

The Demographics of Disability

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EDITOR'S NOTE

Underlying the consideration of who is covered by the Americans with Disabilities Act (ADA) is the question of who counts as having a disability. The estimate of 43 million Americans with disabilities cited in the legislation appears to be a reasonable working number, although it is likely to prove modest under the definition of disability used in the ADA. Although a definition of disability that would yield a precise count (either you're in or you're out) would appease our desire for precision and quantification, we would in the process lose an important component of this public policy: the understanding that disability itself is not always precise and perfectly quantifiable. As we massage working definitions while implementing the ADA, let us remember that the world of disability is dynamic: it can differ from one day to the next and varies according to the person and the situation.

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In this article, I will examine the various definitions of disability, how to organize existing data in order to estimate who might benefit from the Americans with Disabilities Act (ADA), and how the data might be used by those responsible for implementing the Act. After analyzing and considering the ADA definition of persons with disabilities from the perspective of researchers, disability advocates, and people with disabilities, I will compare and discuss estimates of the size of the population with disabilities according to these perspectives. I will present information on the types of impairments and geographic variation in disability rates and will then discuss how existing data can inform us about the extent of discrimination. In conclusion, I will suggest how to improve our ability to estimate the impact of the ADA and evaluate its progress.

WHO COUNTS AS A PERSON WITH A DISABILITY? CONCEPTUAL DISTINCTIONS

By any reckoning, persons with disabilities comprise the single largest minority group ever defined, eclipsing the elderly and black populations (about 26 million and 28 million, respectively). Furthermore, the population is extremely heterogeneous. The definition and estimation of its size has been based on demographic research by census and survey that shows variation both in severity of disability and in identification of persons as having a disability, whether by self-assessment or assessment by others. For convenience, let us adopt a working definition of disability as a limitation in the performance of actions and/or activities resulting from some physical and/or mental difference. Let us call such physical and mental differences *impairments*.

Seemingly little disagreement exists over the concept of impairment, in large part because the assessment of impairment often takes place at the clinical level and most persons are content to leave conceptual arbitration to health and other clinical professionals. This is not the case for the concept of disability, as persons who consider themselves to have a disability, professionals who study disability, and the general public disagree about its meaning. It is no surprise that if disability is per-

ceived to mean different things to different people, demographic counts and estimates of the number of persons with a disability will also differ. Resolving differences in estimates is extremely important if we are to determine accurately the magnitude of disability and the discrimination associated with it.

ANALYSIS OF THE ADA DEFINITION

I will briefly review the ADA definition of a person with a disability as meeting one or more of the following criteria:

- a. A physical or mental impairment that substantially limits one or more of the major life activities of such individual
- b. A record of such an impairment
- c. Being regarded as having such an impairment

This definition was used in section 504 of the Rehabilitation Act of 1973. Clearly, our working definition is incorporated under part a. The ADA goes further, however, by including individuals defined under parts b and c. Note that persons who consider themselves disabled but are not considered by others to be so are implicitly included in the ADA definition.

The ADA definition restricts disability to impairments that substantially limit one or more of the major life activities. The Senate and House reports accompanying the Act provide guidance as to what constitutes major life activities and substantial limitations:

A physical or mental impairment does not constitute a disability under the first prong (part [a]) of the definition for purposes of the ADA unless its severity is such that it results in a "substantial limitation in one or more major life activities." A "major life activity" means functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, working, and participating in community activities. (U.S. House of Representatives 1990, 51)

Because the concept of major life activity is defined by examples, the precise range of activities covered by the definition is not clearly circum-

scribed. A further clarification relating to “substantial limitation” is given:

A person is considered an individual with a disability for purposes of the first prong (part (a)) of the definition when the individual’s important life activities are restricted as to the conditions, manner, or duration under which they can be performed in comparison to most people. (U.S. House of Representatives 1990, 52)

Although the term “substantial limitation” is well defined, precisely who is covered by the Act remains subject to interpretation because of the manner in which life activities are defined as noted above.

In comparing the ADA definition of disability with other perspectives, I will highlight the relationship of different definitions to estimates of the prevalence of disability in the population. In particular, I will compare the estimate of 43 million persons with a disability as referenced in the ADA with estimates derived from other perspectives.

THREE PERSPECTIVES

There are several ways of looking at the definitional issue: the perspective of researchers, the perspective of advocates for persons with disabilities, and individual self-perception. I address the perspective of researchers first.

THE PERSPECTIVE OF RESEARCHERS

Disability is often equated by researchers with limitations in performing socially expected roles and activities—working, parenting, voting, and so forth—because of a health condition. This perspective has been elaborated by, among others, Saad Nagi (Nagi 1965; 1969; 1991). In the United States, disability policy often focuses on major roles and activities, particularly work and ability to live independently in the community.

