

Disability in America

*by Vicki A. Freedman, Linda G. Martin,
and Robert F. Schoeni*

*Nearly 50 million
Americans have
a disability.*

*Disability affects
young and
old alike.*

*Late-life disability
has declined in
recent years.*

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About the Authors

***Vicki A. Freedman** is director of Polisher Research Institute of the Madlyn and Leonard Abramson Center for Jewish Life (formerly Philadelphia Geriatric Center). Freedman is a population epidemiologist with training in both the demography and epidemiology of aging. Her research focuses on the implications of population aging for U.S. public policy, with an emphasis on disability and long-term care issues.*

***Linda G. Martin** is a scholar in residence at the Institute of Medicine. While writing this Population Bulletin, she was president of the Population Council. Her current research focuses on health trends among the elderly in Asia and the United States. Trained as an economist and demographer, she has published extensively on aging in Asia.*

***Robert F. Schoeni** is senior associate research scientist at the Institute for Social Research, and associate professor of economics and public policy, the University of Michigan. Schoeni is an economist and demographer who studies the economics of aging, labor economics, and welfare and poverty policy. From 1998 to 1999, he served as a senior economist at the Council of Economic Advisers, Executive Office of the President of the United States.*

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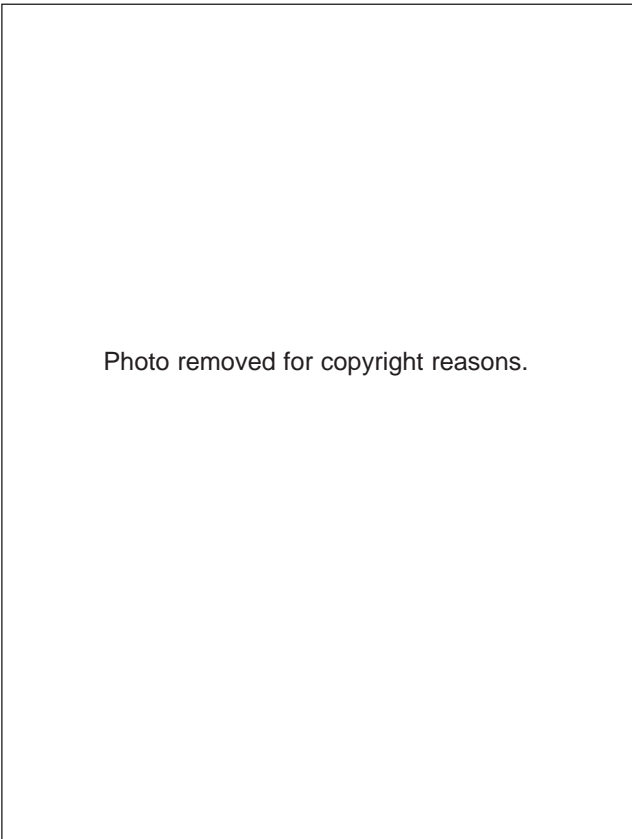
Disability in America

by Vicki A. Freedman, Linda G. Martin, and Robert F. Schoeni

Nearly 50 million Americans—one of every five people ages 5 and older—have a disability, according to the 2000 U.S. Census. That number is expected to grow over the next 25 years as the U.S. baby-boom generation enters the ages most prone to disabling injuries and illnesses. Participation in society to the fullest extent possible by people with disabilities, whether young or old, has been a goal of U.S. policies and programs, but translating this aim into reality requires confronting a series of challenges.

One major challenge involves identifying the population with disability. “Disability” refers to an individual’s capacity to function within a given social and environmental context. An illness or injury may result in disability for one activity but not another, or for one occupation but not another. A home or work environment can be created or modified to help an individual with disabilities to function more independently. Moreover, disability is not static: A person can develop a short-term disability—for example, due to a fall or stroke—and then recover.

The complexity of the term has given rise to various definitions and indicators, and there is no accepted gold standard for counting the population with disability. The U.S. Census estimates offer a broad overview of the extent of limitation and disability across the nation; nationally repre-



Susie Fitzhugh

Disability affects both young and old. According to the 2000 U.S. Census, 2.6 million children ages 5 to 15 have a limitation or disability.

sentative, well-designed surveys and studies have produced differing but equally credible estimates.

A related challenge involves projecting the number of people who will have a disability and need support in coming decades. Such projec-

There is a growing array of support systems to help people with disabilities.

tions involve debates among experts about the extent to which life expectancy will rise, and whether the risks of developing and recovering from a disability are increasing or decreasing. Over the last few decades, disability appears to have diminished among older people; but it is not clear whether younger people have experienced a similar improvement. At this time, reasons for the decline in disability are not clear, adding to the difficulty in forecasting trends.

The numbers are important because the costs of support systems—both human and technological—for people with disabilities are substantial. At the same time, the benefits of enabling all who live in the United States—irrespective of age or ability—to participate in society are potentially enormous. Disability is associated with reduced workforce participation and related economic consequences. Although the elderly are more likely than the young to develop disabilities, the majority of Americans and the majority of people with disabilities are of working age. About equal numbers of people with disabilities are men and women. Minorities, the very old, the poor, people who are divorced or separated, and people living in the South have an especially high rate of disability.

There is a growing array of support systems to help people with disabilities participate in school, work, and leisure activities, and for older people to maintain independent living. Technological innovations are expanding and may support some of the tasks that now require human assistance. A variety of federal assistance programs exist for children, adults, and the elderly. Newer policies and programs emphasize legal protections for individuals with disabilities and the removal of barriers to participation. These policies require, among other things, changes to entryways and the inside of public buildings, and they promote the use of technological aids by people with disabilities. The goal of such programs is to allow all members of society, irrespective of age or ability,

to participate in a meaningful way in American society.

This *Population Bulletin* provides a broad overview of disability in America in the 21st century. It presents a review of basic concepts and measures along with the latest statistics depicting the demography of disability and recent U.S. trends. It also describes support systems and supportive living environments for individuals with disabilities as well as current federal programs and policies. Understanding disability is an important step in ensuring that Americans of all ages and abilities have the opportunity to participate fully in society.

Concepts and Measures

There are several classification schemes and frameworks for defining disability, but there is no gold standard for measurement.¹ Disability is not an attribute of an individual. Instead, disability exists when an individual's physical, cognitive, or psychological capacity does not fit the demands of a given task within a specific environment. In some instances, the term disability refers to how a task could be performed in a specific environment *without* technological or human assistance; in other cases, disability refers to a person's ability to function with such support. A child who has a hearing impairment, for example, may have difficulty demonstrating mastery of material in school without technological aids, but may be able to successfully participate with the aids. An adult with a spinal cord injury may have difficulty working without assistance, but may succeed in employment with a wheelchair, adaptive computing devices, or assistance from a job coach. Or an older adult may need assistance bathing in a bathtub but not in a walk-in shower equipped with grab bars and a seat. In each of these examples, the individual has an underlying disability but is able to participate in life activities with assistance.

Evolving Perspectives

Despite the lack of consistent terminology or measurement, several overarching perspectives have emerged that guide efforts to enumerate the extent of disability in the U.S. population. Over time these perspectives have evolved from a strictly medical model that emphasizes medical conditions or organ impairment to a model that recognizes the social and environmental context of disability and the importance of participation.² The different perspectives are important to consider because they lead to fundamentally different ways of thinking about, measuring, and classifying disability in the population. For instance, the classic medical model leads one to focus on underlying health problems; the functional limitation model distinguishes the role of the environment from underlying health; and the most recent classification system, the International Classification of Functioning, Disability and Health (ICF), links health conditions to participation in society.

Classic Medical Model

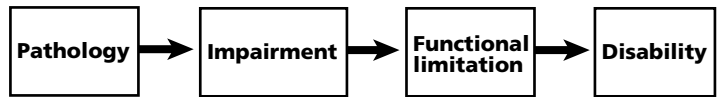
In the classic medical model, the characteristics of the person, rather than the environment, are salient in defining disability. Measures rooted in this model classify individuals according to the underlying biological or anatomical cause. For example, special-education data classify children according to impairment categories (visual, hearing, speech or language, learning, orthopedic, mental health, autism, and traumatic brain injury). This approach leads one to focus on cure or rehabilitation related to a health problem.

Nagi's Functional Limitation Model

The importance of the social context of disability was made explicit by Saad Nagi and others³ in a model that depicts disability as a four-stage process: first, *pathology*, or compromised organ function due to chronic or acute conditions or injury; second, *impairment*, or the loss of system func-

Figure 1

Nagi's Functional Limitation Model



Source: Adapted from S.Z. Nagi, "Disability Concepts Revisited: Implications for Prevention," in *Disability in America: Toward a National Agenda for Prevention*, ed. A.M. Pope and A.R. Tarlov (1991): 309-27.

