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BEFORE THE

COMMITTEE ON GOVERNMENT REFORM
SUBCOMMITTEE ON HUMAN RIGHTS AND WELLNESS
U.S. HOUSE OF REPRESENTATIVES

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Good afternoon, Mr. Chairman and Members of the Subcommittee.

It is a pleasure to appear before you today to discuss the Department of Health and Human Services' (HHS) programs for people with disabilities and the President's New Freedom Initiative. We are pleased that you are holding this hearing to better understand Federal initiatives and programs that affect the quality of life of Americans with disabilities.

This is an issue that President Bush took on early and vigorously when he came into office. In February 2001, one of the first initiatives he announced was the New Freedom Initiative, which builds on the Americans with Disabilities Act, the landmark legislation signed into law by President George H.W. Bush in 1990. In announcing the New Freedom Initiative, the President said, "We are more mindful now of the hardships that come with disability, more generous in responding to the needs of our citizens, more grateful for [their] contributions to society. Old misconceptions about physical and mental disability are being discredited. Old barriers are falling away. Our task is now clear: we must speed up the day when the last barrier has been removed to full and independent lives for every American with or without a disability."

Under the leadership of Secretary Thompson, nine Federal agencies formed the Interagency Council on Community Living to evaluate their policies, programs, statutes and regulations to determine whether any should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities and reported back to the President with their findings. On March 25, 2002, HHS presented the President with *Delivering on the Promise: Compilation of Individual Federal Agency*

Reports of Actions to Eliminate Barriers and Promote Community Integration. The Report consisted of more than 400 specific solutions each Department identified to support community living for the nearly 54 million Americans living with disabilities.

The Department of Health and Human Services plays a major role in addressing the New Freedom Initiative challenge set by the President. It conducts and supports a variety of programs and initiatives to provide assistance and support to people with disabilities and their families.

Through the Medicare and Medicaid programs, we provide health care and supportive services to approximately 13 million Americans with disabilities in a wide range of settings. Our Administration on Developmental Disabilities (ADD) is the President's New Freedom Initiative in action. ADD, through the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), funds and oversees over 180 grants to promote opportunities and services that result in individuals with developmental disabilities living in and contributing to their communities.

Our Administration on Aging (AoA) operates a comprehensive network -- Federal, State and local organizations that coordinate and deliver community supports to Americans over age 60, many with disabilities, and their caregivers. Our Substance Abuse and Mental Health Services Administration (SAMHSA) funds a variety of activities and services to meet the needs of individuals with mental disabilities and substance abuse disorders. Primary health programs funded by the Health Resources and Services Administration (HRSA) serve people with disabilities, as do several of our other "mainstream" programs such as those within the Indian Health Service, and programs in

the Administration for Children and Families (ACF) such as Head Start, Temporary Assistance for Needy Families (TANF) and other family services programs.

The Office of the Assistant Secretary for Planning and Evaluation maintains an extensive research agenda on a number of disability, aging and long-term care policy issues, and there are substantial disability related research initiatives underway within the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH).

Our Office for Civil Rights, in collaboration with the Department of Justice and other partners, works to ensure compliance with civil rights laws that prohibit discrimination on the basis of disability in HHS federally conducted and federally assisted programs and is responsible for ensuring that State and local government health and social service programs comply with the Americans with Disabilities Act.

In October 2002, Secretary Thompson created the Office on Disability in response to a key HHS solution recommended in the report *Delivering on the Promise*. The office serves as the focal point within HHS for the implementation and coordination of policies, programs and special initiatives related to persons with disabilities.

The array of HHS programs serving people with disabilities is broad and diverse but the programs are bound together by a fundamental commitment to: (1) promote the independence and quality of life of individuals with disabilities; (2) enable people with disabilities to receive the services they need in the most integrated settings possible; and (3) support people with disabilities in their efforts to work.

Who are People with Disabilities?

One of the Administration's key contributions to policymakers working on disability programs is the collection and dissemination of data on the number and characteristics of Americans with disabilities. At any one time, 40 to 50 Federal activities may be funding, collecting and/or compiling data on disabilities in the U.S. These activities include program eligibility information, administrative data, ongoing surveys, special surveys, and research. These activities focus on the general population or special subsets, such as children, working age adults, the elderly, or people disabled by mental illnesses. Data collection activities may focus on work, education, program utilization, or the national prevalence of disability. Data are collected as household surveys, in person interviews, or via telephone.

