

The Social and Policy Context of the Act

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EDITOR'S NOTE

Persons with disabilities are often perceived as second-class citizens and are offered second-class opportunities. Many disability policies reflect these perceptions by promoting segregation and dependence. The disability-rights movement, with the independent-living movement at its center, has made some progress in changing societal attitudes about persons with disabilities. This progress is reflected in the legislative building blocks that preceded the Americans with Disabilities Act and in the ADA itself.

Focusing disability policy on the promotion of independence and integration is no small task. The ADA requires us to understand that civil rights for persons with disabilities involves an accommodation imperative and necessitates an individualized assessment for each situation. West sets the stage for this challenge as she explores the social and policy environment that generated the ADA.

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As a declaration of equality for persons with disabilities, the Americans with Disabilities Act (ADA) sends a clear directive to society regarding what its attitudes toward persons with disabilities should be: respect, inclusion, and support. The ADA is the result of two decades of effort, mainly by the disability-rights movement and its allies, to change policies based on quite different attitudes: pity, patronization, and exclusion. In establishing equality of opportunity, full participation, independent living, and economic self-sufficiency as the nation's proper goals for persons with disabilities,¹ the ADA reflects a commitment to its own prescription.

In this article, I will examine the social and policy context of the ADA in terms of the evolution of attitudes toward persons with disabilities. I will consider both societal attitudes toward persons with disabilities and the attitudes persons with disabilities hold toward themselves. I will examine these attitudes through three lenses: the experience of disability in America, the changing language of disability, and federal disability-rights legislation over the past 20 years. I will analyze how our public policies and our language, both the results of negotiation, have defined and reflected the changing relationships between persons with disabilities and the society at large. This article documents a gradual change in attitudes, of which ADA is the latest outcome.

CURRENT STATUS OF PERSONS WITH DISABILITIES

Only in the last decade have we begun to consider persons with disabilities as a distinct minority group that can be described in terms of demographic characteristics and in relation to other minority groups. (See the articles by LaPlante and Yelin in this volume.) Although the limited data that we have for this purpose often raise more questions than they answer, we can make significant descriptive statements.

When compared with other minority groups, persons with disabilities are distinguished in virtually every category by their disadvantaged status. The ADA notes:

Census data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally.²

A few specific examples illustrate the status of persons with disabilities in the late 1980s:

- Fifty percent of adults with disabilities had household incomes of \$15,000 or less. Only 25 percent of persons without disabilities had household incomes in this bracket.³
- Two-thirds of all Americans with disabilities between the ages of 16 and 64 were not working at all. Sixty-six percent of these would have liked to work. (Louis Harris and Associates 1986)
- Where only 15 percent of all adults aged 18 and over had less than a high-school education, 40 percent of all persons with disabilities aged 16 and over had not finished high school. (Louis Harris and Associates 1986)
- Whereas 56 percent of all students participated in post-secondary education programs, only 15 percent of students with disabilities did. (Wagner 1989)
- Persons with disabilities participated in social events (e.g., dining out, movies, attending sporting events) far less frequently than persons without disabilities. (Louis Harris and Associates 1986)

Furthermore, the situation for persons with disabilities has grown worse in the last two decades—at least in terms of economic well-being. A recent study concluded that in the mid-1960s the income levels of persons with disabilities were close to those without disabilities. Their relative well-being declined in the next decade, reaching a low in the recession of the early 1980s. Since then, people with disabilities have regained most of the ground they lost; however, those gains are very unevenly distributed and increases in household incomes have come mainly from increased wage earnings by household members who do not have disabilities. Nonwhite persons with disabilities who are not well educated are the worst off (Burkhauser, Haveman, and Wolfe 1990).

DISCRIMINATION AGAINST PERSONS WITH DISABILITIES

It is generally accepted that discrimination plays a significant role in the outcomes described above. Congress believes that the elimination of discrimination will facilitate the achievement of the goals of equal opportunity, full participation, independent living, and economic self-sufficiency. The establishment of "a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities"⁴ is the ADA's contribution toward meeting these goals.

Discrimination against the estimated 43 million persons with mental and physical disabilities has been documented repeatedly (Arangio 1979; English 1971; Livneh 1982; Presidential Commission on the Human Immunodeficiency Virus 1988; U.S. Commission on Civil Rights 1983; U.S. Senate Committee on Labor and Human Resources 1989). Findings in the ADA hold that society has tended to isolate and segregate persons with disabilities⁵ and that discrimination continues to be pervasive in virtually all aspects of life.⁶ The ADA finds that persons with disabilities have been "subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness" primarily because of social stereotypes.⁷ Persons with disabilities who are members of other groups that frequently encounter discrimination, like African Americans and women, may encounter dual discrimination (Brown 1981; Burkhauser, Haveman, and Wolfe 1990), leaving them to wonder on which basis they are rejected.

Discrimination against persons with disabilities might be considered to have two aspects: (1) *prejudice* and (2) *barriers*. Persons with disabilities share with other groups the experience of being the target of prejudiced, or "pre-judged" attitudes. However, many of the barriers confronted by persons with disabilities are unique to them.

