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

THE FUTURE OF SIPP FOR ANALYZING DISABILITY AND HEALTH

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Office of the Assistant Secretary for Planning and Evaluation

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I. INTRODUCTION

Disability and health policy issues are among the most critical facing our nation today. As our population ages, disability and health will become even more critical in the future. Therefore, it is essential that SIPP collect information on disability and health.

This paper describes SIPP data elements in SIPP pertaining first to health and secondly to disability, examines some broad policy needs for health and disability issues from the program and policy perspective of the Department of Health and Human Services (DHHS), and contains recommendations for the future design of SIPP.

According to the Committee on National Statistics (CNSTAT) Interim Report, SIPP has two main goals: to obtain better information in studying the dynamics of Federal program participation and to describe the income distribution of the population, particularly the lower end of that distribution.

SIPP was not intended to be a health survey nor a disability survey. Yet, program participation and income are so closely related to disability and health that SIPP's goals cannot be fully met unless data on disability and health are collected in a consistent, thoughtful manner.

Disability in particular is an integral part of Federal program participation. There are numerous Federal programs targeted on persons with disabilities which provide cash assistance, supportive services, rehabilitation, or finance health care. In addition, there are Federal research programs, which develop or adapt technologies to assist persons with disabilities. The impact of these programs is enormous. In fiscal year 1989 alone, $85 billion or 8 percent of all Federal outlays was targeted *JUST* on nonelderly persons with disabilities. (Burwell, January 1990)

Furthermore, disability and health status influence income in a major way. For example, economic impacts are virtually guaranteed when a person suffers an injury and can no longer work. Depending on the nature and scope of the injury, the person may retire early on disability, seek another type of work, be able to return to his original work only after a lengthy absence, or even die.

Income also profoundly impacts virtually every aspect of disability and health. Low-income is associated with higher rates of functional disability (McNeil, Doyle), significant developmental limitations, higher proportions of self-reported poor health status, greater morbidity, higher use of physician and hospital care, and greater chances of dying from virtually all chronic diseases. (Weiner, 1990) Furthermore, low-income people are less likely to be covered by private health insurance. (USPHS)

Since the inception of SIPP, disability and health data have been collected, but mostly on an ad hoc rather than a consistent basis. Wave 3 of the 1984 Panel was an especially rich source of information on disability and health. The analysis of disability and health data on Wave 3 provided many valuable program and policy insights. These data also illustrated how SIPP could more accurately describe the program participation and income of the American people by taking their disability and health into account.

SIPP has the capacity not only to continue to be the major source of economic data, but also to contribute unique information on disability and health. The richness of SIPP's economic data makes this possible. Historically, national population-based surveys provide much of what we know about both the health and economic characteristics of the American people. However, while health surveys have paid scant attention to collecting data on economic well-being, economic surveys have paid scant attention to collecting health and disability data. Until SIPP, few surveys contained detailed data on disability and health and economic well-being. Thus, policymakers and researchers have been unable to adequately explore relationships between economic well-being, disability, and health.

II. HEALTH DATA ITEMS ON SIPP

A. Definition of Health

Health can be defined as a state of complete physical, mental, and social well-being. Health is not simply just the absence of infirmity, disease, or disability. Ill health and disability are not synonymous, as they describe very different aspects of well-being.

B. SIPP Health Data Items

Health insurance coverage is the only health item contained in the SIPP core and the only health item asked of everyone, including children. Other health items, which are limited to adults aged 15 or over, include: overall health status, bed-disability days, use of hospital and physician care, access to health care, and reasons for not having health insurance. These items were gathered in Topical Modules at least once during every SIPP Panel. In 1984, these items were included as part of the overall Wave 3 Topical Module on Health and Disability. During the 1990 Panel, health items were once again part of an overall disability section (as in 1984) asked during Wave 3 and (is currently planned) for Wave 6. Specifically, health items were asked during Wave 6 of the 1985 Panel, Wave 3 of the 1986 Panel, and Wave 6 of the 1987 Panel, Waves 3 and 6 of the 1988 Panels, and Wave 3 of the 1989 Panel.

Medical care expenses were asked as part of the section on program eligibility during Wave 7 of the 1987 Panel, Wave 4 of the 1988 Panel, and Wave 4 of the 1990 Panel. Spells of Medicaid coverage were included as part of the Topical Modules on Recipiency History during Wave 2 of the 1986, 1987, 1988, 1989, and 1990 Panels.

The following major types of health items are found in SIPP:

1. Health Status

In population-based surveys, health is typically defined by self-reported answers to a subjective question on health status. The SIPP question is identical to the one used over the years by the National Health Interview Survey (NHIS) and reads as follows:

> “Would you say --‘s health is excellent, very good, good, fair, or poor?”

Most people rate their health as excellent, very good, or good, especially those at younger ages. According to the 1984 SIPP, 88 percent of working-age adults (aged 18-64) and 54 percent of the elderly reported their health to be excellent, very good, or good. (MPR, 1989) People in fair or poor health status are more likely to be older, Black, poor, or to have lower levels of education. (NCHS)

Fair or poor health is highly correlated with disability. According to the 1984 SIPP, 5 percent of working-age adults reported themselves in fair or poor health compared to 50 percent of those with a disability and 75 percent of those with the most severe disabilities (those who needed the help of another person in order to perform basic activities). (MPR, 1989)

2. Restricted Activity Days (Bed-Disability Days)

The number of days in which activities were restricted for health reasons is another overall health measure. Restricted activity days are measured in SIPP by the number of bed-disability days, that is the number of days during the last 4 months in which the respondent spent more than half the day in bed due to illness or injury. The NHIS contains three measures of restricted activity: days missed from work (for adults), days missed from school (for children), and bed-disability days (for all ages).

The average number of bed-disability days was higher for persons with disabilities than for others. In 1984, persons with no disabilities spent an average of only one day in bed during the last four months compared to over a week (7.8 days) for persons with any kind of disability, and nearly 4 weeks (25.6 days) for those with the most severe disabilities. (MPR, 1989)

3. Use of Hospital Care

There are many kinds of health care providers. SIPP asks about only two types of service--the most expensive (hospital care) and the most common (physician care). The number of nights and the number of stays spent in a hospital were asked in SIPP for two time periods: during the past year and during the past 4 months. A question on whether any of these stays were in a VA or military hospital was also asked.

Hospital stays are relatively rare, even over a year's time. In 1984, 13 percent of persons aged 18 or over reported a hospital stay during the past year. A long recall period (13 months) is also used in the NHIS, because hospital stays are such significant events in people's lives that they can often remember basic details a year later. (MPR, 1989)

In SIPP, it is not possible to calculate the length of a hospital stay for different episodes, as data are only gathered on the overall number of stays and the total number of nights. Length of stay can be computed from other surveys, such as the NHIS, which separately obtains the number of nights spent in the hospital for each stay.

Additions to the hospital stay questions were incorporated in later Panels. A question on the reason for the last hospital stay (childbirth, surgical, or other medical) was added in the 1987 and subsequent Panels. This was an important change. More hospital discharges were for delivery than for any other reason--3.9 million out of 33.4 million in 1988. (Adams) Therefore, depending on the purpose, hospital stay analyses are typically done either with or without childbirth. In addition, this question enables analyses of surgical procedures to be conducted. The answer categories to this question were further expanded in Wave 3 of the 1990 Panel, when at the request of the National Institute of Mental Health (NIMH), two additional categories--mental or emotional problem or disorder and drug or alcohol abuse problem or disorder--were added. In order to respond to data needs on mental health, a question was also added on whether or not any of the hospital stays reported by the respondent had occurred in a psychiatric unit or hospital.

4. Use of Physician Care

The question on the use of physician care gathers information on the total number of visits or calls to a medical doctor during the last year and the last 4 months. The NHIS employs a two-week reference period for physician care, but asks details about each visit.