Within this array, there are major sources of information on people with disabilities. These include the following: (1) Decennial Census; (2) Survey of Income and Program Participation; (3) National Health Interview Survey; (4) Medicare Current Beneficiary Survey; (5) Health and Retirement Study; and (6) National Long-Term Care Survey. (See Attachment A for detailed descriptions.)

The term "disability" encompasses a wide range of functional limitations and conditions. Various data sources yield different estimates, depending upon how disability is defined. For example, the Survey of Income and Program Participation reported that 53 million Americans, or 19.7 percent of those living in non-institutional settings, had a disability in 1997. About 12.3 percent of the population reported a severe disability, and 3.8 percent had long-term care needs (need for assistance from another

person with basic activities of daily living such as eating, dressing, transferring from bed to chair, walking, and toileting).

One important type of disability occurs when functional limitations are severe enough to affect the ability to work. In 1997, about 16.9 million persons, or 9.8 percent of the population age 16 to 64 reported that they were limited in the amount or kind of work they can do.

Another indicator of disability is whether a person receives benefits under Federal disability cash benefit programs operated by the Social Security Administration (Social Security Disability Income [SSDI] or Supplemental Security Income [SSI]). In March 2004, about 10.5 million persons under age 65 received such benefits. To qualify for these cash benefit programs, individuals must meet strict disability standards, not be engaging in substantial gainful activity, and have a disability that is expected to continue for at least a year or result in death.

HIGHLIGHTS: MAJOR HHS PROGRAMS SERVING PEOPLE WITH DISABILITIES

Americans with disabilities, including those with mental, sensory, cognitive, developmental, or physical disabilities are part of the population served by all HHS “mainstream” programs because by the broadest definition, almost one in five Americans has a disability. For example, approximately 13 percent of the children enrolled in Head Start programs nationwide have a disability.

However, I will highlight here the larger HHS programs focused more precisely on serving people with disabilities.

Health and Long-Term Care Services

Dependable, high quality health care is a critical need for people with disabilities. HHS supports the delivery of health care services under the Medicaid, SCHIP, Medicare and Indian Health Service programs. People with disabilities qualify for Medicaid in a number of ways, but approximately 8 million people with disabilities qualify explicitly on the basis of meeting the SSI financial and disability eligibility criteria. These individuals are entitled to the full range of Medicaid financed services offered in their State, including physician and hospital care. Although Medicare is principally a health care program for people over the age of 65 (including many with disabilities), it also provides health coverage for individuals with disabilities who receive SSDI, generally after a two-year waiting period. Approximately 6.4 million people under age 65 receive Medicare on the basis of a disability.

Many individuals with functional impairments require assistance with the tasks of daily living. Medicaid, the State-Federal health care program for low-income people, is by far the largest public payer of long-term supports for people with disabilities. In 2003, States and the Federal government spent approximately \$44.8 billion Medicaid dollars on nursing home services, serving approximately 1.6 million people (at some point in the year); \$11.3 billion on institutional settings for people with mental retardation, serving 110,572 people with mental retardation or developmental disabilities. Still yet, \$27.8 billion was spent to support individuals in the community with home and community-based services, personal care and home health.

Promoting Community-Based Long-Term Care Services

The legislation that authorizes Medicaid requires participating States to offer nursing home care, but offers States the option to provide Medicaid community-based services. Yet, most consumers and their families prefer to receive services at home, in the community for as long as possible. As one American told us: “I fear that [as my needs increase] if I can’t have attendant care when I need it in my home, I will be institutionalized. And what I will lose, then, is the last thing that I have. It’s my freedom.”

The Administration and its State partners are listening. While Medicaid spending is still biased toward institutions, the ratio is shifting dramatically, with the proportion targeted toward home and community care increasing. For instance, in 1990 Federal-State Medicaid spending for community care represented 13.7 percent of Medicaid long-term care spending; in 2003, it was 33.2 percent.