PREJUDICE

Prejudice is an attitude that distorts social relationships by overemphasizing some characteristic, such as race, gender, age or disability (U.S. Commission on Civil Rights 1983). Although a range of prejudicial attitudes is examined later in this article, let it suffice now to note that prejudice often gives birth to myths, stereotypes, and stigma, which are associated with a negative exaggeration of the individual's impairment to the exclusion of other attributes. Persons with disabilities have long encountered a generic stereotype, which holds that "you are less of a

person if an aspect of your functioning is impaired." Impaired functioning translates to the assumption of impaired personhood.

This prejudicial outlook about the capabilities of persons with disabilities has foreclosed certain opportunities to them. An employer may not consider hiring a receptionist who is blind, assuming that he would be incapable of performing the tasks of the job. A training program for dentists may refuse to admit a candidate who cannot hear, assuming she would be unable to understand the instructors or communicate with patients.

Women and other minority groups share the experience of being the recipient of prejudiced attitudes and concomitant discriminatory policies and practices. One of the damaging effects is that many come to believe what they hear and internalize the experiences of discrimination they confront, resulting in beliefs of inadequacy and low self-esteem.

BARRIERS AND THE ACCOMMODATION IMPERATIVE

The other aspect of discrimination against persons with disabilities is *barriers*, defined as *any aspects of the social or physical environment that prohibit meaningful involvement by persons with disabilities*: stairs for a person in a wheelchair; lack of a TDD for a person who cannot hear seeking to use the phone; a health service for a person who cannot hear and is not provided an alternative way to communicate.

This second aspect of discrimination against persons with disabilities—barriers—generates an *accommodation imperative* when the exercise of their civil rights is at issue. The accommodation imperative requires that efforts be undertaken to render the experience in the environment available in a meaningful way to the person with a disability. Without the accommodation imperative, the notion of equal opportunity for persons with disabilities may be inviable. An opportunity may not be equal if there is neither accommodation nor accessibility. A job on the third floor of a building with no elevator is not an equal opportunity for a person in a wheelchair. An educational program for a student who is blind that provides no alternative reading method, such as braille or a reader, is not an equal opportunity.

In order to achieve nondiscrimination, society enters into a contract with a person who has a disability. Society agrees to structure or manipulate the social and physical environment in every reasonable way with the goal of creating an experience that is a meaningful equal opportunity for the individual with the disability. This obligation may involve

an allocation of resources or an expenditure of funds. The person with a disability agrees to make the same effort at citizenship that we expect from everyone else.

The ADA affirms that it is not enough to hang up a sign and say, "We do not discriminate on the basis of disability." In order for an opportunity to be truly equitable, more is required from society than a passive commitment to equal opportunity. Whereas simply eliminating exclusionary policies may at times be sufficient for people with disabilities and members of other special classes (e.g., racial and ethnic minorities and women), there are times when more may be required.

Often a stated goal of nondiscrimination policy for persons in other stigmatized groups is to be treated in a neutral fashion, or just like everyone else; this may not be the case for persons with disabilities. The goal may be to "forget" that the individual is a woman, or an African-American, as standards are applied. It is often said that the law should be administered in a "color blind" fashion. While this may be the case in some situations for persons with disabilities, in other situations the goal, in fact, may be the opposite: a recognition of the functional impairment and an effort to adapt an environment or situation to enhance functioning and/or discover alternatives that will yield meaningful involvement. Rather than viewing the environment as a series of obstacles that exacerbate an impairment, the ADA requires it to be seen as a medium that can provide opportunities to ameliorate the results of functional impairments or to develop alternatives that enable accomplishment of a particular task.

One of the most significant aspects of the accommodation imperative is that it must be individualized. Although persons with disabilities are a group—and may be considered a "protected class" for purposes of civil rights, or a set of people defined by particular characteristics in terms of eligibility for certain services and programs—people with disabilities are, more than any other descriptor, individuals. The uniqueness of each person with a disability in terms of how that disability may or may not affect his or her functioning and in what circumstances is an essential aspect of considering discrimination against persons with disabilities.

Unlike race and gender, moreover, disability is often a dynamic and changing characteristic. A disability that may require no accommodation in one situation may demand complex technological intervention in another. Furthermore, some disabilities change in their intensity from day to day or week to week and may require different accommo-

dations at various times. The same impairment often affects individuals differently. A critical aspect of accommodations is flexibility.

While ordinary citizens and national leaders may have a definitive sense of what it means not to discriminate against a racial minority, this is not the case for persons with disabilities. Until recently, persons with disabilities have been a notably silent and nonvisible minority in society. The addition of the accommodation imperative to the concept of civil rights requires a change in our thinking.

ATTITUDES TOWARD PERSONS WITH DISABILITIES

Being the target of discrimination and negative attitudes may be the one common experience shared by the diverse group of persons with disabilities. Research documents that persons without disabilities perceive persons with disabilities with a range of negative attitudes (English 1971), although the percentage holding these biases is unknown. Studies about attitudes toward persons with disabilities have been ongoing since the 1950s.

