

DISABILITY: FEDERAL SURVEY DEFINITIONS, MEASUREMENTS, AND ESTIMATES**Introduction**

Disability definitions are important for federal and state policies, programs, and planning, as well as for individuals with disabilities and their families. How federal and state programs define disability determines who will qualify for and how they will receive benefits from Social Security, Medicare, Medicaid, and state and local programs.

Because providing services to people with disabilities places heavy demands on service delivery and fiscal resources, reliable estimates of the number of people with disabilities are critical for federal and state agencies. The definition of disability ultimately determines the costs of the various programs.

The definition of disability also determines who will be protected from disability-based discrimination. Federal disability rights laws, such as the Americans with Disabilities Act of 1990 (ADA), define the types of impairments that qualify as a “disability” and warrant regulatory protection from discriminatory treatment.

This report examines how four national surveys, sponsored by the federal government, define and measure a critical aspect of disability, namely whether the disability limits a person’s ability to perform everyday life activities. The four surveys explored are the American Community Survey, the Survey of Income and Program Participation, the National Health Interview Survey, and the National Long-Term Care Survey.¹ The report begins with a brief discussion of the ADA and how it defines disability. Next, the definitions, measurements, and prevalence of disability

as it limits everyday life activities are examined, using data for the most recent year available, in the four surveys.* These limitations are explained in more detail below. Finally, the report concludes by discussing the sources of some of the variation in disability data and by illustrating how broader definitions of disability yield higher prevalence rates. For comparability, data are reported for persons of all ages and for persons age 65 and older.²

Americans with Disabilities Act

The Americans with Disabilities Act (ADA) is a civil rights law for people with covered disabilities. The ADA prohibits discrimination on the basis of disability in employment, public services and facilities, transportation, and in telecommunications, and by state and local governments. The ADA protects individuals with disabilities or individuals associated with someone with a disability.³

The ADA defines disability as a physical or mental impairment that substantially limits one or more major life activities, a history or record of such an impairment, or a perception by others as having such an impairment.⁴ Although the ADA definition does not define major life activities, the term generally refers to seeing, hearing, speaking, walking, breathing, performing manual tasks, learning, caring for oneself, and working.⁵

Rulings by the Supreme Court and lower courts have narrowed the legal standards or definitions by which people are qualified to receive legal protections for their disabilities

* Table 5 at the end of this report compares the measures and prevalence of disability across the four surveys.

under the ADA. According to the National Council on Disability, these court rulings have served to bar people who were previously considered to have a covered disability from litigating under the ADA.⁶

In addition to the ADA, other laws provide protections for persons with disabilities with respect to housing, education, and voting, as well as programs, employment, and contracts involving the federal government.⁷

Disability in National Survey Research

Each of the four surveys includes broad measures of disability, as well as measures of limitations in everyday life activities, including activities of daily living (ADLs) and instrumental activities of daily living (IADLs). The surveys also distinguish the degree of these limitations by level of need (e.g., “has difficulty performing,” “needs help,” or “receives help”). The ADL and IADL measures include some or all of the following activities:

- ADLs
 - Bathing
 - Dressing
 - Eating
 - Toileting
 - Getting in or out of bed or a chair
 - Getting around inside the home
- IADLs
 - Preparing meals
 - Going outside the home
 - Managing money
 - Using the telephone
 - Taking prescription medicines
 - Doing housework

American Community Survey

The American Community Survey (ACS) was designed to collect more frequently the information contained in the long form questionnaire of the decennial census.⁸ The ACS is an annual survey with a nationally representative sample of approximately 700,000 households from the civilian noninstitutional population. It includes measures of the number of people with a disability at the national and state levels, and assists federal, state, and local agencies in planning for services and developing programs for persons with disabilities.⁹

Disability is defined in the ACS as any long-lasting condition, such as blindness, or a condition lasting six months or more causing one or more limitations in functional activities, mental or cognitive abilities, self-care, mobility, or the ability to work at a job. The ACS includes six items on disability:¹⁰

1. Does this person have any of the following long-lasting conditions:
 - a. Blindness, deafness, or severe vision or hearing impairment?
 - b. A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?
2. Because of a physical, mental, or emotional condition lasting six months or more, does this person have any difficulty in doing any of the following activities:
 - a. Learning, remembering, or concentrating?
 - b. Dressing, bathing, or getting around inside the home?
 - c. (If age 16 and older) Going outside the home alone to shop or visit a doctor’s office?

- d. (If age 16 and older) Working at a job or business?

