



TESTIMONY OF

STEVEN JAMES TINGUS  
DEPUTY ASSISTANT SECRETARY FOR PLANNING AND EVALUATION  
DISABILITY, AGING AND LONG-TERM CARE POLICY  
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE THE

HOUSE COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM  
SUBCOMMITTEE ON INFORMATION POLICY, CENSUS, AND  
NATIONAL ARCHIVES

ON

JUNE 4, 2008

Good afternoon, Chairman Clay and distinguished Members of the Subcommittee.

Thank you for inviting me here today to talk with you about Federal statistical data on people with disabilities – the current state of our efforts and resources and what we need to think about as we move into the future.

My name is Steven James Tingus and I am the Deputy Assistant Secretary for Planning and Evaluation (ASPE), Office of Disability, Aging and Long-Term Care Policy at the Department of Health and Human Services. Before I came to HHS, I was the Director of the National Institute on Disability and Rehabilitation Research in the Department of Education. Perhaps more important than my positions in the Administration, my career experience in rehabilitation research and independent living...as you can see...I have lifelong personal experience living with a disability.

I will use my time to tell you a bit about my personal experience, because it illustrates the need for accurate disability data for use by policymakers and program developers. As you requested, I will comment on the GAO report, “Modernizing Federal Disability Policy,” and the National Council on Disability’s recent report, “Keeping Track: National Disability Status and Program Performance Indicators.” Next, I will talk about the extensive disability data resources we have today, and finally, offer some thoughts about future disability data development.

## My Own Story

I was born with a rare form of muscular dystrophy that is associated with limited mobility and difficulty using my arms to reach. I am a heavy user of assistive technology. For example, I sleep using a ventilator each night and rely on a power wheelchair to work and participate in the community. I also rely on personal assistance to enable me to take care of activities of daily living such as food preparation, dressing and personal hygiene at home and in the workplace. Advancements in disability research, disability service programs and assistive technologies have made the difference for me between a life of dependence, and possibly institutionalization and – the life I have – living in the community and pursuing a great career.

I came into the world when parents were advised to send people like me to “schools for the handicapped.” This was before the Individuals with Disabilities Education Act and the Rehabilitation Act of 1973. Disability services, especially in the education arena, were State and local services, if they existed at all. Around the time the Rehabilitation Act was passed, I had a teacher who told me and my parents that she believed I could succeed in regular schools. The Davis, California school system said they would be willing to give it a try but I would need to be mobile. Our local Muscular Dystrophy Association paid for my first power wheelchair, enabling me to become the first disabled student mainstreamed into the Northern California schools.

I grew up in parallel to the rapid development of private and public services for people like me. When I finished high school, I was fortunate to be eligible for the SSDI and SSI programs, which gave me access to Medicare and Medicaid benefits. Since I had a pre-existing condition, I was unable to get health insurance to cover my extensive medical expenses on my parents' policy. Access to public benefits meant that I could attend college and graduate school. I was on Medicare and Medicaid from 1981 through 1995. When I finished school, I had the opportunity to work for Governor Pete Wilson, at which point I went off the public programs; I have been a proud taxpayer ever since.

I am grateful for the progress I have made, it is a credit to my family and to all the formal and informal services from which I have benefited. I am glad there are many others like me. But there is no question that to keep our Nation's disability research and programs moving forward, so that many more can realize their dreams and potential, policymakers and other stakeholders need credible data about people with disabilities and the services and technologies they use.

### Americans with Disabilities and the Programs that Serve Them

Who are people with disabilities? In 2002, 51 million people (18 percent of the population) living in the community had some level of disability, and 33 million (12 percent of the population) had a severe disability. (SIPP data, as reported in "Americans with Disabilities, 2002) Although the prevalence of disability increases with age, disability affects persons of all ages. The majority of people with disabilities (56 percent)

are age 15-64. Among adults aged 15-64, 11.8 million (6 percent) reported the presence of a condition that makes it difficult to remain employed or find a job.