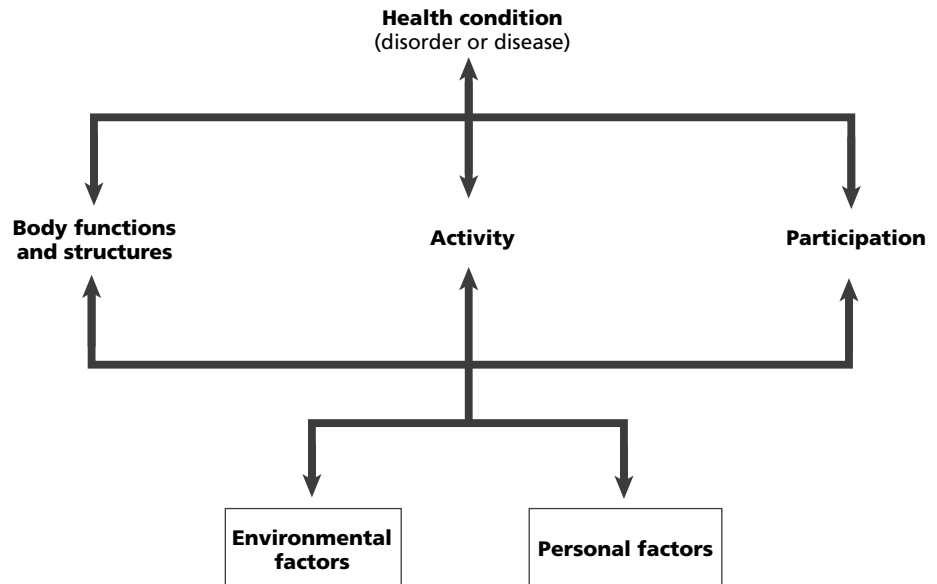
tion; third, *functional limitation*, defined as limitations in physical or mental actions due to the loss in system function; and finally, *disability*, or the inability to carry out socially defined roles or activities (see Figure 1). In this model, disability exists if the functional loss is sufficient to restrict an individual from performance of a socially defined role.

The International Classification of Functioning, Disabilities, and Health (ICF)⁴

The World Health Organization (WHO) first provided in 1980 a unifying framework for classifying the consequences of disease, standardizing disability terminology internationally, and improving health surveillance systems. The original version of this system, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), recognized four stages: *disorder*, *impairment*, *disability*, and *handicap*. In this approach, disability is defined as a limitation in activity, whereas handicap refers to the existence of a relative disadvantage compared to others because of the limitation. The ICF, revised in 2002, provides a systematic coding scheme for comparing the consequences of health conditions across countries and over time (see Figure 2, page 6). Similar to the ICIDH, body functions and structures are linked to activities; however, the ICF explicitly links these dimensions to *participation*, defined as "involvement in life situations." The model also makes explicit contextual

Figure 2

International Classification of Functioning, Disabilities, and Health (ICF)



Source: Adapted from World Health Organization (WHO), *Towards a Common Language for Functioning, Disability, and Health* (2002): 9.

factors—the individual’s health condition, the environment, and other personal factors—that may influence and interact with the process by which body functions and structures relate to participation.

Measuring Disability

A substantial number of public programs address disability; definitions vary widely and tend to reflect the purpose and target population (see Box 1).⁵ In some cases definitions are limited and based on the population eligible for programs that serve a specific type of disability, such as miners with black lung disease, veterans with a service-related condition, or individuals qualifying for disability benefits under Social Security. Administrative records from these programs capture just a portion of the population with disability—those who apply and meet program qualifications.

Estimates of all Americans with disabilities are usually based on survey or census-based measures. For example, the U.S. Census, the Survey of Income and Program Participation (also conducted by the Bureau of the Census), or the National Health Interview Survey (conducted by the National Center for Health Statistics) provide estimates of the U.S. population with disability. The numbers are different from those based on administrative records from programs because people are more likely to self-report a disability than enroll in a disability program.

National data collection efforts have also adopted varied definitions and methodologies (see Box 2, page 8). These efforts tend to ask questions about underlying health conditions; the effect of conditions on functioning or activities; and the need or use of support systems (most often human help or technological assistance).

The overlapping and at times conflicting definitions of disability make

Box 1

Programmatic Definitions of Disability

Black Lung Program. Miners totally disabled due to pneumoconiosis.

Developmental Disabilities Programs. Severe, chronic disabilities attributable to mental and/or physical impairment that manifest before age 22 and are likely to continue indefinitely. They result in substantial limitations in three or more of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency, as well as the continuous need for individually planned and coordinated services.

Social Security Disability Insurance for Adults (SSDI) and Supplemental Security Income (SSI). The inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) that can be expected to result in death or that has lasted or

can be expected to last for a continuous period of not less than 12 months.

Social Security Disability Insurance for Children (0-17). Any medically determinable physical or mental impairment or combination of impairments that causes marked and severe functional limitations and that can be expected to cause death or that has lasted or can be expected to last for a continuous period of not less than 12 months.

Veteran's Disability Benefits. Service and nonservice-connected injuries or illness that reduce earnings capacity.

Vocational Rehabilitation. A physical or mental impairment that results for an adult in a substantial impediment to employment; the adult can benefit from vocational rehabilitative services.

Workers' Compensation. Work-related injury, accident, or illness that limits or prevents work.

The majority of people with a limitation or disability are younger than age 65.

the basic task of describing the demography of disability quite challenging. In this *Bulletin*, we present data from one of the largest and most recent sources of disability in the United States—the 2000 Census—supplemented with data from several recent national surveys.

Demography of Disability

The 2000 Census of the United States provides a broad overview of the extent of functional limitation and disability across the nation and by sex, age, and other demographic characteristics.

Age and Sex

According to the 2000 Census, nearly 50 million people—or almost one-fifth of the population age 5 or older—indicate having one or more

of the limitations or disabilities defined in Box 2, page 8. Contrary to popular notions, the majority of people with such limitations are younger than age 65. More than 30 million Americans of working age have a limitation or disability, compared with 14 million age 65 or older and roughly 5 million between ages 5 and 20 (see Table 1, page 9).

There are more men than women with disabilities in every age group up to age 65. In the older ages, however, women vastly outnumber men (8.3 million versus 5.6 million) because they have a higher rate of disability and because there are many more older women than older men in the population.

The prevalence of disability increases with age. Only 6 percent of those ages 5 to 15 have a limitation or disability, but 42 percent of those ages 65 and older do. Although older people make up just 13 percent of the population age 5 or

older, they account for more than one-quarter of those with a limitation or disability. Overall, rates of having any limitation or disability are about the same for men (19.6

percent) as for women (19.1 percent). Within age groups, however, males generally have greater rates of limitation and disability than females up to age 65.

Box 2

Definitions of Disability in Census and Survey Data

Census 2000 asked about six types of limitation and disability for the civilian, noninstitutionalized population age 5 or older:

- **sensory limitation** (blindness, deafness, or a severe vision or hearing impairment);
- **physical functioning limitation** (condition that limits walking, climbing stairs, reaching, lifting, or carrying);
- **mental limitation** (because of a condition lasting six months or more, difficulty learning, remembering, or concentrating);
- **self-care disability** (because of a condition lasting six months or more, difficulty dressing, bathing, or getting around inside the home);
- **“go outside the home” disability** (because of a condition lasting six months or more, difficulty going out alone to shop or visit a doctor; asked only of those ages 16 and older); and
- **employment disability** (difficulty working at a job or business; asked only of those ages 21 and older).

The **Survey of Income and Program Participation** includes eight disability-related criteria for the noninstitutionalized population age 15 or older:

- **assistive technology accommodations** (used a wheelchair, a cane, crutches, or a walker);
- **functional limitation** (difficulty seeing, hearing, speaking, lifting/carrying, using stairs, walking, or grasping small objects);
- **self-care disability** (difficulty with getting around inside home, transferring, bathing, dressing, eating, toileting);
- **instrumental-care disability** (difficulty going outside, keeping track

of money and bills, preparing meals, doing housework, taking prescriptions, using the telephone);

- **mental or emotional condition** (a learning disability, mental retardation, developmental disability, Alzheimer’s disease, or other condition);
- **mental or emotional condition** interfering with day-to-day activities (frequently depressed or anxious, trouble getting along with others, trouble concentrating, trouble coping with day-to-day stress);
- **work disability** (condition that limited the ability to work around the house, and for those ages 16 to 67 at a job or business); and
- **work disability benefit receipt** (received federal benefits based on an inability to work).

The **National Health Interview Survey** includes six criteria related to limitations and disability for the noninstitutionalized population:

- **self-care disability** (needs help with bathing, dressing, eating, transferring, toileting, or getting around inside for ages 3 and older);
- **routine care disability** (needs help with everyday household chores, doing necessary business, shopping, or getting around for other purposes for ages 18 and over);
- **work limitation** (unable or limited in the amount or kind of work because of a physical, mental, or emotional problem for ages 18 and older);
- **mobility limitation** (difficulty walking without equipment);
- **cognitive limitation** (difficulty remembering or periods of confusion); and
- **other limitation** (limited in any way in any activities because of a physical, mental, or emotional problem).