In 2002, according to the ACS, one in five persons age 65 and older had limitations in mobility or self-care. In addition, persons 65 and older and persons of all ages were two times more likely to report difficulty with mobility outside the home than with self-care inside the home. Table 1 reports the number and percentage of people with these limitations both for all ages and for those age 65 and older.

Table 1. ACS: Activity Limitations, by Age, 2002		
	Numbers in Thousands	
	All Ages	Age 65+
Total Population	280,717	33,565
Has Difficulty with Self-Care (Age 5+) ¹	6,720 2.4%	3,075 9.2%
Has Difficulty with Mobility (Age 16+) ²	13,374 4.8%	6,174 18.4%
Has Difficulty with Self-Care or Mobility ³	15,257 5.4%	6,742 20.1%

¹Refers to question 2b; ²Refers to question 2c; Source: AARP Public Policy Institute analysis of 2002 ACS.

Survey of Income and Program Participation

The Survey of Income and Program Participation (SIPP), conducted by the U.S. Census Bureau, is a national household panel survey of the civilian noninstitutional population that began in 1984. A relatively consistent set of questions measuring disability was asked in 1990, 1991-1992, 1993, 1994-1995, and 1997.

SIPP provides an extensive set of age-related disability questions: for persons age six and older, disability questions cover limitation in functional activity, ADLs, learning disabilities, and use of assistive devices such as canes, crutches, walkers,

and wheelchairs; for persons age 15 and older, questions also cover IADLs and mental and emotional conditions; persons age 16 and older are queried about their ability to work at a job.¹¹

SIPP identifies individuals as having a disability if they have experienced *any* of the following conditions for six or more months:¹²

1. Used a wheelchair, cane, crutches, or walker
2. Had difficulty performing one or more functional activities (seeing, hearing, speaking, lifting/carrying, using stairs, walking, or grasping small objects)
3. Had difficulty with one or more ADLs, including getting around inside the home, getting in or out of bed or a chair, bathing, dressing, eating, and toileting
4. Had difficulty with one or more IADLs, including going outside the home, keeping track of money and bills, preparing meals, doing light housework, taking prescription medicines in the right amount at the right time, and using the telephone (age 15 and older)
5. Had one or more specified conditions (a learning disability, mental retardation or another developmental disability, Alzheimer’s disease, or some other type of mental or emotional condition)
6. Had any other mental or emotional condition that seriously interfered with everyday activities (frequently depressed or anxious, trouble getting along with others, trouble concentrating, or trouble coping with day-to-day stress)
7. Had a condition that limited the ability to work around the house
8. If age 16 to 67, had a condition that made it difficult to work at a job or business

9. Received federal benefits based on an inability to work

According to the 1997 SIPP, approximately one in six persons age 65 and older reported needing help with or being unable to perform ADLs or IADLs.¹³ Table 2 shows the numbers and percentages of all persons and persons age 65 and older who needed help or were unable to perform ADLs or IADLs.

	Numbers in Thousands	
	All Ages	Age 65+
Total Population	267,665	32,064
Needs Help with ADLs ¹	4,276 1.6%	2,304 7.2%
Needs Help with IADLs (Age 15+) ²	9,444 3.5%	5,204 16.2%
Needs Help with ADLs or IADLs	10,076 3.8%	5,339 16.7%

¹Persons needing help with or unable to perform activities in question 3; ²Persons needing help with or unable to perform activities in question 4.
Source: McNeil, Jack, *Americans With Disabilities, 1997*, Current Population Reports, P70-73, U.S. Census Bureau, February 2001.

National Health Interview Survey

The National Health Interview Survey (NHIS) is a national household interview survey of the civilian noninstitutional population. Conducted annually since 1957 by the National Center for Health Statistics, the main objective of the NHIS is to monitor the health of the United States population through the collection and analysis of data on a broad range of health topics.¹⁴

In the NHIS, disability refers to any long-term reduction (i.e., limitation) in a person’s life activities as a result of a chronic condition.¹⁵ More specifically, activity *limitation* refers to a long-term reduction (three months or more) in a person’s capacity to perform the average

kind or amount of activities for his or her age group as a result of a chronic condition.

Age-related disability questions cover ADLs (personal care needs) for those age three and older, IADLs (routine needs) and work limitations for those age 18 and older, and limitations in walking and remembering for all age groups.¹⁶

According to the NHIS, more than one in eight individuals age 65 and older needed help with ADLs or IADLs in 2002. Table 3 reports on all persons and persons age 65 and older needing help with ADLs and IADLs due to chronic conditions.