At the most basic level, disability refers to limitations in performing actions or activities because of an impairment. An impairment is a loss of mental, anatomical, or physiological structure or function that may be caused by active disease, residual losses from formerly active disease, and congenital losses or injury not associated with active disease (Nagi

1991; World Health Organization 1980). Impairments refer to body structure and the functioning of its various subsystems indicated by signs and symptoms such as reduced pulmonary function, restricted range of joint motion, particular categories of impairments like paraplegia, and particular diagnoses of health conditions—for example, AIDS. It is important to note that impairments encompass not only physical and sensory losses, but chronic diseases as well. This definition of impairment is consistent with that of the ADA (U.S. House of Representatives 1990, 51).

Disability involves limitations in actions or activities that are due to such impairments. Limitations may include individual difficulty as well as incapacity in doing things. By focusing attention on incapacity, disability is confined to the “tip of the iceberg” (Verbrugge 1990). In the ADA, limitation is broadly defined as restrictions in the conditions, manner, or duration under which activities are performed compared with other persons.

Although there is not much disagreement over the terms *impairment* and *limitation*, many disagree about what constitutes disability. Largely, this debate concerns the extent to which disability refers to actions versus activities. Actions are the basic units of human performance (Homans 1974). That disability involves action distinguishes it from a purely biological and medical phenomenon (i.e., impairment), which disability clearly is not. But to what actions does disability refer? There is a seemingly infinite range of actions to consider. Physical and mental actions are the ways through which individuals interact with the physical and social world. Talking, thinking, remembering, walking, seeing are examples of actions. Activities very often are the components of occupying roles like student or teacher. Playing, working, reading a newspaper are examples of activities.

The utility of this conception is its recognition that a specific activity can be accomplished by different sets of actions. Individuals can sometimes modify how an activity is performed by changing the actions that are required. A person with paraplegia may not be limited in the activity of driving if he or she has a car fitted with hand and arm controls, for example. Certain actions can sometimes compensate for others that a person is limited in performing without changing the essential nature of the activity.

Given these observations, it follows that a specific impairment will not necessarily have the same impact on activities that different people can do. The impact depends on the nature of the activities, the human

and physical capital of the individual (e.g., intelligence, education), and characteristics of the individual's environment (e.g., family and community support). Due to differences in their nature and the degree to which they are valued, there is often considerable flexibility in the extent to which various activities can be modified.

Nagi refers to problems in performing actions that are caused by impairments as *functional limitations* and problems in performing activities as *disability*. The WHO definition of disability is "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (World Health Organization 1980). In the WHO framework, disability refers to problems due to impairments in performing actions (functional limitations) and activity (World Health Organization 1980, 14), but problems in performing highly valued roles are defined separately as *handicap*.

In the ADA, the examples of major life activities include some actions, such as seeing or hearing, that are often referred to as functional limitations, and some activities, such as working, that are well within what is generally considered the traditional province of disability. Underlying the concept of actions and activities is a basic typology of human function that suggests a breakdown of human activity into different levels of action systems. Another possibly more useful typology may be one that ranks activities in terms of their life importance. Granger suggests that activities can be ordered by their importance in fulfilling human drives (Granger 1984). At the more basic level are survival activities such as personal care and activities to maintain the individual's household. At a higher level are activities related to economic survival and recreation. Higher-order drives include recreation and satisfaction of creative urges. Verbrugge (1990) argues that disability is defined by limitations in all valued domains of human activity or function.

It is clear that the field of disability research has not reached a consensus on the definition of disability. I do not attempt to resolve these conceptual differences here but only to illustrate the implications of these differences in definitions for who counts as having a disability.

DEMOGRAPHIC ESTIMATES OF IMPAIRMENT AND DISABILITY

Impairment. The National Health Interview Survey (NHIS) provides estimates of the numbers of persons at all ages who have impairments as well as those with limitations in activities due to a health condition or

impairment, whether physical or mental. The most prevalent disease reported in the United States is chronic sinusitis, which affects about 34 million persons (Adams and Benson 1990). Some 31 million persons have arthritis, followed by 28 million with hypertension and 28 million with a deformity or orthopedic impairment. Based on a different survey, almost 50 percent of the working-aged population has one or more chronic health conditions or impairments (Ferron 1981). Some 79 percent of persons aged 60 years and older had at least one of nine common diseases (Guralnik et al. 1989).