Over the past three years, HHS has awarded approximately \$121 million in grants to States to influence and accelerate this shift. The “Real Choice Systems Change” grant program provides States and other eligible entities with funding to make lasting improvements to their home and community-based services programs. We will be awarding another \$31 million this year. This unprecedented, multi-year investment, is designed to support systemic changes that will enable individuals with disabilities to: (1) live in the most integrated community settings appropriate to individual support needs and preferences; (2) exercise meaningful choices about their living environments, the providers of service they use, the types of supports and the manner in which services are provided; and (3) obtain quality services in a manner as consistent as possible with their

community living preferences and priorities. These grants address a range of topical concerns, including “money follows the person,” quality, employment supports, community care for children, and respite care for adults, to name a few. This year, grants will address mental health systems, family to family health care information centers, quality of community-based services, integration of housing and services, and others areas.

Another component of this effort is the collaboration between the Administration on Aging (AoA) and the Centers for Medicare and Medicaid Services (CMS) to provide States with an opportunity to effectively integrate their long-term support resources for consumers into a coordinated system. Twenty-four States have now received Aging and Disability Resource Center grants to develop streamlined access to long-term care for people with disabilities of all ages. And AoA and CMS are committed to funding additional States in FY 2005.

Promoting Consumer Choice and Control

One of the most promising developments in Medicaid community care is the development of consumer directed models and the policy changes to promote them. The best-known model of Medicaid consumer directed care is the “Cash and Counseling Program” which was designed and supported by the Office of the Assistant Secretary for Planning and Evaluation, CMS, and the Robert Wood Johnson Foundation. Under this program, and others like it, people who use Medicaid personal assistance are offered the opportunity to receive individual budgets, rather than services provided by an agency. The individual budget gives the consumer the flexibility to select what services he or she will use and who will deliver them; in addition, there may be flexibility to buy certain

products that contribute to the individual's independence. Consumers typically select caregivers who are family members or friends. The consumer's use of the funds is supported by a counselor, and "fiscal intermediary" agencies help with the paperwork. But the consumer is at the center of it all-in the driver's seat of his or her own life. According to rigorous research findings, participants in these programs report close to 100 percent satisfaction; quality is very high; and, there is less reliance on nursing home services. People stay at home and in control of their own lives much longer.

CMS promotes the use of these models through Medicaid Independence Plus Waiver Initiatives and grants to support consumer direction. In addition, the LIFE Accounts Initiative, included in the President's 2005 budget, would promote consumer and family directed services.

Caregiver Support

Most people with disabilities who receive community-based services rely exclusively on family members and friends. It has been estimated that the value of the "free care" provided by these "informal caregivers" exceeds \$257 billion annually, and that one of every four people in the U.S. is a caregiver for a family member or friend with a disability. These individuals report that they provide this care because of their personal relationship with the recipient. But we also know these caregivers sometimes need support. Prolonged caregiving can adversely affect one's physical and psychological health, current and future employment status, and earning capability. HHS supports key initiatives to support caregivers with training, information, and respite care. The Administration on Aging's National Family Caregiver Support Program provided \$159.1 million this year to provide outreach with information to about 8 million individuals, as

well as assistance, counseling, training, respite care, and supplemental services to over 500,000 caregivers. Family caregivers of individuals with disabilities who are over age 60 or under age 18 are eligible for assistance under this program.

In his 2005 budget, the President proposed innovative demonstrations under the Medicaid program that would enhance the ability of individuals with disabilities to live and fully participate in the community. With \$18 million proposed for FY 2005 (\$327 million over the five-year demonstration period) these demonstrations would address adult respite-testing the provision of respite for caregivers of adults as a Medicaid service; children's respite-testing the provision of respite for caregivers of children as a Medicaid service; and alternatives to psychiatric residential treatment for children-providing family and community-based programs for children with psychiatric disabilities as an alternative to psychiatric residential treatment facilities.

In addition, in his 2005 budget, the President proposed a \$3,100 personal tax exemption for certain qualified individuals with disabilities and their caregivers when the person with a disability lives with the caregiver.

Supporting a Quality Long-Term Care Workforce

When "formal" services are needed, it is critical that we have in place a committed workforce to provide high quality services. Secretary Thompson has done a great deal to bring a national focus to addressing the crisis in recruiting and retaining such a workforce for community-based and institutional settings. Providers report turnover rates that are sometimes in excess of 100 percent a year. The Office of the Assistant Secretary for Planning and Evaluation recently co-sponsored a national conference on this issue with the Department of Labor, bringing together workers,

researchers, providers, policy makers, and people with disabilities to explore new solutions. In addition, we are conducting the first nationally representative survey of direct care workers who serve people with disabilities, starting this summer with nursing home workers. We will explore the characteristics, attitudes, and job satisfaction of these individuals. Finally, CMS has awarded approximately \$12 million since 2003 in grants to States to improve the recruitment, training, support and retention of direct service workers with an emphasis on the provision of a health care benefit for direct service workers.

