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INTRODUCTION

Achieving the Right to Live in the World

Americans with Disabilities and the Civil Rights Tradition

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SEEKING THE RIGHT TO BE IN THE WORLD

Writing two years after the passage of the 1964 Civil Rights Act, Jacobus tenBroek, S.J.D., Harvard; J.D., University of California, professor at the University of California, began an article for the *California Law Review* by observing: "nothing could be more essential to personality, social existence, economic opportunity—in short, to individual well-being and integration into the life of the community—than . . . the public approval, and the legal right to be abroad in the land."

To be denied this right, or to experience the ire of others because one exercises it, invites the direct disadvantages segregationist policy inflicts on those whom it isolates. Accustomed himself to being denied access to the civic and commercial infrastructure because of his blindness, and often himself deprived of the right to be in the world, tenBroek was propelled throughout his career by the ambition to secure equality. His writing teems with illustrations of the growing national commitment to desegregation and equal opportunities for minorities, and the article is infused with the emancipatory optimism of the period.

Yet in 1966 Professor tenBroek himself had no legal recourse when he was precipitously and arbitrarily denied carriage on a train or plane for which he had purchased a regular ticket. Nor did he have a legal remedy when restaurants declined to serve him, or banks refused to let him deposit his money. Despite his accomplishments and inarguable competence, he expected to be held the responsible party if, in traversing the university campus, he fell into any open pit left by a repair crew or was injured in a collision with a campus vehicle. For, in virtue of his blindness, Professor tenBroek, founding president of the National Federation of the Blind and editor of *The Braille Monitor*, suffered an attenuation of the right to be in the world.

So in 1966, in the early days of an unprecedented era of liberation brought by new civil rights laws to previously marginalized groups, tenBroek probed to see what protections the law offered people who, on the basis of their disabilities, encountered inferior treatment in, and even segregation from, the civic and commercial worlds. The disabled lacked the civil rights protections afforded women and minorities by the Civil Rights Act of 1964. But beyond the lack of civil rights protection, tenBroek observed, people with disabilities lacked critical legal support in their efforts to negotiate the world. He asked:

Does the law assure the ... disabled, to the degree they are ... able to take advantage of it, the right to leave their institutions, asylums, and the houses of their relatives? Once they emerge, must they remain on the front porch, or do they have

the right to be in public places . . . and to receive goods and services in . . . places of public accommodation? . . . What are the standards of care and conduct, of risk and liability, to which they are held and to which others are held in respect to them? Are the standards the same for them as for the [nondisabled]? (tenBroek, p. 842)

In the next four pages, tenBroek adduces statute after statute and case after case to learn whether the law of the time acknowledges that people with disabilities have a right to be in the world: integration is "the policy of the nation" (tenBroek, p. 847) ... but it is widely disregarded by courts. A principal explanation is the erroneous attitudes of actors within the legal system: "jurors are almost entirely ablebodied (blind people are excluded from jury service), and the judge has sound ... limbs, fair enough eyesight, and, according to counsel, can hear everything but a good argument." Drawing only from their own experience and ignoring the perspectives of people with disabilities, "The judge or juror ... provide ... a standard of reasonableness and prudence ... including some often quite erroneous imaginings about the nature of ... disability." (tenBroek, p. 917)

For the nondisabled are situated very differently from the disabled, tenBroek reminds us. Their "basic rights of effective public access have been long established and newly vindicated." (tenBroek, p.848) He then observes that, in sponsoring and affirming the 1964 Civil Rights Act, both President Johnson and the Supreme Court declared that denying equal access to public facilities to any group of citizens was a moral and social wrong and a burden on commerce. Although the protection the Civil Rights Act offers explicitly is against discrimination based on race, color, national origin, sex and religion, tenBroek supposes that being in the world is a human right, pertaining to all persons who are members of the community. Therefore the legal system must evolve to acknowledge the right of the disabled to access public facilities equitably. People with disabilities are human persons with community membership, he says, yet they are frequently subjected to arbitrary action and are for the most part without legal redress when turned away from trains and planes, travel, lodging, rental housing and "from bars, restaurants and places of public amusement, from banks to rent a safety deposit box, from other kinds of banks to give a pint of blood, and from gambling casinos." (tenBroek, p. 851)

Other public policy approaches to disability outside of the civil rights paradigm both predate ten Broek's powerful discussion and continue in effect today. The United States tax code contains an additional personal exemption for blindness, amounting to \$850 in 1999, included on the theory that personal subsistence costs are higher for the blind.2 Social Security provides two quite different benefit programs, both, however, rooted in the assumption that people with disabilities cannot work. Disability benefits (SSDI) replace work-based income; disabled individuals are eligible to receive disability benefits if they qualify for Social Security by having met income thresholds for forty quarters, and if they accumulated at least twenty of these quarters within the ten years before they became disabled. (These requirements are reduced proportionately for younger workers). Individuals qualify as disabled if they have a disability that is expected to last (or has lasted) at least one year, or to result in death, and that prevents them from doing any substantial gainful work. Benefits are based on a formula that reflects average earnings and age; and individuals who are receiving disability become eligible for Medicare benefits after 24 months.3 The justification for Social Security disability benefits parallels that for retirement benefits: those who are no longer able to work should have access to income replacement as a form of insurance "earned" at least in part by their earlier participation in the workforce.

The second Social Security program, Supplemental Security Income (SSI), is an income supplement for certain low-income, categorically needy persons, including those with disabilities. Unlike Social Security disability, SSI is fully need-based. To qualify, disabled individuals must fall below very strict asset (\$2000 for an individual and \$3000 for a couple) and income ceilings (\$500 per month for an individual and \$750 per month for a couple). Legal resident aliens who arrived in the United States after August, 1996, are ineligible for SSI unless they meet the requirement of forty work quarters to qualify for Social Security. SSI is a "welfare" program, justified as providing a minimal safety net for the categorically needy. As such, it has been criticized by opponents of welfare, who see it as paternalistic and encouraging of dependency; this criticism played a major role in the decision to exclude legal immigrants from SSI if they arrived in the United States after the effective date of congressional welfare reform. Whatever their plausibility against welfare programs, however, it is important to recognize that these criticisms are inappropriately directed against the income insurance or tax programs, which at least begin with the assumption that disabled people formerly or presently earn income.

As the civil rights paradigm developed, particularly after passage of the Americans with Disabilities Act (ADA), critics of these older approaches claimed that they were inconsistent with the civil rights ideal. In law, this criticism took the form of cases contending that individuals could not both claim the protection of the ADA in their struggles for equal opportunity, and at the same time seek the protection of disability benefits. However, the United States Supreme Court recently held that ADA and Social Security disability claims are not inconsistent, at least if the claimant can explain why she was both unable to work given the opportunities available to her and able to work with reasonable accommodations. Nonetheless, as the discussions in this collection indicate, there remain deep tensions between the view of disability discrimination as a civil rights problem, and the view of disability discrimination as a social safety net issue.

THE CIVIL RIGHTS TRADITION: EXTENDING PROTECTION FROM NONDISABLED TO DISABLED PERSONS

Attempts to amend the 1964 Civil Rights Act to gain explicit recognition for the right of people with disabilities to be in the world began in the 1970s, but all such undertakings were defeated. The reasons were both political and conceptual, with traditional civil rights groups joining the usual opponents of government regulation to block adding disability discrimination to the list of offenses against citizens' civil rights. Representatives of the groups protected under earlier legislation feared opening it to amendments that might weaken it. They also resisted increasing the numbers of groups entitled to special protection against discrimination because they did not want to compromise the interests of the originally protected groups by diffusing the focus of antidiscrimination enforcement and enlarging the number of persons eligible for compensatory programs.

Further, many people found it objectionable, and even absurd, to equate the social isolation experienced by people with disabilities with the historical exclusion of individuals on the basis of race, color, national origin, sex and religion. Representatives of groups traditionally disadvantaged on the basis of these characteristics often simply could not conceive that people with disabilities were similarly mistreated, for they supposed that people with disabilities were naturally deficient in their capability to make good use of opportunity. That is, they thought of the disabled as being naturally limited rather than as being artificially limited by arbitrary and prejudiced social practice.

