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

RESEARCH AGENDA:

DISABILITY DATA

August 1995

Office of the Assistant Secretary for Planning and Evaluation

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of the Department of Health and Human Services (HHS) on policy development issues, and is responsible for major activities in the areas of legislative and budget development, strategic planning, policy research and evaluation, and economic analysis.

ASPE develops or reviews issues from the viewpoint of the Secretary, providing a perspective that is broader in scope than the specific focus of the various operating agencies. ASPE also works closely with the HHS operating divisions. It assists these agencies in developing policies, and planning policy research, evaluation and data collection within broad HHS and administration initiatives. ASPE often serves a coordinating role for crosscutting policy and administrative activities.

ASPE plans and conducts evaluations and research--both in-house and through support of projects by external researchers--of current and proposed programs and topics of particular interest to the Secretary, the Administration and the Congress.

Office of Disability, Aging and Long-Term Care Policy

The Office of Disability, Aging and Long-Term Care Policy (DALTCP), within ASPE, is responsible for the development, coordination, analysis, research and evaluation of HHS policies and programs which support the independence, health and long-term care of persons with disabilities--children, working aging adults, and older persons. DALTCP is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

In particular, DALTCP addresses policies concerning: nursing home and community-based services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, children's disability, and linkages between employment and health policies. These activities are carried out through policy planning, policy and program analysis, regulatory reviews, formulation of legislative proposals, policy research, evaluation and data planning.

This report was prepared by HHS's ASPE/DALTCP, in conjunction with a contract between DALTCP and Lisboa Associates. 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 Nancy Eustis.

RESEARCH AGENDA:
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U.S. Department of Health and Human Services

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This package includes the Background Paper which was distributed at the Office of Disability, Aging and Long-Term Care Policy's first "Expert" meeting and the Summary Paper of the meeting's discussion. The Background Paper also includes an Appendix describing national disability data bases. The opinions and views expressed in this package are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services, the contractor or any other funding organization.

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DISABILITY DATA FOR DISABILITY POLICY: AVAILABILITY, ACCESS AND ANALYSIS

Revised August 1995

I. INTRODUCTION

This paper provides background information for a meeting on data sets containing information on health care and long-term supports for persons with disabilities. The primary purpose of the meeting was to inform the research agenda of the Office of Disability, Aging, and Long-Term Care (DALTCP). The meeting was hosted by DALTCP in the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in Washington D.C. on March 31,1995.

We asked participants to assist us to:

1. Assess disability-related national data sets pertaining to health and long-term supports, particularly as related to the policy issues discussed below.

2. Identify useful State, area, private and international data bases, including data from large federally-assisted demonstrations of managed care, integrated health services, long-term care and welfare reform.

3. Identify next steps in analyzing available disability data.

4. Propose priorities for DALTCP's research agenda regarding disability data.

Overview of Paper

The paper begins with two general sections: Conceptual and Policy Framework and General Orientation to Disability Data, the latter of which contains an overview of the Disability Survey (1994-1995 Supplements to the National Health Interview Survey).

There follow sections which discuss policy and research questions ASPE/DALTCP is addressing and a critique of available data on four populations of persons with disabilities: working age adults; persons under age 18; older adults; and special populations.

The concluding section poses key questions in considering a disability data strategy and identifies possible next steps in developing a disability data strategy.

An Appendix provides one-page summaries of numerous national disability data bases.

II. CONCEPTUAL AND POLICY FRAMEWORK

A. Definition of Disability

There are many ways to define "disability". The definition should be broad enough to cover all persons of interest, yet detailed enough that policy makers and program administrators can identify the target groups they try to serve.

For this paper, we consider a disability to be a limitation of activity due to chronic conditions. Such a definition, which is used by the National Center for Health Statistics (NCHS), is "slanted" toward a health perspective. This is in keeping with the Department's mission, which--with the departure of the Social Security Administration (SSA)--is likely to place greater emphasis on health and long-term care policy as they affect persons with disabilities.

In the World Health Organization's (WHO) manual *International Classification of Impairments, Disabilities and Handicaps (ICIDH)* (1980), *impairments* represent disturbances at the organ level; disabilities reflect the consequences of impairment in terms of functional performance and activity by the individual; and handicaps are concerned with the disadvantages experienced by the individual as a result of impairments and disabilities. WHO is currently producing a revision and updating of this classification.

The starting point for this paper should not obscure the difficulty of reaching a broad consensus on one or more definitions of disability or identifying all the variables required to view disability from a variety of policy and program perspectives. In the process of developing a disability data strategy, the full range of conceptual, methodological and definitional issues around disability must be examined thoroughly.

B. Basic Demographics

According to the 1990 Survey of Income and Program Participation (SIPP), approximately 40.1 million Americans living in the community have one or more disabilities because of a physical or mental health condition. There are, in addition, about 2.6 million persons with disabilities who reside in institutions. This population is characterized in the first instance by its diversity. It includes the frail elderly, persons with mental retardation or other developmental disabilities (MR/DD), adults with physical disabilities or mental illness, children with disabilities and veterans. While the specific needs of these groups vary, they share common concerns and aspirations.

C. Policy Context for ASPE's Interest in Disability Data

ASPE provides data and analyses to inform policies of the Department of Health and Human Services (DHHS). Within ASPE, DALTCP has a mandate from the Assistant Secretary to expand its research agenda on persons with disabilities of all ages, focusing on health services and long-term supports. We are conducting and planning a number of disability-related research projects.

In addition, we have responsibilities regarding policy-relevant national survey data, including adding specific questions or entire sections to ongoing surveys (e.g., National Long-Term Care Survey), reviewing surveys sponsored by agencies in the Department, and developing new surveys in cross-cutting areas such as the 1994-95 Disability Supplement to the National Health Interview Survey (NHIS).

Given the cross-cutting nature of disability issues, we are coordinating our work with other departments and agencies, including the Department of Education and the new independent SSA as well as with operating agencies in DHHS and within ASPE itself.

National programs affecting persons with disabilities have developed considerably over the past quarter century. Currently many of these programs are undergoing scrutiny within the Administration and in Congress. Policy-relevant data are needed in a number of areas. Major disability-related initiatives which would benefit from more current data and data analyses include the following:

1. President's Disability Policy Review

The White House has undertaken a broad review of Federal disability policy through a group chaired by Carol Rasco and Alice Rivlin. This group will review the direction of Federal disability policy and provide guidance for the next steps. Specific Work Groups include: Guiding Principles, Accommodations, Children's Issues, Employment of Working Age Adults, and School-to-Work Transition. Judy Feder and Robyn Stone of ASPE are convening the group on Children's Issues.

2. Children with Disabilities on SSI

Rapid growth in the number of children who are receiving Supplemental Security Income (SSI) because of a disability has generated concern and criticism at present. In consequence, a National Commission on Childhood Disability has been mandated by the 103rd Congress. See below.

3. Health Care Reform Initiatives

Access to health insurance is a major concern for persons with disabilities. States and private insurers are undertaking reform initiatives despite lack of a major Federal health reform initiative. Proposals for universal coverage and a ban on exemptions from coverage due to preexisting conditions offered great promise to persons with disabilities. However, this constituency has concerns about the consequences of managed care and various cost containment measures.

In ASPE's studies of the effect of managed care options on persons with disabilities--both children and adults--valid and reliable data have not been readily available.

4. Potential Changes in Medicare and Medicaid

Many States are using managed care plans to serve their Medicaid beneficiaries. While people with disabilities have for the most part been carved out of these initiatives, a number of States are beginning to enroll their SSI (aged and disabled) populations in managed care plans.

There is serious consideration of placing a cap on Federal Medicaid expenditures or turning the Medicaid program into a block grant. The Health Care Financing Administration (HCFA) expects a doubling of nonelderly disabled Medicare beneficiaries between 1980 and 2000. ASPE/DALTCP in conjunction with HCFA is examining changes in the Medicare home health benefit. In general, we need data to project consequences of different scenarios of changes in these major programs for persons with disabilities.

5. Long-Term Support Reform

Debate continues concerning the feasibility of a Federal program to provide block grants to States for home and community-based services, including personal assistance services (PAS), for persons with disabilities. Of particular interest are issues around consumer-directed services. Perhaps a more probable initiative is enactment of tax incentives for private long-term care insurance. Data are needed regarding who buys such insurance.

Also of interest regarding home and community-based services are criteria for assessing State service-delivery "infrastructures" and needs for technical assistance.

In addition, State Governments and the private sector are developing assisted living and other housing-with-services options. This gives added importance to information on the living arrangements of persons with disabilities, along with their preferences. Such information is needed on the disabled population as a whole and various subpopulations of persons with disabilities.

6. Welfare Reform Initiatives

Approximately one-third of women receiving Aid to Families with Dependent Children (AFDC) either have a disability, have a child with a disability or may reside with another adult with a disability (Adler, 1993). Furthermore, research reviewed by the Urban Institute (Acs and Loprest, 1994) gives some indication that women with disabilities (especially those with multiple disabilities) are less likely to exit from AFDC for paid employment within a year.

It is unclear the extent to which job training, if enacted as a part of welfare reform, will address the special needs of persons with disabilities. DALTCP has in progress an exploratory study of impacts on persons with disabilities of welfare reform initiatives in a small sample of States.

7. Assessment of the Americans with Disabilities Act

As reported in Federal Implementation of the Americans with Disabilities Act (ADA), 1991-94 (West, 1994), the potential of the ADA for defending the civil rights of persons with disabilities has only partially been realized. ASPE/DALTCP is particularly interested in access to health and housing facilities.

Our experience is that one cannot assume easy access to health institutions, even though many hospitals and clinics receive Federal support and therefore have been required by the Federal Rehabilitation Act to provide access. Accommodation of persons with disabilities in existing privately-owned rental housing is not directly addressed by the ADA. Documenting the impact of the ADA has special policy significance in today's political climate.

8. The Changing Federal Role: (A) Devolution; (B) Reinvention

A major theme of the current Congress is transferring responsibility for social programs to the States, generally by means of block grants. In the past there has been minimal Federal monitoring of who receives which benefits, and even less information about program impacts. For example, there are few data on which age groups receive services under the Social Services Block Grant.

Although an increased Federal awareness of disability is suggested by the ADA and the President's Disability Policy Review, implementation of block grants potentially for nutrition, welfare, and Medicaid programs may substantially deter any Federal effort to track impacts on persons with disabilities unless provisions for so doing are explicitly incorporated.

The Reinventing Government effort--that is making government "leaner"--has implications for disability data. In an era of diminishing resources, there is consideration of how to consolidate surveys, establish standards for data collection and better organize data collection responsibilities within agencies. Undertaking new data collection initiatives in this environment will require considerable justification.

III. GENERAL ORIENTATION TO DISABILITY DATA

A. Federal Data Bases

The United States has a wide variety of data bases on persons with disabilities--national, State and private. The collection of data on persons with disabilities has made considerable progress over the past decade.

In the near future, data sets will become available that will shed light on the characteristics, service use, expenditures and sources of payment for many groups of persons with disabilities. Most notable is the Disability Survey, which is being administered as a supplement to the NHIS in 1994 and 1995. This survey will serve as the "work horse" of disability analyses for the foreseeable future.

Even with such promising developments, a number of data problems persist. The Department's experience in examining health and long-term care reform options highlighted some of these problems.

- While much is known about the frail elderly and their use of services, relatively little is known about other groups of persons with disabilities such as children, working age adults and special populations (e.g., mentally ill, developmentally disabled) that cut across age groups.

- Though not ideal, the activities of daily living (ADLs) provide reasonable measures of functioning for older persons with physical disabilities; however, we lack equivalent measures for persons with cognitive impairments or mental illness and for children regardless of their type of disability. Self-reported ADL status is inherently a "soft" measure of disability and one subject to a lot of variability in the short run.

- More consistent policies on measures and data systems on persons with disabilities are needed. At the national level, the data systems are largely decentralized and there remain significant gaps in coverage. Improved coordination, planning and priority setting among Federal agencies are required to make possible the best analytic uses of the data bases.

- There should be development of longitudinal data bases (including panel studies) on the general population with disabilities and special subpopulations.

- Increased access is needed to subnational data bases, including State and local surveys, data from federally funded demonstration programs, and proprietary data systems.

- There should be more frequent and routine linkage of survey data with administrative records such as Medicare, Medicaid, and Social Security.

Other specific recommendations for improving disability data collection include:

- Routine inclusion of disability measures in ongoing national data collection systems (LaPlante in National Council on Disability, 1992, p.35).
- In Federal statistical reports, tabulation of findings by disability along with other standard demographic variables (e.g., age, race and income) (LaPlante, ibid.).
- Increased focus on gaining congressional support for expanded data gathering on disability (LaPlante, ibid.).
- Reporting information in the Current Population Survey (CPS) on labor force participation by persons with disabilities every month rather than only in March as is now the practice of the Bureau of Labor Statistics (Yelin, 1992, p.157).

B. Overview of the 1994/95 Disability Survey (Supplement to NHIS)

The 1994/95 Disability Survey, the most comprehensive national survey on disability ever undertaken in this country, will provide information on research and policy issues related to disability. It is the first exhaustive survey of disability since 1978 and the first ever to collect national population-based data on children with disabilities and persons with developmental disabilities.

Data from the 1994/95 Disability Survey will enable us to understand more about people with disabilities--their numbers, characteristics (e.g., demographic, socio-economic, health, participation in Federal programs), service use and expenditures, and aspects of their daily lives (housing, transportation, employment, personal assistance). Data from the survey are relevant to the following policy questions:

- What are the characteristics of people with disabilities who rely on DHHS programs?
- Why is growth in SSI and Social Security Disability Insurance (SSDI) enrollment (and the companion Medicaid and Medicare programs) and costs so high?
- Why is employment among persons with disabilities so low and why do some people with the same disabilities work while others do not?
- What is the extent of disability among children and why is SSI growth so high, what role do recent changes in SSI eligibility (i.e., *Zebley* Supreme Court decision, new childhood regulations, expanded mental impairment criteria) play?

- How do persons with MR/DD access community services and what is the role of Medicaid?

- How do access to health care, health care utilization, and public versus private health insurance coverage vary for people with disabilities?

- What is the impact of racial/ethnic differences in disability?

The 1994/95 Disability Survey grew out of a coordinated interagency and inter-Departmental effort at DHHS to obtain timely and complete disability data.

Under an ASPE contract, Mathematica Policy Research, Inc. produced a design for a national survey of persons with MR/DD as well as detailed measures and data collection instruments. A supplement to the NHIS was proposed as the vehicle for the MR/DD survey. This work served as the foundation for a more comprehensive Disability Survey.

