WHY I BURNED MY BOOK

AND OTHER ESSAYS ON DISABILITY

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Disability Watch

In 1998, Disability Rights Advocates, a small but highly effective public-interest law firm in Oakland, California, published the first volume of *Disability Watch*, its periodic assessment of the status of people with disabilities in the United States. DRA asked me to write the introduction. As the new century begins, the findings of that report still largely describe the situation of Americans with disabilities. For that reason, my introduction to *Disability Watch* can usefully serve to introduce this collection of essays.

During the past generation, Americans with disabilities have pressed for equal access to U.S. society, to school and work and public transportation and public places. Most observers regard passage of the Americans with Disabilities Act in 1990 as the high-water mark of that movement. Two-thirds of the disabled adults responding to one recent survey reported that since ADA their "quality of life" has improved. The evidence presented in this *Disability Watch* does indicate important progress in some areas.

Yet many people with disabilities continue to endure economic deprivation and social marginalization. Depending on age and definition of disability, poverty rates among disabled people range anywhere from 50 percent to 300 percent higher than in the population at large, while a large percentage live on the meager financial aid supplied by federal

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income-maintenance programs. People with disabilities are also less likely to complete high school or college and far less likely to get jobs. The unemployment rate among those who report any form of disability is five times the national average. If they do obtain jobs, it is more likely to be part-time, and on average they will be paid 20 percent less than nondisabled workers.

They tend to be socially isolated too. Despite some improvement in accessibility, people with disabilities are still far less likely than nondisabled Americans to go to restaurants, movies, concerts, sporting events, churches, or stores. They are twice as likely to live alone. Those who grow up with disabilities tend to marry later, if they marry at all. Disabled women in particular marry and form families significantly less often than nondisabled women or even disabled men.

Social isolation and economic deprivation are not new among Americans with disabilities. They have long experienced these stark disadvantages. But the disturbing finding of this *Disability Watch* is that since the mid-1980s these conditions have improved modestly or not at all, and in some areas such as earnings things have actually gotten worse. The question is: why?

Different observers typically offer one of two differing answers. They focus either on the individual or on the environment. They ascribe the socioeconomic disadvantages suffered by disabled persons to their "impairments," or attribute them to the synergy of public policies, institutionalized societal practices, and the built environment. These competing explanations respectively express two contending paradigms of disability: a medical model and a minority model.

The medical model locates the problem of disability in the bodies of "afflicted" persons. By defining disability as a pathological medical condition, it inevitably individualizes the causes of socioeconomic disadvantage: *impaired individuals* cannot function appropriately within society. Some of the studies drawn upon for *Disability Watch* adopt medical definitions of disability. That research defines disability as a limitation in performing "major activities," meaning the endeavors ordinarily "expected" of people in particular age groups. Thus, children are expected to attend school and to engage in play as their major activities. Working-age adults are expected to hold jobs outside the home or to keep house. Older adults are expected to manage their households and to care for themselves. By this yardstick, some 26.8 million Americans (10.3 percent of the total U.S. population) are defined as limited in their ability to perform the major activities expected of persons in their age group. Various studies also report that the most common form of "major activity limitation" is "work disability," a partial or total limitation in an individual's ability to perform a paid job. Such limitations reportedly restrict the employment capabilities of nineteen million working-age adults with disabilities. The trouble is that, as with all medical definitions of disability, these definitions of "work disability" and "major activity limitation" focus attention exclusively on individuals. The definitions implicitly assume that the limitation results from medical pathology and resides within individuals. These ways of measuring disability fail to consider the impact of external, societally created factors in limiting disabled persons' capacity to perform "expected" social roles.

In contrast, research based on a minority model of disability examines the architectural, socioeconomic, and policy environments within which people with disabilities must operate and that shape their experience of disability. Those sorts of studies, which provide the bulk of the data analyzed in *Disability Watch*, present markedly different explanations of the disadvantages suffered by many people with disabilities. The evidence gathered here offers a comprehensive picture of artificially created marginalization and deprivation.