Functional Limitation. As I have categorized the situation above, functional limitations are more fundamental measures of limitations in human action (as opposed to activity). The Survey of Income and Program Participation (SIPP) provides an estimate of 37 million persons, or 21 percent of the U.S. population aged 15 and older, with functional limitations in 1984 (U.S. Bureau of the Census 1986). These include persons who are limited in getting around inside and outside of the home, speaking, hearing, seeing, ascending stairs, lifting, and walking. This list includes four of the major life activities referenced in the ADA. The most prevalent limitation was in walking (19 million). About 13.5 million persons, or 7.5 percent of the population aged 15 and older, cannot perform one or more of these actions.

This is hardly a complete list of functional limitations. Omitted are bodily disposition limitations such as crouching, kneeling, stooping, sitting, reaching, dexterity, endurance, and tolerance, to name a few. In 1978, about half of the population aged 18 to 64 had one or more limitations in walking, using stairs, standing, sitting, stooping, crouching, kneeling, lifting weights over 10 pounds, reaching, handling, or fingering (Lando, Cutler, and Gamber 1982). About 31 percent of such persons were limited in work. Limitations in any of these actions could place an individual at risk of being unemployed. It should be noted, however, that the largest category was for limitations in lifting weights over 10 pounds (50 million) and that the prevalence would be considerably lower if that category were omitted. Nevertheless, the number of persons with functional limitations would far exceed 37 million if all the functional limitations mentioned above were considered.

Canada and Great Britain have recently conducted surveys of disability. The Canadian Health and Activity Limitation Survey employed questions on functional limitations and an open-ended activity-limitation question. It is estimated that, in 1987, around 14 percent of the entire Canadian population (including persons residing in institu-

tions) had a functional or activity limitation (Statistics Canada 1988), while about 15 percent of adults aged 15 years or more fell into these two limitation categories. This survey used a more extensive list of functional limitations than the SIPP, but a smaller percentage of Canadians than Americans were found to be limited in function. In the British survey, a more extensive list of functional limitations than in the SIPP was also used (Martin, Meltzer, and Elliot 1988). About 14 percent of all adults (aged 16 years or more) were estimated to have a functional limitation in 1986. This percentage is also less than the prevalence of functional limitations in adult Americans as measured by the SIPP.

Thus, although I argue that a more extensive list of functional limitations would yield a higher prevalence than does the SIPP, more extensive lists do not yield a higher prevalence of functional limitations in other countries. Survey error, differences in health status, or variations in the environment may account for the observed differences. A more careful comparison and consideration of these survey results is warranted.

Activity Limitation. According to the NHIS, in 1989 there were close to 34 million persons, or 14 percent of the U.S. population, at all ages living outside of institutions who were limited in activities considered normal for their age group (Adams and Benson 1990). About 9 percent of adults aged 18 to 44 years were limited in activity and 22 percent of those aged 45 to 64 years. The NHIS estimate includes persons limited in major life activities such as work and housework, as well as 11 million persons, or 4.5 percent of the U.S. population, who are limited "in any way in any activity" other than the major activities appropriate to their age group. The nature of these limitations has not been documented, but NCHS indicates that it includes community and other social and recreational activities. It is likely that the measure does not include all major life activities as intended by the ADA.

In summary, current data indicate that there are at least 120 million persons with impairments in the United States. Of those, well over 37 million experience selected functional limitations, and at least 34 million persons experience limitations in some major life activities.

THE PERSPECTIVE OF DISABILITY-RIGHTS ADVOCATES

Some disability-rights advocates object that the activity-limitation perspective promoted by researchers does not go far enough: persons with

health conditions may not consider themselves to be limited in activity. Some may be stigmatized and discriminated against just as people are who have an activity limitation. Thus, it is not necessary for a person to be limited in action; what matters is that they have an impairment to which others respond negatively. As with persons with disabilities, adverse treatment may occur directly, as in outright stigmatization or avoidance, diminished earnings, and lack of adequate health insurance, or indirectly, in terms of obstacles in the built environment (Pfeiffer 1987). In short, this perspective argues that the rights of all persons with impairments should be protected.

The definition of disability used in the ADA restricts disability only to those impairments that cause limitations in major life activities. An exception is provided in that persons with impairments who are not limited in major life activities, but are perceived by others to be limited, are included in the ADA. However, it is clear that the ADA definition does not include all persons with impairments. How exclusive the Act will be depends on how the definition of the term "major life activities" evolves as the law is implemented.