The questionnaire was extensively reviewed by the Federal disability community, advocacy groups, and academics. In addition, the questionnaire was voluntarily tested by people with disabilities and their families at the NCHS Cognitive Questionnaire Lab. Finally, a pretest involving 250 households was also conducted in the Washington, DC area.

The 1994/95 Disability Survey is actually a two-year supplement to the National Health Interview Survey (NHIS). The NHIS has been collecting information on the nation's health since 1957. Samples are huge. About 100,000 households representing 240,000 people in the civilian non-institutionalized population will be interviewed.

The 1994/95 Disability Survey has two parts or phases, each of which consist of personal interviews in respondents' homes. Phase I is administered to the 240,000 respondents selected in the NHIS sample. Phase I interviews began in January 1994 and will continue through December 1995. Phase I contains many in-depth disability measures, as well as information on severity, onset, duration, and disabling condition.

Phase I disability measures include standard limitation of activity measures and detailed measures of sensory impairments, functioning of specific body systems, six separate ADLs, six separate instrumental activities of daily living (IADLs), mental illness, assistive devices, childhood disability, and functioning for children under five. People with MR/DD (using the legislative definition) can also be identified.

Many disability measures are standard, while others--notably those on children, mental illness, and developmental disabilities--are new and were derived with this survey in mind. Besides information on disability, data on health care, demographic, socioeconomic, health insurance, and program characteristics of people with and without disabilities are also gathered in Phase I.

Phase II is administered about 6-9 months after Phase I to about 40,000 respondents with serious disabilities. Phase II began in the Fall 1994 and will end in Fall 1996. Phase II collects data on service use and expenditures, housing, long-term care services, home care, personal assistance, respite care, transportation, employment, accommodations, work history, vocational rehabilitation, relationships, family structure, family impact (for children) and child care (for children).

Information from the Disability Survey can 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 re-interview them for longitudinal studies. Final results could be released in early 1997 and preliminary results by early 1996.

IV. DATA ON WORKING AGE ADULTS

A. Key ASPE/DALTCP Policy Concerns

In developing the long-term care proposal in the Health Security Act and defining a benefits package, analysts in ASPE and elsewhere lacked data about working age persons with disabilities and their use of services. We relied primarily on data from the National Long-Term Care Survey (NLTCS) and the model of service use and costs developed by Brookings and Lewin-VHI for projections of target populations and costs for persons aged 65 and over.

In general, we have limited data on working age persons with disabilities in regard to key DHHS policy concerns. These include:

- Use and costs of PAS and related supports. Recent expert meetings confirmed our need for data on uses and costs of PAS and related supports (such as assistive technology or adaptations) and for certain basic health benefits such as maintenance rehabilitation.

- Impacts of increased reliance on managed care on persons with disabilities. Managed care is a centerpiece of most reform initiatives being implemented by many States (e.g., for their Medicaid programs) and by private insurers. While managed care holds promise of providing, under one auspice, an array of needed services by persons with disabilities, persons with disabilities and their advocates express a number of fears and concerns about potential disadvantages of managed care. These center on access to and receipt of appropriate services.

  There are few data to address key questions such as functional and demographic characteristics of persons with disabilities in managed care and the impact of managed care on access to needed services, affordability and costs, and on individual outcomes.

- Incentives or barriers to employment of persons with disabilities. Incentives and barriers to work for persons with disabilities include access to health insurance and to long-term supports. ASPE/DALTCP has in progress research to determine what data are available on the use of PAS and of assistive technology by workers with disabilities to answer questions such as:

  - What number and proportion of workers use PAS, assistive technology, and adaptations and to what extent are these used in the work place?
  - To what extent do employers provide for personal assistance in the work place or pay for assistive technology and other adaptations?

- How persons with disabilities or parents of children with disabilities would be affected by proposed changes in the AFDC program. As mentioned above, ASPE/DALTCP is sponsoring exploratory telephone interviews with officials in five States which have undertaken welfare reform initiatives. In addition, ASPE is sponsoring an evaluation of State welfare reform initiatives. It is anticipated that data collection will include questions concerning AFDC recipients who have disabilities or who have children with disabilities.

B. Existing Data Sources

Numerous Federal surveys collect disability data on the working age population (aged 18-64), but except for the 1994/95 Disability Survey, none focus primarily on disability. That was not always the case. SSA conducted the Surveys of Disability and Work every few years beginning in the early 1960s in order to measure the extent of disability in the working age population and to examine the experience of disabled workers on SSDI and their families. The last Survey of Disability and Work was conducted in 1978 and there are no plans to repeat the survey.

Nowadays, data sources include either special surveys on disability (like the 1994/95 Disability Survey) or the addition of disability questions on non-disability surveys. Besides the 1994/95 Disability Survey, the major sources of information on the entire working age population with disabilities include:

- 1990 Decennial Census,
- 1984, 1990-96 Surveys of Income and Program Participation (SIPP),
- 1957-95 National Health Interview Surveys (NHIS),
- 1987 National Medical Expenditure Survey (NMES), and
- Annual Current Population Surveys (CPS).

In addition, the Medicare Current Beneficiary Survey (MCBS) covers SSDI beneficiaries eligible for Medicare--a small but policy-relevant segment of the working age population with disabilities.

C. Strengths and Weaknesses

The sheer size of the working age population with disabilities is immense. Although disability rates are much lower among the working age population (13.7 percent) than among the elderly (54.8 percent), more people with disabilities are in their working years (21.1 million) than in their elderly years (17.1 million).

The working age population is not only large, but heterogeneous, and is in fact made up of many smaller groups, most of whom are too small to pick up in surveys. These small often policy relevant groups can be based on condition (i.e., mental retardation, mental illness, multiple sclerosis, spinal cord injury), type of impairment (i.e., mental, physical), program participation (i.e., SSDI, SSI, VA), onset (congenital, childhood, early or late adulthood), age, gender, and race. Only the 1994/95 Disability Survey with its huge samples can hope to gather data on many of these small groups.

There are crucial but unresolved definitional and measurement issues among the working age population. No equivalent severity measures and survey questions have been developed for physical versus mental impairments. The standard functioning questions based on ADLs and IADLs often break down. Since mental illness and mental retardation are major disabling conditions in this age group, this is a critical gap.

The relationship between functional disability and work is also not well understood. Some people with the same level and type of disability work while others do not. Besides disability, a host of other factors are important in the decision to begin or return to work. These can include occupation (i.e., sedentary, manual labor), educational attainment, and age (those in their 60s may wish to stop work and retire early).

A small but important segment of the working age population with disabilities are institutionalized (i.e., nursing homes, mental hospitals, prisons) or are homeless. Since few national surveys include this population and since the few surveys which focus on the institutionalized (i.e., the National Nursing Home Survey) have very small samples of the nonelderly, we know little about this group.

Most Federal disability programs focus on the nonelderly and many of these pertain to people in their working years. These programs have administrative records which, if linked to national population-based surveys, could strengthen and expand our knowledge. However, administrative data is often not linked for reasons of confidentiality or simply because no such considerations were made.

V. DATA ON PERSONS UNDER AGE 18

A. Key ASPE/DALTCP Policy Concerns

A major policy focus for this age group concerns issues relating to benefits for children under the Federal SSI program. In 1994, almost three times as many children received SSI benefits (approximately 900,000 children) as did in 1989. This dramatic growth in the SSI program and the changing characteristics of the children who participate--most notably a presumed increase in children with mental impairments--has caused scrutiny of the program by the Administration and the Congress.

By Congressional mandate, the National Commission on Childhood Disability is reviewing the SSI program and the needs of children with disabilities. ASPE/DALTCP has been involved in developing a research agenda for the Commission. In addition, ASPE and DALTCP staff are leading the task force on disability programs for children as part of the Administration's Disability Policy Review.

The Commission has authority to examine:

- causes of program growth;
- eligibility criteria and determination;
- relative merits of voucher rather than cash benefits;
- effects of SSI benefits on children and their families; and
- merits of alternative approaches to helping children achieve future independence and employment, including closer involvement of private organizations in providing services.

In addition the Commission's charge includes consideration of Federal health assistance programs for children and the interactions of SSI with other public medical, special education, and case management programs.

Our plans to date for generating information for the National Childhood Disability Commission include analysis of early data from the Disability Survey; a synthesis of SIPP, Census, and NHIS data, and studies of use of Medicaid-funded services by SSI recipients.

In addition to its work with the Commission and the Disability Policy Review, ASPE/DALTCP and other ASPE programs are undertaking a program of research on children with disabilities. Projects include analyzing use of Medicaid services by children with disabilities, examining managed care programs for children with disabilities, and describing the extent to which school systems meet requirements for provision of related services under the individuals with Disabilities Education Act by using Medicaid benefits.

More broadly, the "reinvention" of the Federal Government and the shift toward consolidating categorical programs, establishing block grants and capping expenditures for major programs (e.g., Medicaid) could have significant impacts on children with disabilities.

We recently awarded seven research grants for projects which make use of available data sets. These include State and local data bases. Topics include assessment of policy implications of alternative functional definitions, patterns of service use and costs within several States, interactions of the AFDC and SSI programs with regard to children with disabilities.

B. Existing Data Sources

Little information exists on children with disabilities. The major sources of information are:

- 1994/95 Disability Survey,
- 1984-96 Surveys of Income and Program Participation (SIPP),
- 1957-95 National Health Interview Surveys (NHIS),
- 1987-88 Survey of Families and Households, and
- 1987 National Medical Expenditure Survey (NMES).

Program records from SSI and the special education programs also contain disability data.

C. Strengths and Weaknesses

It is difficult to measure disability in children-much more so than for adults. Furthermore, the younger the child, the harder it is to understand, articulate, and measure disability. In fact, disability is a very different concept for infants, toddlers, preschool children, school-age children, and adolescents. Whereas play is the usual activity for children aged 3-5 and attending school for those aged 5-17, the usual activity of infants and toddlers (growing, developing?) is unclear and hard to measure. The lack of standard measures meant that new questions needed to be created for the 1994/95 Disability Survey.

Although children constitute about a quarter of the population, national surveys often include few children with disabilities in their samples. This is because the prevalence of children with disabilities is small (about 6 or 7 percent of all children) and because major surveys like the SIPP and the CPS are really focused almost exclusively on adults (people aged 15+ or 16+).

For example, SIPP has collected data on children's disability since its inception, but none on children's SSI participation, because SSI receipt is in the core set of questions designed solely for adults. (This will be remedied starting with the 1996 SIPP.)

While longitudinal data are universally scarce for people with disabilities, their lack is especially crucial for children, who change much more rapidly than adults in regards to disability and everything else. Finally, children live in families. While data on a child's disability is crucial, we also need to know about his or her family and their characteristics in order to gain an accurate understanding of the issues.

VI. DATA ON OLDER ADULTS

A. Key Policy Concerns

While data on older adults with disabilities is more extensive than for other populations, there are significant gaps.

- Modeling Service Use and Costs. Increases in the aging population, especially in numbers of persons over age 80 or 85 who are at greatest risk for needing health and long-term care services, dominates much debate over policies on older adults. A major emphasis of ASPE/DALTCP's recent work with regard to older adults has been modeling long-term care service use and costs by persons age 65 and older using primarily data from the NLTCS.

  Use of the model greatly facilitated development and acceptance of the long-term care proposal for various health reform bills last year. We plan to extend this model to estimating acute care costs in order to project consequences for policy changes such as, for example, adding co-payments to Medicare home health benefits or increasing Medicare Part B premiums.

  We would also expect to examine the impact of integrated acute and long-term care strategies on public and private expenditures. In addition, we propose to extend our capability to understand impacts within States of changing use and costs of acute and long-term services, using Census data, the NLTCS and the Disability Survey.

  A key question is the extent to which increased life expectancy is accompanied by a longer period of disability and chronic illness. There is some evidence from earlier rounds of the NLTCS that the prevalence of disability among the elderly is decreasing. Data from the 1994 NLTCS may provide further assessment of these trends.

- Changes in Medicare Home Health Care Benefits. Medicare home health and skilled nursing facility expenditures have quadrupled in the past five years, from $2 billion to over $8 billion. We are undertaking research in collaboration With the Health Resources and Services Administration (HRSA) and HCFA to understand the nature of these increases and the extent to which Medicare home health benefits are changing from a post-acute care step down benefit into a source of long-term custodial care for the elderly.

  We also hope to link the Medicaid Statistical Information Systems data set with the MCBS to examine the mix of skilled and custodial home care benefits by persons dually eligible for Medicare and Medicaid.

- <u>Subacute Care</u>. Subacute care--i.e., comprehensive, specialized services provided in settings other than hospitals--has emerged as a policy concern for both the Medicare and Medicaid programs and to those involved in health reform. We are attempting to describe use of subacute care in both fee-for-service and managed care settings and its effects on acute (i.e., hospital) and other traditional post acute services. Expected and achieved outcomes are also at issue. At this point data for such analyses are limited, so that we are undertaking case studies of four market areas.

- <u>Long-Term Care Insurance</u>. A key proposal of long-term care reform--incentives for private long-term care insurance--continues to be of interest to Congress and may be pursued separately from other health reform proposals. As noted above, data are lacking on the availability, coverage and use of such insurance. We are particularly interested in assessing the impact of State regulation on the affordability and quality of, as well as consumer satisfaction with various long-term care insurance products.

- Housing with Services. As the long-term care system evolves, more emphasis is being placed on combining housing and PAS for the frail elderly in community settings. We are interested in examining a variety of housing with services options, including board and care homes, assisted living facilities, continuing care retirement communities and others.

  There is a need for current and comprehensive data on such places in order to determine their appropriate role in the long-term care system.

- *International Comparisons*. ASPE has undertaken a project to strengthen collection, analyses and dissemination of comparable data about long-term care in Japan and the United States. This work involves collaboration with HRSA and the Leadership Center for Longevity and Society at Mount Sinai Medical Center. ASPE provides support for analyses of informal caregiving in several industrialized societies.

  Other international efforts are underway as well, including working with WHO on the revision of the ICIDH, with special attention to how it affects disability policy.

  ASPE also participates actively in the International Collaborative Effort (ICE) on Aging, sponsored by NCHS. For example, in one project on the outcomes of nursing home care in five countries, the ICE on Aging researchers have highlighted the need for improved measurement and data collection comparability among nations (Van Nostrand et al., 1993).

B. Existing Data Sources

The major sources of data on the frail elderly include the NLTCS (1 982, 1984 and 1989), the Longitudinal Study of Aging, the Asset and Health Dynamics of the Elderly Survey and the MCBS. The elderly are included in most general purpose surveys like NHIS and SIPP, but sample sizes for the frail elderly--especially those at advanced ages--are typically small.