Promoting Independence Through Work

An important component of the President's New Freedom Initiative is doing everything possible to help people with disabilities to work. Secretary Thompson has said, "Fear of losing access to health coverage is a major obstacle for people with disabilities who want to work." We in HHS work closely with our partners in the Departments of Education and Labor and the Social Security Administration to ensure that our programs: (1) support this important vehicle to independence; and, (2) effectively advance the goals of the Ticket to Work and Work Incentives Improvement Act of 1999, which encourages people with disabilities to work without fear of losing eligibility under Medicare, Medicaid or similar health benefits.

In March, we awarded \$15.7 million in Medicaid Infrastructure Grants to 28 States and the District of Columbia to help people with disabilities find and keep work without losing their health benefits. These grants bring the total number of States with such grant programs to 42, with dollars totaling \$57 million.

Developmental Disabilities Programs

The ACF Administration on Developmental Disabilities (ADD) provided over \$140 million in grants last year to assist the Nation's nearly 4 million people with developmental disabilities (disabilities that begin prior to age 22 and result in major, lifelong impairments). The ADD network in each State consists of a State Developmental Disabilities Council (55 total), appointed by the governor, that promotes innovation and statewide change in service delivery; a State Protection and Advocacy System (57 total) that focuses on the civil rights of individuals with developmental disabilities; and one or more University Centers (61 total) for Excellence in Developmental Disabilities that conducts training, research, community outreach, and information dissemination. In addition, ADD, through its Projects of National Significance, is funding the design and implementation of family-friendly one-stops (31 total) to assist families with a member with a developmental disability to secure the services and supports they need and not navigate multiple human service systems alone. The ADD grantees have a broad portfolio. The DD Act authorizes these grantees to address health, education and early intervention, employment, housing, child care, transportation, recreation, quality assurance and/or formal and informal community services and supports that will enhance the independence, productivity, integration, and quality of life of individuals with developmental disabilities. A sample of ADD's numbers illustrates the New Freedom Initiative in terms of real people. In 2002, 40 States' grantees assisted 5,616 adults with developmental disabilities secure jobs; 32 States' grantees assisted 60,176 children with developmental disabilities secure the services and supports they needed to achieve their educational goals; 22 States' grantees helped 16,775 individuals with developmental

disabilities secure essential care services; and 29 States' grantees helped 5,921 to live in homes of their choosing.

ADD also administers the \$14.9 million dollar disability-related grant programs authorized by the Help America Vote Act. Each State receives a grant to make its election polls accessible to individuals with the full range of disabilities, to develop procedures and acquire equipment that allows individuals with disabilities to vote independently in private, to train election officials and poll workers on how to assist individuals with disabilities in an appropriate manner when they are participating in the voting process, and to inform individuals with disabilities about where accessible voting places are located. Moreover, ADD also administers grants to Protection and Advocacy Systems specifically to assist individuals with disabilities to participate in the voting process from registering, to getting to the places of election, to casting votes.

Support for Young Children with Disabilities and their Family Members

The Maternal and Child Health Bureau, within the Health Resources and Services Administration (HRSA), provides funds to States to improve the health of all mothers, children-including children with special health care needs-and their families. In FY 2004, approximately \$200 million of this Federal investment is being allocated to community-based care for children with special health care needs. These services target the estimated 18 million children with special health care needs who are at increased risk of chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

Special Initiatives

While we are proud of our continued support for and improvement of our disability programs, we are always seeking new avenues to ensure that the needs and interests of people with disabilities are considered and addressed. The HHS Office on Disability, created by Secretary Thompson in 2002, has undertaken several innovative interdepartmental initiatives, including the “Cross Agency and Intergovernmental Young Adult Initiative” to prepare young adults, 16 to 30 years old, for adulthood by supporting States and Tribal Governments in the development of comprehensive systems of care; the “I Can Do It – You Can Do It” physical fitness program for children and youth with disabilities through a mentor approach, and the development of a Surgeon General’s “Call to Action” to increase prevention, awareness and accessibility for people with disabilities seeking to ensure their health and well being.