What these numbers do not tell you is that people with disabilities are heterogeneous. The functional abilities and needs of those with physical disabilities like my own are vastly different from those with intellectual disabilities. People with mental illness face an entirely different situation in the services they require in order to live high quality, independent lives. These differences mean that disability data, programs and policies have to cover a wide variety of needs, resources and interests.

As we learned in the GAO report that we will be discussing at this hearing, there are over 200 Federal programs serving people with disabilities; they are operated by over 20 Federal agencies. In addition there are over 50 State Medicaid programs (including D.C. and the territories) and countless other State, local and private sector efforts. These health, income, employment and other programs add up to the patchwork quilt that is our Nation's disability system.

Most of these programs, coupled with our excellent civil rights protections under the Americans with Disabilities Act, add up to the United States being the best country in the world for a person with a disability. It can be confusing, though. I have spoken to many people with disabilities who know they are getting education, health, income support, employment or other disability services, but they have no clue what programs they are on!

Thanks in large part to President Bush's commitment to the New Freedom Initiative, a lot of these programs are teaming up and talking to each other, working together to serve people in ways that better meet their needs. One fine example is DisabilityInfo.Gov, a one stop resource for information on disability programs and related information.

Some might argue that we need one, coordinated disability program, but I think that would be a step backwards, given the different needs of a highly diverse population of people with disabilities. It is this diversity across our Federal, State, local and private programs that makes our service systems so well developed. This same diversity, however, makes it difficult to define and measure disability.

#### Disability Data Resources

Although many of the surveys conducted by the Federal Government contain at least one question on disability, several collect a considerable amount of information on disability, and are frequently used by policymakers and/or are cited in the media or academic journals.

The National Health Interview Survey (NHIS) helps us monitor the health of the population. Each year data are collected from approximately 87,500 persons of all ages living in 35,000 households. In 1994 and 1995, ASPE and other organizations provided funding to add an extensive set of questions on disability through a supplemental survey

to the NHIS. Detailed data on the conditions associated with the disability, their impact on functioning, living arrangement, caregiver characteristics, accommodations needed, and services used, were collected on all persons in the NHIS.

Several questions on disability were added to the redesigned NHIS in 1997, and have been included each year since then. Since it was first conducted in 1957, the NHIS has proven to be a valuable tool for monitoring the health of Americans. The findings on disability have been mixed. Disability is declining among the elderly, but recent analyses have begun to show increasing disability among working aged adults, some of it associated with increasing weight and obesity. (Health Affairs, January-February 2004, page 168, "Are the Young Becoming More Disabled?", Darius Lakdawalla, et. al.)

The NHIS sample forms the basis for another important HHS data collection effort, the Medical Expenditure Panel Survey (MEPS). Each year MEPS collects detailed information on all of the medical and health services used by a sample of households. Although provider surveys and insurance claims enable us to measure how much spent at the aggregate level in the CMS National Health Accounts, MEPS and similar surveys are critical for understanding who is using these services, and how they and their families pay for them.

The Survey of Income and Program Participation (SIPP) provides another source of disability data on persons of all ages. This panel survey has been conducted since 1984. The 2004 panel consisted of 46,500 households that were interviewed eight times. And

due to a sample cut in 2006, 22,400 households were interviewed twelve times. This household survey contains detailed questions on disabilities and their impact on functioning. SIPP also collects data on the Federal programs that people use. Researchers have used SIPP data to study the characteristics of persons enrolled in SSDI, SSI, and other Federal programs. In addition, SIPP data have been used in simulating the impacts of potential changes in these programs.

A recently implemented survey, the American Community Survey (ACS), collects some of the disability and other data that the other household surveys collect, but the ACS sample is much larger. Although the ACS contains only a few questions on disability, the large sample size enables us to show how disability rates vary across states and local areas. Moreover, since the ACS contains a wealth of household information, it helps us understand the characteristics of persons with disabilities and the families, e.g., their level of education, whether they are foreign born, and how they are currently employed.

Two longitudinal surveys provide valuable information on elderly persons with disabilities. The National Long-term Care Survey (NLTC) is a sample of people age 65 and over with disabilities. This survey has been used to monitor trends in disability and functioning among the elderly. The Medicare Current Beneficiary Survey (MCBS), while not designed specifically as a disability survey, provides valuable data each year on Medicare beneficiaries and the health services they receive.