INDIVIDUAL SELF-PERCEPTION

Here I evaluate whether people consider themselves as having a disability if they are not limited in activity. A telephone survey conducted by the International Center for the Disabled (ICD) in 1986 measured disability both in terms of activity limitation and whether a person considered him- or herself to have a "disability" (self-defined) or felt they would be so considered by others. This survey defined disability in a manner similar to the definition of disability used in the ADA. Of Americans aged 16 years or more, 15 percent were found to have a disability. This estimate is close to the NHIS estimate for the same age range (Rice and LaPlante 1988). About 97 percent of the sample had some level of activity limitation. This survey also asked questions to screen in persons with learning, emotional, mental, or physical disabilities or talking, hearing, or seeing disabilities. The ICD survey attempted to cover all the bases for counting people with disabilities that the NHIS measure of activity limitation could conceivably miss. Because the two surveys yield similar estimates, it would appear that the question on activity limitation, which has been a part of the NHIS protocol since 1957, is a comprehensive measure of the concept of disability as perceived by researchers and individuals. The ICD survey

excluded persons with chronic illnesses and impairments that do not limit activity unless they considered themselves, or felt they would be considered by others, as having a disability.

Many persons with activity limitation do not consider themselves as having a disability. In fact, only half actually considered themselves as having a disability in the ICD survey. Some 47 percent of individuals with limitations stated that others consider them to have a disability after they get to know them well (this percentage drops to 32 percent for first encounters, suggesting that the more that is known about a person with a disability, the more likely they will be perceived by others as having a disability).

Self-identification as a person with a disability was highest (68 percent) for persons unable to perform major activities (i.e., major roles). Only 20 percent of persons limited in other than major activities considered themselves disabled or felt that others would consider them disabled. Of persons who did not consider themselves to be disabled, 20 percent stated that others would consider them disabled. Thus, there are in fact a small number of people who do not consider themselves as having a disability who are considered by others to have a disability. In general, persons are more likely to consider themselves as having a disability or to be so considered by others the more severely limited in activity they are. Thus, arguments of some researchers and advocates to broaden the definition of disability by including less severe functional limitations and impairments appear to expand disability beyond individual perceptions.

RECONSIDERING THE SIZE OF THE POPULATION COVERED BY THE ADA

As Burgdorf (1990) has also observed, the ADA figure of 43 million persons with disabilities is derived from a table providing an estimate of the number of persons with impairments based on the 1980 NHIS (Institute of Mathematica Policy Research 1984). The number is an inappropriate measure of the ADA definition for two reasons. First, impairments are defined in the NHIS to be functional or structural musculoskeletal and neuromuscular abnormalities and other abnormalities of visual and auditory senses, speech, and intelligence (National Center for Health Statistics 1986). The number does not include impairments of internal organs and tissue due to disease, such as HIV or emphysema. If the definition of impairment as including chronic disease were taken into account, the number of persons with impair-

ments would constitute more than half of the population. Second, the estimate is not restricted to limitation in major life activities.

It is estimated from the 1990 NHIS that 34 million persons living outside of institutions are limited in some activity because of an impairment. An additional two million persons reside in nursing homes, facilities for persons with mental retardation, and mental hospitals for persons with mental illness (LaPlante 1989). The activity-limitation measure is a more valid indicator of disability than counts of impairments because it is related to performance of activities. However, it probably undercounts persons with disabilities because, as operationalized in the NHIS, it may not cover all major life activities. Persons identified as having a major activity limitation are most likely to consider themselves as having a disability, but we must be careful not to neglect how public programs, in particular income-security programs, which focus on inability to work, may influence the identities of persons with disabilities.

In response to the question of who counts as having a disability, there is a range of answers depending on whether disability is considered to include basic human actions, like seeing, or walking, or lifting, or whether disability is restricted to more complex activities. Policy must decide at what level the problem of health-related discrimination should be addressed—impairment, basic human actions, or limitations in more complex activities. The stakes in terms of the potential numbers of persons covered are high.

TYPES OF DISABLING IMPAIRMENTS

Different impairments have varying effects on functioning. With the demographic transition from acute to chronic diseases and increasing life expectancy and aging of the population that has occurred during this century, impairments due to chronic disease have become increasingly significant as causes of disability. The emergence of chronic diseases as causes of disability has broadened the conceptualization of disability and how society responds to disability. As shown in figure 1, about 29 percent of these persons limited in activity owe their limitations to physical and sensory impairments. The majority of persons with activity limitations have chronic diseases. Fifteen conditions with the highest prevalence of causing activity limitation are shown in table 1.

