



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

FEDERAL DISABILITY DATA:

**CREATING A STRUCTURE IN THE
1990s TO FURTHER THE GOALS OF
THE ADA**

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Office of the Assistant Secretary for Planning and Evaluation

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This report was prepared by HHS's Office of Family, Community and Long-Term Care Policy (now DALTCP). It was presented at the National Council on Disability Conference "Furthering the Goals of the ADA through Disability Policy Research in the 1990's," Hyatt Regency, Washington, DC. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The Project Officer was Michele Adler.

**FEDERAL DISABILITY DATA:
Creating a Structure in the 1990s to Further the
Goals of the ADA**

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PURPOSE

Landmark legislation has the power to change people's lives for many years to come. The ADA, signed into law on July 26 1990, is landmark legislation for Americans with disabilities. The four goals of the ADA--equality of opportunity, full participation, independent living, and economic self-sufficiency--are broad in scope and bold in nature.

The ADA is not the first piece of landmark legislation. In this century, we have seen the enactment among others of the Social Security Act of 1935, the Civil Rights Act of 1964, and the Social Security Amendments of 1965, under which Medicare and Medicaid were created. We have a strong statistical structure in place to measure the progress and evaluate the effects of this earlier legislation. However, no similar statistical structure exists to describe the role of disability in American society or to monitor compliance with the ADA.

The purpose of this paper is to examine how Federal disability data in the 1990's can be structured to be useful in policy debates that will further the goals of the ADA.

WHY DO WE NEED DISABILITY DATA?

We need disability data, because quite simply disability is critically important. Depending on how disability is defined, there are over 40 million Americans with disabilities of one kind or another. This makes people with disabilities one of the largest constituencies in the country. We know little about them.

First, many Federal programs serve the needs of persons with disabilities. Secondly, disability is a major Federal effort and includes: (1) programs that provide cash assistance, such as Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), and the Black Lung program; (2) programs that provide health insurance and direct medical care such as Medicare, Medicaid, and the Department of Veterans' Affairs health programs, and CHAMPUS for the Handicapped; (3) programs that provide a range of direct supportive services; such as those from the Administration on Developmental Disabilities; the Maternal and Child Health Block Grants; Alcohol, Drug Abuse, and Mental Health Block Grants; State Grants for Children with Disabilities; State Operated Programs for Handicapped Children; Preschool Grants Program; and Infants and Toddlers with Disabilities Program; and, (4) programs that pertain to rehabilitation, such as the Basic Vocational Rehabilitation Service program.

The Federal government is also involved in funding basic research designed to enable persons with disabilities to lead independent lives. For example, there are programs in NASA, the DVA, and DoD's National Strategic Defense Initiative which adapt defense and space-age technology for rehabilitative purposes. Finally, Congress

mandated the establishment in FY 1991 of the National Center for Medical Rehabilitation Research (NCMRR) within the National Institutes of Health.

The budgetary importance of all these programs is tremendous. In fiscal year 1989, 8 percent of Federal outlays or \$85 billion was spent on Federal programs targeted just on nonelderly persons with disabilities. Obviously, persons with disabilities and the programs which serve them are critically important. And obviously, it is crucial to have accurate and timely information on persons with disabilities, particularly in light of the ADA.

WHAT DO WE NEED TO KNOW ABOUT DISABILITY IN THE U.S.?

In order to monitor ADA compliance and perform disability policy research, we need to be able to describe the population with disabilities, to determine the effects of current programs, and to assess the effects of program changes. A very important use for data is modeling the effects of proposed program or policy changes and coming up with estimates of the number of people who would be affected and the amount of money that such changes would cost. In these days of constrained resources, cost estimates are an absolute necessity for sound program planning.