The Health and Retirement Survey (HRS) surveys adults age 51 and older every two years. It provides valuable information on the characteristics and financial resources of persons approaching retirement, and then follows them through their retirement years. It enables us to understand disabilities that occur prior to retirement, as well as the impact of disabilities occurring after retirement.

Besides surveys, administrative data also help us understand how many persons with disabilities are served by Federal programs. SSA provides regular updates on the numbers of people who benefit from SSDI and SSI, and the amounts of the checks they receive. But administrative data provide little personal information beyond age and gender. ASPE and other agencies have been working to merge survey data with administrative records. For example, ASPE, NCHS, CMS, and SSA have merged SSDI, and SSI records, and Medicare enrollment and claims records, with the NHIS.

The resulting data set enables us to answer questions that could not be answered with survey or administrative record data alone. For example, many people with disabilities understand that they receive a check from the government, but they often do not know the name of the program that provides the check. By linking the payment records to the survey data, researchers are able to identify the specific program that provides their support. Furthermore, the utility of such linked administrative and survey data sets would be greatly enhanced by facilitating access by other Federal agencies and academic institutions.

Surveys of providers also provide valuable information on persons with disabilities. The National Nursing Home Survey (NNHS) is a sample of nursing homes and their current residents. It provides detailed data on the extent of the disability and the level of functioning. ASPE is working with NCHS and other agencies to conduct a similar survey of residential care facilities (sometimes referred to as assisted living facilities), which have become an important source of care for many elders, often serving as a substitute for nursing home care at the earlier stages of disability.

While having a variety of data sources on disability provides many benefits to policy makers and researchers, each source measures disability in a particular way. Comparing estimates of the numbers of persons with disabilities across surveys, for example, can be challenging when different questions underlie each of the estimates. Work is underway to standardize the questions used in surveys. For example, the disability questions used on the ACS are being added to the Current Population Survey (CPS) and the National Crime Victimization Survey (NCVS), as well as being tested for use in the NHIS. The CPS is the major source of data for computing employment and unemployment rates. Having disability questions on the CPS will enable us to compute rates for persons with disabilities and others each month.

#### The GAO and NCD Reports

I am pleased that the Comptroller General convened a Forum on Federal Disability Policy and issued a report on the Forum in August of last year. I look forward to hearing

Mr. Bertoni's testimony and I would like to commend GAO on the report entitled "Modernizing Federal Disability Policy."

We at HHS welcome the GAO's line of inquiry: what is working well in our disability programs and what needs improvement? We continually engage in this same conversation, internally and with stakeholders in the consumer, provider and research sectors – for instance, the Centers for Medicare and Medicaid Services regularly holds Open Door Forums, in addition to meeting regularly with consumer and provider groups.

We are pleased to note that the GAO Forum participants recognized the need for more coordination across government programs. This theme is continued in the recent GAO report, "Federal Disability Programs: More Strategic Coordination Could Help Overcome Challenges to Needed Transformation." We agree that partnership and coordination are vital so that individuals with disabilities can make the most of the opportunities out there.

Some participants in the GAO Forum thought it would be a good idea to have one large, national full service disability program. I am glad that the Forum and the subsequent report provided the opportunity for us to discuss how to improve our disability programs. I believe that even if it were possible to combine all the various programs and eligibility groups – it would not serve people with disabilities well.

Speaking for myself, I did not need access to every possible service. My family, for example, provided me with transportation, housing and personal assistance services while

I was in college and graduate school. I am glad I was able to go directly to the services that met my needs. I think that one massive government bureaucracy would detract from the ability of targeted programs to meet targeted and unique needs. It is due precisely to the wide range of programs, I was able to get right to the services and supports I needed when I was a consumer of public benefits.

However, I want to be clear that I think it is very important that services and benefits be well designed and well coordinated. This is exactly why many Federal agencies work together on programs that serve people throughout the lifespan. My Department has invested a lot of resources in single point of entry programs; informally these are known as “no wrong door.” This approach recognizes that people with disabilities and their family members may be confused about eligibility and where to go for what services.