To make disability a category that activates a heightened legal shield against exclusion, it was objected, would alter the very purpose of legal protection for civil rights. For doing so inevitably would transform the goal from creating opportunity for socially exploited people to providing assistance for naturally unfit people. Some even took as definitive of the disabled the selfsame attributions of incompetence they had always deemed biased when applied to women and racial minorities.

Similar reasoning brought into question Congress's authority to force compliance with measures that protect people from socially imposed disadvantage on the basis of disability. Congress can abrogate a state's Eleventh Amendment immunities only as empowered by the Fourteenth Amendment, from which issues broad power to remedy discrimination and prevent future discrimination. But when disability is defined as impairment-related dysfunction and equated with being biologically deficient, weak and incompetent, the inferior economic status and powerless political position of the preponderance of people with disabilities appear to result from their personal limitations, not from the kind of arbitrary and irrational discrimination which warrants intervention in the name of the constitutional guarantee of equal protection.

To understand disability in the former rather than the latter way suggests that the right to be in the world is an entitlement to assistance that disabled people need in order to participate in civic and commercial activity instead of a claim for eliminating arbitrary barriers to access. But the Fourteenth Amendment in no way entitles people to get help because they have corporeal or cognitive deficits. To identify disability with ill-health and deficiency undercuts the propriety of construing access for the disabled as equal protection for civil rights. Consequently, those who thought about disability in this medicalized way doubted the appropriateness of invoking Congress's Fourteenth Amendment enforcement powers to safeguard people with disabilities.

A further complication was that some of the affirmative measures required to remedy the effects of discriminatory practices were not encompassed by traditional civil rights standards. These included such concepts as the removal of barriers caused by architectural and transportation design, and the provision of information through alternative media and adaptive modes of communication. Civil rights advocates had traditionally emphasized the similarities of excluded people to the dominant class and obscured their differences in order to highlight the arbitrariness of their exclusion. But to be people with disabilities require that their differences be acknowledged and accommodated. The difficulty was, then, how to square this need for acknowledgment with the traditional civil rights goal of equal opportunity.

So it seemed to some that, as the United States Commission on Civil Rights pronounced in 1983, "[h]andicap discrimination and, as a result, its remedies differ in important ways from other types of discrimination and their remedies." From the perspective of the then-prevalent politics of homogenization, religious bigotry, racial segregation and sexism manifested themselves primarily in prohibitions against the admission of the practitioners of minority religions, people of color and women to desirable programs and positions. At the time, it was thought that simply purging practices of these prohibitions—opening the doors of schools to children of all races and the doors of workplaces to employees regardless of sex—would result in members of these groups whose achievement heretofore had been limited becoming integrated into the practices of existing institutions and thereby being launched toward success. Thus, people whose race or sex previously disadvantaged them would come to be perceived as not importantly different from the prototypically productive citizen.

But that perspective did not equally envision that boosting the warmth of the invitation to participate would successfully integrate and eventually homogenize people with disabilities. For it is one thing to effect integration simply by repealing the ordinances that require certain kinds of people to use the back door, but it might seem to be quite another when integration requires constructing ramps, instead of or in addition to stairs, up to the door. Similarly, it seems one thing to require that no one be denied full social participation because her spoken English bears the accent of a non-U.S. national origin, but quite another to require that full social participation be effected for people who cannot speak, or hear, at all. Integrating persons of the first sort appears to mean nothing more than ignoring their differences when they practice everyday speech, while integrating persons of the second sort appears to involve supplementing everyday speech by providing an interpreter who Signs.

In sum, even had it been granted that practices prohibitive to the disabled are usually arbitrary, the general thrust of remedying these exclusions was supposed to be of an order different from the remedies needed to repair or forestall discrimination against other groups. One question was whether accommodating a disability requires affirmative steps and consequently calls for public and private effort that exceeds the simple remedy of being tolerant of difference. A further issue was whether prohibiting segregation and exclusion of the disabled, who by definition are uncommonly limited in their ability to perform, would require fundamental alteration of the purpose and nature of commonplace practices. Would, for instance, nondiscrimination demand that cognitively impaired workers be employed side by side with normal ones, and would doing so devastate the efficient productivity that defines commercial aims, thus fundamentally compromising the institution of work? A remedy like this could not help but seem excessive to someone who believes that efficiency is paramount, much less to someone who believes that an individual's cognitive impairment naturally disqualifies that person from useful pursuit of opportunities for self-support and social advancement.

BUILDING LEGAL SAFEGUARDS AGAINST DISABILITY DISCRIMINATION

Of course, from the transformative standpoint brought about by the past two decades of the politics of difference, it now is clear that repairing a long history of discrimination against any group requires changes in institutions that deny recognition to people by neglecting their differences. Equality calls for adjustment to difference, not just tolerance of it. However, for the quarter-century that followed the Civil Rights Act of which Jacobus tenBroek had such high hopes, few provisions to relieve people with disabilities of their exclusion from the opportunities made available to everybody else were integrated into comprehensive legislation aimed at safeguarding them along with other minorities. (The Fair Housing Amendments Act of 1988, 102 Stat. 1619, is a notable exception.) Instead, their protections against discrimination were fashioned mainly by enacting or amending statutes pertaining solely or principally to the disabled.

Important laws of this kind include the Architectural Barriers Act of 1968, 82 Stat. 718; the Rehabilitation Act of 1973, 87 Stat. 355; the Education for All Handicapped Children Act of 1975, 89 Stat. 773; the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1975, 89 Stat. 486; the Voting Accessibility for the Elderly and Handicapped Act of 1984, 98 Stat. 1678; and the Air Carrier Access Act of 1986, 100 Stat. 1080. Section 504 of the Rehabilitation Act was considered the most far-reaching provision against discrimination. Embedded in a multipronged legislative program meant

to resituate people with disabilities by facilitating their getting work, Section 504 enjoined recipients of federal funds against excluding such individuals: "No otherwise qualified handicapped individual... shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal funds."

What these laws have in common is a delineation, either implicitly—as in the Architectural Barriers Act—or explicitly—as in the Rehabilitation Act, of the minority of people they are targeted to protect. Originally, the Rehabilitation Act defined the "handicapped" people it benefited as: "Any individual who (a) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment and (b) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services." In 1974, the act was amended to define a person with a disability as someone who satisfies the following disjunctive test: (a) has a physical or mental impairment, (b) has a record of such a physical or mental impairment, or (c) is regarded as having such a physical or mental impairment.

A year earlier, in 1973, Sections 503 and 504 had been included in the Rehabilitation Act. Section 503, 29 U.S.C. § 793 (a), specifies that holders of federal contracts in excess of \$10,000 "shall take affirmative action to employ and advance in employment qualified individuals with disabilities." Section 504, 29 U.S.C. § 794 (a), provides for "nondiscrimination under federal grants and programs." It directs that: "No otherwise qualified individual with a disability in the United States... shall, solely by reason of handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency."

Although these provisions were groundbreaking at the time the Rehabilitation Act incorporated them, they had much less strength and scope than the civil rights laws of the time offered women and minorities. Section 504 prohibited discrimination "solely by reason of . . . disability," which at least suggests that disability discrimination is acceptable when conjoined with other kinds of bias. In 1986, the National Council on the Handicapped observed that while public policy aimed at eliminating discrimination against other groups generally, the Rehabilitation Act attacked disability discrimination per se and prohibited it only "when it is found in a pristine, isolated, unadulterated form."

Moreover, the means required to remedy discrimination, such as the removal of barriers and the provision of reasonable accommodations, were described only in the implementing regulations for the Rehabilitation Act¹² and thereby were subject to challenge as outside the statutory mandate. The first federal disability rights law that explicitly requires making reasonable accommodations to people's disabilities is the Fair Housing Amendments Act of 1988.¹³

As for scope, only federal contractors and other recipients of federal money were prohibited from discriminating. Further, the Rehabilitation Act does not give victims of disability discrimination a private right of action, and only very rarely did the federal agencies charged with enforcement do anything more in response to complaints than issue findings. The absence of effective enforcement and the indifference of many covered entities to compliance with the Act are evidenced by the pervasive disregard of Section 503's requirement, 29 U.S.C. § 793 (a), that employers receiving federal funds act affirmatively to employ and promote people with disabilities: almost all universities developed affirmative action plans for women and minorities, but almost none have such a plan on file for people with disabilities.