A Sustained Research Investment

I have described a number of data, program and policy activities and initiatives; these efforts are critical to ensuring that our Nation has consumer responsive services in place to ensure the quality of life and independence of people with disabilities. However, it is important not to lose sight of the substantial investments of our National Institutes for Health and Centers for Disease Control and Prevention in research to prevent, treat, and cure conditions that may result in disability. In addition, AHRQ supports the development of empirical research to promote quality services. AHRQ has conducted workshops and provided tools for consumers, providers, advocates, and State and local policymakers to assess consumer needs and plan for successful transition from institutions to community settings.

CONCLUSION

Many of the programs I have talked about today had their roots decades ago, although we continue to improve and modernize them, as individual needs and values change. Working with our State and local partners, and – most importantly – with people with disabilities and their families, we have come a long way, but as President Bush has stated: “...There is much more to do. Though progress has been made in the last decade, too many Americans with disabilities remain trapped in bureaucracies of dependence, denied the tools they need to fully access their communities...I am committed to tearing down the remaining barriers to equality that face Americans with disabilities today. My New Freedom Initiative will help Americans with disabilities by increasing access to assistive technologies, expanding educational opportunities, increasing the ability of Americans with disabilities to integrate into the workforce, and promoting increased access into daily community life.”

We at HHS are firmly committed to meeting the challenge the President has set before us. We know we must continue to listen to people with disabilities and work closely with them, their family members, States, and service providers to continue to improve services and ensure that our Nation’s disability policies are inclusive and responsive to consumer needs.

I am happy to answer questions.

Attachment A

Major US Data Collection Activities on Disabilities

At any one time, 40 to 50 Federal activities may be funding, collecting and/or compiling data on disabilities in the US. These activities include program eligibility information, administrative data, ongoing surveys, special surveys, and research. These activities focus on the general population or special subsets within the population, such as children, working age adults, the elderly, or people disabled by mental illnesses. Data collection activities may focus on work, education, program utilization, or the national prevalence of disability. Data may be collected as household surveys, in person interviews, or via telephone.

Within this array, there are major sources of information on people with disabilities. These include the following:

- Decennial Census;
- Survey of Income and Program Participation;
- National Health Interview Survey;
- Medicare Current Beneficiary Survey;
- Health and Retirement Study; and
- National Long-Term Care Survey

The Decennial Census is conducted every ten years by the Bureau of the Census and is used to apportion seats in the U.S. House of Representatives. Every dwelling in the country received either a short form or a longer version in Census 2000 by post. The longer version contained the disability questions and was mailed to a subsample of 17 percent. Two questions about disability were asked in Census 2000. The first question asked if the person has any long-lasting condition, with two subquestions. The first subquestion asks about sensory impairments (i.e., blindness, deafness, severe hearing or vision impairments). The second subquestion queries about conditions limiting basic physical activities (e.g., walking, carrying). The second question asks whether a physical, mental or emotional condition lasting 6 or more months causes difficulty in a series of activities. The activities, asked as a subset of questions, include learning, dressing, going outside to shop and working. The responses to Census 2000 disability questions were either 'yes' or 'no'. Several Federal agencies use the Census data on disability to fulfill regulatory, mandatory, or programmatic reporting requirements. For the 2010 Census, the Census Bureau plans to ask only short form questions. Detailed questions, such as disability, are being asked in the ongoing American Community Survey.

The Survey of Income and Program Participation (SIPP) is conducted continuously with monthly interviewing by the Bureau of the Census. It obtains information on Federal program participation and describes the income distribution of the population, with a special focus on low income. Three topical modules in 2001 collected data on adult, child and work disability. Questions included age-appropriate activities of daily

living, instrumental activities of daily living, work, schoolwork, sensory impairments, movement and mobility, use of assistance, and the etiological conditions associated with limitations in functioning and disabilities. Responses to questions are in the 'yes/no' format and write-ins.