Not just any information will do. A broad array of data are needed in addition to information just on disability. Specifically since Federal programs rely on other criteria for eligibility, we need information on other aspects of a person's life besides disability, such as income, assets, and work experience (to name a few). Secondly, definitions of disability typically vary by program and this can be problematic. Thirdly, persons with disabilities are not all alike. They include people with chronic mental illness, those with developmental disabilities, persons with mobility limitations, and those with chronic illnesses, to name a few. Finally, persons with disabilities cut across all ages from newborns to centenarians--with different needs for each age group. All this heterogeneity makes it difficult to design disability surveys and to translate survey results into policy analyses.

WHAT DATA DO WE HAVE?

National population-based surveys underlie much of what we know about many topics including disability. National population-based surveys are those which obtain information on individual people and their families by selecting a national sample of addresses and interviewing the people who live there. Nearly all such surveys are collected by the Federal government and many have been in place for decades. These surveys are complex, expensive, and take years to plan.

Numerous Federal surveys are in existence, none of which focus primarily on disability. That was not always the case. The Social Security Administration conducted the Surveys of Disability and Work every few years beginning in the early 1960's. The purpose of these surveys was to measure the extent of disability in the working-age population (18-64) and to specifically examine the experience of disabled workers and their families for use in the SSDI program.

The last Survey of Disability and Work was conducted in 1978. No other disability survey has occurred since that time. Furthermore, while the Surveys of Disability and Work dealt exclusively on the working-age population, we have never had a national population-based disability survey which focused on all ages or on all causes of disability.

As a result, we know almost nothing about some very important policy-relevant groups, such as children with disabilities and people with developmental disabilities. For example, estimates of the number of children with disabilities range from 1 to 10 million. We don't know which estimate is the most accurate and we know little about these children or their families. This became problematic when faced with deciding what the impact of the Zebley decision would be. As for developmental disabilities, we don't even know how many people in this country are developmentally disabled, let alone how many reside in the community or what services they need or use.

Besides national population-based surveys, we also have administrative records for specific Federal programs on disability. However, this information is limited to people who receive program benefits, not those who could potentially receive benefits. . Furthermore, confidentiality restrictions limit data access to only a few agency staff. We also have epidemiological studies or State data, which are useful for specific studies. Therefore, to have an impact on disability data in the 1990's, it is probably wisest to concentrate on national population-based surveys.

WHAT OPTIONS DO WE HAVE?

A national comprehensive survey totally devoted to disability would probably not be ready at least until the year 2000, even if we decided today to create and support one. We need to collect data on ADA compliance before the end of this decade and we need to do it in a cost-effective manner. The most practical way to do this is to build off existing surveys by adding or modifying questions on disability. Although there are dozens of Federal surveys, there are several major or workhorse surveys which serve as the basis for almost everything we know about social policy. The surveys are:

- the Decennial Census
- the Survey of Income and Program Participation (SIPP)
- the Current Population Survey (CPS)
- the National Health Interview Survey (NHIS)

These basic surveys have all collected disability data in some way and at some time, but with the exception of the NHIS, disability data have been collected on an ad hoc, not a routine basis. Even on the NHIS, routine collection of disability data has mainly consisted of questions on limitation of activity.

During the past few years, all of these surveys have had a disability component and all have been approached to add more information on disability. The most ambitious and promising source of disability data and the only one which addresses the four goals of the ADA is the 1993/94 Disability Survey, which is a supplement to the National Health Interview Survey (NHIS), planned to begin in April 1993 and continue through the end of 1994. This is not solely a disability survey, but a disability survey spun off of a health survey.

WHAT IS THE 1993/94 DISABILITY SURVEY?

The NHIS, sponsored by the National Center for Health Statistics (NCHS), contains a 40-minute core interview of a national household sample. The interview covers health status, health care utilization, conditions, and limitations of activity. The contents of the core questionnaire have essentially remained the same since 1957. In addition to the NHIS core, there is also a 30-minute supplementary interview, the topic of which changes every year. During 1993 and 1994, this supplement will be devoted to disability. Results could be available as early as the middle of 1994.

The 1993/94 Disability Survey grew out of a coordinated effort at the Department of Health and Human Services (DHHS) to obtain data on disability. The Departmental Coordinating Group on Disability Data was formed in 1989 to establish a framework for disability data. This was accomplished by reviewing existing data, identifying gaps, and interviewing both DHHS technical staff and policymakers about their disability data needs.