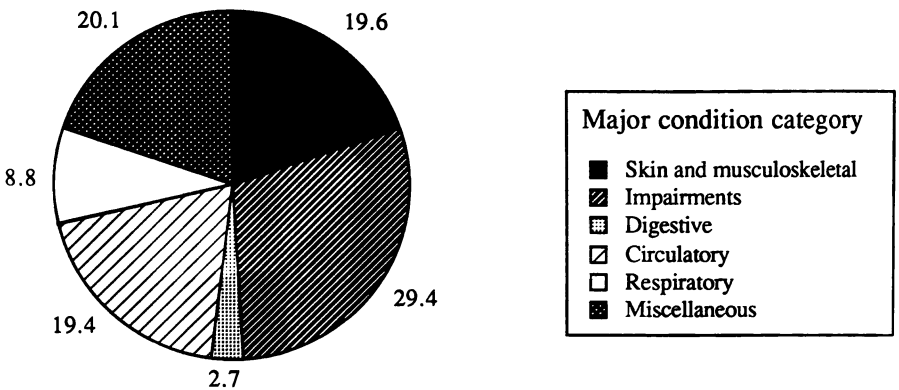


FIGURE 1. Distribution of conditions reported as main cause of activity limitation by major condition category, United States, 1983–1985 (in percent). (Note: Miscellaneous category includes conditions of the genitourinary, nervous, endocrine, metabolic, and blood-forming systems; cancer affecting sites other than these five categories; and mental illness.)

Source: LaPlante (1988).

People with activity limitations have on average 1.6 conditions that cause them to be limited. All conditions identified as causes of a person's limitation and those considered to be the main cause are listed separately. Arthritis is now the leading disease that causes activity limitation in the United States and is second in prevalence to orthopedic impairments (LaPlante 1988). It is important to recognize that chronic disease is often not as highly visible as physical impairment, which may present difficult decisions for disclosure of such information.

Health conditions and impairments vary in the likelihood of causing activity limitation. In table 2, conditions are ranked in terms of the percent of persons with a specific condition who are limited by the condition. Many of the most disabling conditions are childhood diseases, such as mental retardation and cerebral palsy. In general, highly disabling conditions tend to be low in prevalence, whereas those that occur frequently tend not to be highly disabling. The prevalence of disabling conditions, as shown in table 1, is thus a function of the prevalence of the condition and the chance that the condition causes disability. Arthritis is a major cause of disability, not because it often causes disability when it occurs, but because arthritis is highly prevalent in the population.

TABLE 1

Conditions with Highest Prevalence of Activity Limitation, All Ages: United States, 1983-1985

Main cause	Prevalence ^a	%	All causes	Prevalence ^a	%
All conditions ^b	32,540	100.0	All conditions ^b	52,718	100.0
Orthopedic impairments	5,220	16.0	Orthopedic impairments	6,987	13.3
Arthritis	4,000	12.3	Arthritis	6,130	11.6
Heart disease	3,736	11.5	Heart disease	5,575	10.6
Visual impairments	1,438	4.4	Hypertension	3,506	6.6
Intervertebral disk disorders	1,424	4.4	Visual impairments	2,900	5.6
Asthma	1,411	4.3	Diabetes	2,111	4.0
Nervous disorders ^c	1,289	4.0	Mental disorders ^d	1,837	3.5
Mental disorders ^d	1,284	3.9	Asthma	1,783	3.4
Hypertension	1,239	3.8	Intervertebral disk disorders	1,699	3.2
Mental retardation	947	2.9	Nervous disorders ^c	1,601	3.0
Diabetes	885	2.7	Hearing impairments	1,405	2.6
Hearing impairments	813	2.5	Mental retardation	1,047	2.0
Emphysema	649	2.0	Emphysema	994	1.9
Cerebrovascular disease	610	1.9	Cerebrovascular disease	939	1.8
Osteomyelitis/bone disorders	360	1.1	Abdominal hernia	595	1.1

Source: LaPlante (1988).

^aIn thousands.^bSee LaPlante (1988) for content of condition categories.^cNervous disorders include epilepsy, multiple sclerosis, Parkinson's disease, and other selected nervous disorders.^dMental disorders include schizophrenia and other psychoses, neuroses, personality disorders, other mental illness, alcohol and drug dependency, senility, and special learning disorders (mental deficiency is not included).