One aim of this report is to assess the impact and effectiveness of the Americans with Disabilities Act. Itself based on a minority group model of disability, the ADA mandated conversion of the U.S. physical and social infrastructure to make it inclusive of people with disabilities. Seven years later, ramps and blue wheelchair-access symbols and Braille markers seem to have sprouted everywhere. Sign-language interpreters seem now always to interpret public events. Thus, the nondisabled public has the impression that society has been transformed and made accessible. Significant improvements have been made, but *Disability Watch* indicates that to a surprising extent U.S. society continues to restrict or exclude people with disabilities.

The problems begin with modes of transportation. Americans have long considered mobility a major issue, both a core value and, given the vast geography of the country, an inevitable public concern. They have come to regard freedom of movement as a basic right. Yet *Disability Watch* reports that Americans with many kinds of disabilities still often find their mobility rights restricted or denied.

Take for instance public transit. Although a majority of public buses now has wheelchair lifts, those lifts are often broken and bus drivers often receive little training in how to operate them. Because the ADA requires public-transit agencies to include wheelchair lifts only when they buy new equipment, few cars on light-rail, rapid-transit, intercity, and commuter-rail systems can accommodate wheelchair riders. And since the ADA orders full access only at newly built transit stations and at existing "key" stations, inaccessibility prevails in those places too. The U.S. Department of Transportation has designated a mere seven hundred stops nationwide as "key stations." It reports that nearly two-thirds of them are at least partially accessible to wheelchair and walker users, but that just a fifth are fully accessible to people with mobility or sensory impairments. But those figures overstate the effective accessibility of some transit systems. Both Atlanta's MARTA and the San Francisco Bay Area's BART profess to be fully wheelchair-accessible, yet disabled riders report that ticket-vending machines and booths and turnstiles are often inaccessible and that elevators regularly break down. In New York City's commuter-rail system, a mere 28 of 104 "key" stations meet legal access requirements, while the rest of the 490 stations remain unusable. Around the United States, all forms of public transit typically fail to provide the audible or visible information necessary for blind, deaf, or hard-of-hearing passengers to travel safely and effectively, even when such information is legally mandated. Thus, while many public-transit systems claim full accessibility, the vast majority of public-transit buses, cars, and stations still effectively exclude many passengers with disabilities.

When people with disabilities cannot use regular transit, ADA instructs local public-transit agencies to provide paratransit services. Three-fourths of those agencies reportedly offer such services in the form of "special" buses, vans, or taxis. But disability rights activists condemn paratransit as separate and unequal, and with good reason. Eligibility procedures often make new applicants wait months. Service is frequently costly and therefore limited, with lift-equipped vans often charging twenty dollars a ride and some subsidized taxi rides set at a maximum of one hundred dollars' worth of travel a month. Paratransit is also commonly inflexible and inconvenient. Agencies require advance reservations of anywhere from twenty-four hours to as long as two weeks—for each and every trip. As the authors of this report note, it is clear that some local agencies see paratransit, not as "an essential substitute for unusable public transit," but as a charity service for "special" trips such as doctor visits. Whatever the rationale, paratransit perpetuates the social marginalization of people with disabilities. Yet, because they have no other options, disabled passengers use paratransit heavily.

The inconveniences inherent in paratransit services and the pervasive inaccessibility of most public-transit systems have a profound impact on the lives of many Americans with disabilities. Those conditions contribute to their exclusion from community life and block them from gaining employment. In a 1994 survey, one out of four individuals with disabilities who were not working or working only part-time named the "lack of affordable, convenient, accessible public transit as an important reason they could not obtain a job."

