consider your [fill with FIRST health condition from Question 2] to be mild, moderate, or severe?</p>	<p>1□ Mild 2□ Moderate 3□ Severe 4□ Don't know</p>
<p>And what about your [fill with SECOND health condition from Question 2]? Do you consider it to be mild, moderate, or severe?</p>	<p>1□ Mild 2□ Moderate 3□ Severe 4□ Don't know</p>
<p>And what about your [fill with THIRD health condition from Question 2]? Do you consider it to be mild, moderate, or severe?</p>	<p>1□ Mild 2□ Moderate 3□ Severe 4□ Don't know</p>
<p>CHECK ITEM D</p> <p>Is respondent's age greater than or equal to 22?</p>	<p><input type="checkbox"/> Yes - Go to Check Item E <input type="checkbox"/> No - SKIP to Question 6a</p>
<p>CHECK ITEM E</p> <p>Look at 2 Is only one health condition, impairment, or disability reported?</p>	<p><input type="checkbox"/> Yes - Ask Question 5a <input type="checkbox"/> No - Ask Question 5b</p>
<p>5a. Did your [fill with health condition from Question 2] begin before age 22?</p>	<p>1□ Yes 2□ No 3□ Don't know</p>
<p>5b. Which of your health conditions, impairments, or disabilities began before age 22?</p>	<p>0□ None 1□ _____ 2□ _____ 3□ _____</p>

<p>6a. You just reported [fill with incident]. Do you have any reason to suspect you were victimized because of your health condition(s), impairment(s) or disability(ies)?</p>	<p>1□ Yes - Ask Item 6b 2□ No - End Interview 3□ Don't know - End Interview</p>
<p>6b. Which of your health conditions, impairments, or disabilities do you believe caused you to be targeted for the [fill with incident]?</p>	<p>1□ _____ 2□ _____ 3□ _____</p>

Appendix B

Questions Revised based on Round 2 of Cognitive Testing

<p>1a. The next questions ask about any health conditions, impairments, or disabilities you may have.</p> <p>Do you have any health conditions that require you to take medication or to see a doctor on a regular basis?</p>	<p>1□ Yes - Ask 1b 2□ No - SKIP to 1c</p> <hr/> <hr/> <hr/> <hr/> <hr/>
<p>1b. What health conditions do you have that require medication or regular visits to the doctor?</p>	<p>1□ _____ 2□ _____ 3□ _____ 4□ _____ 5□ _____</p> <hr/>
<p>1c. Does a mental health condition currently keep you from participating fully in work, school, or other activities?</p>	<p>1□ Yes 2□ No</p> <hr/>
<p>2. Other than the health conditions you just mentioned:</p> <p>a. Do you have a hearing impairment? b. Are you legally blind or do you have a significant vision loss? c. Do you have a cognitive impairment? (By this I mean an impairment of the mind, such as a brain injury or a stroke, that causes you to have difficulty thinking and/or making decisions.) d. Do you have any other impairments?</p>	<p>1□ Yes 2□ No 3□ Don't Know</p> <p>1□ Yes 2□ No 3□ Don't Know</p> <p>1□ Yes 2□ No 3□ Don't Know</p> <p>1□ Yes - Specify 2□ No 3□ Don't Know</p> <hr/>

<p>3. Do you have:</p> <p>a. Osteo or Rheumatoid Arthritis?</p> <p>b. Cerebral Palsy?</p> <p>c any other disabling condition?</p>	<p>1□ Yes 2□ No 3□ Don't Know</p> <p>1□ Yes 2□ No 3□ Don't Know</p> <p>1□ Yes - Specify 2□ No 3□ Don't Know</p> <hr/>
<p>4a. Do you use any aids to help you with your day-to-day activities? (for example, a cane, wheelchair, artificial limb, hearing aid, or a guide dog)</p> <hr/> <p>4b. Why is necessary for you to use these aids?</p> <hr/> <hr/> <hr/> <hr/>	<p>1□ Yes - Ask 4b</p> <p>2□ No - SKIP to 5a</p> <p>9□ Refused</p> <hr/> <p>1□ Please specify</p> <hr/> <hr/> <hr/> <hr/> <p>9□ Refused</p>
<p>5a. Have you ever been enrolled in special education classes or SPED?</p> <hr/>	<p>1□ Yes - Ask 5b</p> <p>2□ No - SKIP to 6</p> <p>9□ Refused</p> <hr/>
<p>5b. Why were you enrolled in special education?</p> <hr/> <hr/> <hr/> <hr/>	<p>1□ Please specify</p> <hr/> <hr/> <hr/> <hr/> <p>9□ Refused</p>
<p>6. Do you consider yourself to have a disability?</p>	<p>1□ Yes</p> <p>2□ No</p>