Finally, the Rehabilitation Act, in all its sections, concentrates on providing vocational rehabilitation through individualized training, rehabilitation counseling, and independent living and support services to individuals with disabilities, in order to facilitate their employment and economic self-sufficiency. Inclusion and integration into society form a secondary goal. Thus, the Rehabilitation Act's main emphasis is helping people with disabilities overcome their personal limitations, not helping society overturn the limitations biased practice imposes on the disabled.

Frustrated in respect both to drawing the disabled under the shield of the Civil Rights Act and to achieving the equivalent of civil rights protection through other kinds of laws, the disability community turned toward the idea of developing a comprehensive federal statute aimed at forbidding discrimination based on disability. In 1986, the National Council on the Handicapped, a federal agency, published *Toward Independence*, a report that recommended provisions such a law should include and gave the prospective statute a name, "The Americans with Disabilities Act." Subsequently, the council drafted its own bill and had it introduced into the 100th Congress in 1988, but the Congress expired without action being taken.

On behalf of the bill, there was call for greater political visibility. Thousands of Americans with disabilities lobbied their federal representatives, and many engaged in pro-ADA civil disobedience.¹⁵ Disability groups not normally in alliance forged a strong coalition and courted the civil rights leadership. Such organizations as the Leadership Conference on Civil Rights and the American Civil Liberties Union contributed lead personnel who worked full time on securing broad-based support to extend civil rights protection to the disabled.¹⁶

A revised bill was introduced in May 1989. Testimony in support of the bill played upon two main themes. One was reducing the fifty-seven-billion-dollar cost to the nation of disability benefits paid out to people who could become productive taxpayers if discrimination no longer kept them from the employment rolls.¹⁷ This potential outcome was portended by a Harris Organization survey, which found two thirds of unemployed working age individuals with disabilities wanted to work but could not find employment. ¹⁸

The second major theme evidenced in the testimony deplored the irrational and harmful segregation that pervaded the experience of Americans with disabilities. Examples in congressional committee reports cite an individual banned from an auction house because she used a wheelchair and was deemed disgusting to look at, children with Down syndrome denied admission to a zoo so as not to upset the chimpanzee, a woman with arthritis denied a job at a college because the trustees believed "normal students shouldn't see her," and a woman fired from a job because her son had AIDS. 19 Sharon Mistler, who helped to coordinate nationwide ADA advocacy, recalled "being refused service in restaurants and theaters because I was a fire hazard, dehydrating so that I could go to school because my chair wouldn't fit into the bathroom, being kicked off airplanes, being directly told 'We don't want you people next door or on the bus or on the street."

After several amendments and two conferences to reconcile differences in the House and Senate versions, the House approved the final version on July 12, 1990, by a vote of 377 to 28. The Senate approved the act on the following day, by 91 to 6. On July 26th, 1990, President George Bush signed the Americans with Disabilities Act, stating that the nation was "taking a sledgehammer... to a wall which has, for too many generations, separated Americans with disabilities from the freedom they could glimpse, but not grasp." Americans with disabilities had achieved what they hoped would prove a legal remedy against abrogation of their right to be in the world.

THE AMERICANS WITH DISABILITIES ACT

Although achieving the right to be in the world was the primary goal of advocates for disability rights, the Americans with Disabilities Act as enacted was multipurposed. Indeed, Congress enumerated nine separate findings in support of the act. Grouped thematically, the aims of the act included eliminating arbitrary prohibitions against being in the world, ending inequality of opportunity, and reducing the costs to the United States of unnecessary dependency. While not necessarily incompatible, these aims do not always point in the same direction, and the strains among them have become increasingly significant over the ten years since passage of the ADA.

More specifically, Congress, in passing the ADA, found that over 43 million Americans had at least one disability, and that the number was increasing as the population aged, 42 U.S.C. § 12101 (a) (1). In support of achieving being in the world, Congress noted the historical segregation of people with disabilities, (a) (2); the discriminatory effects of architectural, transportational and other barriers, (a) (5); the inferior educational and economic status of people with disabilities, (a) (6); and the various ways in which people with disabilities have been treated as a "discrete and insular minority," (a) (7). In support of achieving equal opportunity, Congress observed that people with disabilities have continued to experience discrimination in critical areas such as voting or employment, (a) (3); that they encounter unequal opportunities in public benefits, (a) (5); and that, unlike other victims of discrimination, they frequently have no available legal means to address such discrimination, (a) (4). Finally, Congress observed that "the continuing existence of unfair and unnecessary discrimination and prejudice . . . costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity," (a) (9). The nextto-last finding summarized all three of these basic aims: "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals. . . . " (a) (8).

Toward these ends, the ADA pursues three major strategies. Title I addresses inequality in employment, Title II, inequality in public services, and Title III, inequality in services and accommodations offered by private entities. In addition to the general statement of purpose just described, some critical further elements are common throughout all three titles. Most importantly, "disability" is defined to include "a physical or mental impairment" that substantially limits at least one "major life activit[y]," a record of having such an impairment, or being regarded as having such an impairment, 42 U.S.C. § 12102 (2). Specifically excluded from the definition of disability, however, are illegal drug use, 42 U.S.C. § 12210; homosexuality, bisexuality and tranvestism, 42 U.S.C. § 12211 (a) (b) (1); and compulsive gambling, kleptomania, or pyromania, (b) (2). Individuals are protected from retaliation and coercion for asserting their rights under the act, 42 U.S.C. § 12203. Individual choice is specifically respected; no one may be required to accept accommodations or other rights under the act, § 12201 (d), unless they choose to do so. Attorneys' fees are available for prevailing parties in proceedings under the act § 12205, and alternative dispute resolution is encouraged for resolving disputes, § 12212. Finally, the act § 12212 claims to abrogate state sovereign immunity from suits seeking any remedies available against private entities under the ADA.

Title I of the ADA, the employment discrimination title, balances equality of employment opportunity against costs of accommodation to employers in a compromise that has proved controversial, as many of the articles in this collection demonstrate. Title I applies

ro employers with more than 15 employees (but not the United States, Indian tribes or cerrain private clubs), § 12111 (5). It prohibits job discrimination against "qualified individual[s]" with disabilities, because of the disability, in terms and conditions of employment. An individual is "qualified" by virtue of his or her ability to perform "essential functions" of the job, with or without accommodation; however, the employer's judgments as to essentiality are critical, particularly if they have been incorporated in a prior written job description § 12111 (8). Prohibited "discrimination" includes practices that curtail equality of opportunity, although once again there are employer-protective limitations. Employers are required to make "reasonable accommodations" for people who can, as a result, succeed on the job; examples of such accommodations include making facilities accessible, restrucruring work schedules and providing readers or interpreters, § 12111 (9). But "reasonable accommodations" do not include actions of "significant difficulty or expense," measured in terms of costs of the accommodation, financial resources of the facility at issue and financial resources of the employer as a whole, § 12111 (10). The Interpretive Guidance issued by the Equal Employment Opportunity Commission (which indicates the commission's positions but does not have the legal force of regulations) recommends that employer and employee use a problem-solving approach to work out which employment practices would afford the disabled employee opportunities to perform on the job that are equal to those of a similarly situated nondisabled employee.²² As several of the contributions to this volume indicate, there has been ongoing tension over the meaning of reasonable accommodations. One source of the tension has been the multiple goals of the ADA itself: whether the goal of reasonable accommodation is to achieve work in the world for people with disabilities, or whether it is principally to "level the playing field" between the disabled and the nondisabled. On the former view, the ADA is an affirmative action statute, aimed to further the right to be in the world of work. On the latter view, however, the ADA is a nondiscrimination statute, simply requiring employers not to erect unjustified barriers in the path of opportunities for people with disabilities.²³ Another source of the tension has been how to balance opportunities for the employee against expenses for the employer.