5. Access to Health Care

Equitable access to health care is a major policy concern. Access to health care in SIPP is simply defined as whether or not a respondent has a usual source of medical care and, if so, the kind of place where care is received (i.e. doctor's office, clinic, hospital emergency room). This question remained basically the same until Wave 3 of the 1990 Panel when three additional categories (psychiatric clinic, psychiatric hospital, private practice psychiatrist or other mental health professional) were added to the list of places in response to data needs from NIMH. Given space constraints, the SIPP question captures perhaps the most basic aspect of access to care. Other aspects include travel time and waiting time.

6. Medical Expenses

Medical expenses questions, which were introduced in the 1987 Panel in response to data needs regarding food stamps, have been included on every subsequent Panel. The two questions simply ascertain whether or not during the last month the family had medical expenses for four categories of care (doctors, dentists, hospitals, prescription drugs) and, if so, the total amount of out-of-pocket medical expenses for medical care.

Medical care expenditure patterns are too complicated to determine in this way. The DHHS launches expensive national population-based surveys, every ten years or so, solely to study medical expenditure patterns. The design of the 1987 National Medical Expenditure Survey (NMES), which was sponsored by the Agency for Health Care Policy Research, called for following sample households for a year and conducting 5 household interviews on medical care expenditures. Afterwards, written permission was obtained from respondents in order to conduct validity checks with doctors, hospitals, health insurers (insurance companies and employers), and Medicare records. During NMES household interviews, expenditures were obtained by first asking about specific medical encounters for each sample respondent and then obtaining details on expenditures. The longitudinal design of NMES was due in part to time lags between receipt of medical care, receipt of the bill, and receipt of payments from insurance companies. The costs of conducting expenditure surveys like NMES are exorbitant. Methodological work needs to be done to see if medical care expenses could be obtained in a less costly manner. However, until that time, the SIPP questions do not contribute much to DHHS analytical needs.

7. Health Insurance Coverage

Health insurance coverage is a core data item in SIPP. Public and private insurance coverage is ascertained for every person in the household including children. Public programs include Medicare, Medicaid, (and in later Panels) CHAMPUS, CHAMPVA, and military health care.

Medicare provides health insurance coverage to aged and disabled persons insured under the Social Security program. In 1988, 30 million aged and 3 million disabled persons under age 65 were eligible for Medicare. There is a two-year waiting period before Medicare coverage is extended to those receiving disability benefits under the Social Security Disability Insurance (SSDI) program. Almost all persons on Medicare under 65 are also SSDI beneficiaries. SIPP gathers information on whether or not respondents have coverage through the two major components of Medicare: the hospital insurance or Part A program and the supplementary medical insurance or Part B program. Coverage under Part A is automatic, while coverage under Part B may be elected with payments of monthly premiums. The vast majority (99 percent) choose Part B coverage, which helps pay for physician's and other services (i.e. laboratory/ diagnostic test, X-rays, equipment). In SIPP, the Medicare number is also obtained (on a voluntary basis). (Office of National Cost Estimates)

Medicare and Medicaid coverage is easily confused by respondents, so SIPP interviewers ask to see the Medicare card and (with permission) copies down the Medicare number. This number can be linked to Medicare claims records for additional analyses.

Medicaid is a joint Federal State program which pays for the health care of low-income individuals. Cash assistance from the AFDC program automatically entitles persons to Medicaid coverage, while receipt of Supplemental Security Income (SSI) usually guarantees Medicaid coverage. There are also a number of optional State programs through which ill or disabled persons can receive Medicaid. Medicaid eligibility is very complex and varies from State to State. People with comparable illnesses, disabilities, and incomes can be eligible for Medicaid in one State, but not in another. (Burwell, January 1990) During fiscal year 1988, nearly 23 million individuals received Medicaid benefits. (Office of National Cost Estimates)

CHAMPUS, CHAMPVA, and Military health care have been handled differently on SIPP over the years. Prior to the 1988 Panel, these types of military-related health coverage were specifically excluded and afterwards, they were included and specifically identified. The Department of Defense (DoD) assumes responsibility for the health care of active and retired military forces and their dependents and survivors. The Civilian Health and Military Program of the Uniformed Services (CHAMPUS) pays for care required outside DoD facilities (usually for dependents and retirees). At the end of 1989, 5.9 million persons were eligible for CHAMPUS. (Office of National Cost Estimates)

The Department of Veterans' Affairs (DVA), which operates a nationwide health care network, provides medical care to eligible veterans. Services must be provided to veterans with a service-connected disability, former POW's, and those with low-incomes. Other veterans are served on a space-available basis. In addition, the Civilian Health and Medical Program of the Veterans Administration (CHAMPVA) provides medical care to spouses and dependents of disabled and deceased veterans.

Private insurance covers most persons under age 65. According to the 1984 SIPP, nearly four in five persons aged 18-64 (79 percent) were covered by private insurance. (MPR, 1989) Private insurance is most often obtained through employment. In SIPP, data are gathered on who in the family is covered, whether the plan was from an employer or union, whether coverage was through an individual or family plan, and the length of time the plan was in effect during the reference period. These data are useful in themselves, but their real richness comes from linking to other SIPP data, such as employment, income, occupation, and size of firm.

Uninsurance refers to the lack of any public or private coverage and is simply obtained as the residual category after all other forms of coverage are ascertained. The number of uninsured persons is often sensitive and controversial. Consistent definitions of different types of coverage are needed in order to look at trends form the same data set or to compare data sets. SIPP estimates of the number of uninsured may be inconsistent over time as well as hard to compare with other data sets, such as the Current Population Survey (CPS) or the NHIS. This is because military-related health insurance was handled differently in earlier and later SIPP Panels.

8. Reasons for No Health Insurance

Information on why an individual has no health insurance is ascertained in Topical Modules. The reasons listed are standard reasons included in DHHS surveys (i.e. job loss, poor health, expensive premiums, do not need insurance). People who are uninsured and the reasons why are of major policy concern. However, this question does not easily stand alone and should only be analyzed in the context of other information. For example, a sizable (but unknown) number of persons are medically uninsurable due to pre-existing chronic health conditions or disabilities. In many instances, health insurance can be purchased, but at excessively high premiums--sometimes as much as $50,000 per year. A medically uninsurable respondent may answer either "poor health" or "too expensive" as a reason for having no insurance. Thus, two different answers could lead policymakers in two different directions.

9. Spells of No (Health) Insurance

Much research has been done on spells of unemployment and spells of welfare dependency. However, there are also spells of no health insurance, which are related to spells of unemployment and welfare dependency. Consequently, point in time estimations of the insured and the uninsured may be misleading. SIPP is helpful in obtaining data on spells, but there are truncation problems. However, these problems are helped somewhat by eliciting the date when uninsured respondents were last insured.

The information gathered on spells of no insurance in Wave 3 of the 1984 Panel was much more extensive than that collected in later Panels. In 1984, data were collected on whether there were periods of time during the last three months when the uninsured respondent was covered by public plans (and if so which plan), the date of last coverage by any insurance, the reasons coverage ended, and finally, (for those uninsured who had previously been covered) the reason why the respondent was still uninsured (could not afford, was rejected, or other reason). This latter item may be especially crucial to policy debates on health insurance. The SIPP question represents one of the few times in national surveys that medically uninsured individuals can be specifically identified and the only time where information on their economic and disability characteristics can be obtained as well. After the 1984 Panel, information on spells of health insurance coverage were limited to two questions in the Recipiency History sections found in the Wave 2 Topical Module from 1986 and thereafter. These questions simply obtained the length of coverage on health insurance (for the insured) and the length of noncoverage (for the uninsured).

10. Length of Time of Medicaid

Information on the length of time that Medicaid recipients have been on the program was added to the Topical Module on Recipiency History beginning in Wave 2 of the 1986 Panel. This Topical Module had previously collected information on the personal history of respondents for the AFDC and SSI programs. While most persons receive Medicaid through receipt of AFDC or SSI, Medicaid is to complicated to accurately infer coverage. Therefore, a separate question on the length of Medicaid receipt was needed.