TABLE 2
 Conditions with Highest Risk of Disability, by Type of Disability, All Ages: United States, 1983-1986

Chronic condition	Number of conditions ^a	Percent causing activity limitation		Percent causing major activity limitation		Percent causing need for help in basic life activities	
		Rank	Rank	Rank	Rank	Rank	Rank
Mental retardation	1,202	84.1	1	80.0	1	19.9	9
Absence of leg(s)	289	83.3	2	73.1	2	39.0	2
Lung or bronchial cancer	200	74.8	3	63.5	3	34.5	4
Multiple sclerosis	171	70.6	4	63.3	4	40.7	1
Cerebral palsy	274	69.7	5	62.2	5	22.8	8
Blind in both eyes	396	64.5	6	58.8	6	38.1	3
Partial paralysis in extremity	578	59.6	7	47.2	7	27.5	5
Other orthopedic impairments	316	58.7	8	46.2	8	14.3 ^b	12
Complete paralysis in extremity	617	52.7	9	45.5	9	26.1	6
Rheumatoid arthritis	1,223	51.0	10	39.4	12	14.9	11
Intervertebral disk disorders	3,987	48.7	11	38.2	14	5.3	—
Paralysis in other sites (complete/partial)	247	47.8	12	43.7	10	14.1 ^b	13
Other heart disease/disorders ^c	4,708	46.9	13	35.1	15	13.6	14
Cancer of digestive sites	228	45.3	14	40.3	11	15.9 ^b	9
Emphysema	2,074	43.6	15	29.8	—	9.6	15
Absence of arm(s) hand(s)	84	43.1	—	39.0	13	4.1 ^b	—
Cerebrovascular disease	2,599	38.2	—	33.3	—	22.9	7

Source: LaPlante (1990). Data are from the National Health Interview Survey, 1983-1986, and estimates (annual averages) based on household interviews of the civilian noninstitutionalized population.

^aIn thousands. ^bFigure has low statistical reliability or precision (relative standard error exceeds 30%).

^cMI-art failure (9.8%), valve disorders (15.0%), congenital disorders (15.0%), all other and ill-defined heart conditions (59.9%).

GEOGRAPHIC VARIATION IN DISABILITY PREVALENCE

Disability prevalence varies considerably across the country and the impact of the ADA may also vary by geographic area. As shown in figure 2, rates of work disability are generally highest in the southern states. The states of Arkansas and West Virginia have the highest rates while Alaska and Hawaii have the lowest. The state populations with highest prevalence also have low educational attainment and income. Haber (Haber 1987) found that much of the variation in disability prevalence at the state level was attributable to socioeconomic differences of the states. He found that six variables explained 90 percent of the variation. These variables included income, employment and unemployment levels, low educational achievement, health, and region. Work in progress by Haber (1990) on 330 metropolitan statistical areas (MSAs) shows a similarly strong effect of socioeconomic variables on work disability prevalence.

The 1980 Census is the only source that provides direct estimates of disability by state or metropolitan area. The Census only included work disability, so measures of activity limitation due to impairment are not available. Until 1982, the NHIS provided estimates of disability for 30

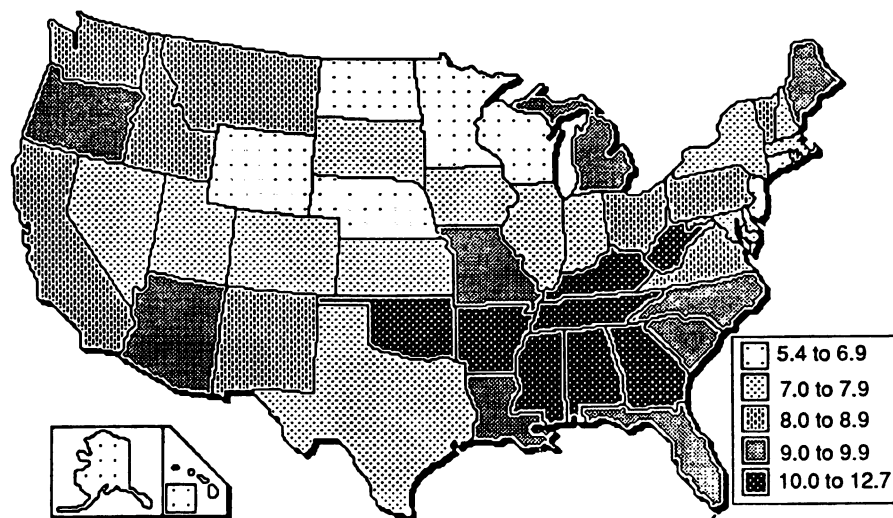


FIGURE 2. Persons aged 16 to 64 with a work disability by state, United States, 1980 (in percent).

Source: United States Census 1980. Reprinted with permission from Kraus and Stoddard (1989).

standard metropolitan statistical areas (SMSAs). In 1980–1981, Denver had the lowest rate of activity limitation (around 6 percent) whereas San Bernadino/Riverside had the highest rate (20 percent) (National Center for Health Statistics 1984). Some of these differences can be traced to the age distribution of these populations, but nevertheless they are large and the communities must deal with them. The ADA applies to nonelderly and elderly persons with disabilities alike, and while employment expectations differ by age, expectations in many other areas of social activity are similar.