Table 1

Limitation and Disability Rates for U.S. Men and Women, by Age and Type of Limitation or Disability, 2000

Age/sex	Number with disability/limitation (millions)	Percent of total population	Type of limitation or disability (%) *					
			Sensory	Physical	Cognitive	Self-care	Go-outside-home	Employment
Total age 5 or older	49.7	19.3	3.6	8.2	4.8	2.6	nr	nr
Male	24.4	19.6	3.9	7.3	5.0	2.2	nr	nr
Female	25.3	19.1	3.4	9.1	4.7	3.0	nr	nr
5 to 15 years	2.6	5.8	1.0	1.0	4.6	0.9	na	na
Male	1.7	7.2	1.1	1.1	6.0	1.1	na	na
Female	0.9	4.3	0.9	0.9	3.1	0.8	na	na
16 to 20 years	2.6	13.3	1.2	1.5	4.0	0.8	5.2	7.4
Male	1.4	14.5	1.3	1.4	4.8	0.8	5.5	8.0
Female	1.2	12.0	1.1	1.5	3.1	0.7	5.0	6.7
21 to 64 years	30.6	19.2	2.4	6.8	3.8	1.9	6.5	12.5
Male	15.7	20.2	2.9	6.6	3.8	1.8	6.6	13.6
Female	14.9	18.2	2.0	7.0	3.7	2.0	6.6	11.4
65 years or older	14.0	41.9	14.2	28.6	10.8	9.5	20.4	na
Male	5.6	40.4	15.6	25.8	9.9	7.5	16.8	na
Female	8.3	43.0	13.2	30.7	11.4	11.0	23.0	na

*One person may have more than one type, thus the overall rate may be smaller than the sum of the types.
na = not asked; nr = not reported.

Source: Authors' analysis of Census 2000 data.

A limitation of physical functioning is the most common of the six types of limitation and disability asked about in the census and listed in Table 1. Eight percent of the population age 5 or older reported a physical functioning limitation, and 5 percent reported what the census defines as mental limitation (see Box 2 for specific definition).

Specific types of limitation and disability affect age and sex groups differently. Of the 2.6 million children ages 5 to 15 with disability, for example, the vast majority are reported to have difficulty learning, remembering, or concentrating. The National Health Interview Survey estimates that 1.3 million children ages 5 to 17 were living in the community in the mid-1990s with mental retardation and/or developmental disabilities, as well as with a health-related school limitation.⁶

Disability related either to going outside or employment is most common among those ages 16 to 20. Employment disability is most com-

mon among those in the prime working ages of 21 to 64; according to the 2000 Census, 13 percent of the working-age population had a work limitation. Among the elderly, in contrast, physical functioning limitation is the most prevalent type of limitation or disability.

Race and Ethnicity

In the 2000 Census, 36 million of the nearly 50 million Americans reporting a limitation or disability were white (see Table 2, page 10). More than 7 million blacks and nearly 7 million people of Hispanic origin also reported having a limitation or disability in the census.

Rates of disability vary widely by race and ethnicity. Among those ages 5 and older, blacks and American Indians and Alaska Natives are most likely to report a limitation or disability—24 percent versus 19 percent for all races in 2000. Asians and whites have relatively low rates of limitation

Table 2

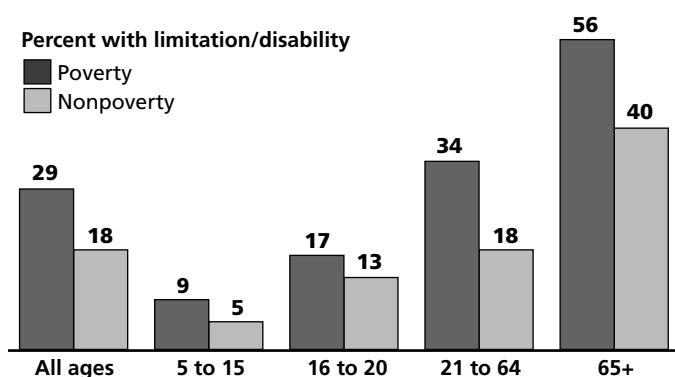
Limitation and Disability Rates by Race, Ethnicity, and Age, United States, 2000

Race and Hispanic or Latino origin	Number (millions)	Percent with a limitation or disability by age				
		Age 5 or older	5 to 15	16 to 20	21 to 64	65 or older
Total, any race or ethnicity	49.7	19.3	5.8	13.3	19.2	41.9
White alone	36.2	18.5	5.6	11.9	17.3	40.6
Black alone	7.4	24.3	7.0	17.6	27.7	52.8
American Indian and Alaska Native alone	0.5	24.3	7.7	16.6	28.6	57.6
Asian alone	1.6	16.6	2.9	12.1	17.4	40.8
Native Hawaiian and other Pacific Islander alone	0.1	19.0	5.1	14.3	22.2	48.5
Some other race alone	2.7	19.9	5.2	17.2	24.7	50.4
Two or more races	1.3	21.7	7.1	16.2	26.8	51.8
Hispanic or Latino (of any race)	6.5	20.9	5.4	17.7	25.1	48.5
White alone, not Hispanic or Latino	33.0	18.3	5.7	11.2	16.7	40.4

Source: U.S. Census Bureau, Census 2000 Factfinder, Summary File 3, Detailed Tables.

Figure 3

Percent of U.S. Population Reporting Any Limitation or Disability by Age Group and Poverty Status, 2000



Source: U.S. Census Bureau, Census 2000 Summary File 3.

and disability—only 17 percent and 19 percent, respectively, in 2000. These rankings by race generally hold for each broad age group. Rates of disability and limitation are especially low for Asian children and high for American Indians and Alaska Natives ages 65 and older. Hispanics have a higher rate of limitation and disability than non-Hispanic whites, except among children ages 5 to 15.

Poverty

According to the 2000 Census, 8.7 million adults and children who reported a limitation or disability also lived in poverty. Those living in the

poorest households were much more likely to report a limitation or disability than those not living in poverty—29 percent compared with 18 percent (see Figure 3). The relationship between poverty and disability has been established by numerous studies,⁷ but it is difficult to sort out the direction of the effect. The relationship may change over the life course,⁸ with childhood poverty increasing the risk of disability later in life, and disability in turn increasing the likelihood of poverty at middle and later ages.

Marital Status and Education

Based on the 2001 U.S. National Health Interview Survey, which asks questions similar to the census, Americans ages 21 to 64 with limitations or disabilities are less likely than the general population of the same age to be married, but more likely to be widowed, divorced, separated, or never married (see Table 3). They are half as likely to have received a college degree or to have been working in the week prior to the survey.

Among the elderly population, there are similar patterns with respect to marital status, although all elderly are more likely to be widowed and less likely to be currently married than working-age people. The

educational differences by limitation/disability status are less stark among the elderly than for 21-to-64-year-olds. Nevertheless, the older population with limitations or disabilities is less educated and less likely to be working than the older population in general.

Geographic Variation

Not surprisingly, the largest numbers of people with limitations and disabilities are in the states with the largest overall populations: California, New York, Texas, and Florida (see Table 4). Yet rates vary by age across states, as shown in Figures 4, 5, and 6 (pages 12

Table 3

Marital Status, Educational Attainment, and Employment Status of All Adults and Adults With Limitations or Disabilities by Age Group, United States, 2001

Characteristic	Ages 21 to 64		Ages 65 or older	
	Adults with a limitation/disability	All adults	Adults with a limitation/disability	All adults
Marital status				
Married	51.3	63.4	46.2	55.9
Widowed	4.5	1.8	40.4	32.1
Divorced/separated	19.5	10.7	8.2	7.0
Living with a partner	6.2	6.5	0.7	0.7
Never married	18.0	16.8	4.2	3.5
Education				
8 years or less	9.7	4.6	23.1	16.2
9-12 years/ high school graduate	49.4	38.7	45.5	46.7
Some college	26.1	28.1	16.5	18.1
College degree or higher	12.5	25.5	10.6	14.5
Work status				
Working in previous week	34.2	73.8	4.5	11.0

Source: Authors' analysis of the 2001 National Health Interview Survey.

Table 4

Ten U.S. States With Largest Populations and Largest Populations With Limitation or Disability, 2000

States ranked by total population	2000 population in millions		State ranking by population with a limitation/disability
	Total	People with a limitation/disability	
1. California	33.9	5.9	1
2. Texas	20.9	3.6	3
3. New York	19.0	3.6	2
4. Florida	16.0	3.3	4
5. Illinois	12.4	2.0	6
6. Pennsylvania	12.3	2.1	5
7. Ohio	11.4	1.9	7
8. Michigan	9.9	1.7	8
9. New Jersey	8.4	1.4	10
10. Georgia	8.2	1.5	9

Note: People with a limitation or disability are age 5 or older.