C. Health Policy Analyses

1. Background

The roughly 31 million Americans with no health insurance are a perennial policy concern. During his 1990 State of the Union Address, President Bush asked the Deputy Secretary of DHHS to create a Task Force to study access to health care with the uninsured in mind. The report from this Task Force has not yet been released.

2. The Uninsured

A number of options over the years have been proposed to allow uninsured individuals to have access to medical care. Typically, these options involve employment (i.e. requiring employers to provide insurance to all or some of their employees and dependents) or Medicaid (allowing low-income individuals to buy into Medicaid). (Moyer)

SIPP has many of the data elements needed in analyzing many of these policy options--source of insurance coverage, employment status (80 percent of the uninsured were employed or dependents of an employed person), size of firm (small businesses typically are subject to different regulations), income (which can be used to determine the ability to pay premiums), disability status (in some years), and family composition. Yet, the two large data bases which figure most prominently in analyzing the uninsured are the CPS and the NHIS.

It is not clear why SIPP has been underutilized, but hopefully this will change, perhaps in part to a seminal study done by Monheit and Short on the dynamics of health insurance coverage. Too often, uninsurance is analyzed at only one point in time. Monheit and Short looked at two cohorts--the privately insured and the uninsured--over 32 months using SIPP data. The results indicated that the uninsured population is heterogeneous and consists of people who are almost always uninsured, those who lose coverage only for a short time, and those who have periodic episodes of uninsurance. Policy options may very well have to be tailored for each group.

3. The Medically Uninsured

The medically uninsured are of great policy interest. These individuals are unable to obtain private health insurance, because of a pre-existing health condition or disability. Many work for small employers, where medical underwriting practices can preclude coverage. The number of medically uninsurable people is not known. Surveys rarely inquire about rejection from health insurance. However, Wave 3 of the 1984 SIPP contained such a question. This question should be analyzed, as the accompanying data on employment and disability could provide a better glimpse of the medically uninsured.

III. DISABILITY DATA ITEMS ON SIPP

A. Definitions of Disability

Disability is hard to define, because so many aspects of human behavior are involved. In 1980, the World Health Organization (WHO) defined disability as:

> “a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being”.

However, while the WHO definition is widespread, it is neither universally accepted nor universally applied. Instead, literally hundreds of definitions have been developed over the years with hundreds of different analytical purposes in mind. The development of a single definition is impossible and probably unwise. Impossible, because consensus could never be achieved and unwise because one definition could not possibly meet all programmatic and analytical policy goals.

The range of disability definitions has a major impact on how disability is determined on SIPP (as well as on all other surveys). In order to meet major policy and analytical goals, many different components of disability need to be obtained. The development of disability questions thus becomes no easy matter. However, SIPP comes closer than many other surveys in defining disability in a comprehensive and policy useful manner.

Disability in surveys has been historically defined in a number of ways: functionally (i.e. the ability to perform functions), programmatically (i.e. the receipt of program benefits), and epidemiologically or medically (i.e. the presence of certain diseases). Disability in SIPP is defined functionally and programmatically, but not epidemiologically or medically. This is sensible given the mandate and purpose of SIPP. Functional and programmatic definitions are most critical for policymakers. While epidemiological definitions are also useful, they are less so for most policy purposes. Furthermore, given the purpose of SIPP, it would not be practical to make the kinds of broad sweeping changes to SIPP that would be needed to collect epidemiological data.

Functional definitions of disability are commonly accepted measures of disability for the population. Furthermore, functional definitions of disability often figure prominently in how eligibility for Federal programs is determined.

Functions can be broad or specific. Specific functions refer to the ability to perform certain tasks, such as climbing stairs. There are numerous kinds of specific functions. Broad overall functions fall into more socially defined categories, which vary by age, gender, class, and culture. These are typically defined as: playing (for children under age 5), attending school (for children aged 5-17), working or keeping house (for adults aged 18-64), and living independently (for the aged).

Programmatic definitions of disability are critically important to policymakers, because they specifically determine who is and who is not eligible to receive benefits. Altogether, there are 43 different definitions of disability used for Federal programs and hundreds for State and local programs. (Weaver) Depending on the situation, policymakers often need to use both functional and programmatic definitions in order to determine who might be eligible for programs if certain features were changed.

B. Federal Disability Programs

Federal assistance to persons with disabilities comes from a wide range of Federal programs and altogether constitutes an enormous share of Federal outlays. SIPP collects data on receipt of several major programs targeted on persons with disabilities. These programs are Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), Black Lung, and Veterans programs. In addition, information is also collected on Medicare and Medicaid--the two respective companion medical programs to SSDI and SSI.

SSDI, which is administered by the Social Security Administration (SSA), provides monthly cash benefits to disabled workers under age 65 and their dependents. SSDI is the primary social insurance program in the country which protects workers from loss of income due to disability. SSDI is not a means-tested program, but certain numbers of insured work-quarters are required. Insured work quarters are those 3-month calendar year quarters in which an individual works, is covered by Social Security, and earns a specified amount. In January 1989, 4.1 million Americans received SSDI benefits. (Burwell, January 1990)

SSI provides monthly cash benefits to low-income aged, blind, and disabled persons. The SSI program is administered by SSA, but many States also choose to supplement Federal payments. While SSDI eligibility consists of work requirements, but not a means-test; SSI has a means-test, but no work requirements. Also unlike SSDI, blind or disabled children can receive SSI. In fiscal year 1989, 3.1 million blind or disabled persons received SSI. (Burwell, January 1990)

Veterans disability pensions provide cash assistance to veterans with service-connected disabilities, that is, they incurred illness or injury while in service. SIPP collects information on whether or not respondents have a service-connected disability and, if so, the disability rating assigned by the VA. These ratings range from 0-100 percent and are based on the presumed drop in income caused by the disability. VA pensions are also given to elderly low-income war veterans who have become permanently and totally disabled from non-service-connected causes. Both types of VA pensions are also available to survivors. In 1989, 2.2 million veterans with service-connected disabilities and 1.2 million without service-connected disabilities received pensions. (Committee on Ways and Means)

Black Lung benefits are paid to coal miners who are totally disabled as a result of pneumoconiosis[1], to widows of miners who died from Black Lung disease, and to their dependents. Almost 400 thousand persons were paid Black Lung benefits in 1988. (Burwell, January 1990)

C. SIPP Disability Data Items

The SIPP core contains only a few disability items found in the SIPP core. They include reasons why a respondent is not working, presence of a service-connected disability, an overall work disability question, receipt of income for health or disability reasons, and participation in disability programs.

The vast majority of disability data are found in Topical Modules, not in the core. The Wave 3 Topical Module on Health and Disability from the 1984 Panel was particularly useful and has provided the basis from almost every SIPP disability analysis. This Topical Module contained information on sensory impairments, body system functioning, activities of daily living (ADLs), instrumental activities of daily living (IADLs), work disability, and children's disability. These questions were improved and asked again during Wave 3 (and perhaps Wave 6) of the 1990 Panel.

Between 1984 and 1990, there was a dearth of disability data on SIPP. During this time, disability questions were included, but only erratically. These questions were designed by selecting portions of questions from the 1984 Panel. Different selections were asked in different Panels. No comprehensive SIPP disability data exists for those years, thus severely limiting the analytical utility of SIPP.

Besides the extensive disability data collected in Waves 3 of the 1984 and 1990 Panels, disability data items were found in the following Topical Modules: sensory impairments and body system functioning (Wave 6 of the 1988 Panel and Wave 3 of the 1989 Panel); ADLs and IADLs (Wave 6 of the 1985 Panel, Wave 3 of the 1986 Panel, Wave 6 of the 1987 Panel, Wave 3 of the 1988 Panel, and Wave 3 of the 1989 Panel); work disability (Wave 2 of the 1986 Panel, Wave 2 of the 1987 Panel, Wave 2 of the 1988 Panel, Wave 4 of the 1988 Panel, Wave 2 of the 1989 Panel, and Wave 3 of the 1990 Panel); and, children's disability (Wave 6 of the 1985 Panel, Wave 3 of the 1986 Panel, Wave 6 of the 1987 Panel, Waves 3 and 6 of the 1988 Panel, and Wave 3 of the 1989 Panel).