	Numbers in Thousands	
	All Ages	Age 65+
Total Population	278,789	33,060
Needs Help with ADLs (Age 3+)	3,772 1.4%	1,971 6.0%
Needs Help with IADLs (Age 18+)	7,207 2.6%	3,945 11.9%
Needs Help with ADLs or IADLs	8,103 2.9%	4,236 12.8%

Source: AARP Public Policy Institute analysis of 2002 NHIS.

National Long-Term Care Survey

The National Long-Term Care Survey (NLTC) is a national longitudinal survey of persons age 65 and older. Sponsored by the federal government, the NLTC provides a nationally representative sample of the entire older population residing both in communities and institutions. (In this report, the NLTC is the only survey that includes persons residing in institutions and samples only persons age 65 and older.) The survey derives its sample from Medicare beneficiary files and has a specific emphasis on functional impairment among older persons.¹⁷ The NLTC was fielded in 1982, 1984, 1989, 1994, and 1999.

In the NLTCS, a person is considered to have a disability if he or she receives help from another person to perform any ADLs or IADLs or is institutionalized in a nursing home, and if any of these conditions have lasted or are expected to last 90 days or more.¹⁸ In addition, respondents with disabilities are asked if they use special equipment or assistive devices to perform activities, and if someone provides standby help to perform activities.

According to the NLTCS, nearly one in five people age 65 and older received help with ADLs or IADLs in 1999. Among noninstitutionalized persons receiving help, approximately 68 percent received assistance with ADLs. Table 4 reports the number and percent of people age 65 and older in communities and institutions receiving help with ADLs and IADLs.¹⁹

Table 4. NLTCS: Activity Limitations and Institutionalization, Age 65 and Older, 1999	
	Numbers in Thousands
	Age 65+
Total Population ¹	34,459
Noninstitutional Receiving Help with ADLs or IADLs	5,124 14.9%
Receives Help with ADLs	3,419 9.9%
Receives Help with IADLs Only	1,706 5.0%
Persons in Institutions ²	1,661 4.8%
Total Receiving Help with ADLs or IADLs	6,785 19.7%
¹ Includes the institutional population; ² Persons in nursing homes and some persons receiving help with ADLs or IADLs in assisted living facilities. Source: Urban Institute analysis of 1999 NLTCS.	

Summary and Conclusion

Many federal and state government programs and budgets depend on reliable estimates of the number of persons with

disabilities. Such measurements are also important for service planning. State agencies such as Area Agencies on Aging are particularly dependent on Census disability data to plan for services.²⁰ The definition of disability also determines whether individuals are eligible for various programs.

The numbers presented in the tables above demonstrate the variability in disability data. The definitions and measurement of disability are different in all of the surveys highlighted in this report. Some of the surveys include broad measures such as the criteria outlined in the SIPP. All of the surveys use measures that focus on everyday life activities, including ADLs and IADLs, and all of the surveys (with the exception of the ACS) query whether assistance is needed or received to perform these activities. Specifically, the NLTCS asks respondents if they “received help” to perform the activity, the SIPP and NHIS ask if respondents “needed help,” while the ACS asks about “difficulty” in performing certain activities.

This report reviewed measures of disability that focus on persons who are limited in, need help with, or receive help with ADLs and IADLs. If broader measures of disability are used, results are much different. To illustrate, in the 2002 ACS, about one in seven persons of all ages meet at least one of the disability criteria, as do more than two in five persons age 65 and older. Similarly, nearly 20 percent of persons of all ages and more than half of persons age 65 and older reported experiencing at least one of the nine conditions outlined in the SIPP disability criteria. Using the broader disability measure in the NHIS, approximately one in eight individuals of all ages and more than one in three persons age 65 and older had a disability in 2002. The NLTCS is the only survey in this report that specifically

emphasizes functional impairment—ADLs and IADLs.

Besides discrepancies in how disability measures are constructed and fielded across surveys, many surveys differ in their sample populations. The ACS, SIPP, and NHIS are general population surveys and include smaller samples of the older population; in contrast, the NLTCs focuses exclusively on persons age 65 and older. Moreover, the three general population surveys provide more information on individuals with physical limitations and less detail on persons with cognitive or mental limitations. Similarly, people in institutions such as nursing homes constitute an important “frail” population that is not included in the ACS, SIPP, and NHIS, each of which surveys only the civilian noninstitutional population.