Source: U.S. Census Bureau, Census 2000 Summary File 3.

and 13). Some of the highest rates for the two adult age groups (those ages 21 to 64, and those ages 65 and older) across all types of limitation and dis-

ability occur in such Southern states as Mississippi, Alabama, Arkansas, Kentucky, and West Virginia. This pattern may reflect the relatively high

Figure 4
Percent of Population Ages 5 to 20 With a Limitation or Disability by State, 2000

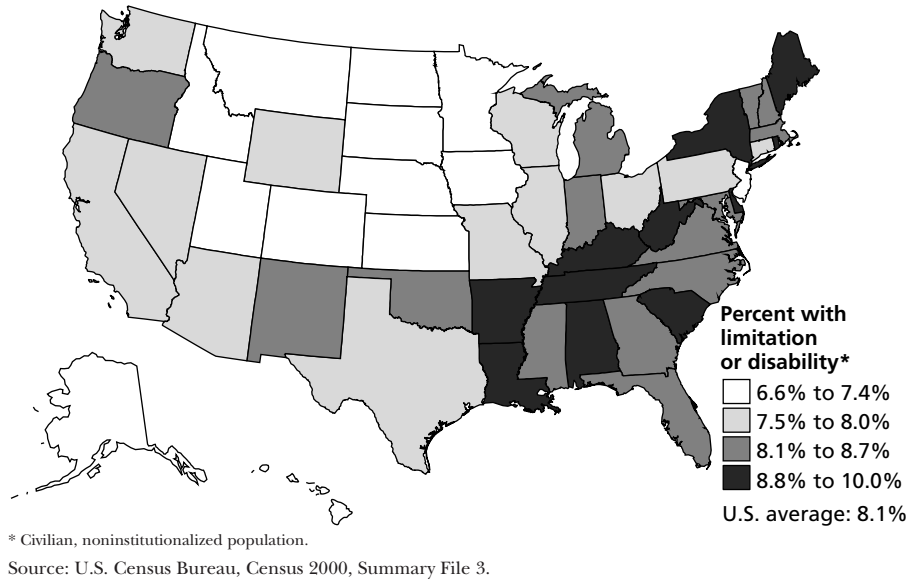


Figure 5
Percent of Population Ages 21 to 64 With a Limitation or Disability by State, 2000

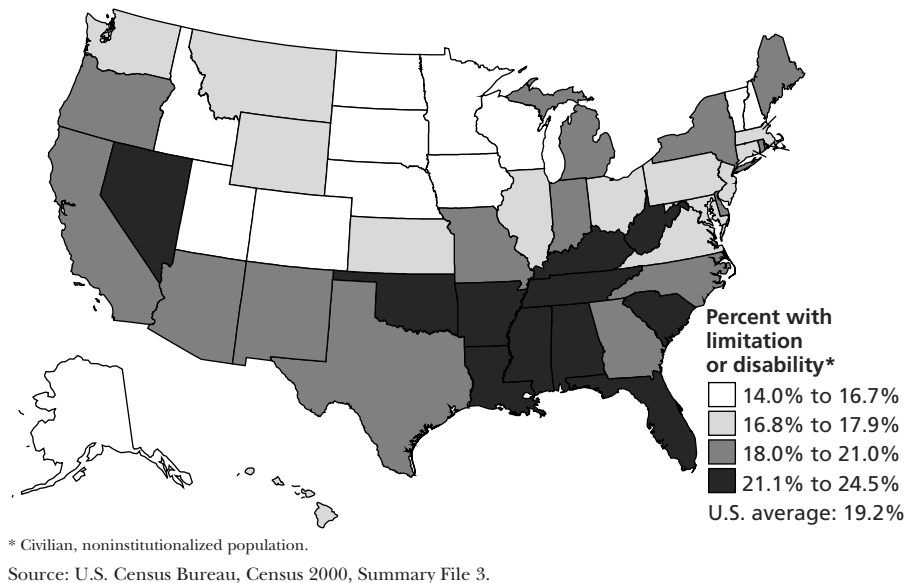
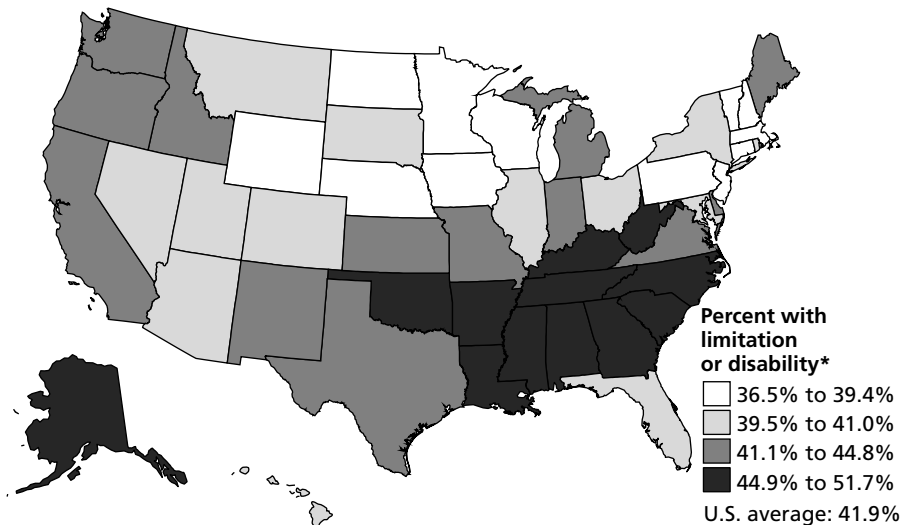


Figure 6

Percent of Population Ages 65 and Older With a Limitation or Disability by State, 2000



* Civilian, noninstitutionalized population.

Source: U.S. Census Bureau, Census 2000, Summary File 3.

poverty rates in these states, and—in Kentucky and West Virginia—be related to the coal mining industry.⁹ However, analysis of 1990 Census data indicates a persistent Southern disadvantage even after accounting for patterns of race and socioeconomic status.¹⁰ The lowest rates of disability are in the Midwestern states of Minnesota, Wisconsin, Nebraska, Iowa, and North Dakota. Also notable are the low disability rates in Connecticut, Delaware, and Massachusetts among those ages 65 and older.

Young people in the District of Columbia, Arkansas, Louisiana, West Virginia, and Kentucky have among the highest limitation and disability rates overall as well as for several of the types of limitations or disabilities. The one exception is mental limitation among young people (not shown specifically in the map), which has the highest rates in Maine, New Hampshire, and Vermont. Mental limitation among the young does not appear to be related to poverty or racial distribution. Hawaii, Alaska, and the Midwestern states have the lowest rates of limitation and disability among youth.

Health Conditions and Disability

Disability is often associated with one or more specific health conditions or injuries. According to the 2001 National Health Interview Survey, the majority of U.S. children and youth under 18 years with disabilities reported emotional, behavioral, and other development problems as conditions associated with their disabilities. Also frequently mentioned were speech problems (16 percent) and asthma and other breathing problems (13 percent).

The leading conditions associated with disability among people ages 21 to 64 are similar to those reported by people ages 65 and older (see Table 5, page 14). Seven of the top 10 conditions are common to both age groups, though in different order: back/neck problems, arthritis/rheumatism, fractures, heart problems, hypertension, diabetes, and lung problems. Among the younger group, depression stands out as the third most commonly mentioned condition contributing to disability. Top-10 conditions among the

Table 5

Top 10 Conditions Associated With Limitation or Disability Among U.S. Adults by Age, 2001

Ages 21-64			Ages 65 and older		
Condition	Percent		Condition	Percent	
1	Back/neck problem	24.8	Arthritis/rheumatism	30.0	
2	Arthritis/rheumatism	15.5	Heart problem	23.2	
3	Depression/anxiety/ other emotional problem	13.3	Hypertension	13.7	
4	Heart problem	10.7	Back/neck problem	12.6	
5	Fracture/bone/joint injury	10.5	Diabetes	12.1	
6	Hypertension	9.1	Vision problem	11.8	
7	Diabetes	8.9	Lung/breathing problem	11.1	
8	Lung/breathing problem	8.9	Fracture/bone/joint injury	10.7	
9	Nervous system condition	6.9	Stroke	9.2	
10	Musculoskeleton problem	5.5	Hearing problem	7.0	

Note: More than one response was possible.

Source: Authors' analysis of the 2001 National Health Interview Survey.

Table 6

Employment Status and Median Annual Earnings by Disability Status, U.S. Adults Ages 21-64, 1997

Disability status	Total (thousands)	Number employed (thousands)	Percent employed	Median earnings	
				Amount	Standard error*
Total ages 21-64	152,886	119,616	78	\$22,941	\$(151)
No disability	125,084	105,624	84	23,654	(157)
With a disability	27,802	13,991	50	17,669	(423)
Severe disability	17,409	5,464	31	13,272	(651)
Mild disability	10,393	8,527	82	20,457	(508)

*The standard error for the median was plus or minus the amount in parenthesis.