In addition to disability data items, SIPP collected information on long-term care items, chiefly the amount of money spent on people who lived in a nursing home. These items were: support for nonhousehold members (Wave 4 of the 1985 Panel, Waves 3 and 6 of the 1986 Panel, Waves 3 and 6 of the 1987 Panel, Waves 3 and 6 of the 1988 Panel, and Wave 3 of the 1989 Panel) and caregiving (Wave 6 of the 1985 Panel, Wave 3 of the 1986 Panel, and Wave 6 of the 1987 Panel).

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[1] Pneumoconiosis is a disease of the lungs caused by the habitual inhalation of irritant mineral or metallic particles (Burwell et al., 1990).

Information on spells of SSI coverage were obtained in Wave 5 of the 1984 Panel as part of the Topical Module on Welfare History and in Wave 2 of the 1986 through 1990 Panels in the Topical Modules on Recipiency History.

Specific details of the SIPP disability items are given below. A discussion of the first major SIPP disability data section--Wave 3 of the 1984 Panel--is given first, followed by a discussion of disability data items in SIPP found in the 1985 through 1989 Panels and ending with a discussion of Wave 3 of the 1990 Panel.

1. Wave 3 of the 1984 Panel

Wave 3 of the 1984 Panel contained some of the most comprehensive survey data collected on functional disability. Information was collected in SIPP for respondents of all ages. Too often, disability data are only collected for the elderly, even though most (62 percent) of persons with disabilities are under the age of 65. (Adler) Data were also gathered on work disability.

Information on functional disability for adults aged 15 or over included a range of functions in Wave 3 of the 1984 SIPP. These functions were: (1) sensory impairments; (2) body system functioning, that is activities which measure the ability of different body systems; (3) self-care tasks or the so-called activities of daily living (ADLs); and, (4) instrumental activities of daily living (IADLs), which are broader than the ADLS.

The questions are structured in a two-tiered design, so that functional severity can be ascertained. First, respondents are asked asking if they have difficulty with a specific function and, if they answer "yes", then they are asked if they can perform the function at all.

a. Sensory Impairments. Sensory impairments include seeing, hearing, and speaking. People with sensory impairments may or may not be disabled in the usual sense. For example, a deaf person may have no limitations in physical functioning or in the ability to work. But, work or other accommodations may be needed. Thus, from a broad policy perspective, it is important to include persons with sensory impairments. Furthermore, blind persons have different eligibility criteria for some programs (i.e. SSDI, SSI).

b. Body System Functioning. A series of questions are asked on the ability of three different body systems to function--lifting 10 pounds, walking 3 blocks, and climbing stairs. These three questions measure different aspects of physical functioning. For example, lifting can be difficult for someone with a back problem, but not for someone in a wheelchair. Walking 3 blocks is probably impossible for someone in a wheelchair, but not for someone with a bad back. Climbing stairs is usually difficult for persons with mobility problems, knee disorders, or those with muscle weakness.

c. ADLs and IADLs. ADLs and IADLs measure perhaps the severest forms of functional disability. Data on ADLs are crucial for policy research, because they are significant predictors of admission to a nursing home, use of paid home care, use of physician services, living arrangements, insurance coverage, and death among the elderly (Weiner 1990) and because they basically define the need for long-term care. They are increasingly used to establish eligibility for long-term care benefits. The presence of ADL limitations (for all but acute conditions) means that some kind of long-term care is needed, because basic activities cannot be performed at all without assistance. In SIPP, this assistance means help (either active or standby) from another person. Some surveys include assistive devices, such as crutches or wheelchairs.

There are 6 or 7 standard ADLs--bathing, dressing, eating, toileting (including going to the toilet), getting in or out of a bed or chair (transferring), and (in some scales) walking. The IADLs include using the telephone, shopping, preparing meals, doing housework and/or laundry, doing yard work, managing personal finances, and taking medications. The health condition responsible for an ADL and IADL limitation is obtained from a list of 23 conditions contained on a flashcard.

Although questions on ADLs and IADLs are contained in SIPP, they were not designed to obtain the number of ADL and IADLs that a person might have. The 1984 SIPP question on getting in or out of bed is the only one question about a single type of ADL activity. There is also a question which asks about a variety of IADls (light housework/meal preparation) and one which combines a number of different ADLs. This question reads:

> “Does…need help from others in looking after personal needs, such as dressing, undressing, eating, or personal hygiene?”

Although most persons with ADL or IADL limitations are elderly, many are not. According to the 1984 SIPP, of the 7.8 million persons in 1984 who resided in the community and who needed long-term care, 3.8 million or 49 percent were under the age of 65. (MPR, 1989) Many surveys limit questions on ADLs and IADLs to the elderly, thus making the results much less meaningful for policymakers. The effect of these proposals on program participation has been difficult to assess with available data.

ADLs and IADLS will probably be even more important to policymakers in the future. A number of recent bills before Congress have proposed that program eligibility for Federal programs, such as Medicare and Medicaid, be determined by the number of ADLs and/ or IADLs that an individual has.[2] However, the 1984 SIPP questions do not allow separate counts of ADL and IADLs to be made.

The 1984 SIPP data are reasonably compare to other major data sets. The Interagency Forum on Aging-Related Statistics, which is chaired by the heads of the Census Bureau, the National Center for Health Statistics (NCHS), and the National Institute on Aging (NIA), commissioned a report comparing estimates from different surveys on the number of elderly persons with ADL limitations. According to this report,

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[2] Indeed, this has already begun. The new Medicaid Home and Community Care option in OBRA 1990 uses selected ADLs for eligibility, specifically toileting, transferring, and eating.

estimates of the number of aged persons with ADL limitations receiving human assistance were 1.5 million persons from the 1984 SIPP compared to 1.3 million from the Supplement on Aging to the NHIS and 2 million from the National Long-Term Care Survey (NLTCS).[3] (Weiner 1989)

d. Work Disability. The work disability questions are asked of persons aged 16 through 72 years of age. Information is obtained from two kinds of respondents--those who have already indicated that they cannot work due to a health condition and all others. Persons who have indicated a work disability are asked to verify that they are limited in the kind or amount of work they can do, when their limitation began, the health reason for the limitation, whether an accident or injury was responsible for work disability, the site of the accident or injury, and the date of last employment.

Persons who have not indicated a work disability are asked if they are prevented from working and if so, for how long. Respondents are also asked if they are able to work full-time or only part-time and if they can work regularly or only irregularly. Finally, persons with work limitations are asked if they are now able to do the same kind of work that they did before the limitations(s) began.

e. Comparisons between Functional and Work Disability. There is considerable overlap between people who are functionally disabled and those with a work disability. Altogether, for persons aged 18-64 years, 21.7 million or 15.1 percent had a functional disability, that is, they had a difficulty with (or were completely unable to) see, hear, speak, or to perform the three body system functions, ADLs, or IADLs. Meanwhile, 18 million or 12.5 percent had a work disability of some sort, that is, they were either prevented from working, were limited in some way, or could only work part-time or irregularly. An estimated 6.1 million persons had a work disability, but no functional disability. The reasons for this are unclear. However, since the 1984 SIPP questions, focused heavily on physical rather than mental disabilities, some of these individuals could have been mentally retarded, mentally ill, or otherwise mentally disabled. Specific questions on mental disability were added in 1990 to alleviate this concern. Large numbers (9.8 million) of people with functional disabilities did not report a work disability. However, this varied greatly by the severity of the functional disability. For example, while 87 percent of those with an ADL or IADL limitation reported a work disability, only 31 percent of those with the mildest functional disability (difficulty with only one activity) also reported a work disability. However, many disabled people work: nearly 700 thousand persons with ADL or IADL limitations were employed either full or part-time. (MPR, 1989)

f. Children's Disability. Children's disability was included those (under age 18) who either had: a long-lasting physical condition which limited the ability to walk, run, or play or a long-lasting mental or emotional condition, which limited the ability to learn or perform regular schoolwork.

