

Disability: It's Complicated

Michele Connolly



It can happen in an instant. A soldier in Iraq loses a leg from a roadside bomb. A baby is born with Down syndrome. An elderly woman loses the ability to speak due to a stroke.

Or it can happen more insidiously. A diabetic with nerve damage can gradually become blind. A man with Alzheimer's disease may lose the ability to care for himself.

All these individuals have a disability. Disabilities vary dramatically and can affect people at any time and at any age. An individual's disability also may change over time. Someone with multiple sclerosis may have a deteriorating condition, but may regain function with rehabilitation.

Disability cannot be directly measured. There is no blood test, medical procedure, or functional test that absolutely measures disability. Disability is a subjective construct used to measure the impact of very real, but disparate, events. Just as the status of an individual changes over time, overall disability levels and trends change as new interventions are discovered, new types of disability emerge, existing types of disability change, and the population ages. The changes are reflected in disability programs, policy, and the definitions we use.

There are dozens of federal disability programs, each of which has its own unique purpose. In 2002, according to Nanette Goodman and David Stapleton in their article, "Federal Program Expenditures for Working-Age People with Disabilities" that was published in the *Journal of Disability Policy Studies*, 11.3% of all federal outlays amounting to \$226 billion

were spent on disability programs, just for the working-age population. During that time, it was estimated that states spent an additional \$50 billion for joint federal-state programs.

Disability data must be collected to address program and policy issues. But disability measures are challenging.

What Is Disability?

In general, disability is defined as a limitation or inability to perform usual societal roles due to a medical condition or impairment. Societal roles include growing, developing, and learning for people under age 18, working for working-age adults (ages 18–64), and living independently for the elderly (ages 65 and older). In addition, usual activities include recreation and interaction with family, friends, and neighbors. Usual activities vary by individual circumstances and age. For example, full-time college students are in their working years (18–64), but may not be ready to join the work force until graduation. The term "elderly" is often described as age 65 and older, yet many people retire later. In addition, growing, developing, learning, working, and living independently are all general terms open to interpretation.

Not all people with medical conditions have a disability. According to 2007 estimates by the Centers for Disease Control and Prevention, 10.7% of the population aged 20 and older (23.5 million Americans) had diagnosed or undiagnosed diabetes. Yet, in December of 2002, about 237,000 (just 4.0%) of disabled workers received Social Security Disability Insurance (SSDI) program benefits as the result of "endocrine, nutritional, and metabolic disorders," a category in which diabetes is the major (but not the only) condition.

Disability can be permanent or temporary. Those who use crutches for a broken leg or who are recovering from knee replacement surgery may not be considered to have a disability by most federal programs because their condition is temporary. However, for purposes of accessibility mandated by the Americans with Disabilities Act (ADA), they are considered to have a disability because they need ramps or curb cuts to get around during recovery. Periodicity also can complicate disability definition. Disability can be ever present (e.g., blindness), episodic (e.g., cancer and mental illness), or somewhere in between (e.g., people with arthritis who have good and bad days).

Disabling conditions can often be successfully treated and corrected. For example, congenital heart defects in infants can be resolved by surgical intervention. Disabilities also can disappear as situations (and thus definitions) change. School-age children with dyslexia may be regarded as having a learning disability, which may entitle them to special education (a disability program). But after they leave school, they may not continue to be considered as having a disability.

Severity is also a consideration. Some measures contain implicit severity indicators. For example, a person may be

asked if she has difficulty climbing a flight of stairs. If she answers yes, she is asked if she is able to climb stairs at all. In this case, there are three levels of severity: able to climb stairs, limited in the ability to climb stairs, or unable to climb stairs at all. Some tasks are so basic that the inability to perform them is considered more severe. A person who reports he is limited in performing one of the activities of daily living, such as going to the bathroom, may be considered to have a more severe disability than someone who is limited in climbing a flight of stairs.

Disabilities can be “visible,” as for people who use wheelchairs, scooters, or seeing-eye dogs, or “invisible,” as for those with mental illness or limited physical endurance. Technological advances, such as prostheses, can give functioning back to a person who has lost a limb due to cancer, combat, or an accident. Whether these individuals have a disability depends on the situation.