If public transit is still largely inaccessible, commercial modes of long-distance travel present major access problems as well. Intercity bus lines, led by industry pacesetter Greyhound, vigorously resisted any ADA requirement that they provide wheelchair access. Thus, commercial intercity bus travel still completely excludes wheelchair riders.[1] Because of limited access to other modes of long-distance travel, people with disabilities that affect their mobility or vision use airlines heavily, yet no law guarantees them the right to fly. The ADA overlooks airline travel altogether, and the Air Carrier Access Act of 1986, the federal law that supposedly ensures disabled Americans' right to fly commercial airlines, in fact contains no guarantee of equal access. This weak law allows airlines to treat access and accommodations for passengers with disabilities "as an afterthought." *Disability Watch* recounts a litany of problems with boarding, seating, debarking, poorly trained personnel, and damage to wheelchairs and other equipment.[2]

The obstacles impeding air travelers with disabilities begin and end on the ground. Because federal law mandates retrofitting terminals for access only when they are renovated, many major airports—Kennedy in New York, Midway in Chicago, Miami, Philadelphia, and Fort Meyers —continue to have serious access problems. ADA does cover airport shuttle services, but under much more lenient requirements than those governing public transit. No surprise then that many airports have no accessible shuttle buses at all. This forces wheelchair riders to pay for costly lift-equipped vans. Some airports do offer accessible shuttles, but these may operate more like paratransit systems than integrated services. For instance at Dallas/Ft. Worth Airport, nondisabled travelers may simply board any waiting shuttle bus, but wheelchair users must reserve a ride on the system's single wheelchair-accessible van twenty-four hours in advance, or they can hire another lift-equipped van at four times the cost. At many airports, shuttle-bus drivers lack adequate training to operate wheelchair lifts and tie-downs, at times endangering their passengers.

Car rental agencies have restrictive policies and practices too. They may not have vehicles equipped with hand controls or may offer them only on bigger, more expensive cars. Rental outlets also often require lengthy advance notice. And some agencies refuse to rent vehicles to disabled individuals unless they can drive the car themselves. Departing from this pattern, Avis recently agreed with the U.S. Department of Justice to change its policy. In the future, the company will permit nondriving customers with disabilities to assume financial liability for rented cars driven by another person.

At least people with mobility disabilities now have lots of places to park, or so many people assume. But in fact, a 1993 national survey by the U.S. Government Accounting Office found even that assumption mistaken. People with disabilities reported that in many public parking lots the spaces designated wheelchair accessible are too narrow or on a slope that is too steep. They also said they often can find no place to park at all, because many public lots have fewer accessible spaces than the ADA requires. GAO investigators confirmed these complaints. While some 5 percent of Americans have "severe mobility limitations," ADA requires smaller lots (under 400 spaces) to make only 4 percent of their spaces accessible, midsized lots (400–1,000 spaces) to have 2 percent accessible, and large lots a mere 1 percent accessible. Yet, the GAO found that well over a third (38 percent) of parking lots they inspected had even fewer accessible spaces than the already inadequate number mandated by ADA. In addition, 57 percent of spaces and aisles were too narrow and 88 percent of the inspected lots lacked the required number of "van-accessible" spaces.

Then there are all those ramps the nondisabled public takes as evidence that public places have been made accessible, implicitly thinking of access as an issue only for people who ride wheelchairs. But once again, subjective public perceptions are mistaken. Many ramps are too steep or too narrow or lack a handrail or lead to a door that cannot be opened. And access obstacles in public buildings do not end at the tops of ramps. Some building entryways are linked to security systems that require voice communication or sight. Wheelchair riders frequently find store aisles too narrow or blocked or carpeted, service counters too high or too narrow, restaurant tables too low, and drinking fountains inoperable. When theaters and lecture halls and other public venues do provide wheelchair-accessible spaces, they often segregate them from the rest of the seats, forcing wheelchair riders to sit apart from friends and colleagues.

Restricted access to information and communication in public buildings is another major problem. Most buildings lack enough signs indicating the location of accessible features or identifying rooms in Braille or raised print. Programs such as museum brochures and transit schedules are often unavailable in large print, Braille, or audiocassette or through staffers trained in sign language. Elevators usually lack either audible signals or Braille signs. Public telephones are often inaccessible. They are too high for wheelchair riders, lack signage appropriate for people with visual impairments, and lack text telephones for deaf people or phones with amplification for hard-of-hearing people. Businesses often do not have TDD numbers.