Title II of the ADA prohibits discrimination in publicly provided services, activities or programs. It parallels Title I in requiring reasonable accommodations for individuals who are "qualified" to receive the public services, in the sense that they meet essential eligibility requirements, with or without reasonable accommodation, § 12131 (2). And it has generated controversies similar to those that have arisen under Title I. In addition, Title II sets out quite specific standards for public transportation, § 12141-12165, surely a critical aspect of the right to be in the world for people with disabilities.

Finally, Title III of the ADA governs public accommodations provided in the private sector. Unlike the other major sections of the ADA, Title III affords protections that are not limited to "qualified individuals." Instead, Title III, § 12182, requires nondiscrimination "in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation." This requires the provision of goods and services in "the most integrated setting appropriate to the needs of the individual" and the opportunity to participate in mainstream activities even if separate activities are also available. It specifically prohibits the failure to remove barriers, the imposition of eligibility criteria unless "necessary for the provision" of the goods or services, and the failure to take steps to avoid excluding people with disabilities unless "taking such steps would fundamentally alter the nature" of the good or service. Title III also has specific accessibility requirements for new construction and for transportation serving the public.

Even here, however, there are noteworthy, cost-motivated exceptions that surely affect being in the world: newly constructed and altered buildings of fewer than three stories are not required to have elevators, unless they are shopping centers, shopping malls or offices of health care providers, § 12183 (b); and over-the-road (that is, long-distance) buses are not required to have accessible rest rooms if the result would be a loss in seating capacity, § 12186 (a) (2) (C). Despite these limits, Title III is the section of the ADA which affirmatively pursues the right to be in the world most directly, although as the chapter by Ruth Colker in this volume indicates, it is not immune from criticism in this regard.

THE ADA IN THE COURTS

Not surprisingly, it took nearly ten years before the United States Supreme Court attacked problems of interpretation under the ADA. In its initial decision interpreting the ADA, the Court held that nonsymptomatic HIV infection is a "disability" under the ADA because it interferes with a major life activity (reproduction), and that a dental office is a public accommodation under Title III of the ADA. The Court also concluded that a practitioner's judgment about whether treatment posed a health or safety threat was entitled to deference only if it was objectively reasonable.²⁴

In five decisions in 1999, the Court addressed several contentious issues under the ADA. The import of these decisions for persons with disabilities is mixed. First, the *Cleveland* decision held that an individual's application for welfare-based disability benefits does not preclude pursuit of remedies under the Americans with Disabilities Act; if the individual can show that although she or he was denied employment, and thus could not work, she or he nonetheless remained qualified to work.²⁵ In an appropriate case, therefore, it is possible for an individual both to claim the need for support because she was denied the opportunity to work, and to assert that she was unfairly denied equal opportunity to exercise her capacity to work.

Second, the Olmstead case challenged a state's refusal to provide recommended community placements for patients with mental disabilities. The state's justification for refusing to provide the placements was financial; because of limited funding, the state contended, requiring immediate community-based placements would "fundamentally alter" the nature of state-provided services. 26 The Court of Appeals had concluded that unwarranted institutionalization was discrimination, and that in assessing the state's "fundamental alteration" defense, the trial court should weigh the costs of providing the two communitybased placements at issue in the litigation against the overall state mental health budget, a comparison favorable to the plaintiffs since it was unlikely that the costs of two communitybased placements would radically alter the structure of state services. In remanding to the District Court, the Supreme Court agreed that it is discrimination under Title II to fail to provide recommended community-based services, but accepted a far less stringent understanding of the fundamental alteration defense: "In evaluating a State's fundamentalalteration defense, the District Court must consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities, and the State's obligation to mete out those services equitably."27 This language in Justice Ginsburg's opinion was joined by only three other justices; Justice Stevens would have supported the Court of Appeals' position, 28 and Justice Kennedy would have given more deference to physicians and state policy-makers, including a decision not to provide community-based placements

at all.²⁹ Olmstead is an important recognition that the ADA opposes the segregation of people with disabilities. On the other hand, disability rights advocates may find it a pyrrhic victory if it results in increased difficulty for plaintiffs seeking to challenge chronic underfunding of state services or if it signals that the Court is willing to take a generally broad view of the costs and hardships that limit ADA requirements. Eva Kittay's discussion, in Part A below, is powerful testimony to the importance of the support that allows people with disabilities to remain in their homes and communities rather than experiencing the segregation of institutionalization.

The other three cases decided in 1999 significantly curtailed and confused the understanding of disability under the ADA. Unlike other civil rights statutes, the ADA requires a threshold determination that an individual is disabled before he or she can claim the act's protection. Narrowing the understanding of disability will both limit the scope of the act and could, depending on the form the narrowing takes, reconceptualize the act as being nothing more than a reduction of dependency statute for individuals whose impairments significantly compromise their competency. The three 1999 decisions point to an understanding of disability that insists on significant personal loss of capacities—what has been called the "medical model" of disability. —and grants employers wide discretion in making business decisions. If interpretation of the ADA continues in this direction, it will increasingly function as a statute that balances limited opportunities against their perceived costs. The discussions in Part B of this volume defend different approaches to defining disability, and the discussions in Part C explore whether cost-based limits are justifiable.

In Sutton, the principal case of the three defining disability, the plaintiffs challenged United Airlines' vision requirements for pilots (uncorrected vision of at least 20/100). The Court held that the Sutton sisters' myopia should be assessed in its corrected rather than its uncorrected state, and that they should be regarded as disabled only if, with correction, they were unable to perform a major life activity such as working. Although they could not meet United Airlines' standard for pilots despite the fact of vision that was fully correctable, the sisters could and did work as pilots for a United feeder airline, and so were not disabled. The Court offered three reasons for this conclusion: the language of the ADA indicates that its focus is whether a person is presently disabled; disabilities must be evaluated on an individualized basis; and Congress's statement of purpose in the ADA did not include all of the people whose disabilities are sufficiently corrected to enable them to function effectively. Indeed, the Court said, Congress's estimate of the numbers of people with disabilities (43 million in 1990), clearly indicates that Congress did not mean to sweep the majority of Americans with corrected disabilities within the reach of the ADA.

In a second decision handed down with *Sutton*, the plaintiff Hallie Kirkingburg challenged a refusal by Albertson's to continue to employ him as a commercial truck driver because he had monocular vision. Albertson's decision rested on a federal safety requirement; although waivers of the requirement became available, in fact, because of doubts about whether the regulation really was justified, Albertson's did not seek a waiver for Kirkingburg. Before his vision was properly assessed by Albertson's, Kirkingburg had worked for over a year without any vision-related difficulties; although he later received a federal waiver, Albertson's refused to rehire him. In rejecting Kirkingburg's challenge, the Court first commented that Kirkingburg's monocular vision should not be regarded as a disability unless it was a "substantial limitation," judged on the basis of his ability to compensate for the impairment.³³ The principal focus of *Kirkingburg*, however, was whether the plaintiff was "otherwise qualified," and the Court held that Albertson's was entitled to rely on a

federal regulation in determining that he was not, without further inquiry into the reasonableness of the regulation or its application in the particular case.³⁴ Kirkingburg thus faced a paradox: he was not disabled because of his ability to compensate for his lost vision in one eye, but Albertson's was free to rely unquestioningly on a federal regulation that judged individuals with monocular vision to be unsafe drivers.

In the final decision, Vaughn Murphy challenged his dismissal from United Parcel Service because of hypertension that exceeded federal safety regulations for truck drivers. The Court held that whether the impairment—hypertension—substantially limited a major life activity must be determined based on the quality of the individual's life with mitigating measures taken into account. Thus Murphy could be considered disabled only if, with medication, his hypertension made him unable to continue working. ³⁵ Unfortunately for Murphy, although his hypertension was not controlled to the level that permitted him to meet federal safety standards, it was sufficiently controlled to permit him to perform at least some jobs, and so, the Court concluded, it did not interfere with the major life activity of working.