No description of disability is complete without addressing ability. We all have many abilities—even if we have a disability. Abilities can be task-specific, such as lifting a bag of groceries, or more general, such as the ability to work. Many people with disabilities are able to work. President Franklin D. Roosevelt was confined to a wheelchair due to polio. One of the world’s most brilliant theoretical physicists is Stephen Hawking, a man who continues to publish and lecture while almost completely

paralyzed from amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig’s disease).

Federal Disability Definitions and Programs

Altogether, the federal government employs a staggering 67 definitions of disability, which can be pared down to 41 after overlaps are accounted for. Besides federal definitions, hundreds more disability definitions exist for state, local, and tribal governments. As most are either derived from or similar to federal definitions, our focus is on federal programs.

Federal disability definitions are not written in stone, as federal definitions (and regulations) are rooted in congressional legislation and executive branch rules and regulations. Changes to federal disability definitions result from new legislation, regulations, reauthorizations, and court decisions. These and other definition changes affect estimates of disability prevalence rates and trends (see History of Federal Disability Programs). Most recently—on September 25, 2008—President George W. Bush signed the ADA Amendments Act (ADA-AA), which broadened and clarified the interpretation of the definition of disability that had become narrowed due to court decisions.

The many and varied federal disability programs suggest it is highly unlikely that there will ever be a single federal

History of Federal Disability Programs

Disability programs are as old as this country. The first disability program (and definition) was enacted by the Continental Congress on August 26, 1776, to provide compensation for “every officer, soldier, or sailor losing a limb in any engagement or being so disabled in the service of the United States so as to render him incapable of earning a livelihood.”

Federal disability programs in the United States are historically rooted in veterans’ disability programs, which dominated federal disability for most of our history. As times changed, so did veterans’ disability programs and their impact on society, including the formation of disability programs for the nonveteran population.

During the Civil War, an estimated 360,222 soldiers died on the Union side and 281,881 were wounded, many of whom were amputees. The best estimate of Confederate dead is 258,000 (Drew Gilpin Faust in *The Republic of Suffering*). No figures are available for the number of wounded Confederate soldiers. The huge number of disabled soldiers (called invalids) and dependent widows and orphans called for an extensive Civil War pension system.

The Civil War pension definition of disability, similar to that of the American Revolution, was dependent on the ability to work. Disability pensions were given to “... any person who served in the military or naval service, received an honorable discharge, and who was wounded in battle or in the line of duty and is not unfit for manual labor by reason thereof, or who from disease or other causes incurred in the line of duty.” Pension benefits for the massive number of surviving dependents (i.e., widows) represented the first

large-scale social program in this country. This may have served as the precedent for dependent coverage in today’s Social Security and other programs.

Approximately 204,000 wounded veterans came home from World War I. Veterans’ disability compensation was expanded and modernized to “... establish courses for rehabilitation and vocational training for veterans with dismemberment, sight, hearing, and other permanent disabilities.” The focus shifted from providing disability benefits to those who were incapable of work to providing services to help veterans with disabilities return to work. This policy shift reached over into the civilian population, when, by 1920, the Basic Vocational Rehabilitation Services program was established to help people with disabilities (not just veterans) attain gainful employment.

The 1944 Servicemen’s Readjustment Act, known as the GI Bill, was enacted to provide returning veterans from World War II (including those with disabilities) a college or vocational education. Benefits included educational costs, a stipend, one year of unemployment compensation, and home and business loans.

A striking social change occurred after World War II at the University of Illinois at Urbana-Champaign, where returning veterans with disabilities successfully obtained a college education. Some 30 years before the enactment of the Individuals with Disabilities Education Act and about 50 years before the ADA, these veterans showed the importance of architectural changes (accommodations) and personal assistance.