In the interview phase, DHHS policymakers indicated a range of data needs on disability. These included:

- What are the characteristics of people with disabilities who rely on DHHS programs? While program records contain characteristics of people with disabilities, data are limited and rarely contain information on family characteristics, such as health insurance coverage and income.
- Why is growth in SSI and SSDI enrollment and costs so high? Applications for SSI and SSDI grew 12 percent from 1990 to 1991 compared to only 4 percent between 1988 and 1989.
- Why is employment among persons with disabilities so low? Reasons why some people with the same disabilities work while others do not are unclear. Although

people with disabilities have relatively low employment rates, many do work. In 1984, 9½ percent of those receiving SSI or SSDI were employed.

- What is the extent of disability among children? As a result of the Zebley Supreme Court decision and the new SSA childhood regulations, the number of children on SSI is growing rapidly about 100 thousand children were added last year.
- How do persons with mental retardation and other developmental disabilities access community services? In 1991, per capita Medicaid costs for persons in intermediate-care facilities for the mentally retarded (ICF-MRs) were \$52,700--an increase of 40 percent over 4 years. We know almost nothing about the community side. We need to know more about these individuals: their numbers, characteristics, the services they use and the costs of these services.
- How does access to health care vary for people with disabilities? The cause and the stage of disabling conditions play a major role in access to health care, but that role is unclear. People with the most severe disabilities use 6 times more physician visits and 3½ times more hospital stays than those with no disabilities. Sources of health insurance coverage also vary--51 percent of those with the most severe disabilities are on Medicare or Medicaid compared to 4 percent of those with no disabilities.
- What is the impact of racial/ethnic differences in disability? Disability varies by race and ethnicity, but we don't know why. Among nonelderly adults, the most severe functional disabilities are found in 1 in 50, Whites, 1 in 33 Blacks, 1 in 30 Hispanics, and 1 in 20 American Indians. We need to know more about why disability rates vary so much and if there are differences in the receipt of disability benefits from SSI and SSDI and their medical companion programs--Medicaid and Medicare.

After policy interviews were held and the Department's disability data were closely examined, the consensus was that while our need for information on disability was great, little information existed. There were no plans for data collection until 1990, when four separate disability surveys were proposed by different components in DHHS. All proposing agencies agreed to coordinate their efforts into the 1993/94 Disability Survey. Coordination was a sensible and cost-effective approach. The four surveys, which evolved into the 1993/94 Disability Survey were:

1. National Survey of Persons with Developmental Disabilities, proposed by the Office of the Assistant Secretary for Planning and Evaluation (ASPE), was a survey of persons with mental retardation and/or developmental disabilities. This survey was proposed because increasingly, programs and policies treat individuals with mental retardation and/or developmental disabilities as a single group where eligibility is determined functionally rather than diagnostically. Estimates of the developmentally

disabled population are not known and range from 1.2 to 4.5 million. No such survey has ever been done.

2. SSI Low Income Survey, proposed by the Office of Supplemental Security Income (SSA), was a survey of actual and potential SSI recipients designed to obtain basic information for policy analysis, program expansions or changes, and outreach efforts. The last such survey, the Survey of Low-Income Aged and Disabled (SLIAD) was conducted in 1974.
3. National Disability Survey, proposed by the Office of Disability (SSA), was a survey of working- age adults who either are or could potentially receive SSDI so as to assess policy issues such as rehabilitation and work incentive strategies. This survey builds off the experience of the Surveys of Disability and Work conducted by SSA during the 1960's and 1970's.
4. National Child Health Assessment and Planning Project, proposed by the Bureau of Maternal and Child Health and Resources Development, Public Health Service, was a survey of children with disabilities. Estimates of disabled children range from 1 to 10 million, depending on how disability is defined and which ages are included. A 2½ year planning grant to the Albert Einstein College of Medicine, Department of Pediatrics, Bronx, New York was instrumental in designing the survey.