Source: J. McNeil, *Current Population Reports P70-73* (2001): table 4.

elderly but not among the younger group are stroke and vision and hearing problems. Alternative sources such as the Survey of Income and Program Participation have yielded similar findings,¹¹ while other studies indicate that falls and motor vehicle crashes were behind many of the conditions that are associated with disability and limitation among those ages 18 to 69.¹²

Work and Disability

Estimates of the adult population with a work limitation vary.¹³ According to the 2000 Census, 21 million people ages 16 to 64 had a work disability. The Current Population Survey, which asks people whether they have a condition that either limits the kind or amount of work they

can do or that prevents them from working, found that 18 million people (10 percent of the 2002 U.S. population ages 16 to 64) had such a disability. The Survey of Income and Program Participation found that 18 million people had disability-related employment problems in 1997.

People with a disability are less likely than others to work at a job or own a business.¹⁴ According to the Survey of Income and Program Participation, 84 percent of working-age adults with no disability were employed in 1997 (see Table 6), compared with 82 percent of people with a mild disability and just 31 percent for those with a severe disability. Individuals with no disability had median annual earnings of approximately \$23,700 in 1997, whereas those with

mild disability earned just over \$20,000 and those with a severe disability earned approximately \$13,300.

Disability Dynamics

Disability depends on the health of an individual as well as the social and physical environment and the activities of interest. All of these factors can change frequently; therefore, the risk of having a disability is a highly dynamic phenomenon. The risk of disability not only changes over an individual's life course, but can also change from month to month or week to week.

At the population level, the extent of disability is affected by changes in the demographic composition of the population, medical discoveries in treatment and rehabilitation, technological innovations in support systems, and behavioral risk factors for disease progression (such as smoking, poor nutrition, lack of exercise, or poor adherence to medication regimens). Terms most commonly used to describe disability dynamics at the population level include "disability prevalence" and "disability incidence." Disability *prevalence* is the proportion of the population at a given point in time that has a disability. In contrast, disability *incidence* is the proportion of the population (usually restricted to those who do not have disability) who develop disability within a given time frame (for example, during the course of a year).

Numerous studies have identified factors that are linked to disability incidence, particularly at older ages.¹⁵ This literature reveals considerable diversity in the definitions of disability, the populations studied, and the time interval for measuring incidence. Nevertheless, the risks of disability onset are consistently higher for people with depression, multiple illnesses, infrequent social contacts, vision impairment, or little physical activity. Other factors—particularly nutrition and the physical environment—are also likely to be

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About half of all U.S. adults with a disability work at a job or own a business.

involved in the onset of disability but have received less attention by researchers.¹⁶

The course of disability follows varied trajectories among individuals, even in the oldest age groups. Some older people experience a rapid decline to dependence, others experience a gradual loss of function or remain largely independent, whereas a substantial proportion see improvements in functional status.¹⁷

Disability Trends

The risk of developing a disability differs among different age groups, income levels, occupational groups, and by a number of demographic characteristics, including race and education. Trends in the prevalence of disability have also followed different paths among these groups.

The enrollment of U.S. children in disability programs has increased over the last few decades.

Children

Disability and limitations are challenging to measure for children both because children develop at different rates and because the kinds of activities in which children can participate change as they age. For various years between 1984 and 2000, the National Health Interview Survey measured children's limitations with specific activities that included play; school; self-care; employment (for those 18 and older); and household activities because of a long-term chronic condition. Analysis of these data suggests that the risk of disability for Americans ages 3 to 21 rose from 6 percent in 1983 to 7 percent in 1996, but was stable between 1997 and 2000.¹⁸

The enrollment of U.S. children in disability programs also has increased over the last few decades.¹⁹ The most important program for disabled children is the Supplemental Security Income program (SSI), which is part of the Social Security system. In 1975, just 107,000 children under 18 were enrolled in SSI. This number almost tripled within the next 15 years to 300,000 by 1990, and more than tripled again by 2002 to more than 900,000.

These trends in SSI enrollment seem to suggest that disability has increased among children in the United States. However, participation in government assistance programs (including SSI) is influenced by a variety of factors other than disability. During the 1990s, enhanced outreach activities informed families of eligible children about the program, the mental impairment category expanded to include more children, reviews of the disability status of enrolled children were less frequent, and the process that determines whether children are disabled was modified. Each of these factors may have accounted for part of the dramatic recent increase in SSI participation.

Adults

Participation in disability programs by working-age adults has also increased.²⁰ Social Security Disability

Insurance (SSDI), which is described below, is the primary source of cash assistance to working-age people with disabilities. Enrollment in SSDI by disabled workers was steady at roughly 3 million between 1980 and 1990, but increased markedly to exceed 5 million by 2002. Enrollment in SSI—the other primary source of disability assistance—also increased to 4.8 million blind or disabled nonelderly recipients by 2002, after a more moderate increase from 1.8 million to 2.4 million between 1980 and 1990. Analysts have proposed several explanations for these increases, including:

- The loosening of eligibility requirements in 1984, which induced some workers to choose disability benefits over employment;
- Changes in the severity of health-related impairments; and
- A reduced willingness of employers to hire people with disabilities as an unintended consequence of legislation intended to protect the right to work for individuals with disabilities.

Other data indicate not just an increase in program enrollment but also an increase in the number of people with a disability in the working-age population. The most comprehensive recent evidence shows that the percentage of adults needing help with personal care or routine needs (such as eating, bathing, dressing, getting around the house, doing household chores, conducting necessary business, shopping, or getting around for other purposes) increased between 1984 and 1996, the latest year with comparable data.²¹ Among 40-to-49-year olds, for example, disability rose from 212 per 10,000 to 278 per 10,000 over the period—a 30 percent increase in 13 years. At face value, this trend suggests an alarming rise in disability. However, people's responses to questions about their limitations may have been affected by the growing availability of disability transfer programs during this period. Even among people with identical health, those who receive payments

from a disability program are more likely to report themselves as having a disability. As a result, it is unclear whether the trends in disability and disability program participation represent a true worsening of health for working-age adults.

Elderly

Since declines of late-life disability were first reported more than a decade ago, more than a dozen studies based on eight national surveys in the United States have assessed trends in the prevalence of disability and physical and cognitive limitations as self-reported by elderly respondents.²² Most of these studies have found clear declines in disability and limitation in functioning among the older population.

Between 1984 and 1993, for example, there was a substantial decline in the percentage of the 65 and older population reporting difficulty with four functions:

- Seeing words in a newspaper (22 percent to 17 percent);
- Lifting and carrying 10 pounds (34 percent to 27 percent);
- Climbing a flight of stairs (35 percent to 31 percent); and
- Walking a quarter-mile or three city blocks (38 percent to 32 percent).²³

Other studies have demonstrated declines of similar magnitude in functional limitations.²⁴ The improvement has been attributed in part to the shifting demographic and socioeconomic composition of the U.S. elderly population.

Similarly, the proportion of older people experiencing difficulty with such routine care activities as shopping, preparing meals, and managing money—sometimes called *instrumental activities of daily living* (IADLs)—declined substantially in the 1990s. These declines may be linked to improved health, but may also reflect the extent to which activities are assisted by technology, including modern conveniences.²⁵ For example, some older Americans no longer have to go to the store to shop or to

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Many seniors with disability live in supportive living environments—such as nursing homes, assistive-living facilities, and retirement communities.

the bank to manage money, and many have microwave ovens to facilitate cooking. Moreover, many more seniors live in supportive living environments—such as continuing care retirement communities, assisted living facilities, and other retirement communities—that provide assistance with these tasks.

The evidence has been less clear about trends in self-care activities such as bathing, dressing, toileting, and walking around inside, which are also sometimes called *activities of daily living* (ADLs). A recent attempt to resolve inconsistencies across national surveys found consistent evidence that, during the 1990s, the proportion of older people getting help with ADLs declined. Conclusions are sensitive to the specific time period and whether individuals who use assistive devices alone (but do not receive personal assistance) are considered to have a self-care disability.²⁶

There is even less evidence regarding trends in cognitive function among the elderly. One study shows that, from 1993 to 1998, the proportion of those age 70 or older who were severely cognitively impaired declined from 5.8 percent to 3.8 percent,²⁷ but a follow-on study to 2000

using slightly different methodology finds little change.²⁸ The extent of change measured in these studies also may be influenced by the inclusion or exclusion of the institutional population, among other factors.

There has been limited research on possible explanations for these trends in late-life disability. Notably, the educational level of the older population increased substantially within a short period and probably played a role in reducing disability.²⁹ There is also some evidence from recent decades that some chronic conditions, such as arthritis, are less debilitating even as the prevalence of many chronic conditions has increased among the older population.³⁰ Some analysts have speculated that earlier diagnosis and better management of such conditions may have led to lower reported disability; however, one investigation of the role of medication use in recent declines did not demonstrate such a link.³¹ Shifts in the employment sector toward less physically demanding jobs in earlier life may have led to less disability in late life. Healthier diets, more exercise, and reductions in smoking also may have played a role. For such measures of disability as self-care and routine care that are influenced by the older person's living environment, technological advances, and social role expectations, the declines may reflect changes in those factors, apart from changes in underlying health.