Functional Disability Measures in the NHIS-D

Functional disability measures were the most complex, as many body systems are involved, but they are also the most widely accepted and often the most useful for policy and program purposes. Functional measures included the following:

- Limitations in or the inability to perform a litany of physical activities (e.g., walking, lifting 10 pounds, reaching)
- Serious sensory impairments (e.g., inability to read newsprint, even with glasses or contact lenses; hearing and speaking impairments)
- Mental impairments (e.g., frequent depression or anxiety, frequent confusion, disorientation, or difficulty remembering) that seriously interfered with life during the past year
- Long-term care needs (e.g., needing the help of another person or special equipment for basic activities of daily living (bathing, dressing, going to the bathroom) and instrumental activities of daily living (going outside, managing money and/or medication))
- Use of selected assistive devices (e.g., scooters, wheelchairs, Braille)
- Developmental delays for children identified by a physician (e.g., physical, learning)
- Inability to perform age-appropriate activities for children under age 5 (e.g., sitting up, walking by age 3).

Questions about mental impairments were difficult to develop due to the stigma of mental illness. The NHIS-D based the question series on an earlier supplement on mental illness in conjunction with the cognitive questionnaire lab. It was found that four approaches needed to be used: symptoms (e.g., frequent depression, anxiety, confusion, disorientation, difficulty remembering, getting along with others), a diagnosis, use of prescription psychotropic drugs, and use of community mental health services. For example, some respondents would report a diagnosis of schizophrenia, but not report any symptoms, prescription drugs, or use of services. Other individuals would report use of psychotropic drugs for schizophrenia, but not report any symptoms, diagnosis, or use of services.

The final question designed to determine disability was whether a person reported that his or her mental illness seriously interfered with his or her life during the past year.

A major flaw in the mental disability measures was the lack of a question on psychosis. One was proposed: "... Do you see things other people don't see or hear things other people don't hear?" The question did not work. Non-psychotic respondents answered yes in the cognitive lab, explaining that they were color-blind, had better than 20/20 vision, or had excellent hearing.

definition of disability. Two federal disability programs illustrate the complexity we face in defining disability by specific criteria—IDEA, the Individuals with Disabilities Education Act, and the Social Security Administration's SSDI program. Besides disability, both programs employ a number of other factors in their eligibility criteria.

Measuring Disability Through Surveys

National population-based surveys are the best source of overall disability rates, profiles, and trends. Surveys collect data on a rich variety of other sociodemographic and economic characteristics so it is possible to understand the lives of people with disabilities. These data can be used to understand policy issues that cannot be examined using the often limited information in administrative program records. For example, while the Social Security Administration has data on those who receive SSDI benefits, the agency does not collect data on who might be eligible.

It is challenging to replicate disability definitions and legislative eligibility criteria in surveys, but not impossible. Perhaps the hardest part of disability survey measurement is translating federal legislative definitions into plain English survey questions that can be understood by respondents. It can be done, however, by careful work in the cognitive questionnaire labs, pretests, and statistical analyses. Statisticians also must address other critical survey issues, such as the effects of where the questions fit into the overall survey (context), mode (telephone, mail, or personal interview), and self versus proxy response.

Data sets from the large surveys discussed here are made available to researchers as public use data (stripped of personal identifiers) after confidentiality and privacy concerns are met.

Several major national population-based surveys contain items on disability. These surveys include the National Health Interview Survey (NHIS), conducted by the National Center for Health Statistics, the Surveys of Income and Program Participation (SIPP), and the American Community Survey (ACS), conducted by the U.S. Census Bureau and the replacement to the long form of the decennial census.

The purpose of the NHIS is to monitor the nation's health. The NHIS—which covers the civilian, noninstitutionalized population—was established in 1956 and is the world's longest-running health survey. Altogether, approximately 35,000 households containing about 87,500 individuals are sampled each year. Interviews are conducted in person. The major disability items on the NHIS ascertain limitation of activity (e.g., working and going to school). Besides basic health information, special supplements are collected on areas of public health concern, such as cancer screening, smoking, and mental health.