Several studies have indicated that males have more negative attitudes toward persons with disabilities than females (English 1971). Favorable attitudes are more likely to occur among persons with higher incomes and educational levels (Livneh 1982). Mental disabilities are the most negatively perceived (Arangio 1979). The sources of these negative attitudes include sociocultural conditioning and childhood influences (Livneh 1982). The terms "handicappism," "physicalism," and "normalism" have been offered as disability correlates to "racism" and "sexism" when referring to prejudices toward persons with disabilities (Longmore 1985).

Persons with disabilities have documented and described a number of second-class relationships with society. They have articulated the experience of being invisible or ignored; of engendering discomfort; of being objects of pity; of being adulated as inspirational for overcoming seemingly insurmountable obstacles; of negotiating a bargain with society.

The experience of being repeatedly ignored or unnoticed has been described as one of "disconfirmation," whereby one is denied recognition as a person (Golfus 1989). Disconfirmation comes in many forms: being deserted by former friends after sustaining an impairment or

being dismissed by a receptionist who is too busy with “real work” and “important people.” Disconfirmation comes frequently from the very individuals and programs designed to support people with disabilities. Persons with disabilities experience rejection from both services and individuals (e.g., counselors, educators, therapists) because they do not fit into a prescribed mold of behavior or symptoms. The message is, “There’s nothing wrong with the program, there’s something wrong with you.”

Persons without disabilities frequently experience discomfort and embarrassment when interacting with persons with disabilities (U.S. Commission on Civil Rights 1983). They may feel unsure of how to act around a person with a disability. (Should they offer help? Should they ignore the disability? Should they comment on the disability?) The discomfort could reflect an awareness that persons without disabilities are vulnerable to death, injury, and disease—a vulnerability most of us are eager to forget. Anyone can become a person with a disability virtually in a matter of seconds. Finally, discomfort may come from a concern about what other people will think if you associate with a person with a disability: will you be considered second rate by association? Feelings of discomfort have caused proprietors to reject persons with disabilities from restaurants, movie houses, zoos, and other public places. Proprietors may believe they will drive other customers away because they engender discomfort and even revulsion.

Persons with disabilities are frequently looked upon with pity (U.S. Commission on Civil Rights 1983). This is most clearly seen in fundraising efforts by nonprofit organizations, which may depict individuals with disabilities in a pity-invoking manner in hopes of appealing to charitable instincts. When a charitable attitude goes overboard, it may turn into pity or patronization. Attitudes of pity are rarely accompanied by attitudes of respect for the dignity of persons with disabilities, but are grounded in the belief that “I am better than you are.” Pity and patronization rarely engender independence and empowerment, but rather dependence and low self-esteem.

Persons with disabilities have often been looked upon with horror. Portraying having a disability as a “fate worse than death” sends a clear message to persons with disabilities. This attitude is often utilized to sell insurance policies or “scare” people with certain conditions into getting treatment so they don’t regress and reach this state “worse than death.” For example, a recent memo from the general manager of an insurance agency to agents included a photo of a body next to a

wrecked car, with the caption: "Do you think he's dead? He's not, but he might have been better off if he were. He is dead from the waist down. He'll never walk again." The memo was intended to inspire agents to sell disability insurance (*Disability Rag* 1990).

Many persons with disabilities resent being viewed as heroes or heroines, as remarkable achievers, as inspiration for the average person with everyday problems. The person with the disability may be described as "courageous" or "inspirational" because he or she accomplishes things while having a disability, or in spite of it. Commenting on being repeatedly described as "courageous," Stephen Hawking, the brilliant Cambridge University scientist who has Lou Gehrig's disease, noted his aversion to being repeatedly labeled a superhero because he has a disability. Readers of the *Disability Rag*, a voice of the disability-rights movement, noted that being described as "courageous" was the one aspect they hated the most about how people with disabilities are portrayed in the media (*Disability Rag* 1990). They see it not as a view of respect and equality, but as one where a person with a disability is not considered to be like every one else.

Many of these attitudes are reflections of a widely held conviction in our society that youth, beauty, and success are to be striven for at virtually any cost. This conviction leaves scant space for tolerance of persons with disabilities, much less for any affirmation of their equality. Furthermore, these attitudes define persons with disabilities from the perspective of society at large, not from the perspective of persons with disabilities themselves. Persons with disabilities have been defined negatively by society; their identity has been shaped by society and given to them.

To negotiate this imposed identity, persons with disabilities have struck a bargain with society, according to one disability-rights activist (Johnson 1989). The society agrees to marginal acceptance of the person with the disability as long as that person cheerfully strives to be normal. The more normal he or she becomes, the more acceptance the person gains. Many persons with disabilities are uneasy with this bargain. Their discomfort has in part spurred the disability-rights movement, which strives to place self-definition in the hands of persons with disabilities.

Changing attitudes toward persons with disabilities is a long, slow process. Attitudes are learned and conditioned over many years. Changing attitudes will take time. In recent years, the disability-rights movement has begun that process.