WHAT IS THE DESIGN OF THE 1993/94 DISABILITY SURVEY?

The 1993/94 Disability Survey will have two parts. The first part or Phase I will be given immediately after the NHIS core interview is administered in all sample households. Phase I will collect basic descriptive information on the prevalence of disability and identify the four populations of particular policy interest. The Phase II interview will follow Phase I two months later and only be given to persons with disabilities who were identified in Phase I. The Phase II interview will collect detailed information on service use and expenditure patterns--key information for policy analysis.

Two years of data collection--1993 and 1994--are needed in order to get a large enough sample. Nationwide, about 200,000 people in 100,000 households will participate in Phase I, with approximately 40,000 people in Phase II.

The Disability Survey has been extensively reviewed throughout the Federal disability community during the last year. In addition, the questionnaire has been voluntarily tested by people with disabilities and their families through the NCHS Cognitive Questionnaire Lab. A 250 household pretest was also conducted in the Washington, DC area this fall.

The Disability Survey has some other attractive features. Information can be linked to the rich data on health care and utilization gathered in the core NHIS and we can learn about the characteristics of both individuals with disabilities and members of their families. The data can also be linked to administrative disability records at SSA and Medicare records at HCFA. Furthermore, while the Disability Survey is a one-time or snapshot survey, provisions can be made to follow respondents back and reinterview them for up to 10 years. Thus, the Disability Survey can be used as the basis for longitudinal studies.

HOW IS DISABILITY DEFINED IN THE DISABILITY SURVEY?

The hardest part of designing any disability survey is deciding how to define disability. Since there is not even a single framework for defining disability, it is not surprising that there is no single recognized definition of disability, either for research or for policy purposes.

Disability or an inability (or difficulty) to perform societal roles, is hard to define, because so many aspects of human behavior are involved in determining societal roles. Furthermore, these roles vary by age, gender, and culture.

DHHS has devoted considerable time and resources to designing the Disability Survey so that disability can be measured from many aspects. Phase I, which contains the measures of disability, was designed to include in-depth measures of almost every broad definition of disability--functional, sensory impairments, mental/cognitive impairments, receipt of disability benefits, childhood disabilities, developmental disabilities, and the use of assistive devices. The different types of measures also include severity, nature, onset, and duration. Compromises had to be made, but the resultant product contains strong state-of-the-art measures.

Many of these measures have appeared for years in other surveys, but specific components of the questionnaire--notably those sections dealing with children, mental illness, and developmental disabilities are new. Due to the lack of good measures of childhood disability, we derived new ones, including those which pertain to infants and toddlers. New measures were also constructed to identify people with developmental disabilities. Similarly, a group of esteemed psychologists from the National Committee on Vital and Health Statistics designed the questions on mental illness and cognitive impairments.

Finally, questions adapted from the ADA definition itself on the perception of disability are also included. These questions are:

- “Do you consider yourself or anyone in your family to have a disability?”
- Who is this? Anyone else?

- Would other people consider you or anyone in your family to have a disability?
- Who would others consider to have a disability?"

HOW CAN THE DISABILITY SURVEY BE USED TO MONITOR ADA COMPLIANCE?

The 1993/94 Disability Survey is the only survey which can help us understand the impact of all four ADA goals. The Disability Survey is constructed so that while Phase I will measure the prevalence of disability, Phase II will collect data on the lives of people with disabilities, such as transportation, housing, caregiving, use and out-of-pocket costs for services, social interaction, employment, accommodations, and vocational rehabilitation.