These decisions understand disability to be a property of the individual that can be superceded by corrective treatment or mechanical devices. Their result is that individuals will find it more difficult to claim the protections of the ADA to the extent that they have overcome or corrected their disabilities, as Arlene Mayerson and Matthew Diller point out forcefully in Part B below. They may also find it more difficult to claim that the major life activity of "working" means the ability to explore a range of options, rather than merely being able to obtain any kind of employment at all. As this book goes to press, this and many other issues about the direction and impact of the ADA remain unresolved in the courts; their resolution may greatly affect the extent to which the ADA furthers the rights of people with disabilities to be in the world.

UNRESOLVED ISSUES

Despite the passage of ten years and the exponential growth of litigation, theoretical treatment of the ADA remains sparse and much more limited than that afforded other civil rights statutes. Compared with the enormous volume of literature about race little attention has been paid to the theoretical understanding of disability. Nor is there agreement about how to integrate the health-related and socially conditioned aspects of the disability experience. In general, there has been almost no progress in linking the conceptualization of disability to efforts to facilitate understanding and achieve the purposes of disability discrimination law.

Moreover, the fundamental question of what approach to justice the ADA represents—whether it should be viewed as a nondiscrimination or an affirmative action statute—left unresolved in the congressional statement of purpose has not been explored extensively. But it is critical to understanding the ultimate directions that will and should be taken with respect to the ADA as interpretation of the statute evolves. This neglected discussion is taken up in the contributions to Part A of this volume, especially in those by Patricia Illingworth and Wendy Parmet, Richard Arneson and Thomas Pogge. So is the further theoretical question of whether justice offers the best foundation for pursuing the purposes of the ADA, or whether appeals to other values—the good, the virtues, or the moral quality of social roles—are more compelling.

The initial premise of citizens with disabilities who believed disability discrimination law would secure their right to be in the world was that they are just people seeking the

same opportunities others take for granted.³⁶ Nevertheless, the threshold issue in applying the ADA is not whether an individual is the same as other people but whether the person is disabled. Mark Kelman addresses the importance of this special assignment of disability status in the opening essay in Part B of this volume; in essays in the same section, Mary Crossley and David Wasserman both question whether disability or the stigmatization of difference is the underlying issue of justice that is most compelling. In Part A, Lawrence Becker, Eva Kittay and Alasdair MacIntyre all consider this question.

Despite the Court's 1999 decisions, there are many uncharted areas about the meaning of disability, several of which are explored in Parts B and C of this volume. The Court's apparent embrace of the understanding of disability in terms of deficiencies in the disabled person has already drawn much criticism. The essays by Ron Amundson, Mary Crossley and Anita Silvers in Part B criticize various aspects of this medicalized understanding of disability as individual impairment. Amundson addresses the assumption that biological normality can be distinguished from biological dysfunction, Crossley criticizes the coherence of the distinction employing the examples of pregnancy and obesity, and Silvers considers the complexities of employing a functional account of disability in the context of disability discrimination law. Whether the Court will continue down this path remains to be seen.

Moreover, deciding who is disabled continues to be troublesome in other respects. Imprecisions in the ADA's definition of disability, which requires that limitations be substantial and that the limited activities be major, contribute to the confusion about who is protected by the ADA. If current legal trends continue, it appears that "major life activity" will be defined in very basic terms, to include activities such as breathing, moving, thinking, working or reproducing. If a person must be substantially incapable of executing such broad activities to qualify as disabled, the class of people who are disabled will be limited to the more severely incapacitated, and the applicability of the ADA will be correspondingly limited. As Iris Marion Young points out in Part C, such narrowing has the risk that those who do not qualify for the protection of the ADA will resent those who do. At present, as Ruth Colker's empirical work demonstrates, a very high percentage of plaintiffs lose on summary judgment on issues involving the definition of disability, and it seems possible that the Court's 1999 decisions will only entrench this trend.³⁷

Perhaps the problem with the 1999 cases is that they did not raise the third prong of the ADA's definition of disability: whether the individual was "regarded as" disabled. How this prong is understood will surely make a major difference to the reach of the ADA. This is the prong that brings the ADA most in line with other civil rights statutes, for in order to come within it, an individual need not prove an actual feature of him or herself but merely that a judgment made by someone else invoked the relevant category—in the case of the ADA, the category of disability. Some appellate court decisions, however, appear to be reading the definition of actual disability into the "is regarded as" prong. Courts have held, for example, that an employer must regard the individual as unable to perform a major life activity, and not just erroneously judge the individual's ability to do the job under consideration, in order to "regard" the individual as disabled.³⁸ On the remedy side, another critical issue for "is regarded as" plaintiffs is whether they are able to claim the advantages offered by the ADA to actually disabled plaintiffs. "Is regarded as" plaintiffs may be able to demonstrate that they are "otherwise qualified" by showing that they are able to perform essential functions of the job, rather than all of the position's functions. They also may be entitled to reasonable accommodations.³⁹ Linking "is regarded as" plaintiffs to "actually" disabled plaintiffs in this way seems to make particularly good sense for the case of

plaintiffs who have limited impairments requiring accommodations but are erroneously viewed by their employers as completely unable to work in their current jobs. The approach has been criticized as "absurd," however, because it may entitle plaintiffs who are not actually disabled to claim protections as though they were disabled. ⁴⁰ This controversy, like others about the ADA, reaches deeply to questions about the nature of justice the ADA is meant to provide.

A further "gatekeeping" issue in applying Title I of the ADA is whether the individual is "otherwise qualified." In Kirkingburg, the Court indicated a willingness to defer to employer judgment, at least where the employer was relying on federal safety regulations. How far this deference will extend, however, remains an open question. At least some lower court decisions have indicated a willingness to impose standards on employers. For example, plaintiffs have been required to show only that they can perform "essential functions" of the position, 41 and employers have been required to reassign employees to other available jobs that are within their capacities. 42 Kirkingburg, however, viewed the statutory language as quite deferential to employer judgment. How "otherwise qualified" is understood is critical to the kind of protection afforded by the ADA. If individuals must be able to fit within employer judgments, understood in a broadly deferential way, then the ADA will require limited rethinking on the part of employers about what they have traditionally expected of employees. But if employers must meet substantive standards of reasonableness in judging qualifications, they may be forced to reassess traditional patterns, to reconsider whether it is how jobs are constructed that has led to judgments that people with disabilities cannot "do the job." In Part C-1 below, Peter Blanck, Gregory Kavka, Michael Stein and Iris Marion Young take different stances in considering this issue.

If individuals are "otherwise qualified," the ADA requires "reasonable accommodations," but not if these result in "undue hardship" to the employer. Once again, the extent of deference to employer judgment is critical to the reach of the ADA. So, too, is the issue of costs; one of the standard economic objections to the ADA is the costs its critics allege it imposes on employers—an objection directly criticized by Michael Stein in his contribution to this volume. If "reasonable accommodations" require only inexpensive assistive devices, significant job restructuring will not take place. By contrast, if employers are required to rethink how jobs are organized and job responsibilities are assigned, the world may adjust far better to the differences of individuals. Thomas Pogge, writing in Part A, and Anita Silvers, in Part B, disagree about whether it is reasonable to demand the reform of common practices so as to include people with disabilities.

Both "reasonable accommodations" and "undue hardship" are highly fact-specific judgments, so it is not surprising that there is little legal theory interpreting these concepts. Some cases, however, once again suggest deference to the employer; for example, USAir was not required to rethink its decision to abandon part time positions in order to accommodate an employee whose working hours were limited by carpal tunnel syndrome. Another issue here that has yet to be decided is what it means for the employer to concentrate on facility-specific costs, rather than costs for the enterprise as a whole, in arguing that costs are too great for accommodations to be required. Still a further cost-based issue will be the difference between discrimination and actuarially justified differences that are allowed for insurance benefits.