C. Strengths and Weaknesses

For purposes of determining disability status among the elderly, surveys tend to focus on the ability of respondents to carry out ADLs and IADLs. However, operational measures of these activities vary widely across surveys. There are discrepancies regarding the sources of assistance; some measures focus on active personal assistance, others include standby or supervisory assistance and still others cover assistive devices. The lack of consistent measures has contributed to a wide range of estimates of size of the frail elderly population.

Measures of cognitive disability have not kept pace with the measurement of physical disability. This is a major concern, in light of the policy focus on persons with Alzheimer's Disease and related dementias.

Existing sampling frames are inadequate for accurately and efficiently identifying places where frail elderly persons reside. The growth of housing with services options means that elderly persons with disabilities can live in places other than their own home or a nursing home. These alternative living arrangements include board and care homes, assisted living facilities, continuing care retirement communities and other related group living arrangements.

The Census Bureau classifies places as households or group quarters, the latter being subdivided into institutional and non-institutional group quarters. Unfortunately, this classification means that assisted living facilities and similar arrangements can show up in any or all of these categories. This makes screening and sampling extremely expensive and inefficient.

Other problems include small sample sizes for persons aged 85 or over, inadequate coverage of minority elderly, insufficient geographic detail, obstacles to administrative record linkages, and paucity of longitudinal data for measuring transitions in old age. Most critically, we lack an appropriate conceptual framework with corresponding measures to study disability across the lifespan.

VII. DATA ON SPECIAL POPULATIONS

A. Key ASPE/DALTCP Policy and Research Concerns

In general, it is important to note that proposed cutbacks in the SSI program, State and private health reform initiatives, and potential changes in Medicare and Medicaid are all policy issues which affect special populations of persons with disabilities. In addition, racial, ethnic, and gender differences in service needs and use are increasingly important variables in designing programs, given the increasing heterogeneity of the U.S. population and increased incidence of disability among minority populations.

An issue regarding special populations which is of particular concern to ASPE/DALTCP is how well persons with serious mental illness or mental retardation are served by a "generic" system of home and community-based services. For example, ASPE/DALTCP is proposing to convene a meeting to address the long-term care needs of persons with developmental disabilities involving mental retardation and whether they are best served by separation from or integration with other long-term care programs.

One interesting concept involves identifying tracer "conditions", whereby persons with particular disabilities--especially the more rare populations--could be tracked in terms' of service use, expenditures and payment sources.

Eligibility determination for a system serving multiple populations is a particular issue. For example, persons with serious mental illness are concerned not only about selfcare functions but also with functioning in social and recreational settings as well as at work. This population is also concerned that bureaucratic gatekeeping based on ADL impairments would not offer eligibility to needed services for them.

Further, persons with mental illness often have periods of relative good health and functioning but argue that continued access to long-term supports during these times would be cost-effective in that health would be sustained over longer periods with supervision and other supports. The MR/DD population tends to need supervision or cuing to perform ADLs, as well as help with IADLs. Hence eligibility based on need for hands on help with self care activities is inappropriate.

A focus of the President's Disability Policy Review is the transition of young adults from school to work. Various policies and programs have an impact on readiness to work of a young adult with disabilities including not only special education interventions and the availability of suitable employment but also access to health insurance and needed personal assistance and assistive devices.

Other special populations, e.g., persons with mental illness or developmental disabilities, are also concerned with linkages between long-term supports and social, recreational, and work settings.

B. Existing Data Sources

In light of a variety of policy and program concerns, data needs on special populations can be grouped into four categories: (a) prevalence data for the population as a whole and major subgroups; (b) data on socioeconomic status, health status, functioning and related demographic characteristics; (c) data on service use, service needs, service costs; and, (d) data on developments over time for special populations as they move from childhood to adulthood to old age.

Special populations with certain disabilities (e.g., MR/DD) are rare in the population as a whole, though they are significant from a policy perspective. Existing surveys often fail to include measures for identifying them. There are three nationally representative surveys with some information about special populations: SIPP, NHIS and NMES.

For some special populations, e.g., persons with developmental disabilities, there also exist State surveys and narrowly focused studies, covering participation in selected programs or particular living arrangements (such as large residential facilities). All are able to shed some light on special populations.

C. Strengths and Weaknesses

The principal limitations across the three national surveys include:

- Inadequate flexibility in the data to distinguish between mild and moderate disability from severe disability.

- Focus on Federal program participation rather than comprehensive coverage of individuals' service needs.

- Insufficient coverage of nonmedical family and community-based services, such as day care, supported employment, crisis intervention, assisted living and case management.

- Small or non-representative sample sizes.

In addition, NHIS and SIPP are limited to the non-institutional population, with SIPP beginning with respondents age 15 and over. NMES included persons in facilities, but tended to exclude those in small community-based residential settings.

More narrow surveys and studies provide a rich source of information about special populations. However, without a clear idea of the representativeness of the persons included in these studies, it is not possible to put the findings in context.

The Disability Survey, which is being administered as a supplement to the NHIS over a two year period, will go a long way toward remedying many of these concerns (though, as noted, it is household-based and excludes institutions).

VIII. A DISABILITY DATA STRATEGY

A. Key Questions

In developing a disability data strategy that meets ASPE's specific policy research agenda and at the same time serves the interests of the research community more broadly, a number of questions suggest themselves.

1. Content

- What are the relative priorities on collecting data at the level of:
  - persons?
  - families and households?
  - providers?
  - environment?
  - specific programs?

- Is there a need for a "minimum data set" of disability-related data elements that are routinely collected?

2. Coverage

- Since many major national surveys cover only the civilian noninstitutionalized population, how can coverage be extended to persons in institutions, persons in the armed forces and persons living abroad as part of an overall disability data strategy?

- Should a higher priority be given in the future to separate disability surveys or inclusion of standard disability measures in existing surveys?

- What would be needed to assure that standard disability measures are included in existing or planned surveys?

3. Sampling

- How can existing sampling frames, which are built around housing units and group quarters (institutional and non-institutional), be changed to identify more easily persons with disabilities who live in alternative housing arrangements (assisted living facilities, board and care homes, independent living facilities, etc.)?

- What are the key policy-relevant subgroups of persons with disabilities, for which sufficient sample sizes are needed for accurate estimation along critical dimensions?

- What strategies are needed to assure representativeness of key disability-related subgroups in sample surveys?

4. Periodicity

- What can be done to collect data on persons with disabilities on a more regular and predictable basis?

- Given budgetary realities, should the emphasis be on one time or occasional surveys that collect a lot of data or more regular and frequent surveys that collect fewer data?

- In light of budgetary realties, what relative priority should be given to: (a) longitudinal surveys, (b) panel surveys, and (c) cross-sectional surveys?

5. Access

- What can be done to assure the timely production of useful and widely available public use tapes?

6. Administrative Records

- What can be done to improve access to administrative records and link them to national survey data?

7. Subnational and International Estimation

- To what extent should Federal resources be expended to generate estimates at the State and sub-State level on the prevalence, incidence and types of disability?

- What role should the Federal Government, DHHS and ASPE play in promoting State and subState data collection on disability?

- What role should the Federal Government, DHHS and ASPE play in fostering expansion and comparability in international data collection and coding (i.e., ICIDH) on disability?

8. Modeling

- How can microsimulation models on financing and personal assistance services for persons with disabilities be developed and what would be the critical features of such models?

B. Potential Next Steps

The following is a list of potential next steps for ASPE that could help articulate and support a policy relevant disability-related data strategy.

- Exploration of accessing data from demonstrations and waiver programs (e.g., 1115 waivers) for analysis, with emphasis on the methodological and cost implications of this approach for related data collection.

- Provision of technical assistance to States in their disability-related data collection efforts.

- Support for expanded analyses of existing disability-related data by researches and policy analysts.

- Encouragement of linkages of administrative records to survey data.

- Promotion of the use of disability measures; in general, purpose surveys to help monitor the impact of new policies and programs (e.g., block grants) on persons with disabilities.

- Hosting of a disability data conference, resulting in proceedings, special issue of a journal and/or a book.

- Establishment of a Federal interagency coordinating body on disability statistics (analogous to the Federal Interagency Forum on Aging Related Statistics).

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X. APPENDIX: NATIONAL DISABILITY DATA BASES

HOUSEHOLD AND/OR PERSON-BASED SURVEYS

- American Housing Survey (AHS)
- Asset and Health Dynamics Among the Oldest Old (AHEAD)
- Health and Retirement Survey (HRS)
- Current Population Survey (CPS); 1981-1993 March Supplements
- Decennial Census
- 1994/95 Disability Supplement to the National Health Interview Survey
- Epidemiological Catchment Area Study (ECA)
- Longitudinal Study of Aging (LSOA I and II)
- Medical Exam Study
- National Household Survey on Drug Abuse (NHSDA)
- Medicare Current Beneficiary Survey (MCBS)
- National Comorbidity Survey
- National Health and Nutrition Examination Survey I Epidemiological Followup Study (NHEFS)
- National Health Interview Survey (NHIS)
  - 1988 Child Health Supplement
  - 1989 Mental Health Supplement
  - 1990 Supplement on Assistive Devices
  - 1991 Supplements
  - 1994 Access to Care Survey
- National Long-Term Care Survey (NLTCS)
- National Medical Expenditure Survey-Household Survey, Survey of American Indians and Alaska Natives, Institutional Population Component (NMES)
- National Mortality Followback Survey (NMFS)
- National Organization on Disability/Harris Survey of Americans with Disabilities
- National Survey of Families and Households (NSFH)
- National Survey of Veterans (NSV)
- New Beneficiary Survey and Followup
- Panel Study of Income Dynamics (PSID)
- Supplement on Aging (SOA I and SOA II)
- Survey of Income and Program Participation (SIPP)
- Surveys of Disability and Work

PROVIDER BASED SURVEYS

- Annual Census of Patient Characteristics: State and County Mental Hospital Inpatient Services
- National Ambulatory Medical Care Survey (NAMCS)
- National Employer Health Insurance Survey (NEHIS)

- National Health Provider Inventory (NHPI)
- National Home and Hospice Care Survey (NHHCS)
- National Nursing Home Survey (NNHS)
- National Survey of Shelters for the Homeless

ADMINISTRATIVE

- Medicaid Statistical Information System (MSIS)
- Rehabilitation Services Administration Case Service Report (RSA-911)
- Social Security Administration (SSA) Administrative Data

OTHER SURVEYS

- Area Resource Files (ARF)
- Behavioral Risk Factor Surveillance System (BRFSS)
- National Consumer Survey
- National Education Longitudinal Surveys
- National Longitudinal Survey of Youth (NLSY79) and Children of the NLSY79
- National Longitudinal Transition Study of Special Education Students
- National Spinal Cord Injury (SCI) Statistical Center Database
- Survey of Disabled Veterans (SDV)
- Users' Responses to Assistive Devices for Physical Disability

HOUSEHOLD AND/OR PERSON-BASED SURVEYS

American Housing Survey (AHS)	
Contact	HUD User (800) 245-2691
Sponsor	Division of Housing and Demographic Analysis, Office of Policy Development and Research, Department of Housing and Urban Development
Frequency	National survey conducted in 1973-1981, 1983, 19850 1987, 1989, 1991, 1993, 1995; metropolitan survey conducted annually since 1974.
Purpose	To provide a current series of information on the quality and quantity of the housing stock in America, as well the characteristics of its occupants.
Design	There are two components of the American Housing Survey: a national sample and rotating samples of metropolitan areas. Initial sample of housing units was drawn in 1973 and partly replaced in 1964 and 1994; updated continuously. Data collected through interview of unit occupants, or if vacant, informed persons such as landlords, rental agents, neighbors.
Content	Housing costs, physical condition and age of the unit, utilities used, residential mobility, neighborhood services available to residents, and needed housing improvements. Detailed demographic and income data are collected for household members.
Disability Measures	Health/disability status is not generally in the survey; although in the 1978 national survey and 1979-82 metropolitan survey there were special supplements containing disability data. The supplements included questions on difficulty getting around, health conditions causing difficulty, and housing modifications needed.
Coverage	Housing units from urban and rural areas.
Sample	Approximately 56,000 units in the national survey. Also samples 44 metropolitan areas throughout the U.S. on a four year cycle (11 areas annually).
Products	Public use data tapes, publications, CD-ROM.
Future	Ongoing
Comments	Data collection focuses on housing units, as well as individuals and families in the units. Survey regularly goes back to the same home to measure change.

Asset and Health Dynamics Among the Oldest Old (AHEAD)	
Contact	F. Thomas Juster, University of Michigan (313) 764-4207 Willard Rodgers, University of Michigan (313) 763-6623 Beth Soldo, Georgetown University (202) 687-6805
Sponsor	National Institute on Aging
Frequency	1993, with biannual follow-ups for all respondents
Purpose	Monitor transitions in physical and cognitive capacity in advanced old age; relate changes in health and economic resources to intergenerational transfers; examine the relationship of late life changes in physical and cognitive health patterns.
Design	Piggybacking on Health and Retirement Survey (HRS) screening of 70,000 households; supplemental sample of 80+ from Master Enrollment File (HCFA); computer-assisted personal interviews (CAPI) for those 80+, computer assisted telephone interviews for those 70-79.
Content	Physical and cognitive health, economic status, family structure, demographics, housing, service use.
Disability Measures	ADLs, IADLs, use of devices, personal assistance, financial management abilities; tests of memory and acuity, Wechsler Adult Intelligence Scale, Dementia Test; quality of life scale, depression diagnosis and treatment; condition list.
Coverage	Sample from screen within Health and Retirement Study as well as the HCFA Master Enrollment File; civilian non-institutionalized population.
Sample	8,200 respondents age 70+; 2300 age 80+; oversamples African Americans and Florida residents.
Products	Public use data tapes; wave I data currently available.
Future	Proposed continuation of the survey from 1995-1999.
Comments	Detailed ADL questions: if get help, how often, which devices are used, if have difficulty.