Specific data items which will help us understand the four ADA goals are given below:

Equality of Opportunity

- Ability to Work
- Access to Health Care
- Employment
- Work History
- Employer Accommodations
- Occupation
- Earnings
- Health Insurance Coverage and Rejection
- Federal Program Participation (SSDI, SSI, AFDC, IEP, etc.)
- Service Use (i.e. therapies, personal care, mental health)
- Vocational Rehabilitation
- School Attendance
- Wealth
- Race/Ethnicity/Gender/Age

Full Participation/Social Integration

- Social Activity
- Family Relationships
- Impact on Family (for children)
- Child Care
- Educational and Recreational services (for children)
- Federal Program Participation (SSDI, SSI, AFDC, IEP, etc.)
- Service Use (i.e. therapies, personal care, mental health)

Independent Living

- Sensory Impairments
- Assistive Devices
- Communication

- Mobility and Functioning
- ADLs/IADLs
- Ability to Work
- Mental Illness/Cognitive Impairments
- Mental Retardation
- Developmental Levels (for children)
- Case Management
- Service Use (i.e. therapies, personal care, mental health)
- Self Direction
- Personal Care Attendants/Caregivers
- Home Care
- Housing and Modifications
- Home ownership
- Transportation

Economic Self-Sufficiency

- Ability to Work
- Access to Health Care
- Employment
- Work History
- Occupation
- Earnings
- Interest income
- Health Insurance Coverage and Rejection
- Federal Program Participation (SSDI, SSI, AFDC, IEP, etc.)
- Ownership of Home and Motor Vehicles
- Wealth

HOW CAN OTHER BASIC SURVEYS HELP MONITOR ADA COMPLIANCE?

The other basic surveys--the Decennial Census, the SIPP, the CPS, and the NHIS--can also help monitor at least some parts of ADA compliance during this decade, although not to the same extent as the 1993/94 Disability Survey. Each survey has its strengths and each has a major purpose other than disability. We will not be able to change these surveys into disability surveys, but we can modify their design so that the ADA and other disability policy can be evaluated. Very often, this means simply adding or strengthening items which would identify people with disabilities.

Specifically, these surveys could be improved with regard to disability data in the following ways:

- Decennial Census: *Insure that disability is collected in the Year 2000 Decennial Census by participating now in the planning process.* The purpose of the

Decennial Census is to collect data every ten years to be used for Congressional redistricting, as called for in the U.S. Constitution. However, a variety of demographic and socioeconomic data have also been gathered for almost 200 years. The strength of the Decennial Census is that it is the only survey in this country which can provide estimates for virtually every geographic entity from the nation as a whole to States, counties, Indian reservations, and blocks. Limited information on disability in one form or another have been collected in most years since 1830. The 1990 Decennial Census gathered information on disability from Americans aged 15 or over through three questions: one on the ability to work, one on the ability to get around outside the house, and one on the ability to take care of personal needs. The Decennial Census can be used to provide estimates of the need for disability services in small areas. It is also the, only major survey which includes people who live in institutions, as well as the community.

- SIPP: *Insure that disability data are collected in a routine manner when the SIPP is redesigned starting in 1995.* SIPP or the Survey of Income and Program Participation is sponsored by the Census Bureau and began in 1983. The purpose of SIPP is to measure the economic well-being of the American people by looking at the income distribution and participation in Federal programs. SIPP is a longitudinal survey consisting of 9 interviews spread over almost three years. People in approximately 19,000 households are interviewed annually for SIPP. SIPP is a rich source of information on income, employment, health insurance, and assets, because these factors figure prominently in Federal program participation. So too does disability. However, disability data have been gathered only on an ad hoc, not a routine basis. In 1984, questions on disability were added to SIPP, which have been a valuable source of information on disability. Disability questions were reintroduced in 1990/91 and are being planned for 1992/93. If SIPP were to routinely collect disability data, we would be able to examine issues on employment, income, and poverty in much greater detail. We would also be able to look at changes in employment, program participation, and health insurance coverage over time.
- CPS: *Insure that disability data are expanded and collected in a routine manner when the CPS is redesigned starting in 1995.* The CPS, or Current Population Survey began in 1942 to measure the monthly unemployment rate. The CPS is sponsored by the Bureau of Labor Statistics, Department of Labor. The sample size is 50,000 households per year. The March Supplement of the CPS is also used for the Federal government's official estimates of income and persons living in poverty. The CPS is the basis of practically every economic model and is hence used for nearly every Federal cost estimate involving social programs. However, disability data are limited to a few questions, mostly on the ability to work. There are no questions on children and none on any other type of functioning. Since the CPS is such a valuable source of data for program planning and legislation, it is imperative that the disability questions be strengthened. If that were to happen, the CPS could be used as a strong monitor of ADA compliance, particularly for employment issues.