The SIPP, sponsored by the U.S. Census Bureau, examines income, labor force data, assets, and participation in and eligibility for dozens of federal programs. The SIPP, which started in 1983, has been a rich source of sociodemographic data, including disability, but now is in the process of being redesigned. The SIPP was designed as an overlapping set of longitudinal panels, each generally lasting about three years. SIPP panels ranged from 14,000 to 36,700 households representing the civilian, noninstitutionalized population. Respondents were interviewed largely through in-person interviews every four months on a basic set of questions (income and

participation in the labor force and federal programs) and on topical modules on various subjects. The disability module was asked at two points one year apart. Unfortunately, it appears that under the SIPP redesign, the disability questions will be reduced and that disability will only be obtained at one point in time. Other features, such as panel length, may be changed.

The ACS, which began in 1996, is designed to provide data every year that was previously collected by the long form of the decennial census every 10 years. The ACS (and previously the decennial census) is the only source of sociodemographic and economic data at the state and local levels. More than 3 million households participate in the ACS by mail, with follow-up personal interviews if necessary. ACS estimates can be obtained by states, counties, cities, metropolitan areas, and population groups of 65,000 or more. Starting in December 2008, the U.S. Census Bureau will release three-year estimates for population groups of 20,000 or more.

At first, the ACS used the 2000 census questions, but much statistical and methodological testing has been done. The latest version—now being collected in the 2008 ACS and scheduled to be collected in the 2009 Annual Social and Economic Supplement to the CPS—contains six separate items on hearing impairments, visual impairments, mental impairments, physical impairments, activities of daily living (self-care), and instrumental activities of daily living. In the ACS, the item on work disability has been dropped for methodological concerns. A list of the current ACS questions is contained in Disability Items from the 2008 American Community Survey.

Prevalence of Disability

Disability is widespread, but the exact number of Americans with disabilities depends on the measure or definition used.

In 2006, according to the ACS, nearly 41.3 million Americans (standard error 16,000), or roughly more than one in seven aged 5 or older, reported a disability. During 2006, estimates from the NHIS indicated that 35.8 million people of all ages reported a limitation in their usual activity due to a chronic health condition. This comes to 12.2% (standard error of 0.2%), or about one in six Americans. It is important to note that while disability prevalence increases with age, most people with disabilities are not elderly. The ACS reports that 65% of those with a disability are under age 65; the NHIS estimates that figure to be 67%.

A fair amount of variation is expected between results from the ACS and NHIS. Disability definitions differed, even though a great deal of overlap exists in the concepts—if not the specific questions—and each had a different design and data collection mode. The ACS focused on broad categories of disabilities (i.e., physical, mental, sensory, self care, going outside, and the ability to work). The NHIS measures disability as limitations in the ability to carry out usual activities by age group (i.e., going to school, play, work, self care).

Disability estimates among working-age adults from the 1994 National Health Interview Survey Supplement on Disability (NHIS-D) yielded four figures, depending on which broad measure was used. These measures, based on about 100 questions, were functional, work disability, perceived as having a disability as defined in the ADA, and receipt of

Social Security Disability Insurance (SSDI)

The SSDI program is the largest disability program in the world and the primary program for working-age adults in this country. SSDI and Social Security retirement are funded by the Federal Insurance Contributions Act, or FICA, payroll tax, paid by employers and employees.

The SSDI definition of disability is “the inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment which can be expected to result in death or to last for a continuous period of not less than 12 months.”

The SSDI definition of disability is “all or nothing.” There is no partial disability, as under Workers’ Compensation, nor are there degrees of disability, as for veterans’ programs. Eligibility is achieved through a five-step sequential process based on coverage under Social Security, disability, employment, education, age, and vocational factors. Those who are denied SSDI have the right to appeal the decision under certain circumstances. After 24 months of SSDI benefits, Medicare is extended to SSDI beneficiaries, even though they are under age 65. The Social Security system pays benefits to two additional categories of people with disabilities: disabled widow(er)s aged 50 to 59 and adults aged 18 or older who were disabled in childhood (ADC) and who have

at least one parent who receives (or received, if deceased) Social Security retirement or disability benefits.