Inaccessibility in hotels remains a common problem too. The vast majority of U.S. hotels still have not instituted legally required access features. They do not supply devices to alert deaf guests of fire alarms, ringing phones, or someone knocking at the door. They fail to provide raised-print maps of hotel locations for visually impaired guests. They have too few rooms with wheelchair-accessible bathrooms.

One in four Americans with disabilities cites one or more of these various access obstacles as limiting their use of facilities that serve the general public.

If public buildings continue to have significant access problems, private housing remains pervasively exclusionary. A tiny fraction of U.S. houses and apartments are accessible or even readily adaptable for prospective residents with disabilities. One study cited in *Disability Watch* found that a mere "2.9 percent of Americans lived in homes with any kind of accessibility features," yet 29.2 percent of U.S. families included "at least one member with a disability." The extraordinary shortage of accessible or adaptable housing makes the search for suitable housing a seemingly futile quest. It forces many families with newly disabled members, who are often elderly, "to exclude" the member with the disability, which often means putting that person in an institution. Yet, unlike businesses, private homeowners have no tax credit available to subsidize and encourage modifications to residential housing. In addition, while the Fair Housing Amendment Act of 1988 requires property owners to allow disabled tenants to make necessary alterations, it puts the burden of those changes exclusively on the tenants. The act does mandate certain limited accessible and adaptable features in newly built multiunit housing and prohibits disability-based discrimination in the rental or sale of most multiunit apartment buildings and some single-family houses. But newspaper reports indicate that local authorities usually fail to enforce any of these provisions. Thus, this law is having only a very limited impact on the extreme shortage of accessible housing.

Perhaps the greatest progress toward the integration of people with disabilities has appeared in U.S. public schools. Americans have long viewed education as the key to economic opportunity and to full participation in society, yet for decades many states by law barred youngsters with specified disabilities from attending public schools. As of 1975, most children with disabilities in the United States either received no public education at all or were denied equal educational services. By the late 1990s, the impact of federal laws and the efforts of disability rights advocates have produced significant changes. Most children with disabilities now attend public schools. A growing proportion is mainstreamed. And a majority of teenagers with disabilities completes high school. High-school graduation, of course, greatly improves their job prospects.

But "mainstreaming" also has its negative side. Public-school districts too often assume that "mainstreaming" or "full inclusion" is the most appropriate solution for all children with disabilities. In fact, that strategy is proving disastrous for deaf children. Placing them in mainstream classrooms denies them the opportunity to learn American Sign Language, inhibits their acquisition and development of skills in any language, and effectively isolates them among hearing children. The Deaf community has vigorously opposed these ill-considered practices, but its cogent dissent has gone largely unheeded.

In addition, despite considerable progress toward integration of disabled students for whom mainstreaming is appropriate, many public schools still contain "formidable" physical barriers. Although no one gathers data nationally on accessibility in U.S. schools—a major deficiency that demands correction—a 1989 opinion survey did report that one-fifth of parents with children in special education and one-fifth of public-school educators rated access in their schools' physical facilities as only "fair" or "poor." Confirming these perceptions, a 1995 GAO study found that a majority of school districts needed to improve access and that in some large districts, such as Chicago and New Orleans, most school buildings were inaccessible. In addition, a court ruling against the Oakland, California, public-school system found "multiple, pervasive architectural barriers" in every one of its one hundred schools. These conditions persist despite the flexibility of federal laws that require "overall access to programs and activities," rather than removal of all physical barriers in every building. The greatest problems occur in central-city school districts that have more limited financial resources, whereas wealthier suburban districts have made better progress toward accessibility. Much work remains to be done in order to reach the goal of access to public education for all of America's children and youth.

Taken together, the data presented in *Disability Watch* show that, seven years after passage of the ADA, U.S. society still often limits or excludes people with disabilities. The evidence here suggests four reasons for the slow pace of compliance with disability rights laws and the continuing marginalization of Americans with disabilities.