Health and Retirement Survey (HRS)	
Contact	F. Thomas Juster, University of Michigan (313) 764-4207
Sponsor	National Institute on Aging
Frequency	1992, re-interviews in 1994.
Purpose	To look at factors that affect the age at which people retire and the evolution of health and economic status during retirement.
Design	Baseline study in 1992, face-to-face interviews (6% by telephone); follow-ups by mail/phone every second year for twelve years.
Content	Health and cognitive conditions, retirement plans, attitudes and perspectives, family structure and transfers, employment status and job history, disability, demographics, housing, mobility, income, wealth, health insurance, and pension plans.
Disability Measures	Physical and cognitive functioning, physiological measurements of health and functioning, chronic conditions, job-related limitations, employment history, welfare disability applications, SSDI application, and benefits received.
Coverage	Wave I interviews of persons born between 1-1-31 and 12-31-41 and their spouses.
Sample	7,600 households (12,600 persons).
Products	Preliminary data tape of Wave I is currently available, more complete data available in early 1995; data from Wave II available in spring of 1995.
Future	Proposed continuation of the survey from 1995-1999, with possible introduction of a new cohort in 1998.
Comments	• detailed measures of functioning and cognitive impairment • excellent source of information on the incidence of disability and impact on work status and employer response to disability

Current Population Survey (CPS); 1981-1993 March Supplements	
Contact	Jack McNeil (301) 763-8300
Sponsor	Bureau of the Census for Department of Labor's Bureau of Labor Statistics
Frequency	Monthly since 1942
Purpose	To obtain data on employment and unemployment.
Design	Longitudinal. Nine waves of interviews are conducted at four month intervals over a 30 month period for each panel. There is a standard core interview supplemented by periodic topical modules. All disability measures are found on selected topical modules.
Content	Monthly data on demographic and employment characteristics, with a March supplement on work disability, health insurance and program participation.
Disability Measures	Work disability for persons aged fifteen and older (prevented or limited in work, left job for health reasons, under age 65 and receiving Medicare or SSI, receipt of SSDI).
Coverage	Civilian non-institutionalized population.
Sample	Approximately 50,000 households annually.
Products	Publications, public use data tapes.
Future	Redesign for 1995 is underway.
Comments	• only looks at work-related disability • no disabling conditions

Decennial Census	
Contact	Jack McNeil (301) 763-8300
Sponsor	Bureau of the Census
Frequency	Every ten years since 1790
Purpose	To provide a basis for reapportioning seats in the U.S. House of Representatives.
Design	Every dwelling in the country receives either the short form with basic population and housing questions. A sample of 17% of households gets the longer form with additional questions, including those related to disability. The disability questions are about the ability to work, mobility, and self-care limitations. These questions are asked of the adult population aged 15 and over, and proxies may be used to answer these questions.
Content	Basic demographic and housing characteristics of the population.
Disability Measures	Persons are asked if they have a physical, mental, or other condition for at least six months that limits their ability to work or entirely prevents them from working, difficulty With activities such as going outside or shopping, and difficulty taking care of their personal needs.
Coverage	Households; Group Quarters - institutional and non-institutional.
Sample	All U.S. households.
Products	Books, Tables, CD-ROM, Diskettes, Public Use Tapes.
Future	Plans for Year 2000 in progress.
Comments	• no questions concerning mental illness or mental retardation, assistive devices, or personal assistance, nor are there specific questions for children, working age adults, or elderly persons • measures of self-care have not shown reliability for the non-elderly • no questions for children • no questions on disability conditions • includes both community and institutional residents • can be analyzed at State, county, and national levels

1994/95 Disability Supplement to the National Health Interview Survey	
Contact	Michele Adler, DHHS/ASPE (202) 690-6443
Sponsor	National Center for Health Statistics
Purpose	To provide information on research and policy issues related to disability, including the prevalence of disability, the characteristics of people with disabilities (e.g., demographic, socioeconomic, health, participation in Federal programs), their service use and expenditures, and aspects of their daily lives (housing, transportation, employment, personal assistance).
Design	Personal interviews and self-reports. Phase I (January 1994-December 1995) is asked along with the core interview given to the 240,000 NHIS respondents. Phase II (Fall 1994-Fall 1996) is administered about six months after Phase I to about 40,000 respondents with serious disabilities. Data linkages with SSA and Medicare records can also be made.
Content	Phase I collects data on the prevalence, severity, type, duration, and disabling conditions; the health care, demographic, socioeconomic, health insurance, and program characteristics of people with and without disabilities. Phase II collects data on service use and expenditures and aspects of daily life (housing, long-term care services, home care, personal assistance, respite care, transportation, employment, accommodations, work history, vocational rehabilitation, relationships, family structure, family impact and child care).
Disability Measures	Disability measures in Phase I include standard limitation of activity measures and detailed measures of sensory impairments, functioning of specific body systems, six separate ADLs, six separate IADLs, mental illness, assistive devices, childhood disability, and functioning for children under five. People with mental retardation and other developmental disabilities (using the legislative definition) can also be identified.
Coverage	Civilian non-institutionalized population.
Sample	100,000 households or 240,000 over two years.
Products	Public-use tapes/publications (late 1995-1997).
Comments	• the only national comprehensive survey of children's disability and persons with developmental disabilities that has occurred in this country, the first such survey to have occurred on the working age population since 1978, and the most complete disability survey on all ages • disability definitions are exhaustive and state-of-the-art and sample sizes are quite large • there is a potential for re-interviewing respondents with disabilities at some point in the future, if funds permit

Epidemiologic Catchment Area Study (ECA)	
Contact	William Narrow (301) 443-3774
Sponsor	National Institute of Mental Health
Frequency	One-time.
Purpose	To assess the prevalence of mental and addictive disorders and to estimate service use.
Design	Face-to-face interviews done twelve months apart (waves I and II); telephone interview (face-to-face in CT) six months after wave I; institutional residents interviewed in waves I and II only--no telephone interview, use of Diagnostic Interview Schedule (DIS).
Content	Use of health services: ambulatory specialty mental and addictive, general medical, and human services, as well as admissions to hospitals and residential treatment centers; diagnostic data.
Disability Measures	Receipt of disability compensation; having to give up regular activities; diagnosis of mental illness; symptoms used as indication of impairment; unable or limited in work because of emotional or mental impairment.
Coverage	Household and institutional residents aged 18 years and over in five areas: New Haven, CT; Baltimore, MD; Durham, NC; St. Louis, MO; and Los Angeles, CA.
Sample	18,571 (household); 2,290 (institutional).
Products	National Technical Information System (NTIS) is contact for public use tapes; NIMH has list of 400+ publications.
Future	Ten year follow-up being conducted at Baltimore site; mortality follow-up at New Haven site.
Comments	• largest and most comprehensive community-based epidemiologic study in the mental health field • provides information on need and demand for mental health services • allows for comparison of service use patterns by persons with different diagnoses • not nationally representative • permits ability to assess use of multiple facilities

Longitudinal Study of Aging (LSOA I and II)	
Contact	Julie Dawson Weeks, NCHS (301) 436-5979
Sponsor	National Center for Health Statistics, National Institute on Aging
Frequency	Baseline survey in 1984, and followup waves in 1988, 1988, 1990. LSOA II followup interviews will be conducted every two years starting 1996.
Purpose	To measure change in health status, physical functioning and living arrangements, including movement into and out of institutions, among a cohort of older Americans as they move into and through the oldest ages.
Design	LSOA I baseline data is from the 1964 Supplement on Aging; LSOA II repeats the study with a new cohort from the 1994 NHIS core questionnaire, the 1994 Disability Supplement and SOA II. Personal interview at baseline, telephone interview at followup.
Content	Information on key activities (NAGI, ADLs, IADLs), helpers, living arrangements, nursing homes use, health insurance, family support, and self-perceived health status obtained in all waves. Information on basic demographic characteristics, work history, conditions and impairments, community services, income and assets obtained at baseline.
Disability Measures	Questions on difficulty performing seven ADLs, six IADLs, and NAGI; help in performing ADLs and IADLs. Also questions on impairment, health related retirement, and prevalence of disabling health conditions.
Coverage	Civilian non-institutionalized persons age 70+.
Sample	7,541 elderly persons.
Products	Public use tapes, CD-ROM, NDI/Medicare disk updates, publications.
Future	Original LSOA interviewing ended in 1990, but there will be ongoing record linking. Update on cause of death and Medicare coming in 1995. For LSOA II three follow-back waves will be conducted at two year intervals starting in 1996.
Comments	• first longitudinal study of the community-based elderly population • use of the LSOA I and II together will enable users to identify changes in functional status, medical conditions and impairments, living arrangements, and social supports across cohorts • can be linked with HCFA Medicare files and National Death Index • efforts are being made to include disability measures in LSOA II that allow for the ability to "crosswalk" estimates of prevalence of disability across surveys, e.g., NHANES III, AHEAD and NLTCS

Medical Exam Study	
Contact	Martynas Ycas (202) 282-7089
Sponsor	Social Security Administration
Frequency	1996
Purpose	To determine the distribution of persons with physical disabilities and mental impairments in terms of Social Security standards.
Design	Personal interview.
Content	To be determined.
Disability Measures	Measures of physical disability and mental impairments. Specifics yet to be determined.
Coverage	National household population age 18 to 69.
Sample	To be determined.
Products	To be determined.
Future	Plans for one time data collection in 1996

National Household Survey on Drug Abuse (NHSDA)	
Contact	Joseph Gustin, Project Officer, NHSDA, SAMHSA/OAS, (301) 443-0021
Sponsor	Substance Abuse and Mental Health Services Administration
Frequency	1971-72, 1974, 1975, 1976, 1977, 1979, 1982, 1985, 1988, 1990-95.
Purpose	To measure the incidence and prevalence of use of illicit drugs, licit drugs used illegally, alcohol, and tobacco. To analyze patterns and demographic correlates of substance use.
Design	Screening/interviewing conducted person-to-person at respondents home using paper and pencil instruments. Consistent collection of all "core" prevalence variables over time plus modules that permit addition/deletion of new topics. Sensitive data are accessed through self-administered answer sheets. Continuous data collection with calendar year survey periods. Three major race/ethnicity domains are sampled (non-Hispanic non-Blacks, non-Hispanic Blacks, and Hispanics).
Content	Drug-related variables, e.g., age at first use, recency of use, frequency of use for 12 different drug categories, problems associated with substance use, etc., plus demographics, income, program participation, pregnancy, employment, health status, access to health care, mental health, criminal behavior and arrest and related factors.
Disability Measures	Questions on respondent problems associated with drug use are used to measure drug dependence.
Coverage	U.S. civilian noninstitutionalized population age 12+.
Sample	Stratified multistage area probability sample. Sample size: 18,000. Oversampling of youth, non-Hispanic African Americans, and Hispanics
Products	Reports include (a) Population Estimates (b) NHSDA Main Findings and (c) Advance Report - NHSDA Preliminary Estimates. Special analytic reports are periodically produced on topics of current interest. Public Use Data Files are issued upon request (available in SAS format for years: 1979, 1982, 1985, 1988, and 1990-1993 (ASCII format for 1990 and 1991). Also, selected reports are available in electronic form via the Internet.
Future	Survey planned for 1996 (proposed for 1997). Proposed conversion of the survey instruments into electronic format (CAPI/audio CASI) in 1997-98.
Comments	Rapid reporting of survey results (six months after data collection).

Medicare Current Beneficiary Survey (MCBS)	
Contact	Gerry Adler (410) 966-7938
Sponsor	Health Care Financing Administration
Frequency	Continuous panel since 1991, interviews approximately every four months.
Purpose	Originated from the need to provide valid estimates of health care spending by different age groups, to describe the effects of the Medic-are program on its beneficiaries, and to model the effects of proposed program changes.
Design	Sample from HCFA's Medicare enrollment file.
Content	Utilization, sources of payments for services, health insurance coverage, health status and functioning, access and satisfaction.
Disability Measures	Disability related to duty in armed services; level of functioning in ADLs and IADLs; use of devices and personal assistance is also included. Only sample survey of Medicare disabled program beneficiaries.
Coverage	All Medicare beneficiaries; community and institutional residents.
Sample	12,674 (round one); 11,736 (two); 11,064 (three); 12,600 (four); approximately 16,000 (eleven); survey is supplemented annually and subject to rotation after round thirteen.
Products	Public Use file for Round 1 and Round 4 is available (linked with Medicare claims); 1992 fully linked public use file will be available in 1995.
Future	Plans to follow some individuals for up to four years.
Comments	• functioning questions indicate severity of impairment by asking if the person gets help, if someone stands by, or if special equipment is used • data are linked to Medicare administrative files, providing information on services used • because it has three rounds per year, facilitates analysis of changes in the beneficiaries and their use of services; follows individuals through different care settings • surveys those who have Medicare coverage: (a) not nationally representative of individuals under age 65 who have a disability or of the potentially disabled population, but (b) is representative of the population age 65 and over • no disability indicators for cognitive impairment, severe mental illness, or general emotional problems • longitudinal design permits observation of individual changes over time

National Comorbidity Survey	
Contact	Ronald Kessler, University of Michigan (202) 401-7733
Sponsor	U.S. Alcohol, Drug Abuse, and Mental Health Administration
Frequency	One-time survey, data collection 1990-1992.
Purpose	A congressionally mandated survey designed to study the co-morbidity of substance use and non-substance psychiatric disorders; the survey examines not only prevalence and incidence, but also risk factors.
Design	Stratified, multistage area probability sample; supplemental survey of nonrespondents.
Content	Affective, anxiety, substance use, and other psychiatric disorders; risk factor questions such as parental psychopathology, childhood family adversity, social networks and support, stressful life events and activities; utilization of services; unmet need.
Disability Measures	Disability days and work cutback days to mental disorders, substance use disorders, and other reasons; truncated set of ADL-type questions.
Coverage	Persons aged 15-54 in civilian, noninstitutionalized population in the 48 contiguous States; supplemental sample of students living on campus or in group housing.
Sample	8,098 respondents
Products	Public use data tapes will be available in the next couple of years.
Future	Possible reinterview and a new cross-section of data for the year 2000.
Comments	• a first survey to administer a structured psychiatric interview to a national probability sample in the United States • use of the Composite International Diagnostic Interview (CIDI), which can be administered by trained interviewers who are not clinicians (also used in the ECA) • capability of studying regional variation and urban-rural differences • relies on retrospective reports to assess prevalence of lifetime disorders; need for longitudinal data to meet this limitation • diagnostic assessment based on a single structured interview

National Health and Nutrition Examination Survey (NHANES)	
Contact	Vicki Burt (301) 436-7080 ext.116
Sponsor	National Center for Health Statistics
Frequency	1971-1975 (NHANES I), 1976-1980 (NHANES II), 1988-1994 (NHANES III); a special study of the Hispanic population was conducted in 1982-1984.
Purpose	To assess the health status of the US population; to estimate the national prevalence and investigate trends in selected disease and risk factors; and to monitor trends in prevalence, awareness, treatment, and control of diseases.
Design	Respondents are interviewed at home, then examined, tested and interviewed again in a mobile examination center. NHANES III offered a home examination option for those unable or unwilling to come to mobile examination center.
Content	Data on health insurance; income and income assistance; family housing characteristics; physical and cognitive functional impairments; selected disabilities/conditions; and health and nutrition status.
Disability Measures	Measures in NHANES III include functional limitations (cognitive, physical and social), as well as the presence of selected health conditions. Questions asked of persons 17+ (60+ from 1988-91) regarding physical functioning, i.e., difficulty in performing certain physical activities, and need for assistance with ADLs and IADLs. Includes questions on use of assistive devices. Respondent are asked about receipt of Social Security benefits due to disability.
Coverage	Civilian, non-institutionalized population aged two months and older. (NHANES I covered persons aged 1-74 years; NHANES II covered persons 6 months to 74 years).
Sample	NHANES III has a total sample of 40,000 persons two months of age and over. Oversample of children age two months to five years, persons age 60+, Black Americans, and Mexican Americans.
Products	Public use tapes, publications.
Future	NCHS will attempt to secure adequate funding for a full scale NHANES in 1988, or will conduct a scaled back NHANES in 1998 with limited subgroup coverage and examination.
Comments	• use of direct testing rather than self-reporting • records can be matched with the National Death Index and HCFA Medicare claims data • useful for the study of the contribution of multiple diseases to disability in old age (NHANES III) • ADL and IADL questions were asked only of the 60+ population from 1988 to 1991 • long intervals and variations in wording between surveys make comparisons in certain areas problematic