Active Life Expectancy

The World Health Organization (WHO) has developed a useful model for thinking about population-level linkages among morbidity, disability, and mortality.³² The model depicts the proportion of a cohort that survives to a specific age without experiencing a particular event—the onset of disease, disablement, or death. Based on this framework, one can calculate summary measures that combine information about disability and mortality into various averages

and projections. “Active life expectancy at birth,” for example, represents the average number of years lived from birth before the onset of disability. “Active life expectancy at age 65” represents the average number of years lived after age 65 before the onset of disability.

In recent decades, the U.S. population has made significant gains in active life expectancy at birth and at age 65. Between 1970 and 1990, U.S. males gained an average of 4.8 years of life, 2.3 years of which were expected to be without disability.³³ U.S. females over the same 20-year period gained 4.2 years of expected life—1.2 years of which were without disability. By 1990, U.S. males could expect to live 72 years, nearly 59 of them without disability, and females on average were living to age 79 and to age 64 without disability. In 1990, a 65-year-old male in the United States could expect to live an additional 15 years, more than 7 of these years free of disability. Females who had reached age 65 in 1990 could expect to live 19 more years—nearly 10 years without disability.

The literature also suggests large racial, economic, geographic, and education-related disparities in the number of active years lived by U.S. residents.³⁴ Black Americans, for example, live fewer years—and a greater proportion of those years are with disability. Rural residents outlive urban residents, but their additional years are primarily disabled ones.³⁵ And data from the 1990s suggests that Americans with more education are spending a smaller proportion of their lives with disabilities, whereas Americans with less education are seeing an expansion of this period with disability.³⁶

Support Systems

Support systems for people with disabilities include personal care services, technological assistance, and other strategies employed to accomplish daily tasks.³⁷ These systems,

whether at home or in group settings, make it possible for people with disabilities to “carry out their daily lives, gain access to their world, and participate as citizens.”³⁸ In the United States, supports are not well integrated or coordinated for any age group, but the array of choices is growing. Such services and strategies are made available through a patchwork of public and private providers and programs, often with complex and nonoverlapping eligibility rules. The various terms used to describe support systems are not used uniformly or consistently within the disability community or across age groups.

Personal Assistance

Personal assistance, also called “personal care” or “personal assistance services”³⁹ refers to hands-on, stand-by, or supervisory help provided to people of any age. Personal assistance services for people with disabilities may be provided in the community (sometimes called community-based long-term care services) or in group or institutional settings. Assistance may be provided with a variety of day-to-day tasks including self-care (activities of daily living such as bathing, dressing, feeding, transferring, or toileting); household tasks (instrumental activities of daily living such as cooking, cleaning, shopping, ordering and managing medications, making appointments); mobility; paramedical needs (such as skin care, injections); leisure activities; communication (for example, assisting with telephone use); and transportation.

The majority of personal assistance services are provided informally by family members. In 1994, 3.4 million adults ages 18 to 64 and another 3.9 million adults ages 65 and older reported receiving personal assistance; nearly three-fourths of adults ages 18 to 64 with a disability and two-thirds of those ages 65 and older with a disability rely only on informal care.⁴⁰ The remainder use some type of paid assistance, often in conjunc-

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Technology is an increasingly important component of support systems for people with disabilities.

tion with unpaid care. Relatives (most often adult children and spouses) make up the majority of informal caregivers to adults. The overwhelming majority of children with mental retardation and/or developmental disabilities who live in the community do so with one or both parents.⁴¹

Paid personal assistance includes a variety of services both in the community and in group settings. The terminology varies from program to program, but in general there are three broad sets of options for individuals in the community: home health agencies, personal care attendants, and adult day services. (Supportive living options are discussed on page 22).

Home health agencies provide individuals in their homes with nursing, personal care, and therapy services to

promote, maintain, or restore health and maximize independence. Home health care grew rapidly during the 1990s but then reversed course after the Balanced Budget Act of 1997 changed the way home health agencies were reimbursed through Medicare. Such agencies also sometimes offer end-of-life care under a hospice care entity. According to the latest available National Home and Hospice Care Survey, 11,400 home health agencies served 1.4 million home health patients in 2000.⁴²

Personal care attendants may be hired through home health agencies or may be contracted individually by people with disabilities (the latter arrangement is sometimes called consumer-directed or self-directed care). Medicaid programs vary tremendously across states with respect to the use of consumer-directed models of care for people with disabilities.⁴³ The practice of consumer-directed care is a growing phenomenon, however, and is perhaps most common in California.

Adult day services provide community-based health and social services in a protective group setting to adults with disabilities. These structured, comprehensive programs provide less than 24-hour care but do furnish a variety of health, social, and other related support services in a protective setting during any part of a day. Adult day centers generally operate programs during normal business hours five days a week. Some programs offer services in the evenings and on weekends. In 2002, there were roughly 3,400 adult day care centers in the United States.⁴⁴ The majority of people using adult day services live with a relative in the community and have cognitive impairments.⁴⁵

Technological Assistance

Technology is becoming increasingly important in the lives of people with disabilities, as it is for all Americans. Some technologies—such as automatic teller machines, direct deposit,

and shopping online—were not originally designed to overcome disabilities and have become everyday conveniences for many Americans. Other technologies are used to bridge the gap between an individual's capacity and the demands of his or her environment. Such technologies include: mobility devices such as walkers, canes, and wheelchairs; bathing devices such as shower stools; and adaptations to cars, computers, and telephones that assist people with disabilities in carrying out their day-to-day activities. The number of devices available in the marketplace for people with disabilities has expanded from 6,000 products only a decade ago⁴⁶ to over 29,000 products by 2002.⁴⁷

Assistive technology versus medical equipment. Assistive technology refers to equipment that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. In contrast, federal programs and health insurers have adopted more restrictive definitions, often limiting consideration to what is termed "durable medical equipment" that is considered medically necessary.⁴⁸

The use of assistive technology has been steadily increasing in the United States since the 1980s.⁴⁹ According to the National Health Interview Survey, among the adult noninstitutionalized population in 1994, an estimated 7.4 million people used such devices for mobility limitations; 4.6 million for orthopedic impairments (including missing limbs); 4.5 million for hearing impairments (not including those who use hearing aids that fully compensate for their hearing impairment); and one-half million for vision impairments.⁵⁰ Among older people with disabilities living in the community, about two-thirds used some form of assistive technology to help them carry out activities of daily living. The most common are simple devices that assist with mobility, such as canes and walkers.⁵¹ Mobility devices are also prevalent in nursing

homes, where 62 percent of residents used wheelchairs and 24 percent used walkers, according to a 1999 survey.⁵²

Environmental modifications.

Assistive technology can refer to items that are portable (such as a cane or walker) or a permanent part of the environment (such as a hand railing). Those changes made to a given environment to facilitate day-to-day activities are sometimes referred to as “environmental modifications.” Modifications may involve technological solutions (such as stair gliders); removal of barriers (such as widening hallways or doorways); or other changes to the environment (such as removing clutter or throw rugs) to enhance safety or independence. The prevalence of modifications nearly doubled between 1978 and 1995.⁵³ In 1995, half of older Americans reported having at least one dwelling modification and one-fourth had an unmet need for modifications.

Accessible, adaptable, and universal design. Another class of adaptations in the physical environment relates to products that are designed to be usable by people of all abilities and all ages.⁵⁴ Noted architect Ron Mace identified important distinctions within this class of adaptations that are highly relevant for people with disabilities.⁵⁵ The three distinct classes are *accessible housing*, *adaptable features*, and *universal design*:

- **Accessible housing** includes features such as wide doors, sufficient floor space for wheelchairs, lever- and loop-type handles on hardware, grab bars in bathrooms, switches and controls within easy reach, and entrances free of steps and stairs. Requirements for accessible housing vary widely and are enumerated in state and local building codes and federal regulations.
- **Adaptable features** include those that can be concealed or omitted and easily installed as needed. In adaptable housing, for example, a wall would be built to allow the pos-

sibility of installing a grab bar, but the grab bars would be installed only when actually needed.

- **Universal design** is defined by the Center for Universal Design as “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.” Examples of universally designed features are lever handles to open doors, higher electric outlets, lower light switches, and adjustable counter tops for the kitchen.

In public spaces, the growth of barrier-free environments may be directly linked to the passage of the Americans with Disabilities Act in 1990. The act (summarized in Box 3, page 24) prohibits discrimination against people with disabilities in a variety of domains including employment, transportation, and public accommodation. Facilities such as hotels, theaters, restaurants, shopping malls, stores, office buildings, and private social service agencies must remove barriers when such removal is readily achievable, and new construction must be accessible.