<p>CHECK ITEM A</p> <p>Look at 1b, 1c, 2, 3, 4b, and 5b. List ALL health conditions, impairments, and disabilities reported by the respondent. NOTE Only list each reported condition one time.</p> <p>0□ None reported - GO to Additional Questions</p> <p>1 _____ 6 _____ 2 _____ 7. _____ 3 _____ 8. _____ 4 _____ 9. _____ 5 _____ 10. _____</p>	
<p>Is ONLY one health condition, impairment, or disability reported?</p>	<p><input type="checkbox"/> Yes - Ask 7 <input type="checkbox"/> No - SKIP to 9</p>
<p>7. Has your [fill with health condition from Check Item A] lasted longer than six months?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p>
<p>CHECK ITEM B</p> <p>Is respondent's age greater than or equal to 22? (Look at control card Item 17)</p>	<p><input type="checkbox"/> Yes - Ask 8 <input type="checkbox"/> No - SKIP to 11</p>
<p>8. Did your [fill with condition from Check Item A] begin before age 22?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No SKIP to 12 <input type="checkbox"/> Don't know</p>
<p>9. You just reported [fill with conditions from Check Item A]. Which of these has lasted longer than six months?</p>	<p><input type="checkbox"/> None 1<input type="checkbox"/> _____ 2<input type="checkbox"/> _____ 3<input type="checkbox"/> _____ 4<input type="checkbox"/> _____ 5<input type="checkbox"/> All</p>
<p>CHECK ITEM C</p> <p>Is respondent's age greater than or equal to 22? (Look at control card Item 17)</p>	<p><input type="checkbox"/> Yes - Ask 10 <input type="checkbox"/> No - SKIP to 11</p>

<p>10. Which of your health conditions, impairments, or disabilities began before age 22?</p>	<p>0□ None 1□ _____ 2□ _____ 3□ _____ 4□ _____ 5□ All</p>
<p>11. Because of a health condition, impairment, or disability, do you have difficulty or need help:</p> <ul style="list-style-type: none"> a taking care of yourself, such as bathing, dressing, or eating? 1□ Yes 2□ No 3□ Don't know b communicating, such as talking with or listening to other people? 1□ Yes 2□ No 3□ Don't know c learning any new skills or activities? 1□ Yes 2□ No 3□ Don't know d with mobility, such as bending, walking, or climbing stairs? 1□ Yes 2□ No 3□ Don't know e making important decisions for yourself about your health care, education, or career? 1□ Yes 2□ No 3□ Don't know f living independently, such as preparing meals, shopping for groceries and personal items, and doing housework? 1□ Yes 2□ No 3□ Don't know g managing your finances, such as keeping track of your money and paying bills? 1□ Yes 2□ No 3□ Don't know 	
<p>12. During the incident you just told me about, do you have any reason to suspect you were victimized because of your health condition(s), impairment(s) or disability(ies)?</p>	<p>1□ Yes 2□ No 3□ Don't know</p>

Part 2. Discussion of Papers

Discussion of the Disability Survey Papers Presented at the Statistical Policy Seminar

by Katherine D. Seelman, National Institute on Disability and Rehabilitation Research

Good afternoon. I am pleased to be here today on behalf of the National Institute on Disability and Rehabilitation Research. I want to underscore several points that were made here this afternoon.

Along with many others, I have worked over the years to assure inclusion of people with disabilities in our data collections. Any data collection that has policy implications—whether in employment, crime, health, or other areas—must include a way to identify the implications for people with disabilities. Today's session includes papers that demonstrate that we have made some progress in that direction.

There is a critical need for interagency collaboration to assure inclusion of people with disabilities in data collections. At the present time, as today's papers indicate, there are independent efforts underway to identify ways to measure impacts upon people with disabilities. Our presenters described significant progress in including people with disabilities in their respective data collections. However, the questions that identify people with disabilities are being developed, to a great extent, independently of one another. I recognize that there is some overlap among participants in the respective efforts. Nonetheless, whether by mandate or purpose of the data collection, the disability measures differ.