THE DISABILITY-RIGHTS MOVEMENT

It has been suggested that the ultimate test of a minority group is self-identification (Hahn 1985). Persons with disabilities, like other oppressed groups, move to claim the power to define themselves, to develop their own identity, culture, and pride. This movement toward self-identification can be seen in the growth of the disability-rights movement, the independent-living movement, the evolving political sophistication and power of the disability interest groups in Washington, the changes in language we use to talk about people with disabilities, and shifts in public policy.

Seventy-four percent of people with disabilities surveyed by Louis Harris and Associates (1986) said they feel at least some sense of common identity with other people with disabilities. Forty-five per cent said they feel that people with disabilities are a minority group in the same sense as African Americans and Hispanics. Those who were younger and who had disabilities beginning at earlier periods in their lives were more likely to see people with disabilities as a minority group.

Persons with disabilities, however, face unique challenges in solidifying as a minority group. Although the negative experience of encountering discrimination and demeaning attitudes is common to other minority groups, many of the positive minority-group experiences are lacking for persons with disabilities (Johnson 1987; Kriegel 1969). Unlike other minority groups, persons with disabilities have generally grown up in isolation from each other and there is no sense of a subculture or of positive shared experiences with which they can identify (Johnson 1987; Zola 1988). Emphasis on functional limitation has encouraged persons with disabilities to "overcome" their disabilities, not to identify with them (Hahn 1985). Some have noted that there is a case to be made for segregated schools for youngsters with disabilities, in order to foster disability identity and culture (Johnson 1987; Thomas 1989).

The trademarks of minority pride, such as slogans, rituals, clothing, hairstyles, and songs, are in their infancy in the disability community. The equivalent of "Black is Beautiful" or "Sisterhood is Powerful" has yet to emerge from the disability community (Zola 1988). The challenge of turning stigma into pride is at the heart of solidifying persons with disabilities as a minority. One disability-rights commentator

noted, "If we neglect the cultural aspects of our movement, we will fail" (Johnson 1987, 9).

Although the emergence of persons with disabilities as a cultural minority is just beginning, the disability-rights movement has grown considerably in the last decade. Leadership of disability organizations and interest groups is increasingly in the hands of persons with disabilities themselves and federal programs affecting persons with disabilities are more often administered by persons with disabilities.

At the heart of the emergence of the disability-rights movement is the philosophy of independent living. The independent-living philosophy emerged in the 1960s bolstered by the civil-rights movements for African Americans, the women's rights movement, and the tenor of the times, which challenged the status quo. Persons with severe disabilities were seeking alternatives to institutionalization, segregated programs, and service delivery systems that offered limited alternatives and little support for self-determination. Independent living, at its core, is a set of values dedicated to self-determination and personal control over one's own life. Equal opportunity to participate in all aspects of society, including freedom of choice and risk taking, are tenets of the independent living philosophy (DeJong 1979; Lachat 1988).

The independent-living movement has rejected the role of patient for persons with disabilities and has embraced consumer-controlled decision making instead. The fact that many disabilities are conditions that may be lifelong has led to a rejection of the medical model, which sets the goals of palliation or cure, embracing instead a management approach that seeks maximum independence. Living in the community as other members of society do, and not in institutions and segregated settings, is another trademark of independent living.

This evolving consciousness of independent living has been a significant contributor to a growing sense of a disability community and a call for civil-rights reforms. Independent living has also emerged as an important service-delivery model with hundreds of centers currently providing services throughout the country. The independent-living consciousness has shepherded in a gradual shift in policy focus from custody to cure to care to rights.

THE LANGUAGE OF DISABILITY

A recent article in the *Wall Street Journal* about the Americans with Disabilities Act was entitled "Disabilities Act Cripples through Ambi-

guity" (Weaver 1991). In a recent effort to raise money for persons with disabilities, Jerry Lewis described a wheelchair as "that steel imprisonment that long has been deemed the dystrophic child's plight" (*Disability Rag* 1990, 30)

Contrast these with some current posters recently issued by the National Easter Seal Society. A person in a wheelchair sits at the bottom of a flight of stairs and the caption reads: "For some people the search for an apartment is all uphill." Another poster pictures a person's hand meeting a person's hook (prosthetic device) for a handshake. The caption reads, "Sometimes the worst thing about having a disability is that people meet it before they meet you" (*Disability Rag* 1991, 36).

The difference in the language of these statements indicates efforts to move away from patronizing and stigmatizing descriptors to empowering and respectful terminology. The language also reflects the thinking that the individual's particular impairment is less of a difficulty than the person's reception by society at large. In testifying before Congress in support of the passage of the ADA, Governor (formerly Senator) Lowell Weicker of Connecticut (1989) noted that the biggest obstacle for people with disabilities was not so much what God hath wrought, but rather what man has imposed by custom and law.

The language used in the ADA, and throughout this book, is what is often called the "people first" language: for example, "individuals with disabilities" or "persons with disabilities." This terminology evolved as a rejection of descriptors that focus on the impairment, not the person: for example, the deaf, the blind, the disabled, cripples.