The surveys also differ in their consideration of the length of time an individual has had or is expected to have a disability or conditions causing a disability. The ACS and SIPP require individuals to have disabling conditions lasting six months or more. In contrast, the NHIS and NLTCs require these conditions to last three months (or 90 days) or more.

In addition to differences across surveys, differences within surveys occur over time with revisions to questions that measure disability—sometimes as a result of court rulings that may narrow the legal definitions of a person with a disability.²¹ Thus, continually modified disability questionnaires can make it difficult to track disability trends.

Notwithstanding changing and varying definitions and measurements, several studies document some decline in the overall

rate of disability.²² However, persons have a greater chance of developing disabilities as they age. The increased longevity of Americans, along with the rise in overall population, means that the total *number* of individuals with disabilities will increase.

Disability trends provide insight into factors that help drive future changes in service delivery and program spending. The trend in declining disability rates could have important implications for Medicaid spending and for the long-term fiscal solvency of the Social Security and Medicare programs.²³ While such declines in disability rates may ameliorate financing challenges, they are unlikely to be a panacea.²⁴

To assist policymaking and program planning, many researchers and policymakers have called for greater consistency and coordination across major national surveys. The National Council on Disability, the Assistant Secretary for Planning and Evaluation, and the National Institute on Aging have noted the lack of consistent disability definitions and measurements, the wide range of estimates of persons with disabilities, and the lack of reconciliation between disability data sources.²⁵ Coordinated efforts among government agencies could reconcile major discrepancies and facilitate greater consistency in disability definitions and measures used across major national surveys.

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- ¹ The four surveys discussed in this report are widely cited for disability data. There are other major national surveys that include disability measures such as the Medical Expenditure Panel Survey, the National Health and Nutrition Examination Survey, the Current Population Survey, and the Medicare Current Beneficiary Survey.
- ² The National Long-Term Care Survey does not include persons under age 65.
- ³ U.S. Department of Justice, *A Guide to Disability Rights Laws*, August 2001.
- ⁴ Ibid.
- ⁵ See the U.S. Department of Justice <www.usdoj.gov/crt/ada/qandaeng.htm>.
- ⁶ National Council on Disability (NCD), "National Disability Policy: A Progress Report, December 2000-December 2001," July 2002 <www.ncd.gov/newsroom/publications/pdf/progressreport_07-26-02.pdf> [hereinafter *National Disability Policy*].
- ⁷ Ibid. *A Guide to Disability Rights Laws*
- ⁸ <www.census.gov/acs/www/SBasics/What/What1.htm>
- ⁹ Uses for questions in the ACS are presumably similar to uses for questions in the long form questionnaire of the Decennial Census. See U.S. Census Bureau, *Uses for Questions on the Census 2000 Forms*, March 1998.
- ¹⁰ See questions 16 and 17 in the Census 2000 long form <www.census.gov/dmd/www/pdf/d02p.pdf>.
- ¹¹ U.S. Census Bureau, "Census Bureau Data on Disability," <www.census.gov/hhes/www/disable/intro.html>.
- ¹² McNeil, Jack, *Americans With Disabilities, 1997*, Current Population Reports, P70-73, U.S. Census Bureau, February 2001.
- ¹³ Ibid.
- ¹⁴ <<http://www.cdc.gov/nchs/about/major/nhis/hisdesc.htm>>
- ¹⁵ The NHIS also measures activity restriction, a relatively short-term reduction (less than three months) in a person's performance of activities below his or her normal capacity, usually as a result of acute conditions. Adams, PF, Hendershot, GE, and Marano, MA, "Current Estimates From the National Health Interview Survey, 1996," *Vital and Health Statistics*, Series 10, No. 200, October 1999.
- ¹⁶ The NHIS queried respondents about their limitations in personal care (ADL) and routine needs (IADL) starting in 1997. Blackwell, DL and Tonthat, L. "Summary Health Statistics for the U.S. Population: National Health Interview Survey, 1997," *Vital and Health Statistics*, Series 10, No. 204, March 2002.
- ¹⁷ <<http://cde.duke.edu/>>
- ¹⁸ Manton, Kenneth G. and Gu, XiLiang, "Changes in the Prevalence of Chronic Disability in the United States Black and Nonblack Population Above Age 65 from 1982 to 1999," *PNAS*, Vol. 98, Issue 11, 6354-6359, May 22, 2001 [hereinafter *Chronic Disability*].
- ¹⁹ Ibid.
- ²⁰ Calsyn, Robert J., et al., "Should Disability Items in the Census Be Used for Planning Services for the Elderly?" *The Gerontologist*, Vol. 41, No. 5, 583-588, October 2001.
- ²¹ Ibid. *National Disability Policy*.
- ²² Several studies have documented declines in overall disability rates (any limitation): see Freedman, Vicki A., et al., "Recent Trends in Disability and Functioning Among Older Adults in the United States: A Systematic Review," *JAMA*, Vol. 288, No. 24, Dec. 2002; Cutler, David M., "Declining Disability Among the Elderly," *Health Affairs*, Vol. 20, No. 6, 2001; Manton, Kenneth G. and Gu, XiLiang, *Chronic Disability*; Schoeni, Robert F., et al., "Persistent, Consistent, Widespread, and Robust? Another Look at Recent Trends in Old-Age Disability," *Journal of Gerontology: Social Sciences*, Vol. 56B, No. 4, 2001; Waidmann, Timothy A. and Korbin Liu, "Disability Trends Among Elderly Persons and Implications for the Future," *Journal of Gerontology: Social Sciences*, Vol. 55B, No. 5, 2000; Freedman, Vicki A. and Martin, Linda G., "Understanding Trends in Functional Limitations Among Older Americans." *American Journal of Public Health*, Vol. 88, No. 10, Oct. 1998; Crimmins, Eileen M., et al., "Further Evidence on Recent Trends in the Prevalence and Incidence of Disability Among Older Americans From Two Sources: LSOA and the NHIS," *Journal of Gerontology: Social Sciences*, Vol. 52B, No. 2, 1997.
- ²³ Ibid. *Chronic Disability*.
- ²⁴ See also Cutler, David M., "The Reduction in Disability Among the Elderly," *PNAS*, Vol. 98, Issue 12, 6546-6547, June 5, 2001.
- ²⁵ National Council on Disability, *National Disability Policy*; National Institute on Aging-National Bureau of Economic Research, "Workshop Summary: Disability Decline: What We Know; and What We'd Like to Know," November 30, 2001; Assistant Secretary for Planning and Evaluation, "Disability Data for Disability Policy: Availability, Access and Analysis," August 1995 <<http://aspe.hhs.gov/daltcp/reports/resagdd.htm>>.