First, there is as yet a great deal of ignorance about what constitutes accessibility and reasonable accommodation and regarding the achievability of those objectives. Many business people and property owners are misinformed and therefore anxious and angry. In particular, they mistakenly believe access and accommodations are costly. In fact, incorporating accessibility in the design of new buildings increases construction costs by no more than 2 percent. Retrofitting for access can prove more expensive, but ADA requires such modifications only when buildings are being renovated or when they are "readily achievable" in existing buildings and would not cause "undue" financial hardship. Most of the time the price of barrier removal and installation of accessible features is relatively low. In 1993, small businesses spent an average of $3,327 on retrofitting for access, with individually owned businesses spending even less, $2,535. And the federal government rebated 50 percent of these costs under the Disabled Access Tax Credit. The remaining expense should be more than reimbursed by the addition of new customers who have disabilities. Common fears about the price of job accommodations for employees with disabilities also overstate those costs. Nearly 70 percent of job accommodations cost $500 or less, with almost a fifth incurring no expense at all because they entail merely the rearrangement of work spaces or work patterns. Further, many business people overlook that the expense of job accommodations is usually much less than the cost of training a replacement employee. So, concludes *Disability Watch*, complaints about the financial impact of accommodations and accessibility are greatly exaggerated and cannot be used as an excuse to evade compliance with the law. Besides, compliance now will avoid costly lawsuits later.

Most architects are also still uneducated about how to design for equal access. *Disability Watch* urges readers to note two innovative approaches: "adaptable design," a strategy that incorporates certain basic access features and allows for others to be added conveniently later as they are needed, and "universal design," a scheme that plans spaces and equipment so that everyone can use them.

Second, social integration of Americans with disabilities is slow because federal laws and policies contain serious defects. Some civil rights statutes have weak enforcement provisions. For example, not only does the Air Carrier Access Act fail to guarantee travelers with disabilities equal access to airlines, it offers no injunctive relief in court, only administrative relief. And the ADA's requirements to make public transit accessible allow agencies as long as twenty years to comply. No wonder that, as *Disability Watch* notes, "some transit districts have not even begun the ADA-mandated planning phase for improving accessibility, let alone made any actual improvements."

Other federal policies continue to promote dependency rather than productivity. The government spends forty times as much on social-service benefits as on vocational rehabilitation. Its regulations and practices also still deter many disabled people from seeking employment by penalizing them with the loss of essential assistance or health insurance if they go to work. In one survey, almost a third of working-age adults with disabilities said that threat stood in the way of their taking a job. National policies could facilitate productivity by removing these work "disincentives." Policies could also foster competitive job skills among disabled individuals by subsidizing their acquisition of computer technology. In the midst of a technological revolution so often vaunted as liberating for people with disabilities, it is amazing that while one-tenth of disabled working-age adults say they would need adapted equipment to hold a job, only 1.3 percent actually own such equipment.

Federal policies also promote institutionalization rather than community integration. Not only is there no homeowners tax credit to encourage accessibility in residential housing, but Medicaid funding favors nursing-home placement over enabling disabled people to live in their own homes. As a result, the number of institutionalized disabled

Americans, the vast majority of them elderly, stands at an all-time high of 2.1 million.

In combination, these flaws in federal policies and laws effectively perpetuate the social segregation and economic deprivation of people with disabilities. Some policies actively promote marginalization. Other statutes delay removal of physical and social barriers to integration.

Third, even when the legal requirements for access and accommodations have already gone into effect, compliance is dilatory because local authorities often fail to enforce them. For example, a current lawsuit by disability rights activists charges San Francisco city building inspectors with routinely exempting new construction from state accessibility codes. As a result, hundreds of recently constructed buildings exclude wheelchair riders. Similar problems occur when local public-works departments neglect to remove barriers in streets and on sidewalks. Enforcement and compliance varies widely from community to community depending on three factors: the priorities of local public officials, the resources available to them, and the degree of activism by local disability communities. The last element is proving especially important.