The terminology "disabled" and "disability" is generally preferred to "handicapped" and "handicap." In proposing a change in the name of the U.S. Senate Subcommittee on the Handicapped to the U.S. Senate Subcommittee on Disability Policy, Senator Tom Harkin (D-Iowa) noted that the term "handicapped" has a negative connotation and it was the responsibility of the subcommittee to do the opposite of what the name implied: "It is our responsibility to develop public policy which removes the barriers in this society for people with disabilities and enables them to pursue their independence in an environment of respect and support . . ." (Harkin 1989).

The names of other important national organizations have changed in recent years also. The National Council on the Handicapped is now the National Council on Disability. The President's Committee on Employment of the Handicapped has become the President's Committee for the Employment of People with Disabilities.

This year a New York foundation—the National Cristina Foundation—sponsored a contest, offering a \$50,000 reward to whoever could come up with a word or phrase for the abilities of people with disabilities. This phrase was intended to convey a positive empowering message about persons with disabilities, rather than the negative demeaning messages so much of the terminology implies. The winning phrase was “people with differing abilities.”

There are differences of opinion about the proper language of disability in the disability community and elsewhere. Some feel that the energy spent on determining the proper language is better spent on “real” issues, like accessing attendant services (*Disability Rag* 1990). Other people see their disability as a central feature of their identity and choose to call themselves “deaf people” or “cripples” (Zola 1988). In their view, to consider the disability as a secondary feature is not being true to their identity. Another view is that preoccupation with particular language and terminology is evasive, euphemistic, and contains the seeds of backlash. In fact, one entry to the contest sponsored by the National Cristina Foundation was “severely euphemized” (*Disability Rag* 1990, 14)

LEGISLATIVE BUILDING BLOCKS FOR THE ADA

The ADA is the culmination of years of legislative action. Legislation for people with disabilities can be thought of in at least three categories: programs and services, income maintenance, and civil rights. Numerous pieces of civil-rights legislation promoting the full participation and independence of persons with disabilities predate the adoption of ADA. In addition, many programs and service-delivery systems that provide education, training, and support services for persons with disabilities have been established by the federal government. Although some of these programs have been criticized for promoting dependence rather than independence (Berkowitz 1987), a good number are intended to support the goals of the ADA.

In the last two decades, federal laws have made incremental changes that created the possibility of enacting the ADA. These laws are grounded in the core concepts pervading the ADA: full participation and independence. Although bills were repeatedly introduced since the mid 1960s to amend generic civil-rights laws to include persons with

disabilities (Burgdorf 1990), none received serious legislative consideration. In 1977 the White House Conference on Handicapped Individuals recommended amending all titles of the Civil Rights Act of 1964 to include discrimination on the basis of disability. Nor did legislation introduced in the mid 1980s to provide antidiscrimination protection for persons with HIV and AIDS gain serious consideration.

In 1986, the National Council on Disability, a presidentially appointed disability-policy agency, issued a report to the President entitled *Toward Independence*, recommending the enactment of comprehensive antidiscrimination legislation for people with disabilities. This report was followed up by another one, *On the Threshold of Independence*, in 1988, which included a draft of the legislation. At that same time the Presidential Commission on the Human Immunodeficiency Virus issued its final report calling for similar legislation. The National Council asked then Senator Weicker, the historical legislative champion of disability rights, to introduce the legislation. Senator Weicker agreed. When the Senate changed from a Republican to a Democratic majority in 1987, Senator Tom Harkin became chairman of the Subcommittee on Disability Policy. He joined Senator Weicker, then the ranking minority member of the subcommittee, to champion the ADA, and eventually to become its chief sponsor in Congress.

With the unique opportunity of a civil-rights initiative emanating from a Republican administration agency, the well-organized disability-interest groups, joined by the newly emerging AIDS interest groups, seized the opportunity for action. It was at this point that Congress seriously began to consider comprehensive antidiscrimination protection for persons with disabilities.

The following federal laws could be considered legislative building blocks for the ADA:

- *The Architectural Barriers Act of 1968*⁸ mandated that all buildings constructed, altered, or financed by the federal government after 1969 be accessible and usable by persons with physical disabilities. In 1973, the Architectural and Transportation Barriers Compliance Board (ATBCB) was established to develop guidelines and accessibility standards and to enforce these standards. The guidelines took effect in September 1982.

- In 1973, *sections 501, 503 and 504*⁹ were enacted as part of the Rehabilitation Act. Section 504 prohibits discrimination against otherwise qualified persons with disabilities in any program or activity receiving federal funds and in executive agencies and the Postal Service.

Sections 501 and 503 require affirmative-action plans for the hiring and advancement of persons with disabilities in the federal government and any contractors receiving federal contracts over \$2,500.

Section 504 is the most significant building block for the ADA. Its 17-year history of implementation has delineated many core concepts of the ADA, such as "reasonable accommodation" and "undue burden." Numerous court decisions have examined questions raised by section 504, such as how to determine when a person with a disability is "otherwise qualified," when a "reasonable accommodation" crosses the line and becomes an "undue burden," and when a person with a disability presents a threat to the health and/or safety of others. The implementing regulations for section 504, which emanate from numerous federal agencies and are voluminous, have offered definitions of key terms, such as who is and is not considered a person with a disability. The article in this volume by Nancy Lee Jones provides an analysis of section 504.