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[3] These comparisons were made using a standard set of ADLs and a similar question (human assistance). More ADLs and broader assistance categories (e.g. assistive devices) would increase the size of the estimates.

TABLE 1: Comparisons Between Numbers (in millions) of Functional and Work Disability for Persons Aged 18-64: April 1984			
	Functionally Disabled	**Not Functionally Disabled**	**Total**
Work Disabled	11.9 (8.3%)	6.1 (4.2%)	18.0 (12.6%)
Not Work Disabled	9.8 (6.8%)	115.6 (80.6%)	125.4 (87.4%)
Total	21.7 (15.1%)	121.7 (84.9%)	143.4 (100.0%)

SOURCE: Mathematica Policy Research, Inc., *Task I: Population Profile of Disability*, Report to DHHS, Office of the Assistant Secretary for Planning and Evaluation, Washington, DC, 1989.

2. The 1985 Through 1989 Panels

a. General Functioning. General functioning questions about sensory impairments (seeing, hearing, speaking), three body system functions, and two IADLS (getting around inside and outside) and one ADL (getting in and out of bed) were originally asked in Wave 3 of the 1984 Panel, but were not re-asked until Wave 6 of the 1988 Panel and Wave 3 of the 1990 Panel.

b. ADLs and IADLs. Selected ADL and IADL questions were asked from time to time during the period from 1985 through 1989. In the Long-Term care Topical Modules (later re-christened Home Health Care), questions were asked on "dressing, undressing, eating or personal hygiene" (ADLs); light housework (IADL), preparing meals (IADL), getting around outside (IADL), and keeping track of bills (IADL). These questions are not as analytically useful as intended, because many standard ADLs and IADLs were omitted. Thus, it is impossible to get a count of the number of persons with different numbers of ADL limitations.

c. Long-Term Care Items. There were several long-term care items on SIPP during 1985 through 1989, which were included in the "Support for Nonhousehold Members" Topical Module, which asked about payments for persons living outside the household (like in nursing homes). Thus, data on aged spouse paying for the care of a spouse in a nursing home were available, although the sample was small. In addition, Topical Modules on Long-Term Care and Home Health Care also contained sections on the type of care needed by the disabled respondent and types of care provided by respondents to disabled people either in or out of the sampled household. These data fill a gap, particularly for care provided to nonelderly persons. Historically, most data on caregiving refer only to the elderly even though they comprise only 59 percent of all noninstitutionalized persons who need long-term care. (Adler 1990)

d. Work Disability. Work disability questions were asked in the Work Disability History Topical Module. These questions were identical to the ones which appeared in the 1984 SIPP. These data are restricted, because many working-age persons with functional disabilities are not limited in their ability to work.

e. Children's Disability. The children's disability questions asked in 1984 were basically re-asked several times later. Beginning in 1988, a severity question was added to the original set.

f. Spells of SSI. Spells of time on SSI were obtained during the Recipiency History Topical Modules. Respondents not on SSI were asked questions about whether or not they had ever applied for or received SSI benefits and, if so, when SSI benefits ended. Respondents already on SSI were asked is they had had other spells on SSI and the length of those spells. Similar questions in these sections were asked in conjunction with Food Stamps, AFDC, and Medicaid. This series of questions is crucial to policymakers, because program turnover appears higher than previously believed.

3. Wave 3 of the 1990 Panel

a. Overview. A full battery of disability questions was reinstated in Wave 3 of the 1990 Panel. The design of the 1990 Panel was unique in two ways, both of which will act to increase the sample of persons with disabilities and make results more meaningful. First, the sample size was restored to that proposed in the original design--19,000 households. During Wave 3 of the 1984 Panel, slightly over 51,000 respondents were interviewed, of which 8,700 (500 children, 4,800 working-age adults, and 3,400 elderly) had disabilities.

Secondly, an oversample of low-income households was included in the 1990 Panel. Persons with disabilities have greater risks of being in poverty than others. According to the 1984 data, one in ten working-age persons with no disabilities lived in poverty compared to one in five persons with disabilities. Almost identical differences were evident for the elderly: 6 percent of those with no disabilities lived in poverty compared to 15 percent of those with disabilities. However, differences in poverty rates were not as high for children as for adults, perhaps because their poverty rate is so implicitly high: 21 percent of children without disabilities lived in poverty compared to 27 percent of those with disabilities. (MPR, 1989)

Disability questions on the Wave 3 1990 Panel were designed by a subgroup of the DHHS Departmental Working Group on Disability Data.[4] The questions were based on the 1984 Panel, but several major improvements were made so that the data could be more useful for policy and program analyses. These improvements were in the following areas: (1) ADLs and IADLs; (2) mental and emotional health conditions which result in disability; (3) children's disability; (4) health conditions responsible for disability; and (5) history of SSDI receipt or application.

b. ADLs and IADLs. The list of ADLs and IADLs questions was expanded and separate questions for each ADL and IADL were asked. The ADL list now includes questions on getting around inside, bathing, dressing, eating, getting into or out of a bed or chair, and toileting. The IADL list includes: getting around outside, using the telephone, keeping track of money or bills, doing light housework, and preparing meals. These changes

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[4] The subgroup consisted of representatives from ASPE, NIMH, NCHS, and the Census Bureau.

added ADLs and IADLs which were previously omitted and now make it possible to obtain the number of ADLs/IADLs for each adult respondent.

c. Mental and Emotional Disabilities. The lack of specific questions or even an emphasis on mental and emotional health conditions responsible for disability no doubt resulted in an undercount of adults with these disabilities. A frequent criticism of the 1984 Panel was that while persons with physical disabilities were sufficiently represented, those with mental or emotional conditions were not. For example, persons who are chronically mentally ill may be able to perform physical functions (including the ADLs and IADLs), but are still disabled, because they require extensive care. Ironically, there was a separate SIPP question on mental or emotional disability for children, but not for adults. Thus, in order to make the SIPP definition of disability more inclusive and to satisfy data needs from NIMH, the disability questions were modified in two ways. First, new lead-ins for questions were modeled after those used in NMES. For example, the lead-in to the list of ADL and IADL questions read:

> “Because of a physical or mental health condition, does…have difficulty doing any of the following by himself/herself (excluding the effects of temporary conditions)?”

Secondly, a new question was added on whether or not the respondent had the following conditions: a learning disability, mental retardation, a developmental disability, Alzheimer's disease, senility or other dementia, or any other mental or emotional condition. This question was modeled after one used in the 1989 Supplement to the NHIS on mental illness.

d. Children's Disability. Questions about children's disability are difficult to ask, particularly for very young children, such as infants and toddlers. Some disabilities are evident at birth (i.e. Down Syndrome), but others do not manifest themselves and may not even be diagnosed until later (i.e. autism and AIDS). Developmental disabilities may easily be confused with normal delays in development.

The usual questionnaire approaches--asking about limitation of activity and functioning--are difficult to interpret for very young children. For example, children under 3 may have no usual activity. Furthermore, functional activities like the ADLs and IADLs are essentially meaningless: ADLs are not even asked until age 5 and IADLs until age 18.

The questions on children's disability in Wave 3 of the 1990 Panel were developed in conjunction with the Department of Education to resolve these concerns. First, unlike the 1984 and other Panels, there were age splits. Consistent with the NHIS approach, children under age 6 were asked if they had "any limitations at all in the usual kind of activities done by most children their age". The receipt of therapy or other diagnostic services was also obtained for these young children. Children aged 6-21 were asked about "limitations in the ability to do regular schoolwork" and if special education services were received. Finally, children aged 3-14 years of age were asked a question on "a long lasting condition that limits their ability to walk, run, or use stairs".