The National Health Interview Survey (NHIS) is conducted annually by the National Center for Health Statistics, Centers for Disease Control and Prevention to provide nationally representative data on the health status, health related behavior, and use of health services by the civilian non-institutionalized population. The 2002 NHIS contains three core interviews (family, child and adult) and special topic modules (e.g., alternative health supplement). Each core asks about health status and activity limitations. Activity limitation questions in the family core include activities of daily living, (e.g., self car), activity of daily living (e.g., household chores, shopping) and the causal health conditions. In the child core, the focus is on school attendance, basic mobility, sensory impairments, and emotional and behavioral difficulties. The adult core queries on movement and mobility, social and recreational limitations, sensory impairments, and the causal health conditions. Question responses are in 'yes/no' and scaled formats.

Medicare Current Beneficiary Survey (MCBS) is a continuous, multipurpose survey of a representative sample of the Medicare population designed to aid the Centers for Medicare and Medicaid Services' (CMS) administration, monitoring and evaluation of the Medicare program. The survey is conducted in three rounds per year, with each round being four months in length. MCBS has a multistage stratified random sample design and a rotating panel survey design. Each panel is followed for 12 interviews. In-person interviews are conducted using computer-assisted personal interviewing. Approximately 16,000 sample persons are interviewed in each round. However, because of the rotating panel design, only 12,000 sample persons receive all three interviews in a given calendar year. The MCBS collects information on health status and physical functioning of Medicare beneficiaries as well as their health care use, cost and sources of payment; health insurance coverage; household composition; sociodemographic characteristics; income and assets; access to care; satisfaction with care; usual source of care, and how beneficiaries get information about Medicare.

Health and Retirement Study (HRS) is a national panel study being conducted by the University of Michigan Institute for Social Research under a cooperative agreement with the National Institute on Aging. The study had an initial sample in 1992 of over 12,600 persons from the 1931–1941 birth cohort and their spouses. The HRS was joined in 1993 by a companion study, Assets and Health Dynamics Among the Oldest Old (AHEAD), with a sample of 8,222 respondents born before 1924 who were age 70 or older and their spouses. In 1998, these two data collection efforts were combined into a single survey instrument and field period. The HRS is intended to provide data for researchers, policy analysts, and program planners who are making major policy decisions that affect retirement, health insurance, saving, and economic well-being. The objectives of the study are: to explain the antecedents and consequences of retirement; examine the relationship between health, income, and wealth over time; examine life cycle patterns of wealth accumulation and consumption; monitor work disability; provide a rich source of

interdisciplinary data, including linkages with administrative data; monitor transitions in physical, functional, and cognitive health in advanced old age; examine the relationship of late-life changes in physical and cognitive health to patterns of spending down assets and income flows; relate changes in health to economic resources and intergenerational transfers; and examine how the mix and distribution of economic, family and program resources affect key outcomes, including retirement, spending down assets, health declines and institutionalization.

National Long-Term Care Survey (NLTC), conducted in 1982, 1984, 1989, 1994, and 1999, is a nationally representative survey of Medicare beneficiaries age 65 or older with chronic functional disabilities. The samples drawn from the Medicare beneficiary enrollment files are nationally representative of both community and institutional residents. As sample persons are followed through the Medicare record system, virtually 100 percent of cases can be longitudinally tracked so that declines as well as improvements in health status may be identified, as well as the exact dates of death. NLTC sample persons are followed until death and are permanently and continuously linked to the Medicare record system from which they are drawn. Linkage to the Medicare Part A and B service records extend from 1982 through 1995, so that detailed Medicare expenditures and types of service use may be studied. Through the careful application of methods to reduce nonsampling error, the surveys provide nationally representative data on: the prevalence and patterns of functional limitations, both physical and cognitive; longitudinal and cohort patterns of change in functional limitation and mortality over 12 years; medical conditions and recent medical problems; health care services used; the kind and amount of formal and informal services received by impaired individuals and how it is paid for; demographic and economic characteristics such as age, race, sex, marital status, education and income and assets; out-of-pocket expenditures for health care services and other sources of payment; and housing and neighborhood characteristics.

Administrative Data. There are numerous sources of administrative data with extensive disability information, collected to implement and administer programs. These data are frequently used for research purposes as well. Notable examples include the Medicaid Statistical Information System (MSIS), Social Security disability programs, the Minimum Data Set (MDS) used in nursing homes, and the OASIS data collected on home health users. The Departments of Education, Labor, HUD, Transportation and others maintain administrative and survey databases on their programs.