Substitution of technology for care. A growing number of studies of community-based long-term care have considered whether assistive technology can substitute for personal care.⁵⁶ Taken together, the studies suggest that assistive technology use is associated with lower costs for paid home care and fewer hours of help with personal care activities, although individual situations vary widely. People with cognitive impairment, for example, may be unable to substitute technology for human assistance, but may benefit from the blending of both. Some disability experts have argued that the complete interchangeability of human aid for technological assistance is neither possible nor desirable because technology cannot provide a key element of personal care—human interaction.⁵⁷

Supportive Living Options

Over the past few decades, people with disabilities, particularly the elderly, have seen their options for receiving care in group settings expand markedly. Although the terminology varies, some of the more common options in use today in the United States include:

Nursing Homes

Nursing homes provide around-the-clock skilled nursing care to people who do not need to be in a hospital but who require care that they cannot get in their homes or out in the community. In addition to skilled nursing care, nursing homes provide meals, help with daily living, and offer recreational activities. An increasing number of nursing homes offer special care units, such as units dedicated to people with Alzheimer's and other forms of dementia.⁵⁸

There is some evidence that the proportion of U.S. elderly living in nursing homes is shrinking or at least remaining stable.⁵⁹

In 1999, there were 18,000 nursing homes in the United States serving 1.6 million people. Nine of every 10 nursing home residents were age 65 or older; nearly three in four were women.⁶⁰ Most nursing home residents are widowed and have some form of functional limitation; between 60 percent and 70 percent have Alzheimer's disease or another form of dementia. The severity of disability in this population has been increasing.⁶¹ In 1996, 83 percent of nursing home residents needed assistance with three or more activities of daily living (such as bathing, dressing, feeding, and toileting), up from 72 percent in 1987.⁶²

Some residents remain in the nursing home for only a short period of time while recovering from a severe illness, injury, or surgery. Others may not be acutely ill but may not be able to live independently or be cared for at home. This latter group of residents may stay for long periods—even years—in the nursing home.

Assisted Living Facilities

Assisted living is perhaps the most common name for supportive living environments for people who need assistance but who do not require the 24-hour skilled nursing care available in nursing homes. The definition and terminology varies by state; other names for these kinds of living arrangements include residential care, personal care, adult congregate care, boarding home, and domiciliary care. At a minimum, most assisted living facilities offer 24-hour supervision and assistance and two to three meals per day. Other common support services include housekeeping and laundry services; medication reminders and/or help with medications; help with personal care activities including bathing, toileting, dressing, and eating; transportation; security; health monitoring; care management; and activities.

The absence of common terminology makes it difficult to estimate the number and characteristics of assisted living facilities in the United States.⁶³ For example, in a national study of assisted living conducted in 1998, there were 11,500 facilities serving approximately half a million people with disabilities, with about one-fourth of residents receiving help with three or more activities of daily living and about one-third having moderate to severe cognitive impairment. The National Center for Assisted Living suggests the figure for 2000 was approximately 33,000 residences housing about 800,000 people.

Continuing Care Retirement Communities (CCRCs)

CCRCs (also called lifecare communities) offer a full range of housing, residential services, and health care to serve older residents as their needs change. CCRCs typically provide several levels of care, including independent living, assisted living, and nursing home care. The number of CCRCs has grown over the last decade; a 1997 government report estimated that in the late 1990s, 1,200

of these communities served approximately 350,000 residents.⁶⁴

Group Homes and Board and Care Facilities

As with assisted living facilities, group homes offer a range of supported services, but typically to younger adults with disabilities. Often these adults are diagnosed with mental retardation or developmental disability (MR/DD). Since the late 1970s, there has been a trend away from large state-owned facilities toward smaller, community-based residential homes. In 2001, 387,000 individuals with MR/DD lived in 122,260 residential care settings.⁶⁵ In 2001, 80 percent of people with MR/DD living in residential care settings were in homes with 15 or fewer residents.⁶⁶ Among the noninstitutionalized adult population with MR/DD, 17 percent have lived in either a group home or some other residential care setting during their lifetimes.⁶⁷

Federal Programs

A variety of government programs in the United States are charged with ameliorating the consequences of disability, particularly as they relate to earnings capacity and economic well-being.⁶⁸ Historically, these programs have been dominated by transfer programs that primarily offer cash assistance. Less often, the programs involve rehabilitation and vocational services, medical care, employment protection, and increasing access to technology.

Major Disability Compensation Programs⁶⁹

There are disability compensation programs targeted to Americans with disabilities at each stage of life: children, working-age men and women, and the elderly. Most programs are funded and managed by the federal government, but state governments also provide important assistance.

Black Lung Disease

The Black Lung program was established in 1969 and provides monthly benefit payments to coal miners who were totally disabled because of pneumoconiosis, or black lung disease. Pneumoconiosis is a chronic dust disease of the lung resulting from employment in or around coal mines.⁷⁰ Payments are paid not only to surviving coal miners, but to their widows and surviving dependents as well. The number of beneficiaries has been falling steadily from its peak in 1974 of almost 500,000. In 2002, there were 71,584 beneficiaries, and only 8,394 were miners; the remaining 63,190 were widows or surviving dependents (see Table 7, page 25). In 2001, the benefit for a miner with no dependents was \$518 per month.⁷¹

Social Security Disability Insurance

The Old-Age, Survivors, and Disability Insurance (OASDI) Programs, typically referred to as “Social Security,” provide monthly benefits to retired and disabled workers, their dependents, and their survivors. Benefits for retired workers were established as part of the original 1935 Social Security Act, but benefits to disabled workers were enacted only in 1956. The disability insurance (DI) component of OASDI is funded by a payroll tax paid by workers covered by the program and their employers. Currently almost all workers—96 percent—are covered by DI.

Unlike Supplemental Security Income (SSI, see below), DI is not a means-tested program. To be eligible for DI, workers must have worked a minimum number of quarters with earnings above a specific threshold. In 2002, the quarterly earnings eligibility threshold was \$810. The number of quarters required for a person to become fully insured is based on the number of years the person lived after age 21 before becoming disabled. Someone who becomes disabled at age 33 would need to have accumulated 12 quarters of covered

There are disability compensation programs targeted to Americans with disabilities at each stage of life.

employment by that time to become eligible for DI.

For DI, disability is defined as the inability to engage in “substantial gainful activity” because of physical or mental impairment. The impairment must be verifiable medically and last at least 12 months, or it must result in

death. The amount of benefit payment that a disabled worker receives is determined by a variety of factors—most important, the average earnings in covered employment up until the time of disability. During the 2000-2001 period, the average monthly benefit for disabled workers was \$919.

Box 3

The Americans With Disabilities Act

The Americans with Disabilities Act (ADA) was signed into law on July 26th, 1990, by President George H.W. Bush. The ADA prohibits discrimination against people with disabilities in a variety of domains including employment, transportation, and public accommodation.

Definition of disability. The ADA defines disability as a physical or mental impairment substantially limiting one or more major life activities; an individual must have a record of such impairment or be regarded as having such an impairment. In terms of employment, the law defines a “qualified individual with a disability” as a person with a disability who can perform the essential functions of the job with or without reasonable accommodation.

Employment. Under the ADA, employers, employment agencies, labor organizations, and joint labor-management committees must have nondiscriminatory application procedures, qualification standards, and selection criteria, and they must make reasonable accommodation to the known limitations of a qualified applicant or employee unless to do so would cause an undue hardship.

Transportation. In the domain of transportation services, all publicly and privately purchased or leased orders for new buses and rail cars must be for accessible vehicles. Paratransit services must be accessible to, and usable by, people with disabilities, and they must provide a level of service equivalent to that provided nondisabled persons. All demand-response service provided to the general public and privately funded fixed route services must purchase accessi-

ble vehicles only. Newly purchased over-the-road coaches purchased after July 26, 1996 must be accessible. New bus and rail terminals must be accessible. Key rail stations must be accessible within three years with extensions available up to 20 years (30 years for some rapid or light rail stations). Amtrak stations must be accessible in 20 years. Within five years, one rail car per train must be accessible.

Public Accommodation. All entities licensed to do business with or serve the public, such as hotels, theaters, restaurants, shopping malls, stores, office buildings, and private social service agencies, must assure that criteria for eligibility of services do not discriminate. Auxiliary aids and services are required unless they result in an undue burden or fundamentally alter the nature of the goods or services. Entities must remove barriers from existing facilities when such removal is readily achievable. If not, alternative methods of making goods and services available must be provided. Facilities accessible to the maximum extent feasible must be established. In major structural renovations, a path of travel to the altered area, including restrooms and other services, must be accessible. New facilities must be accessible. Generally, other than for health-care facilities and multilevel shopping malls, elevators need not be provided in buildings with fewer than three floors, or fewer than 3,000 square feet per floor.

Reference

More information about the Americans with Disabilities Act may be obtained at www.ADA.gov.

The number of DI beneficiaries was fairly constant between the early 1980s and early 1990s, with 4.5 million recipients in 1991. In 1996, 6.1 million people were receiving DI benefits, up 36 percent in just 5 years. By 2002, the number had reached 7.2 million (including 5.5 million disabled workers, 1.5 million dependent children, and 150,000 spouses).