National Health and Nutrition Examination Survey I Epidemiological Followup Study (NHEFS)	
Contact	Christine Cox, NCHS (301) 436-5979 x115
Sponsor	National Center for Health Statistics, National Institute on Aging
Frequency	1982-84, 1986, 1987, 1992.
Purpose	To measure changes in individual participants' characteristics between NHANES I and NHEFS; to track morbidity, mortality and institutionalization associated with suspected risk factors; and to provide a natural history of chronic disease and functional impairment.
Design	Personal interviews or telephone interviews are conducted with subjects or their proxies. Also collected are nursing home and hospital records of overnight stays, and death certificates of decedents.
Content	All waves were. asked about specific diseases and medical conditions. Collects morbidity, disability, and mortality data; demographic information; medical history and health care facility stays; functional status; health habits and risk factors such as blood pressure, smoking, cholesterol levels, alcohol consumption, nutritional deficiencies, estrogen use, impaired pulmonary function, and weight.
Disability Measures	Extensive functioning measures. Questions on difficulty with ADLs, assistance with ADLs, and use of special equipment. Also questions on chronic diseases.
Coverage	The civilian noninstitutionalized population who completed a medical examination of NHANES I in 1971-1975.
Sample	14,407 persons between the ages of 25 and 74 in 1971-1975
Products	Public use data tapes and documentation are available from the National Technical Information Service. Descriptions of the study methodologies are available in the NCHS Vital and Health Statistics Series I reports. Data from the 1992 study will be released in 1996.
Future	No current plan to reinterview subjects after the 1992 follow-up; however, there are plans to continue to follow passively through death certificates.
Comments	• extensive data collection on individuals, including the non-elderly, for 20 years; an oversample of women age 25-44 in NHANES I supplies a large sample of nonelderly for the followups • can follow incidence of disability as cohorts age • all baseline NHANES I and NHEFS waves can be linked to each other

National Health Interview Survey (NHIS)	
Contact	Gerry Hendershot (301) 436-7093
Sponsor	National Center for Health Statistics
Frequency	Annually since 1957; survey is in the field continuously.
Purpose	To provide nationally representative data on the health status, health related behavior, and use of health services by the U.S. population.
Design	Core questionnaire on health and disability status. Periodic supplements on selected topics; e.g., 1994 and 1995 Disability Survey. Face-to-Face home interviews with trained Census personnel.
Content	Demographics, health and disability status, acute and chronic conditions, use of doctors and hospitals, income, health insurance, and program participation.
Disability Measures	The core questionnaire measures limitations at four levels: unable to perform major activity, limited in major activity, limited in nonmajor activity, and not limited in activity. Looks at prevalence of chronic conditions or impairments and restricted activity days.
Coverage	Civilian non-institutionalized population.
Sample	50,000 households (125,000 persons) annually; in 1995 will include approximately 40,000 households and 100,000 persons.
Products	Publications (e.g., Advance Data Reports), public use data tapes, CD-Rom.
Future	Major redesign of questionnaire for 1996 is underway.
Comments	• repeated cross-sectional, with capability for providing longitudinal information; can establish trends in prevalence of disability • using core, cannot estimate how many ADL or IADL limitations a person has • core interview does not have information on cognitive impairment; does include information about chronic and mental conditions; new design will include measures of depression • only asked IADL questions in certain circumstances • no measures of assistive devices within core, however, this subject was covered in 1990 supplement • for those age 65 and above, core asks if need help with ADLs and IADLs, but not for each ADL and IADL individually; also asked of persons under age 65 who report limitations
While there are some gaps with disability measures in the core interview, many of these issues are addressed in the various supplements, such as those described below. For the special questionnaires, one adult is subsampled from the family; self-response is required. (In some supplements, questions are asked of everyone in household, and proxy responses are allowed.)	
1988 Child Health Supplement	
Disability Measures	Various medical conditions, including missing limbs or permanent impairment, stiffness, or deformity of any limbs; asks questions about development, learning disabilities, and emotional or behavior problems lasting three months or more.
Comments	questions regarding development, learning, and behavior may give an indication of the number of individuals with such problems, but there is insufficient information regarding severity
1989 Mental Health Supplement	
Disability Measures	Diagnosis of major mental illness, ADLs, IADLs, social functioning, disability payment due to mental illness.
Comments	• duration and severity of problems in functioning • perhaps the best information currently available about the disabilities of adults with serious mental illness; however, it contains no reliable information on children with serious mental illness

National Health Interview Survey (NHIS) (*continued*)	
1990 Supplement on Assistive Devices	
Disability Measures	Sets of questions about specific devices for mobility, hearing, vision, and speech; special features in the home designed for disabled persons.
Comments	• may slightly overestimate those with chronic illnesses or impairments who use devices such as wheelchairs, etc. which may be used due to acute conditions • gives estimates of unmet need
1991 Supplements	
Disability Measures	Hearing; difficulty in or help with ADL and IADL related measures; chronic and disabling conditions; mental health.
Comments	mental health questions do no relate to a specific diagnosis of illness; do not know what the reason is for certain emotions
1994 Access to Care Survey	
Disability Measures	Focuses on unmet needs, particularly on the acute care side; asks what kinds of services were needed.
Comments	• useful when used along side the core interview to gain a better picture of disability • service need does not necessarily indicate severe disability

National Long-Term Care Survey (NLTCS)	
Contact	Larry Corder, Duke University (919) 684-6758 Ken Manton, Duke University (919) 684-6758
Sponsor	National Institute on Aging; ASPE
Frequency	Intermittent 1982, 1984, 1989, 1994, 1999.
Purpose	To provide nationally representative data on the disability status and use of long-term care by the disabled elderly (age 65+).
Design	Separate questionnaires for disabled elderly in the community and those in institutions. Occasional supplements on informal caregiving (1982, 1989), healthy aging (1994), and decedents (1984, 1994). Household interviews were screened via telephone.
Content	Demographics, health and disability status, measures of physical and cognitive functioning; housing and neighborhood characteristics; use of medical providers and prescription medicines; use of formal and informal long-term care; health insurance; income and asset information.
Disability Measures	Institutional questionnaire looks at cognitive functioning and limitations in ADLs. Community questionnaire asks about limitations in ADLs and IADLs, cognitive functioning, who provides help, and use of devices and personal assistance.
Coverage	Medicare beneficiaries age 65+.
Sample	5,000-6,000 community interviews; 1,300 institutional interviews.
Products	Publications; public use data tapes.
Future	Decision to be made about 1999 survey.
Comments	• excellent source of information about disability in the older population • provides large samples of the "oldest" old population • currently have four points in time to use in longitudinal comparisons • includes information on severity of limitations and use of assistive devices • some questions are not asked in both community and institutional questionnaires, making it difficult to compare people moving from different care settings • for persons in institutions, ADL questions are answered by a proxy which may or may not be beneficial

National Medical Expenditure Survey-Household Survey, Survey of American Indians and Alaska Natives, Institutional Population Component (NMES)	
Contact	Barbara Altman (301) 594-1400
Sponsor	Agency for Health Care Policy and Research (AHCPR)
Frequency	Decennial (approximately): 1987, 1977.
Purpose	To obtain information on health care utilization, expenditures, and sources of payment.
Design	Separate surveys for nationally representative samples of the civilian north institutionalized population, American Indian and Alaskan Native population, and for residents of nursing homes and facilities for persons with mental retardation. Four or five rounds each survey year.
Content	Demographics; health status; health care access and utilization for the complete year, expenditures and sources of payment; insurance status; employment information; income and assets; facility information and institutional expenditures in institutional survey.
Disability Measures	Detailed ADL and IADL measures; duration and intensity of impairment; use of devices; indicators of work and activity limitations; modified indicator of physical functioning; yearly total of disability days; indicators of receipt of disability benefit; ICD-9 coding indicating individual conditions; separate question asks specifically about mental retardation, cerebral palsy, spina bifida, and autism.
Coverage	Civilian non-institutionalized population; institutionalized population in nursing and board and care homes and facilities for persons with mental retardation.
Sample	Approximately 14,000 households in civilian population and 2,000 households in the American Indian and Alaskan Native population; 810 nursing and personal care homes; 691 facilities for persons with mental retardation; 5,726 residents of nursing and personal care homes; 4,421 residents of MR facilities.
Products	Publications; public use data tapes.
Future	New survey planned for 1996 currently in pretest stage; will not include the mental retardation facilities or special data collection on American Indians or Alaska Natives.
Comments	• institutional population sample tracks resident's movement between facilities and into the community • cannot provide prevalence estimates for conditions associated with disability • provides multiple measures of disability that allow for comparisons or creation of combination of measures • provides possibility of analysis at the family level and at the individual level

National Mortality Followback Survey (NMFS)	
Contact	Jim Spitler (301) 436-7464 James A. Weed (301) 436-8952
Sponsor	National Center for Health Statistics and various co-sponsoring Federal agencies.
Frequency	Intermittent: 1961, 1962-63, 1964-65, 1968, 1986, 1993.
Purpose	To supplement information on the death certificate with information on important characteristics of the decedent that may have affected mortality.
Design	Data collection instruments include: death certificates, next-of-kin informant questionnaires (primarily telephone interview), mail questionnaires to health care facilities used by decedent in last year of life, and medical examiner/coroner reports.
Content	Demographic characteristics, socioeconomic status, health status, lifestyle patterns, measures of physical and cognitive functioning, use of formal and informal long-term care, health insurance, income and asset information, cause of death, and lifetime nursing home use.
Disability Measures	Questions asked of next-of-kin concern memory impairment, decedent's need for assistance or special equipment to perform specific ADLs during last year of life, and presence of specific chronic conditions. The facility abstract record (FARS) collects data on diagnosis according to International Classification of Diseases (ICD) version 9, and the Clinical Modification (ICD-9-CM).
Coverage	For 1986 survey adults aged 25 and over who died in 1986. For 1993 survey, persons aged 15 and over who died in 1993.
Sample	Information is gathered on approximately 20,000 deaths selected from the Current Mortality Sample; a 10 percent sample of death certificates were received from the States.
Products	Publications, public use tapes. CD-Rom for surveys after 1986.
Future	Uncertain
Comments	• nationally representative sample • includes institutionalized populations • collects data on duration of specific conditions prior to death • excludes children under age 15 who have died in 1993, and persons under 25 in previous surveys • excludes data for Oregon in 1986 and South Dakota in 1993

National Organization on Disability/Harris Survey of Americans with Disabilities	
Contact	Martin Walsh (202) 293-5960
Sponsor	National Organization on Disability
Frequency	1994
Purpose	To study the attitudes and experiences of Americans with disabilities in regard to quality of life, employment and social opportunities, political and religious participation, financial status, lifestyles, job discrimination, personal assistance and equipment needs, and access to health care.
Design	Telephone interview of approximately 25 minutes with persons with disabilities. Proxies used when person with the disability was unavailable or unable to be interviewed. Also a comparison group of a sample of 1,115 adults without disabilities were asked a number of the survey questions. Many questions from survey were also asked in a 1988 survey.
Content	Type/severity/impact of disability or health condition; life satisfaction, social impact; employment status; health insurance; health care access; trends and the ADA; religion; ability/willingness to work; technology and computers; person and household characteristics.
Disability Measures	Screens respondents as a person with a disability if a disability or health problem prevents the individual from participating fully in work, school or other activities; if respondent states that he/she has a learning disability, emotional/mental disability, physical disability, or a talking, hearing, or visual impairment. Also includes respondents who consider themselves as a person with a disability. Once screened in, the survey asks for medical diagnosis of disability or health condition.
Coverage	Non-institutionalized persons with disabilities aged 16 and over.
Sample	1,021 sampled nationally.
Products	Summary of findings available through publication, tape and computer disk. Public use data tapes are available.
Future	National Organization on Disability will continue to survey attitudes about people with disabilities.
Comments	• national survey to study the attitudes and experiences of Americans with disabilities • this survey taken four years after the ADA reflects a similar landmark survey conducted by Louis Harris and Associates four years before the ADA

National Survey of Families and Households (NSFH)	
Contact	Larry Bumpass, University of Wisconsin (608) 262-2182
Sponsor	National Institute of Child Health and Human Development
Frequency	1987-88, original sample reinterviewed in 1992-93.
Purpose	To measure the changing composition of families over time and interactions among family members.
Design	One adult per household was randomly selected to be the primary respondent, with a shorter self-administered questionnaire given to the co-habitating partner or spouse of this respondent.
Content	Demographics, family relationships and interactions, household composition, education and work, economic and psychological well being
Disability Measures	Asks who requires care or assistance in the household because of a disability or chronic illness, and which of these persons required the most care or assistance.
Coverage	Non-institutional population.
Sample	Interviews with 13,017 and main cross-section of 9,643.
Products	Series of NSFH working papers, public use data tapes.
Future	1992-93 data should be available in late 1994 or early 1995.
Comments	• not designed as a disability survey, but can look at the household as a unit rather than and individual person, thereby getting some idea of the level of disability and burden households are facing • addresses the duration of disability by referring to care in past twelve months; also refers to continuing burden by asking if person is still receiving care • ADLs and IADLs are addressed, though not as precisely as in disability focused surveys. IADL questions are asked of those over the age of fifteen; needs in personal care are asked of all who need assistance • no distinction is made with sensory impairments and other disabilities; no specific questions are asked about mental illness, mental retardation, use of assistive devices; no specific questions addressing young children

National Survey of Veterans (NSV)	
Contact	Susan Krumhaus (202) 273-5108
Sponsor	Department Of Veterans' Affairs
Frequency	1978, 1979, 1987, 1989 (disabled veterans only) 1993
Purpose	To obtain detailed data of social, economic, health status, and health care usage patterns of veterans; to gather information on veterans' awareness and actual receipt of VA benefits and participation in non-VA programs; to provide a current resource of detailed data available for policy analysis.
Design	Telephone interviews with veterans. Proxy interviews with family members were conducted when the veteran was physically or mentally unable to respond. Oversampling was done for veterans with service connected disabilities or conditions who used inpatient or outpatient care in 1992
Content	Socio-demographic characteristics, military service, health insurance, hospitalization and outpatient care, degree of disability, limitations in activities of daily living.
Disability Measures	Rating of disability status by VA-conducted physical exam for veterans with service-connected disability or conditions, work limitations due to all disabilities, limitations in activities of daily living, duration of disability.
Coverage	All veterans in U.S. and Puerto Rico
Sample	11,645 (in 1993)
Products	Public use tapes
Future	Probably in 1998
Comments	In 1989 the survey focused entirely on veterans with service-connected disabilities. In addition to the above-mentioned content, the 1989 survey covered use of long-term care; knowledge, awareness of, and use of VA and non-VA programs; need and use of disability support services; prosthetics; home modifications. Sample size was 9,913.