DISABILITY AND DISCRIMINATION

Another axis in the evaluation of the impact of the ADA concerns the extent of discrimination toward people with disabilities. Not everyone with a disability experiences discrimination. Disability should not be equated with discrimination; some fraction, perhaps even the majority of persons with disabilities, do not feel they are discriminated against. It may be assumed that an even smaller fraction of persons with impairments that do not limit actions or activity feel they are discriminated against. Let us explore how persons with disabilities view their situation, which offers a baseline measure for considering the potential impact of the ADA.

The ICD survey asked a wide range of questions about the perceived impact of disability on quality of life, including work, social life, daily activities, education, and perceived barriers. No other survey has sought to elicit from persons with disabilities what they think can be done to increase their participation in society.

It is clear from the ICD survey that social participation of persons with disabilities is low. They attend cultural events, shop for groceries, and eat out less frequently than persons who do not have disabilities. The survey did not elicit information about specific barriers in social activity, such as the role of attitudes.

Persons with disabilities are less satisfied with life. As we know from Census and the NHIS surveys, the ICD survey found persons with disabilities to be less educated and to have less income. The ICD survey is one of the few surveys to elicit opinions about barriers to work. People with disabilities stated that they were affected by many differ-

ent kinds of barriers, reflecting the nature of their impairments as well as the variety of activities in which they are limited.

Of persons who had work experience while they had a disability, 35 percent stated that their employers had made some accommodation at work. Workplace accommodations have been shown to increase the job opportunities of persons with disabilities. Nagi (1976) found that for persons with similar levels of functional limitations, job adjustments by employers or respondents increased their chances of working. In the ICD study of working-aged persons with disabilities, however, 25 percent also said they had encountered job discrimination (ICD table 34). Thus, the world of work has both supported and hindered significant numbers of persons with disabilities. Of persons with disabilities who work less than full time or were not working, 47 percent stated that employers would not recognize that they were capable of working a full-time job (ICD table 32). Lack of available jobs in the individual's line of work or inability to find any jobs were also mentioned by 40 percent of this group. Other reasons cited for lack of full employment included poor education, lack of transportation, and lack of assistive equipment. However, most persons with activity limitation felt it was the limitation rather than employer's attitudes that prevented them from getting the type of job they desired.

Of those either unemployed and looking for work or unable to work, 77 percent felt that their limitation was more of a barrier than employers' reactions. This compares with 56 percent of those working full or part time (ICD table 37). These data reinforce the notion that many persons with severe disabilities may not be able to work in traditional jobs. If we generalize to data from the NHIS during 1983–1985 (with some trepidation because the data sources are substantially different), of the 9.9 million persons aged 18 to 69 who say that they are unable to work, we might expect that some 23 percent would be able to work if the working environment were made more hospitable. Perhaps up to 44 percent of the 7.6 million persons who are limited in the kind or amount of work they can do would be able to have better jobs if the working environment were made more hospitable. Johnson and Lambrinos (1987) found that negative attitudes toward people with impairments had a negative effect on wages even when social and educational characteristics were taken into account.

One of the most cited findings of the ICD survey is that 66 percent of persons with disabilities who are not working would like a job. Those who are not working include the unemployed, all of whom are by

definition looking for work, those who are retired, keeping house, or going to school. It would be interesting to know specifically what fraction of the population who say they are unable to work want a job. Is it 23 percent or 66 percent of the 9.9 million who are now unable to work who could be employed? This is an important target population that represents a large increase in the American work force. By many counts, however, the reality is that the population of persons with disabilities has been treated as a reserve work force and is more likely to be unemployed when economic times are rough.

Outside the world of work, about 57 percent of persons limited in activity believe that their limitation has prevented them from reaching their full abilities as a person. Conversely, 43 percent feel that their limitation has not prevented them from reaching their full abilities. Of those who cannot perform their major activity, 69 percent feel they are so prevented. The more severe the limitation, the more likely that it prevents fulfillment in work or other activities.

There is no doubt that discrimination toward people with disabilities exists. However, discrimination is not homogeneous for all persons with disabilities. The evidence is that people with disabilities are not equally likely to be discriminated against. Thus, not all of the 36 million persons with activity limitations are discriminated against, and those who are do not experience discrimination to the same degree.

THOUGHTS TOWARD EVALUATION

With the passage of the Americans with Disabilities Act, a new level of demand for data on persons with disabilities has emerged. Because of changes expected to be wrought by the ADA, a variety of information must be collected to assess and monitor opportunities in employment, transportation, public accommodations and public services, and telecommunications. There is a need to assess and monitor the social status and opportunities of persons with disabilities in the United States. Many gaps can be enumerated where important information is lacking. The field of disability statistics lags well behind many areas of health and social statistics. Data collection is often episodic and incomplete. Different agencies collect information for different purposes with little integration. Some of the momentum behind the ADA could be

directed profitably toward data development and coordination (Levine, Zitter, and Ingram 1990).