People become eligible for DI because of a variety of conditions. Mental disorders other than mental retardation accounted for 28 percent of the cases in 2001, double the 1982 percentage. Musculoskeletal disorders accounted for 24 percent of cases.

Supplemental Security Income (SSI)

SSI provides income support to people age 65 or older, blind or disabled adults, and blind or disabled children. Only people with low income are eligible for assistance. Among the elderly, the program is available to all low-income individuals—but among the nonelderly, recipients must be both low-income and blind or disabled.

For SSI benefit determination purposes, disability is defined as being “unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment expected to result in death or that has lasted or can be expected to last for at least 12 months.” The definition means applicants must be unable to work in any job in the national economy for which they are qualified based on age, education, and work experience. Permanent benefits do not begin until after a five-month waiting period.

In 2002, the maximum federal benefit for single people living in their own homes was \$545 per month. Some fraction of income from earnings and other sources is subtracted from the maximum benefit to determine the actual benefit amount awarded. Therefore, for example, a person with earnings of \$500 in a given month would receive a benefit of \$338. In addition, some states have higher benefits than the federal

Table 7

Leading U.S. Disability Programs by Number of Beneficiaries and Amount of Benefit Payments, 2002

Program	Number of beneficiaries (millions)	Total benefit payments (\$ billions)
Black Lung benefits	0.1	\$0.4
Social Security Disability Insurance (DI)	7.2	60.4
Supplemental Security Income (SSI) for blind or disabled		
Under age 18	0.9	0.5
Ages 18-64	3.9	1.8
Veterans disability benefits ^a	2.4	17.6
Workers' Compensation ^b	127.0	49.4

Notes: For Social Security Disability Insurance, the dollar benefit for 2002 was estimated based on total monthly benefit payments of \$5.03 billion.

^a The dollar benefit for 2002 was estimated based on total monthly benefit payments of \$1.5 billion. Column 1 reports the number of recipients with military service.

^b 2001 figures. Column 1 reports the number of individuals covered by the program.

Sources: Social Security Administration, “Social Security Bulletin Annual Statistical Supplement, 2003”; and Department of Veteran’s Affairs, *Program Statistics 2002 Annual Accountability Report Statistical Appendix*: table 12.

amount, raising the benefit payment. In 2002, 4.8 million people under age 65 received assistance under this program; total federal payments to these beneficiaries was \$2.3 billion.

Temporary Disability Insurance

Five states, Puerto Rico, and the railroad industry have social insurance programs that partially compensate for the loss of wages caused by non-work-related disability or maternity. These programs are called temporary disability insurance to denote that benefit payments are paid for only a limited duration. To qualify, workers must have worked a certain number of quarters, made a certain amount in earnings, and be disabled.

Veterans Disability Benefits

Veterans of military service are eligible for assistance to compensate them for both service- and nonservice-connected disability. The assistance includes disability payments, educational assistance, health care, vocational rehabilitation, survivor and dependent benefits, and special loan programs.

In 2002, roughly 2.7 million individuals received benefit payments,

with 2.4 million having disabilities connected to military service. For these people, benefits are not determined at all by the amount of their income, and benefits are paid to widows and dependents upon death. Veterans who qualify because of a nonservice-related disability must have low income to qualify for assistance.

Workers' Compensation

Workers' compensation was one of the first forms of disability insurance that was widely available in the United States. The goal is to provide cash benefits, vocational rehabilitation benefits, and medical benefits when employees suffer work-related injuries, accidents, and illnesses. The benefits are supported by payments made by employers. The program is run at the state level, with a great variety in systems across the 50 states and the District of Columbia. Federal workers are covered by their own system.

In 2001, 127 million workers were covered by workers' compensation programs throughout the nation. Roughly 5 percent of the workforce is not covered by this program—for example, employees in nonprofit, charitable, or religious organizations in some states.

More than \$49 billion was paid out in workers' compensation benefits to injured workers (or their survivors) in 2001, making it one of the largest assistance programs to people with disabilities. The cash benefits are often monthly payments made over a specified duration that typically depend on the severity of the worker's injury. In other cases, benefits are made in one lump sum payment. Benefits are designed to compensate workers for the reduction in their abilities to make a living resulting from the workplace injury; therefore, workers with more severe injuries receive higher benefits.

Other Federal Programs and Policies

In addition to the income support programs listed above, the federal

government also has a number of health, housing, and rehabilitation programs that provide benefits to certain groups of individuals (often those with low income) and that make special eligibility allowances for people with disabilities.⁷² Antidiscrimination policies have also emerged as a tool to enable Americans with disabilities to participate in social, economic, and political activities. Below is a brief description of some of the most salient programs:

- Two health care programs—Medicare and Medicaid—provide the bulk of publicly funded health care to people with disabilities. Medicaid, for example, which is administered by the states, provides nursing-home care, home health care, personal care services, and adult day care to children and adults who are blind, disabled, and/or age 65 and older who meet income and asset tests. So-called Medicaid-waiver programs provide a range of nonmedical support services excluding room and board to individuals who meet eligibility requirements and who would otherwise be in an institution. Medicare provides short-term skilled nursing facility care, home health care, and durable medical equipment to adults age 65 or older and certain younger people with disabilities.
- Supportive housing options are provided to adults with disabilities through the Congregate Housing Services Act of 1978. The Older Americans Act of 1965 provides nutrition, home care, adult day services, respite, transportation, and preventive health services to certain adults ages 60 and older, many of whom have a disability. Home and community-based services are provided through the Social Services Block Grant, as determined by individual states.
- The Rehabilitation Act of 1973 provides services to adults who have a physical or mental limitation that results in a substantial impediment

Workers' compensation was one of the first forms of disability insurance that was widely available in the United States.

to employment, but who also could benefit from vocational rehabilitative services. Services include vocational rehabilitation, employment training, education, and independent living services.

- The landmark Americans with Disabilities Act, enacted in 1990, prohibits discrimination against people with disabilities in a variety of domains, including employment, transportation, and public accommodation (see Box 3, page 24). Since the passage of the act, the federal government has launched several additional programs to remove barriers to participation.
- Most recently, the 1998 Assistive Technology Act and the 2001 New Freedom Initiative specifically target the removal of environmental barriers and increased access to assistive and universally designed technologies.

Future of Disability in America

For more than 25 years, scientists have debated the implications of population aging for disability in the United States.⁷³ Over the last 50 years, American life expectancy at birth has increased from less than 70 years to more than 77 years.⁷⁴ Some analysts have argued that increases in life expectancy would translate into increases in ill health and disability; other analysts have countered that vitality will someday be the norm for all ages. A third camp maintains that the future of aging and disability in America will depend both on individuals' choices—whether they drink to excess, smoke, overeat, or remain inactive—and on medical and technological breakthroughs. Population projections suggest that the sheer number of Americans with disabilities will continue to increase, in part because the country's large baby-boom cohort, born between 1946 and 1964, will begin to reach old age in

2010. Such calculations rarely take into account recent declines in late-life disability, shifts in population composition other than age (such as increases in minority populations and changes in educational levels), or the changes in support systems—both human and technological—that are likely to occur over the next few decades. Nor do they generally consider the potentially beneficial effects of removing barriers to participation or reducing injuries through safety enhancements. However, these potential offsetting effects are likely to be small in the face of the large increases projected over the next few decades in the numbers of older Americans.⁷⁵

Perhaps the important question is not how many people with disabilities there will soon be in the United States, but whether all individuals will be able to participate fully in society and whether they will have equal access to critical health and social services.

Over the last few decades, the United States has undergone an extraordinary transformation in its understanding of disability. The previous and strictly medical way of understanding disability has given way to an ecological understanding that disability exists in a social and environmental context. There also is a growing array of support systems and technological innovations to help people with disabilities participate in school, work, and leisure activities as well as to help older people live independently. A variety of federal assistance programs exist for children, adults, and older people with disabilities. Finally, newer policies and programs emphasize legal protections for individuals with disabilities and the removal of barriers to participation. These changes have created new opportunities for many Americans with disabilities and provide the framework for affording people of all ages and abilities the opportunity to participate fully in the nation's social, political, and economic activities.

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www.prb.org**Disability in America**

Nearly 50 million Americans—one of every five people ages 5 and older—have a disability, according to the 2000 U.S. Census. That number is expected to grow over the next 25 years as the U.S. baby-boom generation enters the ages most prone to disabling injuries and illnesses. Participation in society to the fullest extent possible by people with disabilities, whether young or old, has been a goal of U.S. policies and programs, but translating this aim into reality requires confronting a series of challenges. This *Population Bulletin* provides a broad overview of disability in America in the 21st century. It presents a review of basic concepts and measures, along with the latest statistics depicting the demography of disability and recent U.S. trends. The support systems, technological innovations, public policies, and programs described in this *Bulletin* provide a framework for understanding the current and future opportunities for people of all ages and abilities to participate fully in society.