The age break ended at 15 years, the age of adulthood in SIPP. Thus, these older teenagers were administered the adult questions on disability.

e. Reasons for Disability. The section on health conditions responsible for disability was greatly expanded. In 1984, reasons for disability were only gathered for selected kinds of disabilities: work disability, children's disability, and selected ADLs/IADLs). This design limited the overall usefulness of the disability data. The reasons were selected from a list on a similar flashcard. In 1990, three reasons for disability (including the main one) were asked from a flashcard for all types of identified disabilities. Time limitations required that these reasons be asked about all disabilities together, not for each separate disability.

f. Spells of SSDI. Information on spells of SSDI were asked about during Wave 3 for the first time, although participation in SSI--the other major disability cash assistance program has been a routine data item on SIPP from the beginning. The questions, which were included at the request of the Office of Disability, Social Security Administration, ascertained if respondents had ever applied or received SSDI benefits and, if so, when and for how long.

4. Wave 6 of the 1990 Panel--Changes in Disability

The failure to accurately characterize the dynamics of change in disability status can lead to serious errors in policy judgments about major policy initiatives and disability issues. Therefore, in order to ensure that overall changes in disability are accurately reflected in SIPP, the Census Bureau (at the request of DHHS) asked EOMB to re-ask the Wave 3 disability questions on Wave 6 of the 1990 Panel. In this way, the same disability questions will be asked of the same respondents after a year's time.

Disability is oftentimes a dynamic rather than a static process. The nature and severity of health conditions which result in disability can change over time. Therefore, both the presence and level of disability can also change. Medical interventions and rehabilitative therapies often result in improvements or even complete cures for many conditions. Thus, it is not uncommon for persons with disabilities to recover or to improve to a less severe level of disability.

Conversely, disability can also worsen. Persons with disabilities can become more severely disabled or even die. In addition, persons with no disabilities can become so by contracting a disabling chronic illness or by being injured or impaired.

Overall changes in disability status are much more common than generally realized. According to the NLTCS, 22 percent of elderly persons with 5 or 6 ADLs improved after two years. More change seems to occur among those persons experiencing lower levels of disability. (Manton) According to preliminary data from the 1987 NMES, 41 percent of elderly persons with only 1 or 2 ADLs improved after eight months, 40 percent stayed the same, and 19 percent worsened to having 3 or more ADL's. (Lair)

Transitions in disability status are believed to be even greater for the nonelderly than for the elderly population with disabilities, because disabling conditions tend to result from different causes and to be different in nature for nonaged than for aged persons. Preliminary data from the 1987 NMES indicate that this is so. During the first NMES interview, 1.9 million persons between the ages of 18 and 64 years had at least one ADL limitation. After 8 months, the number was 1.8 million. However, only 49.5 percent of those who had an ADL in the first interview still had one. (Lair)

Changes in disability are not limited to those disabilities which are physical in origin. National community follow-up data from a study conducted by the National Institute of Mental Health (NIMH) indicate that with treatment, one-third of persons with mental illness showed improvements in functioning after 14 months, one-third stayed the same, and the remaining one-third showed no improvement. (Manderschied)

IV. SIPP POLICY RESEARCH APPLICATIONS

A. Overview

Data from SIPP have added new perspectives to numerous health and disability policy issues. This section describes some major health and disability policy and program issues facing DHHS and how these issues have been or could have been addressed by SIPP.

B. The Americans with Disabilities Act (ADA)

Disability issues are in the forefront of domestic policy, as never before. The recent passage of the Americans with Disabilities Act (ADA) on July 26, 1990 is a case in point. The ADA is a major piece of civil rights legislation. Equal opportunity provisions for persons with disabilities are contained in the ADA regarding employment, public accommodation, transportation, State and local government services, and telecommunications. Some provisions of the ADA are in effect now, while others will be implemented later. Thus, the ADA will profoundly impact the everyday lives of many individuals with disabilities in coming years.

In keeping with civil rights goals, a broad comprehensive definition of disability appears in the ADA. The definition is the same one used in Section 504 of the Rehabilitation Act of 1973 and the Fair Housing Amendments Act of 1988. In order to be covered by the ADA, an individual must meet one of the following three tests and have:

> “(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having an impairment.”

Even though SIPP could be instrumental in describing the impact of the ADA, there are no data or reporting requirements in the ADA. However, prevalence rates and evaluation data will almost certainly be required. It is too early to anticipate the precise data elements and evaluations which will be needed, but disability will be no doubt need to be broadly defined, as in Wave 3 of the 1990 Panel. In fact, data from the 1990 Panel will be invaluable in gaining the first overall look at disability in the 1990s by providing the number and characteristics of individuals with disabilities. Furthermore, SIPP data on items such as employment, income, and size of firm can be used to describe employment patterns of people with disabilities. This information will be helpful in assessing the impact of the employment provisions of the ADA.

C. Disability Profiles

Data on the overall population with disabilities, not just those who already receive program benefits, are crucial in understanding the effects of Federal policy and programs. Whereas information about program beneficiaries is needed in order to efficiently run the four major DHHS programs targeted on disability (SSDI, SSI, Medicare, and Medicaid), information on potential beneficiaries is also required, as policy issues frequently involve changes in what is offered by the program and who is eligible.

Over the years, SSA sponsored the Surveys of Disability and Work--a series of national population-based surveys on disability. These surveys, which began in the 1960s, provided much valuable information not only on persons who received benefits from SSDI, but also on the entire working-age population with disabilities. The last such disability survey was conducted in 1978 and no other comparable data base existed until the 1984 SIPP. Wave 3 of the 1984 SIPP Panel is a rich source of data on the entire population of persons with disabilities. However, the sample size of persons receiving SSDI benefits is too small to provide the detailed analyses like those obtained from the earlier SSA surveys.

ASPE awarded a competitive contract in 1988 to Mathematica Policy Research, Inc. (with a subcontract to SysteMetrics/McGraw Hill) in order to mine the 1984 data.[5] The purpose of the contract was to produce four reports: “Task I: Population Profile of Disability”, “Task II: Federal Programs for Persons with Disabilities”, “Task III: Program Participation Patterns among Persons with Disabilities”, and “Task IV: Labor Force Profile of Persons with Disabilities”.

These reports contain the most recent comprehensive look we have on the characteristics of Americans with disabilities. Since SIPP collected disability data for all ages, separate sections of the report are devoted to children, working-age adults, and the elderly. The inclusion of all ages in SIPP was critical from a policy point of view. Most persons with disabilities are under age 65: 22 million adults and 2 million children in the civilian non-institutionalized population compared to 15 million elderly persons. This was an important finding, as little recent data exists on the entire age spectrum. (MPR, 1989)

Another unique feature of the Wave 3 1984 SIPP data was that disability was defined broadly enough for adults so that different severity levels could be constructed. This was meaningful for policy purposes. Initial results from SIPP indicated that the size of the disabled population was huge--37 million adults and 2 million children. However, programs like SSDI and SSI serve only 2 or 3 million people. A more intense look at the data was needed in order to better assess the size of the disabled population in terms of possible program participation. (MPR, 1989)

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[5] Contract No. HHS-88-0047 to the Office of the Assistant Secretary for Planning and Evaluation.

With that in mind, the following six different levels of disability were constructed and analyzed for adults aged 18 or over.

(1) *Level I disability* is the inability to perform ADLs without the help of another person. These ADL were: getting around inside the house, walking, getting in and out of bed, or personal needs (eating, dressing or undressing, or personal hygiene). In 1984, approximately 2,870,000 non-institutionalized adults or 1.7 percent had a Level I disability.

(2) *Level II disability* is the inability to perform IADLs without the help of another person. These IADLs were: getting around outside the house, doing light housework, and preparing meals. The number of adults with a Level II disability was 4,790,000 or 2.8 percent of the population.

(3) *Level III disability* is either an inability to perform more than one of the following activities (seeing, hearing, lifting 10 lbs., walking 3 city blocks, or climbing a flight of stairs) or has difficulty with two ADL's, yet reports no need for assistance from another person. Nearly seven and a half million (7,470,000) adults or 4.4 percent had a Level III disability.