Yet another issue is the defense that making a structure, program or activity accessible will fundamentally alter its nature. In deciding whether to accept such a defense, courts have accorded great deference to the conventions of some kinds of endeavors—for

instance, to universities' academic requirements—but less deference to others—for instance, to professional sports associations' rules of play. Unfortunately, there is almost no legal or philosophical theory to guide judgment about whether a change in practice, made to accommodate an individual's disability, is a fundamental or instead an inessential alteration. There is also dispute about whether it is discriminatory to reduce the resources on which the disabled especially rely for support. Current calls for rationing health care and social services make this a particularly pressing problem to resolve, as many people with disabilities have special health and service needs. In Part C–2, Dan Brock and David Orentlicher take different positions on the ADA's implications for health care allocation, Joel Feinberg considers the intersection of disability and illness, and Norman Daniels explores equality of opportunity for people with mental impairments.

Many critical questions remain unanswered about the significance of the apparent trends to narrow the reach of the ADA. Does the Court's current direction undercut the premise that the disabled are just people seeking to fulfill expectations common to all citizens, such as the right to work defended by Gregory S. Kavka in Part C, or the right to health care? If protection against disability discrimination is interpreted as applying only to a narrowly defined group, are others who do not qualify more likely to resent the statute's protection of those who do? Is the statute more likely to be perceived as unfairly imposing inefficiencies on employers? More likely to impose problematic demands on the health care system? Will there be a call for prohibiting practices that aid only the disabled because these are perceived as discriminating in reverse? This prospect is not simply a legal issue, for it emerges from political concerns about acting preferentially towards minority groups. These practical and political issues are the substance of Part C of the volume.

Can action pursued under the ADA eventually eliminate the social disadvantages from which citizens with disabilities suffer today? In Part C-3, Andrew I. Batavia and Richard Scotch wrestle with this question. Harlan Hahn posits that it will be difficult to make real progress against disability discrimination until courts recognize the extent to which the disadvantageous conditions imposed on the disabled are intentional and not a by-product of benign neglect. Lennard Davis offers a similar analysis, arguing that the justice system unwarrantedly discounts the extent to which hate fuels practices that are injurious to people with disabilities. In their essays, both Ruth Colker, and Lori Andrews and Michelle Hibbert examine trends in judicial responses when people with disabilities seek compensatory relief.

A final set of unresolved problems, for the ADA as well as for other civil rights statutes, is Congress's power to authorize lawsuits that seek to remedy violations by state governments or their agencies. In *Kimel v. Florida Board of Regents*, 45 the U.S. Supreme Court held that Congress does not have the constitutional power under the 14th amendment to enforce prohibitions against age discrimination by state governments. *Kimel* gives no explicit indication of the Court's position about disability discrimination, although it cites *Cleburne*⁴⁶ for the proposition that age classifications, unlike classifications based on race or gender, should not be deemed to reflect prejudice. Federal appellate courts are divided on the parallel issue for the ADA.

Under current constitutional doctrine, Section 5 gives Congress the power to remedy violations of the Fourteenth Amendment but not to expand the Amendment's scope. If differential treatment of the disabled must pass only a rational-basis test to comport with equal protection, the ADA would appear to expand the scope of the Fourteenth Amendment, or so the Eighth Circuit argued. On the other hand, if the Fourteenth

Amendment prohibits invidious discrimination against the disabled, and Congress explicitly adopted the ADA to this end, then the ADA is properly regarded as a remedial statute. 49 The underlying philosophical questions here are the federal power to shape a standard of equal protection and to hold the states to it.

In the decade since the passage of the ADA, regulations to guide implementation of the law have been developed, promulgated and revised; compliance plans have been written (although some entities required to do so have no such plan on file); and cases have been tried, decided, appealed and decided even by the United States Supreme Court. Yet the extent to which the ADA and the exercise of civil rights can or should secure the well-being of people with disabilities remains unresolved. Do the disabled really benefit from a rights-based approach aimed only at removing barriers and leveling the playing field of opportunity? Or should public policy focus instead on making provisions to relieve their special needs? Or should the effort be cultivating virtuous conduct toward people with disabilities on the part of the nondisabled majority?

As the ADA reaches its tenth anniversary, we appear not much theoretically advanced beyond the Supreme Court's unsuccessful attempt to distinguish between nondiscrimination and "affirmative efforts to overcome the disabilities caused by handicaps" in Southeastern Community College v. Davis, a case decided over twenty years ago under Section 504 of the Rehabilitation Act. 50 In Davis, the Court insisted that only nondiscrimination had been authorized by Congress. Subsequently, the Court acknowledged, in a footnote to Alexander v. Choate, 51 the confusion this earlier language had caused. The footnote includes an attempt to distinguish between reasonable accommodation and affirmative action by characterizing the latter as substantially modifying or fundamentally altering the nature of a program. 52 Yet interpretation of the ADA remains beset by this fundamental unclarity.

From a global point of view, the ADA stands as powerful testimony to the expansiveness of civil rights law. In Part D, Jerome Bickenbach, Mairian Corker, and Melinda Jones and Lee Ann Basser Marks contrast the ADA with how disability is treated in English legal systems that lack a civil rights tradition. Their contributions offer a comparative method for weighing whether affirmative measures of support are more central than prohibitions against discrimination in remedying the disadvantages experienced by citizens with disabilities.

Despite standing as a beacon of hope for disabled people around the globe, the ADA has its critics. To them, the statute raises more questions than it answers, and invites more problems for society at large than it resolves for people with disabilities. To a large extent, failure to examine the conceptual, philosophical, political and legal foundations of the ADA invites such complaints. To advance beyond the absence of theory that has attenuated progress during the first decade of the ADA, this volume brings together leading philosophers, legal scholars and political theorists—many of whom have backgrounds in bioethics or in disability studies—to explore these critical issues. In honor of the ADA's tenth anniversary, this volume aims to provide both philosophical and legal analysis that will guide achievement not only of the right to be in the world that Jacobus tenBroek invoked over thirty years ago, but also of the broader goals of opportunity and inclusion envisioned by the civil rights movement that transformed American life in the last half of the twentieth century.

NOTES

¹Jacobus tenBroek, "The Right to Live in the World: The Disabled in the Law of Torts," 54 Cal. L. Rev. 841 (1966).

²26 U.S.C. § 63(c)(3), (f). See also John K. McNulty, Federal Income Taxation of Individuals. St. Paul, MN.: West Publishing Group, 1999.

³42 U.S.C. § 423. For a useful discussion of the differences between Social Security disability and SSI, see Carolyn A. Kubitschek and Barbara Samuels, *Social Security and SSI Disability*. New York: Practising Law Institute, 1999.

⁴42 U.S.C. § 1382c. For a discussion of the impact of the 1996 welfare reforms on the elderly and disabled, see Leslie P. Francis, "Elderly Immigrants: What Should they Expect of the Social Safety Net?" 5 *The ElderLaw Journal* 229 (1997).

⁵Cleveland v. Policy Management Systems Corp., 119 S. Ct. 1597 (1999).

⁶Robert L. Burgdorf, Jr., "The Americans With Disabilities Act: Analysis and Implications of a Second-Generation Civil Rights Statute," 26 Harv. C.R.-C.L. L. Rev. 413, 429 (1991).

⁷United States Commission on Civil Rights, "Accommodating the Spectrum of Individual Abilities," Washington, DC: 1983,149.

829 U.S.C. \$749 (1994).

⁹Pub. L. 93–112, § 7(6), 87 Stat. 355, 362 (1973)

¹⁰Rehabilitation Act Amendments of 1974, Pub. L. 93-516, 88 Stat. 1617 (1974) this volume.

¹¹National Council on the Handicapped, *Toward Independence*. Washington, DC: National Council on the Handicapped 1986, A–19.

1229 C.F.R. part 1630 (1998).

¹³42 U.S.C. §§ 3604(f)(3)(C) and 3604(f)(3)(B)(1988).

14 Toward Independence, 18-21.

¹⁵President's Commission on Employment of People with Disabilities, *Worklife*, Special ADA Issue vol. 3, no. 3, Fall 1990. Washington D.C., p. 2.

16 Worklife, 7, 16.

17 Worklife, p. 13.

¹⁸Lou Harris and Associates. "The ICD Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream" (1986), 50.

¹⁹Robert L. Burgdorf, Jr., "The Americans with Disabilities Act: Analysis and Implications of a Second-Generation Civil Rights Statute," 26 *Harv. C.R.-C.L. L. Rev.* 413, 418–419 (1991).