- 1993/94 NHIS Disability Survey: *Insure that the 1993/94 Disability Survey can begin as scheduled.* The 1993/94 NHIS Disability Survey is the only survey which can realistically monitor ADA compliance before the end of this century. However, funding is problematical. If sufficient funds are not committed by the end of 1992, the survey will not occur.
- NHIS: *Insure that disability be viewed as a major purpose of the NHIS when it is redesigned starting in 1995.* The purpose of the NHIS, as stated in the National Health Survey Act (which is due for reauthorization in 1993) is to collect data on the incidence and prevalence of chronic conditions, and to measure the nation's health status, utilization, and disability. Approximately 50,000 households are included in the sample each year. The NHIS has gathered information on limitation of activity and on disability days, that is days missed from work or school because of illness. However, until the advent of the 1993/94 Disability Survey, no comprehensive in-depth information on disability was ever collected. However, there have been a variety of special topics, such as home care, mental illness, and assistive devices. The NHIS will be redesigned in 1995. Disability items can be strengthened and included in the core NHIS interview, particularly those measures pertaining to mental impairments. Thus, we would be able to see how health care differs for people with and without disabilities. We will, not be able to assess the impacts of health care reform proposals on people with disabilities, unless they can be identified and we can distinguish between physical and mental causes of disability.

LONG-RANGE PLANNING AND CONCLUSIONS

Besides collecting disability data, we should be thinking seriously about future efforts. To be successful, we need to address a series of technical concerns, particularly those involving exactly how disability is defined. We also need to be sensitive to the adaptability of disability data for use in the Nagi and ICIDH frameworks.

Results from the 1993/94 Disability Survey will teach us much about disability in this country. We will learn more about how to measure disability and how to create new surveys. Until we get some results, academic arguments over very basic issues will continue without resolution.

If we take an active role in disability data, we can influence the soundness of the information used to make policy decisions about the ADA and other disability issues. If not, decisions will be made anyway with the benefit of what we know about disability.

The timing is right to make a difference in disability policy and to base that policy on sound information. Right now, support for the 1993/94 Disability Survey is crucial to understanding disability in the 1990's. Other surveys can also be strengthened to provide more information on ADA compliance.

The ADA put disability in the forefront of domestic policy, but unless we can evaluate the impacts of policy, people with disabilities will have difficulty being heard in policy debates.

SOURCES

- Adler, Michele C. (1992). "The Future of SIPP for Analyzing Disability and Health". *Journal of Economic and Social Measurement*. Amsterdam, Washington, Tokyo. Volume 18, 1992 (pages 91-124). [<http://aspe.hhs.gov/daltcp/reports/sipp.htm>]
- Adler, Michele C. (1991). "Programmatic Definitions of Disability: Policy Implications". American Statistical Association, 1991 Proceedings of the Government Statistics Section. Alexandria, VA. (pages 30-35). [<http://aspe.hhs.gov/daltcp/reports/prodefes.htm>]
- Brown, Scott C. (1992). "Bringing 'Handicap' into Disability Research: Developing Tools for Assessment of Progress Towards Improving the Quality of Life for Persons with Disabilities". Presented at the American Public Health Association Annual Meetings, November 1992, Washington DC.
- Committee on National Statistics, National Research Council (1992). "Towards a National Health Care Survey: A Data System for the 21st Century". *National Academy Press*. Washington, DC.
- West, Jane (1991). "The Social and Policy Context of the Act". *The Milbank Quarterly*. Cambridge University Press, New York, NY. Volume 69, Supplements 1/2 (pages 3-24).