New Beneficiary Survey and Followup	
Contact	Howard Iams (202) 282-7092
Sponsor	Social Security Administration
Frequency	1982, followup in 1992.
Purpose	To represent the situations of living non-institutionalized persons in late 1982 who had begun receiving retirement or disability benefits under the Social Security program between mid1980 and mid-1981.
Design	Listings of cash and non-cash beneficiaries (including Medicare-only individuals) drawn from SSA's Master Beneficiary Record. The 1992 Followup reinterviewed these persons as well as a new cohort of workers disabled in 1991.
Content	Demographic information; household composition; employment history; noncovered employment; health status; income and assets; marital history; child care; program knowledge; information on spouse.
Disability Measures	Work related disability, Social Security benefits received because of a disability, rehabilitation and other services received, and ADL and IADL limitations, recent long-term care experiences.
Coverage	Civilian non-institutionalized population.
Sample	18,600 interviews; approximately 12,000 in follow-up.
Products	Publications, public use data tapes.
Future	Uncertain; no current plans for additional follow-up
Comments	• includes detailed ADL and IADL questions: asks if get help from people, provides a scale of difficulty, and use of special equipment; however, detailed information on ADLs in not available at baseline • lack of information on duration of the disability • panel study; gives detailed information about individual changes • looks at rehabilitation and other services used, which may or may not indicate disability • only represents new beneficiaries from a one-year period • follow-up is ten years after the original survey, making it more difficult to analyze changes in respondents

Panel Study of Income Dynamics (PSID)	
Contact	Sandra Hofferth, University of Michigan (313) 763-5131 Frank Stafford, University of Michigan (313) 763-5186
Sponsor	National Institute on Aging, National Science Foundation, National Institute of Child Health and Human Development/Department of Labor and ASPE/DHHS
Frequency	Annually since 1968
Purpose	Original purpose was to collect data on poverty and welfare dynamics. The study has become a general social science resource for longitudinal data on individuals and families.
Design	Interviews conducted in person 1968-72; by telephone since 1973. Ten percent or fewer of the interviews are conducted at the respondent's home. Respondent is the family head or spouse.
Content	Economic and demographic data, with substantial detail on income sources and amounts, employment, family composition changes, residential location. NIA-funded Supplements on health, parental health, long-term care, and intergenerational transfers.
Disability Measures	Questions on health limitations, e.g., limitations on work, have been asked of adults since 1968. The 1986 survey contained substantial questions on ADL and IADL limitations, specifically questions regarding difficulty and assistance with specific tasks. In 1990 questionnaires with ADL, IADL and health questions were mailed to the 50+ population. Since 1992 the core questionnaire asks ADL and IADL questions of the 55+ population. 1995 survey included questions on learning disabilities and special education status of children.
Coverage	U.S. household population
Sample	11,000 families in 1994. Oversample of African Americans and Hispanics.
Products	Public use tapes, CD-ROM, publications. Access to PSID Home Page through http://www.umich.edu/~psid using Mosaic program.
Future	Ongoing. NIA has funded housing supplement to predict situations of dependent care among individuals age 55+.
Comments	• long-term time series data on health limitations • disability questions in the 1990 surveys focus on the 55+ population only • extent of family caregiving included in 1992 survey • long-term nature allows for study of antecedents of disability, intergenerational linkages, and other longitudinal aspects • system can identify SSI recipients in family and link to disability

Supplement on Aging (SOA I and SOA II)	
Contact	Julie Dawson Weeks, NCHS (301) 436-5979
Sponsor	National Center for Health Statistics, National Institute on Aging
Frequency	1984, 1994
Purpose	SOA, a supplement to the 1964 National Health Interview Survey, establishes baseline data (for LSOA) to study changes in functional status among the elderly, and the relationship between social and health factors and death. SOA II is intended to serve as a comparison cohort to the 1964 SOA cohort, and possibly as a baseline for a second Longitudinal Study on Aging (LSOA II). SOA II replicates SOA I to see if there are changes in the disability process, to study the healthy aging, to focus on unmet need, and to examine problems in elderly women.
Design	Cross-sectional national survey collected through household interviews. Interview was with sample person except in cases where the sample person was physically or mentally unable to respond. In such cases adult proxies were interviewed. All persons 70+ who screened in as "disabled" on Phase 1 will receive the expanded Phase 2 Disability questionnaire with the SOA II questions embedded within it; remaining sample of elderly persons will be administered a shorter questionnaire. SOA II was designed as a stand alone survey
Content	Housing and long-term care services, transportation, social activity, work history, health insurance, assistance with key activities, family structure, living arrangements, conditions and impairments, and health opinions and behaviors.
Disability Measures	Questions include difficulty in performing seven ADLs, eight IADLs, NAGI; receipt of help/need of help from another person with specific ADLs/IADLs, condition that causes trouble with ADLs/IADLs, limitations in amount/kind of work, work-related disability, health related retirement, sensory problems, and use of special equipment.
Coverage	Civilian non-institutionalized population age 55+ taken from the 1984 National Health Interview Survey; age 70 years and older in 1994/1995.
Sample	16,000 surveyed in SOA I. Approximately 10,000 elderly members of NHIS households in SOA II.
Products	Public use files, publications.
Future	NHCS and NIA is currently conducting the second Supplement on Aging (SOA II) to the NHIS.
Comments	SOA II collects detail on caregiver or service support, e.g., amount of time each helper spends in assisting the respondent with ADL and/or IADLs

Survey of Income and Program Participation (SIPP)	
Contact	Enrique Lamas (301) 457-3819 Jack McNeil (301) 763-8300
Sponsor	Bureau of the Census
Frequency	A new panel has begun every October since 1983.
Purpose	To obtain information on Federal program participation and to describe the income distribution of the population (especially those with lower incomes).
Design	Longitudinal. Nine waves of interviews are conducted at four month intervals over a 30 month period for each panel. There is a standard core interview supplemented by periodic topical modules. All disability measures are found on selected topical modules. Provides detailed information on disability for all ages.
Content	Core interview collects information on Federal program participation, earnings, occupation, employment, and income. There are also periodic supplements to the core interview, referred to as "topical modules". Disability questions have been asked on topical modules beginning with the 1990 Panel. Other topical modules include history of welfare receipt, mobility, migration history, work disability history, employment history, taxes, assets and liabilities, savings, marital and fertility history, family relationships, real estate, education and training, retirement, support for non-household members, child care, and child support.
Disability Measures	Different questions on limitations by age groups; health conditions; ADLs and IADLs; utilization of health care.
Coverage	Civilian non-institutionalized population.
Sample	Varies from 12,000 to 20,000 households per panel.
Products	Publications, public use data tapes; some products from some waves of the 1993 panel are now available; latest panel file available is 1991.
Future	Redesign for 1995 is underway.
Comments	• contains comprehensive information on disability, as well as related information • questions on functional limitations were asked in 1984 and for children and a small subset of adults in 1988 and 1989; more detailed questions asked in 1984 and the years including and following 1990. Samples were much smaller in the latter years, making it difficult to measure prevalence rates • disability questions were not repeated for the same respondent in 1988 and 1989 (not designed to measure individual changes overtime) • comprehensive disability data collected in 1990 (waves 3 and 6), 1991 (wave 3), 1992 (waves 6 and 9), and 1993 (waves 3 and 6)

Surveys of Disability and Work	
Contact	Marlynas Yeas (202) 282-7089
Sponsor	Social Security Administration
Frequency	Intermittent through 1978.
Purpose	To measure the prevalence of disability in the working age population in the U.S. and determine its effect on persons and their families
Design	Interview with a sample of civilian non-institutionalized population with and without disabilities age 18-64. Interview of 9,900 and noninterview of 1,900.
Content	Demographic information: health care use; disability status and functioning; socioeconomic status; family background; employment; program participation.
Disability Measures	All respondents are questioned about health conditions or illnesses (diagnosed by a doctor and not diagnosed); mobility limitations or inability to perform specific ADL activities; work limitations or inability to work due to health condition; use of assistive technology; and receipt of government benefits (for disability reasons). Question also asked regarding home modifications to accommodate health problems of anyone living in the household.
Coverage	Civilian non-institutionalized population.
Sample	Approximately 12,000 persons.
Products	Publications, public use tapes (of the 9,900 interview cases only).
Future	No plans.
Comments	• the only national survey on disability and work • questions distinguish between temporary ill health and disability - survey can be linked to SSA files • survey lacks questions that directly address the work needs of persons with mental illness or mental retardation, especially in regard to personal assistance, queuing, job coaching

PROVIDER BASED SURVEYS

Annual Census of Patient Characteristics: State and County Mental Hospital Inpatient Services	
Contact	Michael Witkin, CMHS (301) 443-3343
Sponsor	Center for Mental Health Services (CMHS)
Frequency	Annually, 1970-1991
Purpose	To monitor deinstitutionalization of State and county mental hospital additions and residential patients.
Content	Demographic information (age and gender) and geographic information (city, zip code, and State of facility); clinical information (mental disorders, annual admissions, readmissions, and transfers).
Disability Measures	Receipt of services in State and county mental hospitals, can look at clinical information such as mental retardation, developmental disabilities, or mental health disorders.
Coverage	Individuals receiving inpatient services in State and county mental hospitals.
Sample	Universe is 274 hospitals (1991).
Products	The organization will conduct customized research; public reports are published from the data. Annual in-house publication: *Additions and Resident Patients at End of Year, State and County Mental Hospitals, by Age and Diagnosis, by State, US., 1990*. Rockville, MD: Center for Mental Health Services, 1993.
Comments	• information on persons with mental retardation only if they are in a State hospital • limited information on persons with developmental disabilities • data unavailable for certain States • national estimates include all States

National Ambulatory Medical Care Survey (NAMCS)	
Contact	Catharine Burt (301) 436-7132
Sponsor	National Center for Health Statistics
Frequency	1973, 1975-1981, 1985, 1989-present.
Purpose	To collect data on visits to physicians in office-based practices.
Design	One page Patient Record form completed by examining physician to record information about patient's office visits. Specially trained interviewers visited the physicians prior to their participation in the survey and instructed physicians and staff in the methods and definitions to be used.
Content	Patient, physician and visit characteristics. Includes physician diagnosis.
Disability Measures	Physician diagnosis of patient (principle diagnosis and other) is the only measure to estimate disability. Up to three diagnoses are coded and classified according to the International Classification of Diseases, 9th Revision, Classical Modification (ICD-9-CM). The 1991-92 and 1993-94 surveys ask patients if they have one or more of a list of four or five specific conditions (e.g., asthma, diabetes, HIV, depression).
Coverage	Ambulatory patients seen in offices of non-federally employed office-based physicians.
Sample	Approximately 2,000 office-based physicians completed 34,606 Patient Record forms in 1992.
Products	Public use tapes, DC-ROM, publications.
Future	Ongoing
Comments	one-time physician diagnosis; no indication of the onset or duration of condition or disability

National Employer Health Insurance Survey (NEHIS)	
Contact	Gail Poe, NCHS (301) 436-3874 ext. 166
Sponsor	Agency for Health Care Policy and Research, Health Care Financing Administration, and the National Center for Health Statistics
Frequency	1994
Purpose	To produce State and national level estimates of private health insurance spending for National Health Accounts; provide baseline data for evaluating the effects of health care reform; describe the current employment-based health insurance system.
Design	Data collected by Computer Assisted Telephone Interviewing.
Content	Health insurance coverage for employees and their families; cost sharing provisions; characteristics of the plans including services covered, i.e., nursing home care, personal care in the home, home health care; and exclusions and waiting periods for pre-existing conditions.
Disability Measures	No clear disability measures. Survey includes questions regarding preexisting health conditions, substance abuse and mental health.
Coverage	Private and public sector employers.
Sample	33,000 employers. A minimum of 40 interviews in each State. Includes persons identified as self-employed with no employees in the 1992 NHIS.
Products	Data will be released in the Spring 1995 in the form of published reports and electronic data products.
Future	Possible 1996 survey
Comments	• focus is on employer-provided health insurance plans and their coverage policies, not individuals; no utilization data is collected • collects data on the number of persons affected by refusal of coverage due to health problems or conditions • data is being collected for the first time; no trend analysis or comparisons can be made with this survey alone

National Health Provider Inventory (NHPI)	
Contact	Al Sirrocco (301) 436-8830
Sponsor	National Center for Health Statistics
Frequency	1991 only. Previously known as the National Master Facility Inventory (from 1967 every two years until 1982), and Inventory of Long-Term Care Places (1986)
Purpose	To provide national statistics on the number, type, and geographic distribution of health providers; to serve as sampling frames for future surveys in the Long-Term Care component of the National Health Care Survey.
Design	Mail questionnaire sent to health facility administrators with telephone follow-up after three rounds of unsuccessful mailings.
Content	Ownership, number of beds, certification status, staffing and other related facility characteristics. Questionnaire has two components: a survey of nursing homes (demographics, characteristics of residents) and a survey of home and hospice providers (types of services provided).
Disability Measures	Identifies facilities that primarily serve persons with MR/DD, or other physical or cognitive impairments. Survey asks whether the facility provides its residents with assistance with specific ADLs and IADLs.
Coverage	Nursing homes, board and care homes, hospices and home health agencies.
Sample	55,000 facilities and agencies total, approximately 15,500 of which are nursing homes and 31,430 board and care homes.
Products	Public use tapes, publications
Future	No funding for 1995.
Comments	• questions inquire about facility characteristics, not individuals • different data collection techniques between NHPI and earlier National Master Facility Inventory and the Inventory of Long-Term Places make trend reports problematic • names and addresses of responding facilities and agencies provided in public use tapes offer a sampling frame for future researchers