²⁰Worklife, 18.

21 Worklife, 11.

²²"Interpretive Guidance on Title I of the Americans with Disabilities Act, 29 C.F.R. part 1630, Appendix (1998).

²³For an argument that the ADA is a "level the playing field" rather than an "affirmative action" statute, see Allen Dudley. "Comment: Rights to Reasonable Accommodation Under the Americans with Disabilities Act for 'Regarded as' Disabled Individuals," 7 Geo. Mason U. L. Rev. 389 (1999) (arguing that the rights of "regarded as disabled" individuals should be narrowly construed).

²⁴Bragdon v. Abbott, 524 U.S. 624 (1998).

²⁵Cleveland v. Policy Management Systems Corp., 119 S. Ct. 1597 (1999).

²⁶Olnistead v. L.C., 1999 U.S. LEXIS 4368 (June 22, 1999).

²⁷1999 U.S. LEXIS 4368, at 30.

²⁸1999 U.S. LEXIS 4368, at '46 (Stevens, J., concurring in part and concurring in the judgment).

²⁹1999 U.S. LEXIS 4368, at '47 (Kennedy, J., concurring in the judgment).

³⁰See, e.g., Adam A. Milani, "Living in the World: A New Look at the Disabled in the Law of Torts," 48 *Cath. U. L. Rev.* 323, 329 (1999) ("the focus of the medical model is on how the individual adapts to his or her disability, not how society as a whole should deal with people with disabilities").

³¹Sutton v. United Airlines, Inc., 1999 U.S. LEXIS 4371 (June 22, 1999).

321999 U.S. LEXIS 4372, at 22.

³³Albertson's, Inc. v. Kirkingburg, 1999 U.S. LEXIS 4369, at 18 (June 22, 1999).

³⁴1999 U.S. LEXIS 4369, at 39.

35 Murphy v. United Parcel Service, Inc., 1999 U.S. LEXIS 4370 (June 22, 1999).

³⁶See, e.g., Robert Burgdorf, "'Substantially Limited' Protection from Disability Discrimination: The Special Treatment Model and Misconstructions of the Definition of Disability, 42 *Vill. L. Rev.* 408–585 (1997).

³⁷Ruth Colker, "The Americans with Disabilities Act: A Windfall for Defendants," 34 Harv. C.R.-C.L. L. Rev. 99 (1999).

³⁸See, e.g., Weber v. Strippit, Inc., 186 F.2d 907 (8th Cir. 1999); Lessard v. Osram Sylvania, Inc., 175 F.3d 193 (1st Cir. 1999); Standard v. A.B.E.L. Services, Inc., 161 F.3d 1318 (11th Cir. 1998).

³⁹Deane v. Pocono Medical Center, 142 F.2d 138 (3d Cir. 1998) (en banc).

⁴⁰Allen Dudley, "Comment: Rights to Reasonable Accommodation Under the Americans with Disabilities Act for 'Regarded as' Disabled Individuals," 7 Geo. Mason L. Rev. 389 (1999).

⁴¹E.g., Deane v. Pocono Medical Center, 142 F.3d 138 (3d Cir. 1999) (en banc).

⁴²E.g., Smith v. Midland Brake, Inc., 180 F.2d 1154 (10th Cir. 1999) (en banc).

43 Terrell v. USAir, 132 F.3d 621 (11th Cir. 1998).

⁴⁴See Anita Silvers and David Wasserman, "The Double Edge of Convention: Disability Rights in Sports and Education," 18 Newsletter of the Institute for Philosophy and Public Policy, 1 (1998).

452000 U.S. LEXIS 498.

⁴⁶Cleburne v. Cleburne Living Center, 473 U.S. 432 (1985).

⁴⁷City of Boerne v. Flores, 521 U.S. 507 (1997).

48 Alsbrook v. City of Maumelle, 184 F.3d 999 (8th Cir. 1999) (en banc).

⁴⁹Dare v. California, 1999 U.S. App. LEXIS 22351 (9th Cir., Sept. 16, 1999).

50442 U.S. 397 (1979).

51469 U.S. 287 (1985).

52300-301, n. 20.

Foundations

Justice, Goodness and Disability Rights

Civil rights statutes may reflect a wide variety of approaches to justice and rights. Different theoretical approaches, to be sure, will recommend corresponding differences in the range of protections offered. Libertarians will be concerned to protect people from force, fraud and the unjustified deprivation of property. Those who see justice as fair equality of opportunity will aim to remove barriers that make it more difficult for some than for others to have access to major means for achieving the good life, such as education, employment or health care. Others will go further, seeking to assure that each individual is guaranteed at least a minimally decent life.

With respect to the prohibition of discrimination based on race, these theoretical differences are at play in the debates among defenders of limiting remedies to compensation for past injuries and correction of existing discrimination, who believe that the vestiges of discrimination have largely been eliminated in contemporary society; proponents of ongoing efforts to eliminate current and future discrimination; and advocates for more extensive affirmative action. In the area of disability rights, this debate has been complicated by a history of misguided paternalism. Discrimination against people with disabilities has been rationalized by false beliefs about inadequacy, incompetence and difference. The disabled have been segregated by being placed in custodial care in supposedly protective institutions. They have been excluded from public life out of unfounded fears that their attempts to participate would humiliate them, put them at risk or be uncomfortable or burdensome to nondisabled people. This history raises questions about whether a statute directed specifically to preventing discrimination against people with disabilities furthers their equality or threatens to undermine it. Should the ADA be understood as making the ordinary right of equal protection meaningful to people with disabilities? Or, should it be viewed as extending special rights they need if protection for them is to be meaningful? Which of these, or perhaps other, interpretations of the statute and its goals best furthers genuine equality?

In the first essay of this section, Wendy Parmet and Patricia Illingworth attack this concern head on. They argue that positive and negative rights cannot be distinguished, and that the Americans with Disabilities Act is properly viewed as a statute establishing positive rights. Parmet and Illingworth argue that when we see the ADA as a positive-rights statute, and disability as spread broadly throughout the community, we will fully support genuine equality for all.

Richard Arneson also criticizes the nondiscrimination approach, but from the perspective of a prioritarian theory of justice. On Arneson's welfarist, responsibility-catering prioritarianism, institutions and practices should be arranged to maximize moral value, which

The ADA v. the Canadian **Charter of Rights**

Disability Rights and the Social Model of Disability

JEROME E. BICKENBACH

The Americans with Disabilities Act (ADA) has, in its decade of operation, become the model for disability antidiscrimination legislation around the world. To be sure, there are other legal mechanisms for responding to discrimination: Canada, Poland and the Netherlands have constitutional guarantees of equality for persons with disabilities; France, Germany and several other European countries have strict affirmative-action provisions, primarily in the employment sector;3 and Japan and China, among other countries, have strongly worded though not legally binding or enforceable "prohibitions" of discrimination against persons with mental or physical disabilities4 which are founded on the equally nonbinding United Nations declarations.5

The contrast with the Canadian constitutional approach to disability rights provides an interesting comparison with the ADA. The Canadian Charter of Rights and Freedoms provides in Section 15(1) for a general, and on the face of it very broad, guarantee of equality: "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability." The Canadian Supreme Court has been cautious in its interpretation of the scope of this provision as it affects persons with disabilities.6 Inasmuch as successful adjudication using the Charter has constitutional force, all levels of government are bound to act in accordance with the decision. Although individuals can initiate constitutional legal challenges, the federal government of Canada, as well as certain provinces, have found it in their interests to initiate constitutional reviews of their own acts or policies so as to avoid future litigation.

In addition to the constitutional recognition and protection of equality, each Canadian province and the federal government have enacted explicit antidiscrimination legislation (or human rights acts, as they are called), that provide protection against discrimination on the basis of disability. These acts apply to the private sector, unlike the Charter protection, which binds only the various levels of government and its agencies. Their focus, however, is on arbitration and conciliation, and only a few cases make their way (and with extreme slowness) up through the court system. There have been, however, interesting and creative results. For example, a child with cerebral palsy who wished to compete in a bowling tournament won the right to do so, even though that required a change in the rules of the game, inasmuch as she needed to use a ramp to deliver the ball.7 Unfortunately, in recent years, human rights agencies have been dramatically underfunded, with the result that what was once a slow process is now a glacially slow process.