The average age for disabled workers in December of 2005 was 51.9 years for men and 51.7 years for women. Early retirement under Social Security can be obtained starting at age 62. In 2002, the leading causes of disability for disabled workers were mental disorders other than mental retardation (e.g., schizophrenia, severe depression) at 28.1%, musculoskeletal system and connective tissue disorders (e.g., bad back) at 23.9%, diseases of the circulatory system at 10.1%, diseases of the nervous system and sense organs (e.g., multiple sclerosis, traumatic brain injury, epilepsy) at 9.6%, and mental retardation at 5.2%. Disabled widow(er)s had a similar pattern of leading disability causes. However, among ADC, the leading causes were mental retardation at 43.6%, other mental disorders besides retardation at 13.0%, and diseases of the nervous and sense organs at 8.6%.

In December of 2007, slightly more than 7.1 million disabled workers received a monthly average of \$1,004 in SSDI benefits. As of December of 2007, nearly 225,000 disabled widow(er)s received benefits, and slightly fewer than 795,000 received benefits as ADC. Altogether, more than 8.1 million workers, survivors, or dependents received Social Security benefits on the basis of their own disability.

disability program benefits. About 25.7 million working-age adults reported a functional disability (e.g., climbing stairs, seeing); 16.9 million reported a limitation or inability in work; 11.1 million reported that they perceived themselves or others perceived them as having a disability; and 9.1 million reported receiving disability program benefits from SSDI, Supplemental Security Income (SSI), and/or the Veterans' Administration (VA) programs. Discussion of these broad measures is presented in Functional Measures in the NHIS-D.

Future Needs

Disability measurement is constantly evolving as society changes and medical and rehabilitation advances are made. Perhaps the greatest challenge is posed by the large number of veterans returning with disabilities from the wars in Iraq and Afghanistan. As of December 18, 2008, the Department of Defense reported that 4,211 members of the military were killed in Iraq and 558 in Afghanistan. The ratio of troops who survive their wounds is the greatest of any American war. The number wounded was 30,879 in Iraq and 2,605 in Afghanistan as of December 18, 2008. We do know that, besides physical wounds, many returning veterans have either post traumatic stress disorder (PTSD) or traumatic brain injury (TBI)—two challenging disability measures.

As of December 31, 2007, 2.9 million veterans received benefits from the VA Disability Compensation program, and 7.8 million were enrolled in the VA Health Care System during fiscal year 2007. These numbers will grow as more veterans return from Iraq and Afghanistan.

It is too early to see what changes will occur as a result of these wars to veterans' disability programs, nonveterans' disability programs, and society, but this is clearly an area where additional work is needed to improve measurement as a way to improve the treatment and support for this new group of disabled Americans.

Next Steps

There are four major areas requiring attention so we can better examine our disability policy and programs to improve the lives of Americans with disabilities.

Work Disability – The U.S. Census Bureau announced that the work disability item would be dropped from the ACS and the planned 2010 census due to methodological concerns. This is unfortunate. The ability to work is the central focus of most federal disability programs serving the working-age population and is specifically cited as an example of a major life activity in the ADA-AA. Previously, the work disability question has been considered and tested within the context of

Special Education: The Individuals with Disabilities Education Act (IDEA)

The IDEA is divided into Part B, which serves children aged 3 through 21, and Part C, serving children under age 3. The purpose of the IDEA, enacted in 1975, is to make special education and related services available to children with disabilities so they can receive a free and appropriate public education to prepare them for employment and independence as adults. Under Part C, early intervention services are provided to prepare children for an education and eventual independence when they reach adulthood. Not all children with disabilities need special education services.

In the fall of 2005, approximately 6.8 million children aged 3 through 21 received special education and related services under Part B of the IDEA. Disability in Part B is defined as having one of the following 13 conditions: mental retardation, hearing impairment (including deafness), speech



or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, specific learning disabilities, traumatic brain injury, multiple disabilities, deaf-blindness, autism, other disabilities (e.g., asthma, atten-

tion deficit disorder), and developmental delay (for ages 3–9 at state discretion). Individual states establish criteria for each of the 13 categories.