National Home and Hospice Care Survey (NHHCS)	
Contact	Genevieve Strahan (301) 436-8830
Sponsor	National Center for Health Statistics
Frequency	1992, 1993, 1994
Purpose	To collect baseline information about hospices and home health agencies.
Design	The NHHCS is a segment of the Long-term Care Component of the National Health Care Survey. Three questionnaires were used to collect data: the Facility Questionnaire, the Current Patient Questionnaire and the Discharged Patient Questionnaire. Personal interviews were conducted with facility administrators for agency data; staff members for data on patients.
Content	Agency characteristics; basic demographic characteristics; caregiver information; services utilization; and functional status of current and discharged patients.
Disability Measures	Medical diagnosis are recorded from patient medical records; questions on patient's use of personal assistance with six specific ADLs and six IADLs; one question on patient use of specific assistive aids.
Coverage	Current and discharged users of hospice and home health agencies, and agencies that provide home health and hospice (taken from the National Health Provider Inventory).
Sample	1,500 home health agencies and hospices, 9,000 current patients, 9,000 discharged patients. Uses home health and hospice section of the National Health Provider Inventory to select sample.
Products	Public use tapes, publications.
Future	No plans for 1995.
Comments	• linkage between NHHCS and the National Nursing Home Survey; although surveys not funded for the same years • sampling frame of agencies in NHHCS is the same between years, but NHHCS does not follow the same individuals through the years of surveys (uses random sample) • duration of functional impairment is not indicated; assistance with ADLs is asked for one point in time

National Nursing Home Survey (NNHS)	
Contact	Evelyn Mathis (301) 436-8830
Sponsor	National Center for Health Statistics
Frequency	1973-1974, 1977, 1985. Followup surveys; 1987, 1988, 1990.
Purpose	To collect baseline and trend statistics about nursing facilities, their services, residents, discharges and staff in order to satisfy diverse data needs of those who establish standards for, plan, provide and assist with long-term care services. The National Nursing Home Survey Followup (NNHSF) is a longitudinal utilization study intended to trace the cohort of residents sampled in the 1985 NNHS in and out of nursing homes.
Design	Combination of personal interview and self-enumeration techniques: in-person interview of nursing home staff, telephone interview of next of kin, as well as mail questionnaires for patient data.
Content	Current Residents, Discharged Residents, and Next of Kin questionnaires collect data on demographics; health status immediately preceding/during stay; place of residence before/after stay; all prior/subsequent nursing home use; who paid/is paying for care. The Current Residents questionnaire contains information on hospitalizations during nursing home stay; services received in the month preceding interview.
Disability Measures	Data collected on sample residents include diagnosis (current and at admission); selected conditions (including MR), impairments (chronic health and memory), ADLs and selected IADLs, and use of assistive devices.
Coverage	Nursing home facilities, nursing home staff, current residents and discharged residents.
Sample	In 1985, 1,079 nursing homes, 5,243 current residents, 6,023 discharged residents, 9,134 next of kin.
Products	Public use tapes and publications.
Future	1995 update is planned.
Comments	• similarity of the procedures, questions, and definitions of the 1973, 1977, and 1985 surveys permit some trend comparisons • data are available on timing of nursing home use over a lifetime as well as who pays for use • possible to track lifetime patterns for persons with chronic conditions • 1995 survey has been scaled down; the survey will not include Next of Kin or Discharged Residents questionnaires

National Survey of Shelters for the Homeless	
Contact	Martin Abravanel (202) 708-2031
Sponsor	U.S. Department of Housing and Urban Development
Frequency	Periodic: 1984, 1988
Purpose	To obtain data on the number, occupancy, capacity, operational characteristics, funding, and available services of homeless shelters throughout the U.S.
Design	Managers of shelters and administrators of voucher programs for the homeless are surveyed.
Content	Demographics (gender, age, race, family status, employment status); shelter location by population centers and size; service utilization and clinical information of clients; financial information (shelter charges, budget); type of shelter, staffing.
Disability Measures	Services provided to clients: health care, mental health, substance abuse, transportation, case management. Clinical information: physical disability, mental illness, alcoholism, drug abuse, and AIDS.
Coverage	Shelter and voucher programs providing services to homeless persons in counties with populations greater than 25,000.
Sample	205 facilities.
Products	1984 data available in published reports; 1988 available in SPSS format.
Future	Unknown
Comments	• shelter managers' responses do not necessarily represent professional diagnoses and may over or understate incidence of a particular problem • definitions of terms such as mental illness and physical disability were not provided to respondents • population of interest suitable for analysis includes individuals with mental health conditions or physical disabilities, as well as individuals with a dual diagnosis

ADMINISTRATIVE

Medicaid Statistical Information System (MSIS)	
Contact	Dave Gibson (410) 968-0068
Sponsor	Health Care Financing Administration
Purpose	To collect, manage, analyze, and disseminate person specific information on utilization and payment for services covered by State Medicaid programs.
Design	States participate voluntary; MSIS collects selected, standardized data elements on eligibility and paid service claims.
Content	Demographic, eligibility, medical payments and claims, inpatient service, and long-term care service information.
Disability Measures	Based on diagnosis and/or services received.
Coverage	26 States (Florida and Colorado are in initial stages of participation): the data represent 100 percent of these States' eligible population and their Medicaid coverage.
Products	MSIS State Participation Procedures, Tape Specification and Data Dictionary, and Personal Summary Record File Data Description.
Future	New States will be added to the system.
Comments	not all data elements are available from all States no level of functioning measures; will only receive information abut types of impairments by looking at the type of claims paid (but categories are broad, and detailed utilization and payment analyses are not possible) data quality is highly questionable, although improvements are currently underway
Note: HCFA has other data available, including: claims and utilization data; enrollment and eligibility data; other Medicaid data; and public use files data (which are the primary source of information for users that do not have access to HCFA files). The public use files include: utilization (institutional provider files); part B data (physicians, ambulatory surgical centers, supplier files); financial data files; institutional provider identification and certification files; beneficiary entitlement and demographic files; and diskette files. More information can be obtained by contacting HCFA's Bureau of Data Management and Strategy.	

Rehabilitation Services Administration Case Service Report (RSA-911)	
Contact	Larry Mars (202) 205-9404
Frequency	Records collected annually.
Purpose	To provide information on the persons requesting services under the State-Federal Program of Vocational Rehabilitation.
Content	Sociodemographic characteristics; services provided (actual provider and referral source); method of payment for services; type of service received; cost of services; reason for case closure; employment; public assistance; insurance.
Disability Measures	Type and extent of disabling condition.
Coverage	All individuals using services of the State-Federal Program of Vocational Rehabilitation since the Rehabilitation Act of 1973 whose cases are closed.
Sample	Approximately 600,000 cases annually.
Products	Public use files can be obtained.
Future	Plans ongoing to continue a permanent linkage with SSA files.
Comments	• a case is closed whether or not the case is rehabilitated, not rehabilitated, or not accepted for rehabilitation services • to obtain information on individuals following the close of their case, can link this data with SSA data (Earning Summary Record and Master Beneficiary Record) • can examine whether or not rehabilitated persons remain employed and for how long and can also obtain information on income and reliance on public support

Social Security Administration (SSA) Administrative Data	
Contact	Barbara Lingg, (410) 965-0156 Martha Barnhill, (410) 965-0145
Administrative Data from the SSA is published in the ***Social Security Bulletin***; comprehensive information is available in its annual supplement. The 1994 supplement includes more than 250 tables containing detailed information on income security programs; most of the information is on programs administered by SSA (OASDI and SSI). Data is available by diagnostic group for disabled workers and distributions are given by sex, age, and benefit level. Data is also available at the State level. This data is used internally to aid in the administration of SSA programs. Due to privacy restrictions, no public use files are available. Specific requests for information can be directed to the SSA's Freedom of Information Act Office, Ethel Burrows, (410) 965-3962. SSA data can also be linked with other files that can be used within the public domain. Requests on this subject can also be made to SSA.	

OTHER SURVEYS

Area Resource File (ARF)	
Contact	Colleen Goodman (703) 352-7393
Sponsor	Office of Research and Planning/Bureau of Health Professions/Health Resources and Services Administration
Frequency	Since 1971; Expansion and maintenance of the basic ARF is performed on a continuing basis. Current release is February 1995.
Purpose	To consolidate many disparate data elements useful in analysis of health professions issues and developments on a geographic basis. Provides health and health related data available at the county level; provides data for descriptive and comparative analysis of the health care system.
Design	The Area Resource File (ARF) System has been designed to provide data that are geographically and longitudinally consistent. The data are available for each county in the 50 States, across time, permitting cross sectional and time series analyses. The system is composed of the basic ARF county file and the ARF Health Professions Training File, as well as many detailed support files regarding health rare facilities, health professionals, and demographic statistics. Support files are maintained at the county and sub-county levels and provide current as well as time series information.
Content	Principle types of data in the basic county file include health profession descriptors, health professions training, characteristics of health facilities, hospital utilization, health expenditures, morbidity and mortality, and demographic, economic and environmental characteristics. The Basic ARF contains over 7,000 data variables for each county.
Disability Measures	None
Coverage	All counties in the United States.
Products	Printed reports (profiles, selected geographic resources State and county reports), copies of the basic ARF tape, and floppy diskettes containing extracts of the basic county data. Special requests can be provided. Annual updates available on tape.
Future	CD-ROM to be available in 1995.
Comments	• a comprehensive longitudinal data set of county level information • the basic file contains geographic codes and descriptors which enable it to be linked to many files

Behavioral Risk Factor Surveillance System (BRFSS)	
Contact	Mike Waller (404) 488-5292
Sponsor	Behavioral Risk Factor Surveillance Branch, National Center for Chronic Disease Prevention, Centers for Disease Control and Prevention, Public Health Service, U.S. Department of Health and Human Services
Frequency	Annually, 1984 to present. Conducted by participating States ranging from 15 States and territories in 1984 to 54 in 1995.
Purpose	To collect, analyze, and interpret State-specific behavioral risk factor data for use in planning, implementing, and monitoring public health programs. To monitor prevalence of modifiable high risk behaviors which contribute heavily to morbidity and morbidity from noninfectious diseases. BRFSS data are used to guide health promotion and disease prevention programs.
Design	The interviewing instrument consists of three parts: (1) a core series of questions asked by all States; (2) standardized modules of questions on selected topics used at the discretion of the State; and (3) questions developed by any particular State. As feasible questions used in national health surveys (e.g., National Health and Nutrition Examination Surveys and the National Health Interview Survey) are adapted for use in the BRFSS. After each monthly interviewing cycle, data are sent to CDC for editing. In 1991, 36 States used Computer Assisted Telephone Interviewing.
Content	Prevalence of risk factors and medical screening practices including items such as: overweight, no-leisure-time physical activity, smoking, safety belt nonuse, cholesterol screening, breast cancer screening, pap smear. Definitions chosen to match as closely as possible those used in ***Healthy People 2000***.
Disability Measures	For 1995, modules of questions are available for States to use on the following disability related topics: personal health status, health care access, years of healthy life, and quality of life.
Coverage	Each participating State, using random digit dialing selects a random sample of noninstitutionalized persons age 18 and older who have telephones.
Sample	In 1991, State sample sizes ranged from 1,178 to 3,417. Response rates for completed interviews ranged from 65% to 95%.
Products	Public use data tapes, publications, CD-ROM.
Future	Ongoing

National Consumer Survey	
Contact	Lynne Lau (202) 690-6589
Sponsor	Administration on Developmental Disabilities
Frequency	One time, 1987-1990
Purpose	To determine the state of service delivery and satisfaction of persons with developmental disabilities in achieving independence, productivity and integration.
Design	Phone screening, then personal interview. All surveys involved the consumer directly (except with young children). Questions are asked of both the consumer and surrogate if necessary.
Content	Demographics, education, services and satisfaction, independence, integration, productivity, and supports/services/assistance.
Disability Measures	In the screening subject is asked to indicate primary diagnosis/disability as well as other disabilities. The screening also contains a series of assistance questions, including how much assistance subject needs with ADLs, learning, decisionmaking, and living independently. In the core questionnaire more specific questions on need for supports include need for attendant care, home health aides, and adaptive equipment.
Coverage	Persons with developmental disabilities who have been identified by the State's Developmental Disabilities Council primarily through advocacy groups.
Sample	Over 15,000 persons with developmental disabilities.
Products	Individual State reports, summary of reports from Developmental Disabilities Councils.
Future	No plans
Comments	• only national consumer survey of persons with developmental disabilities • involved consumers in all interviews (except children) • no standard survey instrument in all States; five States used their own survey to complete the assessment • each State prepared its individual results; not all States reported on all life areas

National Education Longitudinal Surveys	
Contact	Jeff Owings, (202) 219-1777
Sponsor	National Center for Education Statistics
Frequency	NLS-72: 1972-1986; HS&B: 1980-1992; NELS:88: 1988-1994
Purpose	To collect data on the events, trends, and transitions of students as they progress through the educational system and beyond.
Design	Three surveys in the NELS: National Longitudinal Survey of the High School Class of 1972 (NLS 72), High School and Beyond (HS&B), and National Educational Longitudinal Study of 1988 (NELS:88). Questionnaires (to school administrators, students, teachers, parents) and student records (transcripts, achievement tests).
Content	Of the three longitudinal surveys, HS&B and NELS:88 contain variables most relevant to users interested in disability data. In general, HS&B contains data on high school experiences and events in the years following high school graduation, e.g., post secondary education, marriage, and work. NELS:88 contains data on school, student, parent (family) and teaching staff characteristics, school policies and practices, student behavior and academic performance, family background of students, educational and career plans.
Disability Measures	HS&B and NELS:88 surveys ask questions of student's, parents and teachers on a student's disabilities or health conditions that affect schooling. Under NELS:88 school transcripts indicate if student has an individualized educational plan.
Coverage	NELS:88 samples 8th graders in 1988. HS&B covers high school sophomores and seniors enrolled in public and private schools in 1980. Neither study includes schools specific to students with disabilities.
Products	Data tapes, publications, CD-ROMs with electronic codebooks.
Future	NELS:88 will re-survey in 1998.
Comments	• surveys identify students with mild and moderate disabilities • survey data allows users to compare cohorts in a time-lag basis, to view data for each cohort cross-sectionally, and to produce longitudinal analyses within a cohort