In response to lax implementation and widespread violation of disability rights laws, activists around the United States are increasingly filing civil suits to compel vigorous enforcement. *Disability Watch* reports lawsuits against or settlements with the Days Inn hotel chain, Lone Star restaurants, United Artists movie theaters, Safeway stores, Planet Hollywood nightclubs, Bay Area Rapid Transit, Metropolitan Atlanta Rapid Transit, the San Diego municipal courts, and the operator of a parking-lot chain in San Diego. In all of these cases, the companies and agencies simply ignored the law, sometimes defiantly.

That conduct points to the fourth factor delaying integration of people with disabilities into American society: the refusal to comply with these various laws stems, not just from ignorance, but also from prejudice. Around the United States, people with disabilities report encountering prejudicial and discriminatory treatment. In some cities, bus drivers simply refuse to pick up passengers with visible disabilities. Airline employees are often tardy, uncooperative, or unresponsive and at times physically rough or humiliatingly rude. Working-age people with disabilities recount various forms of discrimination: they have been refused jobs, denied promotions, given less responsibility than nondisabled coworkers, or paid less than nondisabled colleagues doing similar work. In one survey, 40 percent of disabled adults who were unemployed or working only part-time declared employer bias was a factor.

Yet despite the persistence of discrimination against disabled Americans and lax enforcement of the laws to protect their rights, U.S. society cannot avoid disability-related issues. One reason documented in *Disability Watch* is the steadily growing number of Americans with disabilities. Depending on definitions of disability, there are now at least forty-one million, perhaps as many as forty-nine million, people with significant disabilities in the United States. Disability occurs more frequently in lower income groups and among racial minorities, but most of the numerical increase has resulted from the mounting size of the elder population. Here again though, *Disability Watch* corrects some common misconceptions. Most people with disabilities are not old. In fact, a majority (57.6 percent) are working-age, while more than one in ten are under age eighteen. And the most rapid rate of growth in the incidence of disability is occurring in those younger age groups. Among children and teens, much of the increase stems from the rising prevalence or more effective detection of asthma, emotional disabilities, mental retardation, and learning disabilities, while a growing proportion of young adults experience orthopedic, mental, and emotional disabilities. In addition, "disability" involves widely diverse conditions, with many of the more common, such as heart disease, back problems, arthritis, learning disabilities, and emotional disabilities, relatively hidden. Not only are Americans with disabilities a large and diverse population, the experience of disability is typical rather than rare. Nearly one-third of U.S. families have a member with a disability, and most families experience disability at some time. "Disability," conclude the authors of this report, "is a normal part of life."

The prevalence of disability compels greater efforts to address the socioeconomic disadvantages confronted by Americans with disabilities. That thrust should proceed on three related fronts. (1) Public education, particularly of business, to counter the widespread misinformation about the actual requirements of the ADA and other disability rights laws and to combat prejudice against people with disabilities. (2) Legislative correction of the defects in current laws and policies: to strengthen enforcement mechanisms in disability civil rights laws; to eliminate work disincentives in social-service policies; and to promote community integration rather than segregation and institutionalization. (3) Vigorous enforcement of existing laws.

The number of people with disabilities continues to grow. Their presence in American society, their needs and interests, increasingly make themselves felt. And, more and more, disabled Americans are asserting their right to participate in U.S. society, in its schools and places of work and places of business and community affairs. More and more, they are turning to legal and political activism to enforce those rights. As they become active, they are rejecting a medical model of disability and espousing a minority group model. In the end, *Disability Watch* should bring readers to at least this one conclusion: disability issues will not go away, because people with disabilities are not going away.

Notes

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1. After several years of complaints, lobbying, and protests by disability rights activists, Greyhound signed a settlement with the U.S. Department of Justice in November 1999 agreeing to comply with the ADA.

2. Subsequent to the publication of *Disability Watch*, the National Council on Disability issued its comprehensive report on access to airlines, *Enforcing the Civil Rights of Air Travelers with Disabilities: Recommendations for the Department of Transportation and Congress* (Washington, D.C., 1999).