In 1988 section 504, as well as other civil-rights statutes, was amended by the Civil Rights Restoration Act.¹⁰ This legislation overturned the Supreme Court's *Grove City College v. Bell*¹¹ decision and defined coverage of section 504 as broad (e.g., extending to an entire university) rather than narrow (e.g., extending just to one department of the university) when federal funds were involved. The Civil Rights Restoration Act was particularly significant as an ADA building block because of the Humphrey-Harkin provision, which amended the Rehabilitation Act's definition of an individual with a disability. This provision incorporated the standards and approach outlined by the Supreme Court in deciding *School Board of Nassau County, Florida v. Arline*,¹² and clarified that an individual with a contagious disease or infection who posed a "direct threat" to the health or safety of others was not covered by section 504. The amendment was in response to concerns that employers might be required to hire a person with a contagious disease or infection, especially AIDS or HIV infection, when that individual posed a direct threat to others. Lawrence O. Gostin discusses the "direct threat" language, as incorporated in the ADA in his article.

- In 1975, *The Education for All Handicapped Children Act*¹³ was enacted. Now called the *Individuals with Disabilities Education Act*,¹⁴ this law mandates a free, appropriate public education for all children with disabilities. It requires that they be educated in the "least restrictive environment" or with their nondisabled peers to the maximum extent appropriate. Integration of students with disabilities is often

called "mainstreaming." Over four million students with disabilities are currently in programs receiving federal support.

- *The Developmental Disabilities Assistance and Bill of Rights Act*,¹⁵ also enacted in 1975, includes a small federal grant program administered by state Developmental Disabilities Councils and is intended to coordinate and fund services for persons with developmental or severe long-term disabilities whose onset occurred prior to age 22 and usually require lifelong services. Largely in response to substandard and abusive situations in institutions for persons with mental retardation, the bill of rights declared that persons with developmental disabilities have a right to appropriate treatment, services, and habilitation that maximize the developmental potential of the person and take place in a setting least restrictive to personal liberty. Although not enforceable, the bill of rights is a statement of congressional intent.

The Developmental Disabilities Act also established in every state a system of protection and advocacy organizations that are independent of any service-providing organization. They advocate for and represent the rights of persons with developmental disabilities, in addition to providing information and referral services.

- In 1980 Congress passed the *Civil Rights of Institutionalized Persons Act*¹⁶ authorizing the U.S. Department of Justice to sue states for alleged violations of the rights of institutionalized persons, including persons in mental hospitals or facilities for persons with mental retardation.

- In 1984, Congress enacted the *Voting Accessibility for the Elderly and Handicapped Act*.¹⁷ The law requires that registration and polling places for federal elections be accessible to persons with disabilities.

- In 1986 Congress acted to overturn a Supreme Court decision which held that air carriers operating at federally funded airports were not subject to Section 504. *The Air Carriers Access Act of 1986*¹⁸ prohibits discrimination against persons with disabilities by all air carriers and provides for enforcement under the Department of Transportation.

- Although housing was originally included as a part of the first version of the Americans with Disabilities Act, it was dropped when the opportunity materialized to include persons with disabilities in the *Fair Housing Act Amendments of 1988*.¹⁹ The Fair Housing Act added persons with disabilities as a group protected from discrimination in housing. This was the first time the antidiscrimination mandate for persons with disabilities was extended into the private sector. The law

mandates accessibility standards for all new housing construction for multifamily dwellings and ensures that persons with disabilities are able to adapt their dwelling place to meet their needs. Many of the features that appear in the ADA come directly from Fair Housing.

In addition to civil-rights laws, there are a number of programs, services, and organizations that support the independence of persons with disabilities. The breadth and depth of support systems and services for persons with disabilities extends to every state in the Union. There are publicly sponsored programs and services at the federal, state, and local levels of government; private programs exist at these three levels as well. A number of public-private partnerships provide services and programs for persons with disabilities. Many of these are described elsewhere in the book (notably by Paul G. Hearne), and others are listed under Resource Organizations in Appendix B.

Programs and services for persons with disabilities have considerable range. Some are targeted to specific disabilities (such as the state Rehabilitation Agencies for the Blind) and others serve all disabilities. Some provide strictly information and referral services, whereas others provide direct services, such as rehabilitation counseling or legal representation. Still others provide funds for persons with disabilities to pursue higher education or purchase adaptive devices. Some are run by persons with disabilities and provide peer-support services.

Programs and services for persons with disabilities are frequently described as a patchwork—difficult to access, unwieldy, excessively bureaucratic, and of a labyrinthine nature (Berkowitz 1987). Various initiatives have been considered over the years to promote the goals of consolidation and coordination (National Council on Disability 1986, 1988). While the degree of coordination of programs and services varies considerably by state, there is a core of programs in every state that forms a support system for persons with disabilities (U.S. Department of Education 1988).