Table 5. Summary of Activity Limitation Measures and Disability Prevalence in Four National Surveys

Data Source	Sample Population	Disability Duration	Measures	Level of Need	Population	% with Limitations in Everyday Life Activities
American Community Survey (ACS)	U.S. Civilian Noninstitutional Population	6 months or more	<ul style="list-style-type: none"> Self-Care Mobility 	<ul style="list-style-type: none"> Has difficulty with self-care/mobility 	<p>2002</p> <ul style="list-style-type: none"> Total All Ages = 280.7 million Total 65+ = 33.5 million 	<p>2002</p> <ul style="list-style-type: none"> All Ages = 5.4% 65+ = 20.1%
Survey of Income and Program Participation (SIPP)	U.S. Civilian Noninstitutional Population	6 months or more	<ul style="list-style-type: none"> ADLs IADLs 	<ul style="list-style-type: none"> Needs help with/Unable to perform ADLs/IADLs 	<p>1997</p> <ul style="list-style-type: none"> Total All Ages = 267.7 million Total 65+ = 32.1 million 	<p>1997</p> <ul style="list-style-type: none"> All Ages = 3.8% 65+ = 16.7%
National Health Interview Survey (NHIS)	U.S. Civilian Noninstitutional Population	3 months or more	<ul style="list-style-type: none"> ADLs IADLs 	<ul style="list-style-type: none"> Needs help with ADLs/IADLs 	<p>2002</p> <ul style="list-style-type: none"> Total All Ages = 278.8 million Total 65+ = 33.1 million 	<p>2002</p> <ul style="list-style-type: none"> All Ages = 2.9% 65+ = 12.8%
National Long-Term Care Survey (NLTC) (NLTC)	U.S. Population Age 65 and Older	90 days or more; or institutionalized in a nursing home	<ul style="list-style-type: none"> ADLs IADLs 	<ul style="list-style-type: none"> Receives help with ADLs/IADLs Receives stand-by help Uses assistive device 	<p>1999</p> <ul style="list-style-type: none"> Total 65+ = 34.5 million (includes institutional) 	<p>1999</p> <ul style="list-style-type: none"> 65+ = 19.7% > 14.9% community > 4.8% institutional