One great example is the Aging and Disability Resource Center (ADRC) program, a cooperative effort of HHS’s Administration on Aging and the Centers for Medicare and Medicaid Services. The ADRCs were developed to assist States in creating a single coordinated system of information and access for everyone seeking long-term supports, to minimize confusion, enhance individual choice and support informed decision making. Since 2003, 43 States have set up ADRCs. Strategic partnerships across programs are the key to the success of these programs.

A recent report “Keeping Track: National Disability Status and Program Performance Indicators” prepared by the National Council on Disability, provides many suggestions

for improving disability data used in assessing the extent to which Federal programs have improved the lives of persons with disabilities. The report recommends the development of a standard set of disability questions that can be used across all Federal surveys. This is a useful goal to pursue, and considerable effort has been made on this project thus far. If the standardized set of questions is widely adopted, then a number of indicators could be computed from various Federal surveys that would demonstrate how persons with disabilities compare with other people. At the current time only a limited number of comparisons are possible, although we have the core questions in the American Community Survey, which are being incorporated into a growing number of other Federal surveys. These are discussed in more detail in a statement for the record provided by Susan Dudley, Administrator of the Office of Management and Budget, Office of Information and Regulatory Affairs. It is critical, of course, that the multiple administrative and survey data collection efforts are able to continue to identify and gather information needed to meet their unique purposes and users' needs.

The report also suggests a number of measures of the quality of life of persons with disabilities which measure the extent to which they are able to participate in life activities. Many of these measures have not been collected on major federal surveys, and considerable work is needed to develop and test possible questions.

In addition, the report encourages the Federal Government to more fully disseminate data from Federal surveys in a form which compares persons with disabilities to others along several dimensions, including gender and race. Some tables along these lines have been

generated from many surveys, but more can be done, especially as the use of a standard set of disability questions becomes more widespread. We at HHS face this challenge directly as we work, each year, on the National Quality and Disparity Reports to Congress.

#### Moving Forward: Considerations for Developing our Disability Data

As mentioned earlier, good disability information is critical for determining the effectiveness of current programs, legislation, and initiatives to promote the independence and well-being of persons with disabilities. Specifically, we need good data at the population level in order to monitor aggregate changes, and sometimes even at the State or local level. We also need to ensure that data cover all ages of the population such as children, working age adults, older Americans, and persons with specific types of disabilities, including those from various ethnic groups.

Many of our current survey and data collection efforts adequately meet our needs; however, in many cases the information to help formulate policy or evaluate programs is lacking. For example, national surveys are of limited use to policymakers interested in the use of long-term care services by the working age population. The reason is fairly simple: the number of younger persons needing assistance with activities of daily living is relatively small compared to the overall population. To put this in perspective, less than 2 percent of the working age population (aged 25 – 64) needs personal care according to the 2002 Survey of Income and Program Participation. While this

percentage represents nearly two million persons, the survey's sample size is really too small to be of analytic value to policymakers interested in determining the effectiveness of specific programs. We also know relatively little about the prevalence of some types of disability because we do not have good measures. Cognitive impairment and dementia are two specific examples of disabilities where we have wide variations in prevalence because we are still in the early stages of developing statistically valid and reliable measures of these concepts.

We may need new surveys to meet our data needs in some circumstances, yet more innovative approaches to data collection could be useful. We could, for example, add questions to current surveys and supplement current data collection efforts by linking administrative data. Several years of cross-sectional data could be pooled to increase sample sizes. At a minimum, we need to further develop our current measures of disability and continue to think creatively about how best to collect data and to determine the prevalence of certain disabilities.

### Conclusion

Over the past seven and a half years, we have made enormous strides implementing President Bush's New Freedom Initiative. Doors have been opened in education, community living, technology, transportation and work supports, to name only a few. I am pleased to have been able to play a small part in this progress. The President's vision for people with disabilities is not yet fully achieved, however. We remain fully

committed to continuing to develop and use disability data to pursue innovative strategies to ensure that the diverse groups of people who are Americans with disabilities are able to partake in the American Dream.