THE IMPACT OF FEDERAL DISABILITY RIGHTS LAWS TO DATE

The impact of federal disability-rights laws can be assessed in many ways. In fact, much of this volume describes that impact. Three studies attempt to look directly at what that impact has been: The survey by

Louis Harris and Associates (1986) reports how people with disabilities view the impact of federal laws. The others examine the impact of section 504 of the Rehabilitation Act after ten years of implementation.

The 1986 Louis Harris poll, *Disabled Americans' Self Perceptions: Bringing Disabled Americans Into the Mainstream*, asked 1,000 Americans with disabilities if they believed that life had improved for persons with disabilities in the past decade. Seven out of ten believed that life had improved somewhat or a lot. Two-thirds of those polled believed that federal laws passed since the late 1960s to provide better opportunities for persons with disabilities have helped a great deal, or somewhat. The survey noted that this remarkable endorsement for federal programs and laws is unsurpassed in the firm's history of measuring public support for federal laws. Seventy-five percent of respondents to the survey also believed that federal antidiscrimination laws should be strengthened.

An analysis of ten years of enforcement of section 504 of the Rehabilitation Act concluded: "While section 504 has unlocked the door for handicapped persons to enter the mainstream of society, it has failed in its goal of opening that door wide" (Tucker 1990, 915). Three reasons are cited for this limited impact: (1) inadequate enforcement of the law; (2) conflicting interpretations of the "reasonable accommodation" requirement; and (3) the limited scope of the law. Tucker described the federal government's enforcement of section 504 as "at best lethargic and at worst ineffectual" (877).

Percy undertook a comparative analysis of the impact of antidiscrimination laws on employment of people with disabilities at the federal and state levels. He concluded that the federal government has made some progress in employing people with disabilities, "although it falls short of employing persons with targeted disabilities in proportion to their numbers in the general population" (1990, 16). Federal agencies vary considerably in their employment of people with disabilities, with some of the largest agencies falling below the government-wide average.

Overall, state agency representatives and state advocacy-group representatives described their states' efforts to employ people with disabilities as slightly less effective than the performance of the federal government in their state. Both federal and state officials noted that negative attitudes and misconceptions about people with disabilities were obstacles to compliance. They also noted the importance of agency leader-

ship in successful compliance. State officials and advocacy groups saw competition from other policy issues in the state as an obstacle to compliance with employment mandates. The level of federal funding available for complying with employment mandates was a concern of state officials. Percy concluded that although many of the obstacles to complying with employment mandates encountered by state and federal government are similar, there is virtually no evidence of joint commitment or cooperation.

Edward H. Yelin, in his article, suggests that the impact of section 504 of the Rehabilitation Act on employment was one of slowing the pace of worsening conditions. The studies I have cited indicate that life has improved somewhat for persons with disabilities. All agree that there is more to be done.

CONCLUSIONS

The enactment of the ADA is the culmination of two decades of evolution of attitudes toward persons with disabilities. The enactment of the Americans with Disabilities Act is a landmark more for its comprehensiveness than its conceptual novelty. What the Americans with Disabilities Act does, in essence, is (1) to codify many regulatory concepts and guidelines from section 504 and other predecessor laws and (2) to extend the section 504 prohibition against discrimination to the private sector. The net result is that persons with disabilities now enjoy a degree of antidiscrimination protection comparable to that of women and members of other minority groups.

Just four years ago, in 1987, Edward Berkowitz began his book, *Disabled Policy*, with the statement, "America has no disability policy." He went on to describe the many contradictory, uncoordinated, and disparate programs and policies intended to serve persons with disabilities: some promoting dependence and segregation and others supporting independence and integration. With the enactment of the ADA, we can say that America at last has chosen the goals and some of the methods of its disability policy. We have chosen independence over dependence and integration over segregation. The goals for the nation articulated by the ADA will serve as standards against which we can measure and modify other disability policies, programs, and services for persons with disabilities.

The ADA is not intended to be a panacea. The ADA is a law that sends a clear message about what our society's attitudes should be toward persons with disabilities. The ADA is an orienting framework that can be used to construct a comprehensive service-delivery system. It has been said, "The ADA will not get you out of bed in the morning." The ADA is intended to open the doors of society and keep them open, but its effect will be limited unless we are as equally committed to providing adequate education, training, and support services as we are to eradicating discrimination.

NOTES

1. P.L. 101-336, 104 Stat. 327, 42 U.S.C. 12101 §2(a)(8).
2. P.L. 101-336 §2(a)(6).
3. U.S. Senate, August 30, 1989. *The Americans with Disabilities Act of 1989: Report from the Committee on Labor and Human Resources*, 101-116 (to accompany S. 933) at 9.
4. P.L. 101-336 §2(b)(1).
5. P.L. 101-336 §2(a)(2).
6. P.L. 101-336 §2(a)(3) and (5).
7. P.L. 101-336 §2(a)(7).
8. 42 U.S.C. 4151-57.
9. 29 U.S.C 791-94.
10. P.L. 100-259.
11. 465 U.S. 555 (1984).
12. 107 S. Ct. 1123 (1987).
13. P.L. 94-142; 20 U.S.C 1232, 1401, 1405-20, 1453.
14. 20 U.S.C. §1400 et seq.
15. 42 U.S.C 6000-81.
16. P.L. 96-247.
17. 42 U.S.C 1973 (1984).
18. P.L. 99-435.
19. P.L. 100-430.