National Longitudinal Survey of Youth (NLSY 79) and Children of the NLSY79	
Contact	Randall J. Olsen, Ohio State University (614) 442-7348 Paula C. Baker, Ohio State University (614) 442-7375
Sponsor	Bureau of Labor Statistics, U.S. Department of Labor, National Institute of Child Health and Human Development
Frequency	Annually, 1979 to present. Child health data collected biennially since 1986.
Purpose	To chronicle the life course experiences of a large sample of young adults representative of American youth born in the late 1950's and early 1960's.
Design	Annual interviews of the 1979 Youth cohort. In 1986, the survey began including biennial interviews of children whose mothers are part of the original youth cohort, as well as interviews with mothers about their children.
Content	Education; employment; health limitations; residence; family-related experiences of the respondents; physical, emotional or mental conditions. Child survey includes several age appropriate measures that assess socio-emotional, cognitive, physical development and home environment.
Disability Measures	NLSY79 has collected data on type and duration of health limitation since 1979, and work-related injury or illness since 1988. Child Supplement collects data on conditions that prevent regular school attendance, limits or prevents ability to do regular school work, limits or prevents usual childhood activities, requires frequent attention or medical treatment, requires regular use of medicine, or requires use of special equipment. Specific condition and duration of condition is asked of children who have limitations.
Coverage	Individuals who were between the ages of 14 and 21 in 1979. The Child Supplement covers all biological children born to interviewed NLSY women.
Sample	NLSY79: 12,600 men and women. Child Supplement: nearly 9,400 children born to NLSY women as of 1992.
Products	Data tape, CD-ROM, documentation, publications.
Future	Ongoing
Comments	Child Supplement contains disability measures appropriate for children

National Longitudinal Transition Study of Special Education Students	
Contact	Scott Brown (202) 205-8117
Sponsor	Office of Special Education Programs, U.S. Department of Education
Frequency	1987; followup surveys in 1989, 1990
Purpose	To provide longitudinal information on experiences of people with disabilities as they make the transition from secondary school to adulthood, focusing on education, employment and personal independence.
Design	Data on sampled students are obtained from telephone interviews with parents, school records, and school program surveys. First wave in 1989; second wave in 1990-1991.
Content	Sociodemographic characteristics,, type and extent of disability; school achievement; employment; social integration; personal independence; school characteristics and policies.
Disability Measures	Disability category is based on the primary disability designated by the youth's school or district. Specific categories include learning disabled, mentally retarded, emotionally disturbed, speech impaired, visually impaired hard of hearing, orthopedically impaired. Survey also asks about limitations in self-care and functional skills.
Coverage	Students aged 13-21 years, enrolled in secondary school special education during the 1985-1986 school year.
Sample	At least 8,000 students; 1989 included a subsample of over 800 parents and/or their offspring who had been out of secondary school for 2-4 years and who were classified as having a disability.
Products	Publications and public use tapes. Public use tapes including the second wave is expected to be available by the end of 1995.
Future	No current plans.
Comments	longitudinal study; students in the 1987 wave were retained for follow-up in 1990

National Spinal Cord Injury (SCI) Statistical Center Database	
Contact	Dr. Michael Devivo, University of Alabama (202) 205-8117
Sponsor	National Spinal Cord Injury Statistical Center
Frequency	Ongoing, 1973 through present
Purpose	To provide longitudinal evaluation of individuals who have received or are receiving services from a Model Spinal Cord Injury Center.
Design	Model Spinal Cord Injury Center staff gather information from client records. Initial hospitalization/rehabilitation record and annual evaluation records are filled out for each client.
Content	Demographic (age, gender, race, marital status, educational level, occupational training status, death); service utilization (operative procedures); clinical information; financial information (third party payers, hospital expenses).
Disability Measures	Pre-existing medical conditions; associated injuries (e.g., amputations, head injury); functional independence (e.g., self-care, mobility, communication, social cognitive); functional assessment at discharge; number of rehospitalizations evaluated annually.
Coverage	Individuals receiving services from a Model Spinal Cord Injury Center.
Sample	15,000 individuals (cumulative since 1973).
Products	Raw data is accessible only to Model Spinal Cord Injury Centers. Aggregate statistical reports are generated and are available to the public. The National SCI Center will occasionally conduct customized research for non-member organizations for a fee.
Comments	general information on mental and physical disabilities caused by spinal cord injuries is available; individuals are not categorized within particular groups of interest

Survey of Disabled Veterans (SDV)	
Contact	Elizabeth Ahuja (202) 273-5109
Sponsor	Department of Veterans' Affairs
Frequency	1989
Purpose	To obtain detailed data on the social, economic and health characteristics of veterans with service connected disabilities; to gather information on knowledge and usage of VA and non-VA programs; to collect data on disabled veterans to compare to earlier surveys and to assist managers in future decisionmaking regarding VA programs.
Design	Primarily in-person interviews. Proxy interviews with family members were conducted when the veteran was physically or mentally unable to respond.
Content	Sociodemographic characteristics, military service, health insurance, hospitalization and long-term care, use of ambulatory care services; knowledge, awareness of, and use of VA and non-VA programs; physical disability; need and use of disability support services; prosthetics; home modifications.
Disability Measures	Survey asks about type, degree and source of physical disability
Coverage	Veterans with compensable service-connected disabilities in the U.S.
Sample	10,000 veterans
Products	Public use tapes.
Future	No current plans to repeat this survey.

Users' Responses to Assistive Devices for Physical Disability	
Contact	Nancy Brooks, Wichita State University (316) 689-3280
Frequency	One-time survey from 1990.
Purpose	To explore social-psychological outcomes of disability.
Design	Used the American Association for the Advancement of Science's Resource Group of disabled scientists and engineers. Questions were mailed to a population survey of these individuals.
Content	Sociodemographic characteristics; type of disability; type of assistive devices used.
Disability Measures	Type of disability and type of assistive device(s) used; assistive devices broken into eight categories. Frequency of use in private and public settings was measured.
Coverage	American scientists and engineers with physical disabilities, age 19-88.
Sample	595 (47.5% of questionnaires were returned).
Products	Paper of findings is available: Brooks, N. A. "User Responses to Assistive Devices for Physical Disability," Social Science Medicine, 32(12), 1417-1424, 1991.
Future	No follow-up survey.
Comments	• Unique approach; examining the user's view of assistive devices in social settings • Sample that was chosen for analysis due to the fact that scientists and engineers would likely use assistive devices in a variety of social settings

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Special thanks to the contact persons listed for each survey and their assistance in providing the content for this appendix.

SUMMARY OF ASPE MEETING ON DISABILITY DATA

August 1995

I. INTRODUCTION

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) sponsored a meeting of experts on the topic of Disability Data for Disability Policy. The meeting focused on data relevant to health and long-term support. It was hosted by ASPE's Office of Disability, Aging and Long-Term Care Policy (DALTCP) at the Holiday Inn Capital in Washington, D.C. on March 31, 1995.

This day-long meeting was the last of three expert meetings on disability topics, in which DALTCP sought advice for its newly-expanded research agenda on disability. National experts in disability data sets relating to children, working age adults, the elderly, and special populations joined with representatives of Federal agencies to examine the availability of, access to and potential analyses of disability data.

The specific objectives of the meeting were to:

- Assess disability-related national data sets pertaining to health and long-term supports, particularly as related to the policy issues discussed in the background paper *Disability Data for Disability Policy: Availability, Access and Analysis*, prepared by DALTCP staff and distributed to the participants prior to the meeting.

- Identify useful State, area, private and international data bases, including data from large federally-assisted demonstrations of managed care, integrated health services, long-term care and welfare reform.

- Identify next steps in analyzing available disability data.

- Propose priorities for DALTCP's research agenda regarding disability data.

II. SUMMARY OF PARTICIPANTS' COMMENTS AND RECOMMENDATIONS

A. Environment

In the current environment, several participants stated that new Federal funding for large national surveys relating to disability was unlikely. At the same time there is an ongoing need for data in the light of societal changes and policy issues affecting persons with disabilities.

From the perspective of the Department of Health and Human Services (DHHS), changes in the health care system are of critical importance. Data are needed to monitor the impact on persons with disabilities of efforts to control access and reduce costs under managed care systems. Similarly many welfare reforms initiated by States will have an impact on persons with disabilities.

The availability of personal assistance services and the role of consumer choice in service delivery is an important issue for DHHS. Other areas of concern to persons with disability are factors affecting labor force participation (e.g., vulnerability in recessions) and access to affordable housing.

With reduced Federal funding, it will be necessary to search for and make better use of subnational and private sector data sets to explore these issues.

B. Themes

Among the themes highlighted by participants were the following:

1. Longitudinal Data

Participants stressed the need for longitudinal data on disability. National surveys like the National Health and Retirement Survey (NHRS) and its companion Assets and Health Dynamics of the Oldest Old Survey (AHEAD), the National Longitudinal Survey of Youth and the Panel Study of Income Dynamics were mentioned as sources of longitudinal data. Section D below discusses State-level data sources, which may include longitudinal data.

2. Disability Measures

There is a need for a wide range of disability measures on surveys, so that researchers can select particular measures appropriate for their investigations.

Researchers need to report on the precise measures they are using in their analyses.

At the same time, the creation of a minimum data set on disability should be explored; such a data set could be included in all population-based surveys.

3. Interdisciplinary Collaboration

The selection and development of survey domains--e.g., income and assets, health, work, functioning--should be done on an interdisciplinary basis. This was done effectively in the case of the NHRS and AHEAD surveys. (NHRS focuses on a baseline cohort aged 51-61 in 1992. AHEAD includes persons aged 70 or over in 1993.)

4. Control Groups

Where feasible, control groups should be included among survey respondents to compare findings on persons with disabilities to persons without disabilities.

C. Coverage

Participants made a number of recommendations on obtaining updated disability data. Among them were the following.

- Include at least broad questions on disability on all major population-based surveys.
- Expand the number of disability questions on the Current Population Survey. Include among them one or more questions on working conditions and ask the questions monthly.
- Expand AHEAD's survey modules to capture more aspects of disability and test experimental approaches.
- Extend NHRS to younger age groups; among other things this could permit capture of data before and after the onset of disability for some individuals.
- Add Supplemental Security Income status to questions on children in the Consumer Expenditure Survey, the Survey of Income and Program Participation and all other major economic surveys.
- Incorporate hypotheses and measures from epidemiological studies into the development of national surveys; for example, it is possible that clinically-derived measures of cognitive impairment could be adapted to large-scale surveys.

- Oversample children in national surveys.

- Consider more focused surveys rather than oversampling on large surveys; one possibility is a survey of families who have children with developmental disabilities to evaluate the impact of cash payments.

- Track users of services (e.g., mental health services) across different service systems.

- Make greater use of questions from national surveys, e.g., National Medical Expenditure Survey for health expenditure information, in State surveys. With appropriate weights, national surveys could thereby be used for State-level estimation.

- For the planned redesign of the National Health Interview Survey, retain the conditions list and incorporate questions on work capacity plus cognitive, social and physical functioning.

D. Data Sources

Some federally-sponsored surveys have disability data that could be more fully utilized. The revised version of the background paper now provides information on such surveys as: the Behavioral Risk Factor Surveillance System sponsored by the Center for Disease Control (CDC), the National Household Survey on Drug Abuse, and the Department of Veterans Affairs' National Survey of Veterans. The National Institute on Mental Health is currently sponsoring the development of a new national survey with disability-related measures titled Use, Needs, Outcomes and Costs in Child and Adolescent Populations.

In addition to national surveys, it will be necessary in the future to make greater use of subnational data sources, such as:

- State surveys and information systems,
- natural experiments,
- school systems,
- Workmen's Compensation files, and
- data from demonstrations and waiver programs with a disability focus.

Insofar as possible, national surveys should be replicated at the State level or at least key data elements from these surveys incorporated into State surveys. State and local government monitoring systems are another potential source of useful data on persons with disabilities. The benefits to State and local governments in increasing access to their data need to be highlighted.

CDC sponsors Disabilities Prevention categorical grants. Thirty States participate and have research and surveillance systems for traumatic brain injury, spinal cord injury, spina bifida, cerebral palsy, fetal alcohol syndrome, Down syndrome, mental retardation, and sickle cell anemia.

Subsequent to the meeting, one participant sent a letter proposing a way to generate longitudinal data from States. The idea is to identify at least several States (preferably large ones) that have maintained strong data sets on persons with disabilities. Such data sets could be pooled across a specified number of years. The model for this is the DHHS' Administration for Children and Families MultiState Data Archive on foster care.

One largely untapped area is proprietary data bases. It was suggested in the meeting that private firms might be more willing to make their data available if they got some tangible return. Also, the incentive to share data might be enhanced if it were possible to pool data from several sources (e.g., a group of employers) to preserve anonymity.

E. Analyses

The potential for analyses of data on disability issues is great. Several specific suggestions emerged from the participants.

- Identify the top ten questions of disability policy interest and invite researchers to address them. For example, the National Institute on Aging supports nine Demography on Aging Centers around the country; they are available as resources for analyzing policy issues on elderly persons with disabilities, as well as conducting basic research.

- Use new techniques of computer mapping to highlight geographic areas of high and low disability rates.

- Emphasize basic research on the processes of disability.

- Develop more theory-driven and hypothesis-driven surveys on disability rather than trying to answer every conceivable question. Often survey development is guided by policy issues which prove to be transitory. Survey data should focus rather on longer term issues and concerns that undergird policy development.

  NHRS and AHEAD are examples of surveys that were developed around theories about the decision to retire (e.g., structural models of utility functions) and hypotheses about consumption, saving and intergenerational transfer patterns among the elderly.

- Use disability data to monitor the differential impacts of cutbacks in public programs, to evaluate program effectiveness and to improve program operations.

- While additional data on disability are needed, more could be done to analyze existing data. In fact, in an era of cutbacks more will have to be done to analyze existing data.

III. ASPE FOLLOWUP

Some comments were offered on the background paper *Disability Data for Disability Policy: Availability, Access and Analysis*, prepared by DALTCP staff. While generally well-received, the paper was faulted for failing to highlight problems with self-reported data on functional status. There was some question about the advisability of oversampling based on functional status, since the measures are inherently "soft" and since functional status itself is very changeable. Also, it was noted that too little attention was paid to the need for data on pre-disability and post-disability status and to longitudinal data overall.

Participants throughout the day identified actions that ASPE might take to foster disability data development and analyses. One post-meeting correspondent supported the creation of a single agency to manage Federal statistical programs and respond to policy research priorities. Advisory focus groups of key constituencies (e.g., the disability community, State and local officials) could be tapped to identify emerging policy initiatives and service delivery models as input into survey design.

Other actions discussed at the meeting included the following:

- Bring together State officials, private sector representatives and members of the disability community to discuss data design and data access issues.

- Provide technical support to State data initiatives.

- Conduct smaller meetings devoted to the data needs of specific groups of persons with disabilities.

- Promote faster access to Federal data sets through such mechanisms as early results workshops. A current candidate for release of public use tapes as soon as possible is the Disability Survey.

- Facilitate linkages between survey data and administrative records; e.g., Medicare and Medicaid claims data. Also, try to broaden the kinds of information collected for administrative purposes; e.g., by routinely including health and functional status in administrative records.