Ultimately, the impact of the ADA should be to increase the economic and social opportunities of persons with impairments that cause limitations in major life activities. In order to demonstrate such an impact, baseline information is needed on the current economic and social activity of such persons. The ICD survey provides some baseline information. A repeat of that survey after the ADA has had an opportunity to make a difference would provide some data to assess changes from the time of the original study. It is imperative for the evaluation of the ADA that existing data-collection efforts such as SIPP and NHIS continue to field questions on impairments, functional limitations, and limitations in employment and other activities.

Two centrally important axes in evaluating the impact of the ADA concern the definitional issue and the quantification of discrimination. To better address both axes, there is a need to develop data sources that include measures of impairment, functional limitation, activity limitation, and measures of social and economic activity, including individual perceptions of what persons with impairments can do and desire to do. A shortcoming of the ICD survey, for example, is that no data are available on the functional characteristics of the 66 percent of persons who would like a job. These data would help to clarify their employability prospects. National surveys like SIPP and NHIS need to be strengthened in terms of measuring limitations of function and in the broader spectrum of life activities.

Assessing which individuals will benefit from the ADA is not easily done. National data provide estimates of persons with disabilities and/or persons prevented from performing certain activities because of health problems. These data are individual attributions and do not provide information about whether the reason a person says he or she has a disability or is prevented from carrying out certain activities is due to barriers that could be overcome. In that sense, the ADA is a social experiment that could provide such data. To the extent that the ADA is successful in removing barriers, persons with specific impairments and equal levels of functioning should become more active socially and economically.

Another issue concerns the diversity of the population of persons with disabilities. Assessment is more straightforward for mobility problems and physical impairments than for chronic illness. For example, it is straightforward to estimate who benefits from refitting doors in

offices to accommodate a wheelchair: the roughly 1 million people who use a wheelchair. Other examples can be provided of the numbers of persons benefitting from removal of specific architectural barriers (LaPlante and Grant 1988). However, to assess the employability of persons with multiple sclerosis, AIDS, or emphysema requires an understanding of the nature of the impairment and its relationship to functional losses, which may also be dynamic.

There is also a clear requirement for direct estimates of disability prevalence by state and local areas that can be used to determine local needs.

SUMMARY AND CONCLUSIONS

In this article, I have attempted to clarify some of the disparate estimates and ways of measuring disability that have been used in different surveys. The definitional issue has implications for the size of the population that will be covered by the ADA. I have reviewed several perspectives, including that of researchers, disability advocates, and individual self-perceptions, which need to be considered in understanding the meaning of disability. Disability involves limitations in actions and activities because of mental and physical impairments. Comparison of these different perspectives reveals that the differences lie in the range of activities that are considered. At least 36 million persons, over 14 percent of the U.S. population, are limited in selected activities. Depending on what are considered to be major life activities, the population covered by the ADA could vastly exceed that figure.

Little information is available about the extent to which persons with disabilities, however defined, are affected by discrimination and unequal treatment. Limited data are available from one survey conducted by the International Center for the Disabled, which indicate that as many as 66 percent of persons with activity limitations who are not working would like a job. On the other hand, many persons with activity limitations indicate that their limitations are an important cause of their unemployment. About a quarter of persons with activity limitations due to impairments have experienced discrimination in some form.

The impact of the ADA will likely vary by impairment. Because the prevalence of chronic diseases is far greater than the prevalence of

physical and sensory impairments, chronic diseases are more frequently the cause of disability. The risk of disability is highest for impairments with low prevalence. Because states and local areas differ in the prevalence of disability, the impact of the ADA will also be likely to vary by geographic area. For some states, the rate of work disability is more than twice the rate of other states. Yet, research indicates that much of the variation is due to socioeconomic characteristics of areas. This reflects, at the macroeconomic level, that persons with disabilities are more likely to be poor and less educated than persons without disabilities.

Because of differences in understanding what disability is and insufficient knowledge about the extent of the problem of discrimination toward persons with disabilities, assessment of the potential impact of the ADA is challenging. Improvements in data are necessary to better understand the abilities of persons with activity limitations to participate in the work environment and in social and recreational opportunities in the larger physical and social environment. We can hope that the momentum behind the ADA can be directed to provide a data-collection system for an ongoing assessment of the effectiveness of the ADA in increasing the participation of persons with disabilities in society.

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