There is variation among states and localities in how Part B is defined. Children are evaluated by an educational team, specific to particular schools and type of disability. An individualized education plan (IEP) is typically prepared by a multidisciplinary team, tailored to the needs of each child, and periodically reviewed with the child's parents. The IEP changes over time, as children mature and learn.

Part C of IDEA, known as the Early Intervention Program for Infants and Toddlers with Disabilities, served nearly 300,000 children during the fall of 2006. Infants are under age 1, and toddlers are between the ages of 1 and 3.

Part C is a federal grant program to states serving infants and toddlers with disabilities and their families. The purpose of Part C services is to enhance the development of infants and toddlers with disabilities, reduce the need for Part B, and help families meet the needs of their very young children with disabilities. Infants and toddlers served by Part C are defined as either having a developmental delay or a condition with a high probability in a developmental delay based on diagnostic medical measures. Developmental delays include cognitive, physical, communication, social or emotional, or adaptive functioning. Similar to Part B, eligibility for the disability categories is determined by states.

Altogether, in the fall of 2006, approximately 2.4% of the population under age 3 was served by Part C. Slightly less than half (46%) of those served were under the age of 2.

the entire disability series. Yet, work disability is also an aspect of employment. Could the U.S. Census Bureau look at work disability as an employment item? This may be a better fit for methodological concerns.

Second, disability is subjective and not easily verified through methodological work. It appears that participants in the cognitive questionnaire lab reported no limitations in work, even though they were collecting disability benefits. More program knowledge is needed. The SSDI and disability portion of the SSI programs allow and encourage employment and rehabilitative efforts for those receiving benefits (e.g., Ticket to Work).

Mental Impairments – The emphasis, as described in the U.S. Census Bureau report “Evaluation Report Covering Disability” was that methodological work was geared toward the elderly in terms of cognitive impairments. Clearly, this focus needs to be expanded to include returning veterans with PTSD and TBI.

Instrumental Activities of Daily Living – The IADL item was dropped from the ACS. IADLs—which include shopping, using the telephone, and managing money and/or medication—typically refer to activities that involve social interaction and more sophisticated self care. IADLs tend to require more mental and cognitive skills. While in the past, methodological research on IADLs has focused on the elderly, it is worth re-examining these items in light of returning veterans.

ADA-AA – On January 1, 2009, the ADA-AA, which now includes specific examples of major life activities in the law, takes effect. Although many examples appear in the ACS and other surveys, many do not—the ability to work being the most critical. ADA-AA major life activities not typically included in surveys are manual tasks, eating, sleeping, standing, bending, speaking, breathing, learning, thinking, communicating, and working. Methodological work needs to be done to measure progress of the ADA-AA.

Methodological Work – The U.S. Census Bureau is to be commended for its methodological work performed on the ACS and its coordination with other federal agencies. Because definitions of disability are constantly evolving, methodological work and analyses must continue to evolve. Space and time constraints on surveys are real concerns. For example, if one question identifies disability for 90% of a certain category and 10 questions identify 97%, we could analyze who is in the 7% and potentially drop nine questions. Even though the NHIS-D is old, the 100+ questions can be analyzed for overlaps and more efficient disability questions can be designed. Data from other surveys could be used, as well.

Cooperation is required. No one federal program (or agency) is responsible for disability, and no single federal agency is responsible for disability statistics. Disability is too important to ignore. Creative work needs to be done by statisticians, federal agencies, academia, and advocacy groups. ■

Further Reading

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Disability Items from the 2008 American Community Survey

The full questionnaire can be found at www.census.gov/acs/www/Downloads/SQest08.pdf.

The disability questions begin with question 16 and are asked of each person listed at the address. If the respondent is 5 years or older, then question 17 is asked. Otherwise, question 17 is skipped for that respondent. Question 18 is asked of those aged 15 or older. The answer to each question is yes or no.

16. a. Is this person deaf or does he/she have serious difficulty hearing?

16. b. Is this person blind or does he/she have serious difficulty seeing, even when wearing glasses?

17. a. Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?

17. b. Does this person have serious difficulty walking or climbing stairs?

17. c. Does this person have difficulty dressing or bathing?

18. Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone, such as visiting a doctor’s office or shopping?

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