(4) *Level IV disability* includes persons with difficulty (but no inability) with two or more of the following activities (seeing, hearing, lifting 10 lbs., walking 3 city blocks, or climbing a flight of stairs). Slightly over eight million (8,090,000) or 4.8 percent of adults had a Level IV disability.

(5) *Level V* disability includes persons with difficulty (but no inability) with only one of the following activities (seeing, hearing, lifting 10 lbs., walking 3 city blocks, or climbing a flight of stairs). The number of adults with a Level V disability was 13,917,000 or 8.2 percent.

(6) *Level VI disability* includes persons who have no limitations at all in functioning. The largest group in the population was Level VI, persons with no disabilities: 132,524,000 or 78.1 percent.

The MPR reports were invaluable in providing a look at some basic characteristics of persons with disabilities and making comparisons to the rest of the population. Significant differences between those with and without disabilities existed. However, there were also great differences within the population with disabilities. This became evident when severity of disability was considered. Furthermore, those persons with the least severe types of disability (Level V, in particular) differed only slightly from those with no disabilities in many ways: i.e., income and poverty, program participation, employment, health care utilization, health insurance.

These following comparisons (MPR, 1989) contrast characteristics between *working-age individuals* at three levels: those who are the most severely disabled (ADL or IADL limitations, referred to as Levels I and II), those who are least disabled (Level

V), and those with no disabilities at all (Level VI). Similar patterns exist for the aged and for children and are detailed further in the MPR reports.

Disability is highly associated with a number of health and socio-economic variables. The following short summaries illustrate differences between people with and without disabilities and between those with more severe disabilities. These differences reinforce the necessity for obtaining disability data on SIPP.

a. Income and Poverty: The more severe the disability, the more likely a person is to have a low income and live in poverty. The median monthly household income for those with Levels I and II disabilities was $1,000 less than for those with no disabilities: $1,272 compared to $2,263, respectively. The median monthly household income for those with a Level V disability--at $1,900--was less than that for persons with no disabilities, but much greater than that for the most severely disabled. Differences also existed in the proportion who lived below poverty: 23 percent of those persons with Level I or II disabilities lived in poverty compared to 16 percent of those with a Level V disability and 10 percent of those with no disabilities. (MPR, 1989)

b. Program Participation: The degree of reliance on Federal programs increases sharply with level of disability. One-third (33 percent) of those with a Level I or II disability received SSDI and 15 percent received SSI. Only slightly more than 3 percent of those with a Level V disability received SSDI while slightly less than 3 percent received SSI. Participation in SSDI (0.4 percent) and SSI (0.4 percent) was almost minimal for those with no disabilities. (Doyle)

c. Employment: Sizable numbers of persons with disabilities worked, although the likelihood of employment was less for those with the most severe disabilities. In April 1984, however, even at Levels I and II, 20.5 percent were employed either full or part-time. Sixty-four (64) percent of those with a Level V disability were employed compared to 74 percent of those with no disabilities. Regardless of disability, among those who were employed, the vast majority worked full-time: 75 percent of those with Levels I or II disabilities, 83 percent of those with Level V disabilities, and 82 percent of those with no disabilities. SIPP allowed employment rates to be calculated not only for a given month, but also over time. This was an important distinction, because seasonal effects and erratic episodes of employment could be considered. During calendar year 1984, the employment rate for persons with a Level I or II disability was 29 percent compared to 74 percent for those with a Level V disability and 85 percent for those with no disabilities.

Not only do persons with disabilities work, but an estimated 485 thousand persons who receive SSDI or SSI also worked at sometime in 1984. Their annual employment rate was 12 percent. The average number of weeks worked was 34 and the average number of hours worked per week was 30. Their wages were low: 73 percent earned less than $5 an hour. (Martini)

Although the SIPP sample size of SSDI/SSI beneficiaries who worked is small, these figures are of great policy concern. A number of work incentive provisions have recently been introduced into the SSDI and SSI programs. For purposes of SSDI eligibility, disability is defined as the inability to engage in any substantial gainful activity (SGA) due to a physical or mental impairment. SGA is currently defined in monetary terms as earnings less than $500 per month ($300 in 1984). Previously, loss of SSDI benefits would mean loss of Medicare coverage. Therefore, work incentive provisions were introduced to encourage employment by extending the period of Medicare coverage and by allowing certain impairment-related expenses to be deducted when determining eligibility.

Similarly, for SSI, the notion of SGA is used in defining disability. Disabled persons are those who are unable to engage in SGA because of a medically determined physical or mental impairment expected to result in death or that has lasted or can be expected to last for a continuous period of at least 12 months. The SGA limits for SSI are the same as for SSDI. A number of work incentive provisions have also been introduced into the SSI program under the Section 1619 provisions of the SSI Act. In summary, these provisions provide for the continuation of SSI cash benefits even after SGA is reached. The amount of these benefits is gradually reduced until a breakeven point is reached. Medicaid coverage is indefinitely extended in most cases. (Burwell, January 1990)

d. Education: Persons with the most severe disabilities are the least likely to have high levels of educational attainment. Most individuals with Levels I or II disabilities (52 percent) have not finished high school and only 20 percent have gone beyond high school. In contrast, 33 percent of those with a Level V disability did not graduate from high school, while 26 percent had more than a high school education. Persons with no disabilities had the highest average levels of educational attainment: only 18 percent did not finish high school, while 41 percent had more than a high school education.

e. Health Care Utilization: Persons with disabilities are heavy users of medical care. The average number of physician visits in the past year was 13.6 for persons with a Level I or II disability, 4.8 for those with a Level V disability, and 2.6 for those with no disabilities. The likelihood of a hospital stay during the past year was greater as disability increased: 36 percent of those with a Level I or II disability had a hospital stay compared to 16 percent of those with a Level V disability, and 10 percent for those with no disabilities. Time spent in the hospital followed the same pattern. The average number of days spent in the hospital was 8.4 for those with a Level I or II disability, 1.5 for those with a Level V disability, and 0.6 for those with no disabilities.

According to unpublished analyses (Adler 1991), health care utilization for persons with Levels I or II disabilities does not remarkably differ between individuals who have and who do not have health insurance. The average number of physician visits was 13.4 for those with insurance and 14.6 for those without. The proportion with hospital stays during the past year was high for both groups: 37 percent for those with insurance and 31 percent for the uninsured. Furthermore, 11 percent of those with no insurance had at least two hospital stays. It is not clear how these expenses are being met.

f. Health Insurance Coverage is more likely to be from public rather than private sources for persons with disabilities, but there are few differences between the proportion of persons with no insurance. The vast majority of persons under 65 have private health insurance, typically through their own or a spouse's employer. Persons with disabilities are much more likely to have public coverage through Medicare or Medicaid. Approximately 42 percent of those with a Level I or II disability have private coverage only, 30 percent have public coverage only, 14 percent have a combination of public and private coverage, and another 14 percent are uninsured. For those with a Level V disability, 71 percent had private coverage only, 8 percent had public coverage only, 2 percent had a combination of public and private coverage, and 19 percent were uninsured. For persons with no disabilities, 80 percent were covered by private insurance only, 3 percent were covered by public insurance only, 1 percent were covered by a combination of public and private plans, and 16 percent were uninsured.

D. DHHS Disability Programs

1. SSDI and SSI SIPP Data Project

Many policy matters affect the SSDI and SSI programs, both of which are administered by SSA, and their corresponding companion medical programs, Medicare and Medicaid, both of which are administered by the Health Care Financing Administration (HCFA). At the most basic level, information on program beneficiaries is needed. However, the SSA and HCFA research files are not easily geared to analyze characteristics of program recipients. Administrative records do not include people not on the program, even though they might be eligible.

Information on receipt of Social Security was collected in SIPP. However, respondents are often unable to specifically identify which type of benefit they receive. For example, aged respondents may confuse SSA retirement benefits with SSI and vice versa. Similarly, people under age 65 can receive SSI, SSDI, early retirement (at age 62), or some kind of survivor or dependent benefits. These are often difficult to untangle in a household survey situation.