The Interagency Subcommittee on Disability Statistics has been an ongoing means to monitor the progress of the various developments described here

today. The subcommittee includes representatives from agencies that are part of the Interagency Committee for Disability Research. Most Federal agencies and numerous researchers are included. I mention the subcommittee because it is one model of interagency exchange.

Disability statistics can be gathered in two general ways. First, one can conduct a large-scale survey of people with disabilities. Such a survey can include questions to assess numerous factors. The National Health Interview Survey on Disability was such an effort. Conducting a national disability survey is a great undertaking, one that has not been done often enough. However, the large-scale survey inevitably makes compromises in the amount of data that can be collected to address some policy questions.

A second approach to gathering disability statistics is inclusion of appropriate measures in existing data collections, such as the Current Population Survey and the National Crime Victimization Survey. The advantage of this approach is that we can draw upon the full extent of those existing surveys. In addition, we can obtain relevant information on a continual basis rather than having only the large-scale disability survey as an infrequent measurement tool.

We need an effort to develop consistent measurements of disability using short sets of variables. In the past, through the National Academy of Sciences, we have seen efforts focused on measuring functional capacity and on

measuring work disability. There is interest in the government, academic, and consumer communities for an effort to develop measures to assure that people with disabilities are counted in all efforts that help develop policy.

Along with consistent questions about disability, our data collections must be sensitive to the needs of people with disabilities. Some disabilities, such as sensory and cognitive, may present special challenges to data collection. Gerry Hendershot deserves recognition for his efforts to highlight data collection issues. We need innovative strategies to assure that no one is left out of the picture.

Finally, it is time to rethink the ways in which we obtain information about people living in group homes or institutions. Too many of our efforts focus upon the noninstitutionalized populations. The focus on the noninstitutionalized population excludes some people with disabilities from our knowledge base.

A Critique of Current Practices of Measuring Disability in Federal Surveys

by Monroe G. Sirken, National Center for Health Statistics

A. Introduction

The papers that were presented at the policy seminar session "Integrating Comparable Measures of Disability in Federal Surveys" describe the current research efforts of four Federal agencies to collect disability statistics in their respective surveys. The four agencies are the Bureau of Justice Statistics (BJS), the National Center for Health Statistics (NCHS), the Bureau of Labor Statistics (BLS), and the Social Security Administration (SSA). Each agency is making progress in developing and testing questions to identify people with disabilities in its surveys—no small achievement because disability is a multidimensional concept that presents very difficult measurement problems in population and medical provider surveys.

The four agencies are in pretty good agreement on the conceptual aspects of disability measurement as postulated in the *International Classification of Impairments and Handicaps* (1), now known as the *International Classification of Impairments, Disabilities, and Handicaps* (2). Accordingly, the data collection instruments of all four agencies identify people with disabilities in terms of the body functions and structures involved and the extent of personal activity and societal participation limitation. No

doubt, comparability that exists at the conceptual level was facilitated by frequent exchanges of information at the Interagency Subcommittee On Disability and other interagency committees and work groups.

Exchange of information between the agencies appears to have been insufficient, however, to assure comparability between the agencies in the operational aspects of disability measurement. The surveys differ in the kinds of disability questions asked and information sources used, and it appears that each agency is developing its own set of disability questions fairly independently. Program objectives of the four agencies differ, questions to identify people with disabilities being developed by the agencies differ, and counts of people with disabilities identified in the surveys will differ from agency to agency in ways and amounts unknown unless statistical crosswalks, which apparently are not under consideration at this time, are constructed between the disability data collected in the different surveys.

In summary, the four agencies appear to be doing a pretty good job of developing disability measurements responsive to their respective agency needs but do not appear to be concerned about interagency comparability in disability measurement.

Typically, agencies in our decentralized statistical system do not

on their own volition greatly concern themselves with integrating Federal statistical information especially when they perceive, as is often the case, that doing so diminishes their efforts to expeditiously pursue their own program objectives. In contrast to this prevailing viewpoint, I propose the following paradigm:

it is *necessary* and *effective* for agencies to seek consistency and comparability in Federal statistics at the same time they are developing methodologies that meet their own distinct programmatic needs.