REFERENCES

- Arangio, A.J. 1979. *Behind the Stigma of Epilepsy: An Inquiry into the Centuries-Old Discrimination against Persons with Epilepsy*. Lanham, Md.: Epilepsy Foundation of America.
- Berkowitz, E.D. 1987. *Disabled Policy America's Programs for the Handicapped*. New York: Cambridge University Press.

- Brown, D. 1981. Jobs and Disabled Women: Double Discrimination and Little Help from the Women's Movement. *Disabled USA* 4(8).
- Burgdorf, R.L. 1990. History. In *The Americans with Disabilities Act: A Practical and Legal Guide to Impact, Enforcement and Compliance*. Washington: Bureau of National Affairs.
- Burkhauser, R.V., R.H. Haveman, and B.L. Wolfe. 1990. *The Changing Economic Condition of the Disabled: A Two Decade Review of Economic Well-being*. Washington: National Council on Disability.
- DeJong, G. 1979. *The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research*. East Lansing, Mich.: Michigan State University.
- Disability Rag*. 1990. Special Issue We Wish We Wouldn't See . . . (Winter.)
- _____. 1991. Kudos. 36 (March/April).
- English, R.W. 1971. Correlates of Stigma towards Physically Disabled Persons. *Rehabilitation Research and Practice Review* 2 (4): 1-17.
- Golfus, B. 1989. Disconfirmation. *Disability Rag* (November/December).
- Hahn, H. 1985. Disability Policy and the Problem of Discrimination. *American Behavioural Scientist* 28: 293-318.
- Harkin, T. 1989. Resolution introduced to change Senate subcommittee name, November 11. *National Association of Rehabilitation Facilities Rehabilitation Review*.
- Harris, L., and Associates. 1986. *Disabled Americans' Self Perceptions: Bringing Disabled Americans into the Mainstream*. New York.
- Johnson, M. 1987. Emotion and Pride: The Search for a Disability Culture. *Disability Rag* (January/February).
- _____. 1989. The Bargain. *Disability Rag* (September/October).
- Kriegel, L., 1969. Uncle Tom and Tiny Tim: Some Reflections on the Cripple as Negro. *American Scholar* 38: 412-30.
- Lachat, M.A. 1988. *The Independent Living Service Model: Historical Roots, Core Elements and Current Practice*. Hampton, N.H.: Center for Resource Management.
- Livneh, H. 1982. On the Origins of Negative Attitudes toward People with Disabilities. *Rehabilitation Literature* 13 (11/12): 338-47.
- Longmore, P. 1985. A Note on Language and the Social Identity of Disabled People. *American Behavioral Scientist*. 28 (3): 419-23.
- National Council on Disability. 1986. *Toward Independence*. Washington.
- _____. 1988. *On the Threshold of Independence*. Washington.
- Percy, S.L. 1990. *Implementing Civil Rights Policies: The Case of Disability Rights*. Paper presented at the Annual Meeting of the American Political Science Association, San Francisco, Calif., August 28 to September.
- Presidential Commission on the Human Immunodeficiency Virus Epidemic. 1988. *Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic*. Washington.
- Thomas, R. 1989. Testimony before the National Council on Disability, June 8. *The Education of Students with Disabilities: Where Do We Stand?* Washington: National Council on Disability.
- Tucker, B.P. 1990. Section 504 of the Rehabilitation Act after Ten Years of Enforce-

- ment: The Past and the Future. *University of Illinois Law Review* 1989 (4): 845-921.
- U.S. Commission on Civil Rights. 1983. *Accommodating the Spectrum of Individual Abilities*. Washington.
- U.S. Department of Education. 1988. *Summary of Existing Legislation Affecting Persons with Disabilities*. Washington: Office of Special Education and Rehabilitative Services Clearinghouse on the Handicapped.
- U.S. Senate Committee on Labor and Human Resources. 1989. *Hearings on S. 933, The Americans with Disabilities Act of 1989*, Senate Hearing 101-156, May 9, 10, 16 and June 22. Washington.
- Wagner, M. 1989. *The Transition Experience of Youths with Disabilities: A Report from the National Longitudinal Transition Study*. Menlo Park, Calif.: SRI International.
- Weaver, C. L. 1991. Disabilities Act Cripples through Ambiguity. *Wall Street Journal* (January 31).
- Weicker, L.W. 1989. Testimony on the Americans with Disabilities Act. *Hearings before the Committee on Labor and Human Resources and the Subcommittee on the Handicapped on S. 933*, Senate Hearing 101-156. Washington.
- White House Conference on Handicapped Individuals. 1977. *Final Report*, vols. 1-3. Washington.
- Zola, I.K. 1988. The Language of Disability: Problems of Politics and Practice. *Journal of the Disability Advisory Council of Australia* 1 (3): 13-21.