Therefore, the Census Bureau and SSA undertook a joint statistical arrangement in which SIPP public use files was matched to Social Security program information in order to determine the type of benefit received (i.e. SSDI, SSI, SSA retirement).[6] This

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[6] This activity was described in the *Social Security Bulletin, Annual Statistical Supplement*, 1989 (page 353), as conducted:

> "…under the aegis of the agencies' 1967 Memorandum of Agreement on the Exchange of Statistical Information and Service. All work involving the development and analysis of the matched data set at SSA has been carried out, subject to the strictest confidentiality safeguards, by SSA employees acting as special sworn employees of the Bureau of the Census."

was a commendable effort. These data were valuable not only in describing the type of benefits received, but also in depicting the characteristics of persons who received SSDI, SSI, or both.

Cross-program coverage is of special interest. Administrative records typically pertain to only one program. It is not uncommon for a disabled individual to simultaneously receive benefits from SSI, SSDI, and thus, Medicaid and Medicare. Program records exist for SSDI, SSI, Medicare, and (to some extent) Medicaid. But it is never easy and it is usually impossible to learn about these individuals solely from program records.

According to August 1985 data from the SSA/Census project, there is much cross-program coverage: 19 percent of those who receive SSDI benefits also receive SSI and 29 percent of those who receive SSI also receive SSDI. The health insurance coverage of SSDI beneficiaries is a perennial policy concern. Medicare coverage is extended only after a 24-month waiting period has elapsed. However, Medicaid coverage is extended immediately to almost all SSI recipients (depending on the State). According to these data, 80 percent of SSDI beneficiaries had Medicare, 24 percent had Medicaid, 46 percent had private health insurance, and 5 percent were uninsured. (SSA)

2. SSI Children

Relatively few (400 thousand or so) children with disabilities receive SSI. Therefore, although questions have been included on Social Security receipt for children (i.e. dependent benefits), a decision was made not to include questions on SSI receipt for children. However, the number of children on SSI is expected to grow dramatically, possibly by as many as a million because of a recent Supreme Court decision. The Medicaid program would also be affected, since children with disabilities who receive SSI are also eligible for the most part for Medicaid as well.

In *Sullivan v Zebley*, the Supreme Court affirmed a Court of Appeals decision which found that SSA erred in using a stricter test for disabled children than for disabled adults who apply for SSI. Specifically, *Zebley* challenged the method used by the Secretary to determine whether a child is disabled and therefore eligible to receive benefits under the SSI program. At issue specifically was the comparability between the eligibility process for children and adults.

During the course of this process, data on children with disabilities was sorely needed. The only available information came from the 1984 SIPP data and the NHIS. Both surveys could be used to estimate overall prevalence rates of disability. However, while SIPP had data on disability and income, there were no data on receipt of SSI for children. The NHIS, meanwhile, had data on disability and (occasionally) SSI receipt for children, but was weak on family income. Thus, it was difficult to measure the impact of the *Zebley* decision.

E. Special Populations

The overall population with disabilities is so heterogeneous that certain populations need to be studied separately, particularly those which figure prominently in policy. Three of these population have already been discussed (those who receive SSDI, those who receive SSI, and children with disabilities). Two other populations are noteworthy: AFDC recipients and persons with mental retardation or other developmental disabilities (MR/DD).

1. AFDC Recipients

The Aid to Families with Dependent Children (AFDC) population is made up almost entirely of young mothers and their children. Therefore, disability is not a common concern in AFDC policy.

An early analysis of the 1984 SIPP (McNeil) indicated that the overall rate of functional disability among women on AFDC was surprisingly high. A more detailed analysis (Adler, 1988) found that nearly one in four women on AFDC under the age of 45 (22 percent) report themselves as disabled compared to one in eleven (9 percent) such women not on AFDC. In fact, women on AFDC have disability rates nearly as high as women old enough to be their mothers (or grandmothers). For example, the age-specific disability rate for women on AFDC aged 35-44 is 45.9 per hundred--only slightly below the 52.4 per hundred rate for women aged 65-74.

AFDC mothers may not be the only disabled members of the family. Twelve percent of women on AFDC under the age of 45 report that they have at least one disabled child compared to only 3 percent not receiving AFDC.

Disabled and non-disabled women on AFDC differ in so many respects that it is easy to think of them as two separate populations, who may very well have entered and stayed on welfare for entirely different reasons. The non-disabled are younger, have younger and healthier children, have spent less time on welfare, and are more likely to be unmarried. The disabled, on the other hand, are older, more apt to have a disabled child, have longer stays on welfare, and are more likely to have separated from or divorced their husbands. (Adler 1988)

The issue of functional disability may profoundly impact the success of the Administration's JOBS or work-welfare programs, which are currently underway. As a result of what was learned in SIPP, the Office of the Inspector General in the DHHS New York Regional Office is planning a study to determine the level of functional disability among AFDC recipients and to assess its impact on the JOBS program.

2. The Developmentally Disabled Population

The total number of persons with mental retardation or other developmental disabilities is not known, but they figure prominently as recipients of SSDI and SSI. Twenty-four (24) percent of those receiving SSDI and 36 percent of those receiving SSI are developmentally disabled. Furthermore, for many years the fastest growing component of Medicaid has been care received in intermediate-care facilities for the mentally retarded (ICF-MRs).

Many disabling conditions result in a DD, the most common of which is mental retardation. Other frequent conditions include cerebral palsy, autism, and epilepsy. However, the DD definition is not medical, but functional and onset must occur before age 22. In according with the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987, a person has a DD if there are substantial functional limitations in at least three of the following seven major life activities (self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency). (Burwell, July 1990)

It is not easy to identify persons with a DD in surveys. In Waves 3 and 6 of the 1990 Panel, specific questions were asked on whether or not a person had a DD or was mentally retarded. However, age of onset questions are also needed in order to more make this determination more precisely.

3. Long-Term Care

Long-term care is a continuing policy concern. As the population ages, long-term care issues will rise even more sharply in importance. President Bush asked that the Deputy Secretary of DHHS form a Task Force to study long-term care (particularly financing issues) during his 1990 State of the Union Address. The Task Force has not yet released its report.

Overall SIPP data have offered some unique perspectives into the entire area of long-term care. The functional disability items found in Wave 3 of the 1984 Panel and the items in the Long-Term Care Topical Modules of 1985 and 1986 have been useful. Furthermore, asset information on the elderly was incorporated into DHHS' major microsimulation model on long-term care. SIPP was useful overall, because all ages (not just the elderly) were included and because data on income, employment, and program participation have been able to be linked to items on long-term care.

V. CONCLUSIONS AND RECOMMENDATIONS

SIPP data have contributed numerous insights into policy issues on health and disability, with many more to come. Furthermore, health and disability are not stand-alone characteristics but are integral to a useful understanding of how income is distributed and who and why people rely on Federal programs. Thus, the inclusion and expansion of health and disability items on SIPP will have a far-reaching policy impact. The following recommendations were developed with expanding the usefulness of SIPP.

Recommendation 1: Include the full series of disability questions (like in Wave 3 of the 1984 and 1990 Panels). So many Federal programs are targeted on disability, this will make SIPP more truly a survey of income and *program participation*.

Recommendation 2: Include the full series of disability questions twice on the same Panel (not necessarily every year) in order to determine changes in disability.

Recommendation 3: Include an age of onset question in the disability series in order to determine length of disability and to identify persons with developmental disabilities.

Recommendation 4: Ask the SSI recipiency core question of children, as well as for adults. There will be large numbers of children entering SSI, because of the Zebley Supreme Court decision.

Recommendation 5: Ask the health status and health care utilization questions of children, as well as for adults.

Recommendation 6: Include the questions on rejection from and spells of health insurance coverage like those found in Wave 3 of the 1984 Panel in order to identify the medically uninsured and better construct spells of uninsurance.

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