In part B of these remarks, arguments are presented in support of the "necessary" condition of this paradigm, and in part C, research strategies are proposed in support of the "effective" condition of the paradigm. In each part, examples are drawn from the current activities of the four agencies as described in the papers presented at this session.

B. Arguments Supporting the "Necessary" Condition of the Interagency Paradigm

In her commentary on these papers appearing in this report, Dr. Seelman notes that there is widespread interest "... to develop measures to assure that people with disabilities are counted in all efforts that help develop policy." She stresses the importance for policy purposes of counting people with disabilities consistently in all these efforts. Without interagency comparability in disability measurement, for example, it will be difficult to assess the combined effects of the Americans with Disabilities Act on the improving the rights of people with disabilities in different subject areas such as health, labor force, and crime. In the absence of official standards for disability measurement in Federal surveys, who else but the statistical agencies legislatively mandated to collect

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statistics on people with disabilities, have greater responsibility to assure comparability between the disability measurements of their surveys?

Unless the disability survey measurements of the four Federal agencies are integrated, the individual agencies may be unable to effectively meet their own programmatic needs for disability statistics. For example, the Social Security Administration (SSA) will depend on disability information from its single-time National Study of Health and Activity (NSHA) to make projections of the future growth in SSA disability claims. However, unforeseen changes in the national population would require either redoing NSHA, an exorbitantly expensive option, or updating and revising the single-time NSHA-based projections with disability information obtained from other sources. If the latter option is selected, the most likely other sources for the disability information will be the ongoing surveys of the other Federal agencies. Updating the SSA projections in this manner would be precarious unless the measures of disability in Federal surveys are comparable.

C. Research Strategies Supporting the “Effective” Condition of the Interagency Paradigm

There are short-term research strategies and long-term research strategies for coordinating disability survey research activities of Federal agencies. The objective of short-term research is to improve existing methodologies in the current generation of disability surveys. The objective of long-term research is to develop innovative methodologies for the next generation of disability surveys. I argue that coordination of interagency short-term and the long-term survey research activities in disability measurement offers Federal agencies opportunities to enhance their own benefits while benefiting other agencies.

It is noteworthy that short-term strategies for coordinating disability survey research would be particularly fruitful now when all of these four agencies are actively conducting disability measurement survey research. Clearly, research coordination would be cost effective. For example, short-term research coordination provides opportunities to reduce duplication of efforts in questionnaire development and design, including bibliographic searches of disability questions, developing disability questions in cognitive research laboratories, field testing disability questions in split-ballot experiments, etc. It also provides opportunities to make interagency comparisons of disability measurements a vital first step in the direction of disability information integration. For example, simultaneously testing the disability questions for the Current Population Survey (CPS) and the National Crime Victimization Survey (NCVS) offers opportunities to compare the counts of people with disabilities that are based on two versions of short sets of disability questions. Embedding the CPS and NCVS disability questions in the NSHA field tests offers opportunities to compare the counts of people with disabilities that are based on self-reports of disability in CPS and NCVS with counts of disability based on self-reports, medical records, and clinical observations in NSHA.

Long-term strategies for coordinating interagency survey research provide Federal agencies with opportunities to collectively sustain basic research in disability measurement in a decentralized statistical system in which few, if any, individual agencies are likely to undertake such research independently. For example, basic research on the response effects of working memory differences between cognitively impaired and unimpaired respondents in disability surveys could lead to innovations in the design of disability survey instruments and the analysis of disability survey data (3,4).

Recently, a giant step forward in coordinating interagency survey and statistical research was taken when a research grant mechanism was established to foster basic survey research that is oriented to the needs of

Federal agencies. The grant mechanism is called the Funding Opportunity In Statistical and Survey Research (5) and is supported by a consortium of Federal statistical agencies and the National Science Foundation. Fortunately, all four agencies participating in this session are charter members of the consortium of Federal agencies that is in supporting the Funding Opportunity. It would be a relatively simple matter for these four agencies to coordinate and support their common interests in disability measurement research within the framework offered by the Funding Opportunity.

D. A Final Remark

In his paper appearing in this report, Gerry Hendershot suggests that “the time may be right” for proposing standards that require or recommend that all ongoing Federal surveys routinely collect simple measures of disability. Basically, I am in agreement with Dr. Hendershot, but I propose that “now is the right time” to formally establish interagency work groups to coordinate disability measurement research activities among Federal agencies as an initial step in the formal process of developing official Federal standards for disability measurement.

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