Ultimately, when human rights are guaranteed, constitutionally or otherwise, enforcement becomes a judicial matter and is not restricted to providing compensation to one individual whose rights have been violated. Indeed, on occasion courts in Canada have creatively devised techniques for altering offensive legislative provisions, up to the point of excising certain wordings and substituting others. The bluntest tool available to a Canadian court is a declaration that a law (and so state action taken in accordance with the law) is ultra vires; but in practice, Canadian courts have taken to issuing far more subtle and effective orders in order to ensure that equality for persons with disabilities is enhanced and protected. Relying on the Charter's internal logic, courts have held that forms of discriminatory treatment, though arguably justified by a background pressing and substantial state objective (for example, highway safety), nonetheless violated equality because the means in which that objective was sought to be achieved were not rationally connected to the objective. 8 In another high profile case a deaf individual who had argued that hospitals in British Columbia which fail to provide sign language interpreters discriminate against people who are deaf was successful. The Supreme Court of Canada had little difficulty demanding that legislative changes be implemented forthwith to ensure that the province's health sector functioned in line with the constitutional protection of equality.9

At the same time, "judicial legislation" of this sort certainly has its critics and is highly dependent on the membership of the court and their political views.

The Canadian approach to the constitutional enforcement of disability human rights is not without its problems. The discourse of human rights becomes specialized and removed from common understanding. An individual or group who wants to bring a case against a law or policy has the onerous task of bringing before the courts complex constitutional argumentation. The process can take years, is extremely expensive, and can be dismissed without comment by a court that judges the issues of insignificant constitutional importance. Courts, finally, as rule are understandably reluctant to move too quickly or too far when interpreting the highest law of the land.

Although there are many procedural and substantive differences between the Canadian constitutional approach and that adopted in the U.S. and elsewhere, all examples of legal protections against discrimination are a manifestation of what might be called "the human rights approach" to disability social policy. Undoubtedly the single most important social event in international disability advocacy in the past couple of decades, the human rights approach was the product of political action and lobbying in the U.S. and elsewhere from the early 1960s on. 10 The disability rights movement followed and adhered to the strategies and inspiration of civil rights movements responding to racial discrimination, which, certainly in the U.S. context, accounts for the reliance on antidiscrimination protection as the primary expression of disability rights and the mode of their protection.

Early on, disability advocates realized that an essential theoretical presupposition of the human rights approach was a very different conception of disability from that standardly used in the medical community. Relying on decades of work by sociologists and sociopsychologists, 11 advocates gravitated towards the "social model" of disability, in which disability is seen as the outcome of an interaction between intrinsic features of the individual's body or mind (impairments) and the complete social and physical context or environment in which that the person carries out his or her life. 12

Hints of the social model can be discerned in the definition of "handicapped individual" found in the original version of the Rehabilitation Act of 1973 (mirroring the language of Title VI of the Civil Rights Act of 1964), which created a parallel between the disadvantageous social reception of disability and that of race.¹³ A more explicit and considerably

more radical expression of the social model came in 1976 from a group of disabled individuals in the U.K. calling themselves the Union of the Physically Impaired Against Segregation (UPIAS), who defined "disability" as "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers."14

More moderate and defensible versions of the social model of disability argue that while having a disability means being limited in the range of activities one can perform, what accounts for this limitation is often if not always a matter of the environmental context in which human actions occur.¹⁵ In particular, physical and socially created or tolerated barriers limit when they do not prevent the performance of human activities, roles or behaviors which, in composite, account for the sum total of human life in all its social dimensions. The physical and social world creates barriers for people with impairments: stigmatizing attitudes and presumptions of incompetence, failures to accommodate impairment needs, and a general neglect that makes possible the design of products and the built environment that are not fully useable for people with mobility, communication or intellectual impairments. The social world that produces barriers or fails to remove them creates much of the disadvantage of having a disability.

Other recent attempts to describe the social model of disability have sought to describe more carefully the relationship between the intrinsic features of human bodies and minds that account for impairments and the extrinsic features of the physical and social world that, in interaction, yield the experience of disability. Moreover, the relationship between impairments and limitations in the performance of activities is more complex than usually believed. The disabilities that people experience can be linked to a wide range of background impairments, and it is rare to be able to infer from impairment to disability, or vice versa. For example, a person may have limitations in his or her ability to move around in an open public area because of impairments that interfere with walking, or with seeing obstacles or with being able psychologically to deal with strangers. On the other hand, we should be wary of predictions about what people who have visual impairments can or cannot do: some of these predictions merely reflect stigmatizing preconceptions.

The social model of disability, in brief, can be characterized by adherence to the following propositions:

- 1. Disability is a complex phenomenon that results from interactions between intrinsic features of human minds and bodies and features of the physical and social environment in which people live and act.
- 2. Disability cannot be reduced to or be predicted from underlying physical or mental states of the person.
- 3. Disability is not a dichotomous state that people either have or do not have, but is rather "fluid and continuous," 16 existing in various forms and degrees; moreover, disability is a universal human experience.
- 4. Disability cannot be understood independently of the complete context—that is, features of the physical and social environment-of the person's life.

THE ADA AND THE DISABILITY RIGHTS APPROACH

In the U.S. and other industrialized countries, the disability rights movement—underpinned by one or another version of the social model of disability-played itself our against a background of specific social entitlements and related provisions, primarily in the

areas of health, rehabilitation, transportation, education and employment. Historically, these provisions were overtly political responses to the demands of disabled veterans, with the result that disability programming, despite the rights revolution, tends to be reactive and piecemeal.¹⁷ Often, too, disability policies have seemed to be more responsive to the professional needs of service providers and bureaucrats than to people with disabilities themselves.

As an essentially consumer protest, the disability rights movement was fueled by a rejection of this manner of meeting disabled people's needs. Initially at least, what was demanded was not more social programming or even specific entitlements, but a reorientation of the very foundation of disability law and policy. What was needed was an explicit recognition of the human rights of persons with disabilities. All change for the better would flow once it was acknowledged that people with disabilities are not given their rights as a matter of charity or the goodwill of others, but are entitled to them as equal members

The human rights approach, in other words, was at bottom a demand for equality for persons with disabilities. Following the pattern of other civil rights movements, that demand was, so to speak, legally operationalized as antidiscrimination enforcement. The legal mechanism for securing equality thus became enforceable protections against discrimination on the grounds of disability. While the human rights approach put full participation and equality foremost on its agenda, it also reacted against the stereotypes of infirmity and childlike dependency and set its sights on the goals of independence and selfsufficiency. Especially in the U.S., disability advocates adopted and made their own the culture of individualism and a rejection of a paternalistic state. Rather than entitlement programming, which fosters dependence, the goal should be economic self-sufficiency, usually in the form of remunerative employment. Equality, advocates believed, could be best served by enabling people with disabilities to be competitive in the open labor market, giving them a fair and equal opportunity to get and keep a job. The strategy of encouraging people with disabilities to make demands for full inclusion into existing economic structures was motivated by the fundamental faith that full employment for persons with disability was bound to have long-range economic advantages for the society at large. This suggested that what prevented fully inclusive employment could not be the labor market itself but, rather, economically irrational stigma and prejudice of the sort that antidiscrimination legislation is perfectly designed to remedy.

In retrospect, the disability rights approach can be credited with nearly every change in attitude and treatment of people with disabilities in the last two decades, from curb cuts and accessible bathrooms to programs to integrate developmentally disabled children into the public schools. As it has matured, the approach has adopted some of the theoretical developments introduced by feminists and black theorists. More recently, the approach has taken on some of the flavor of identity politics. Yet through it all, faith has been retained in the legal representation of disability rights in antidiscrimination legislation in general and the ADA in particular.

In the face of proven success, it might seem churlish to raise objections to theory and practice of antidiscrimination law or to question whether equality-seeking is always and only a matter of preventing discrimination. Nonetheless, cautious critique is justified if, as I believe, in the contemporary social and economic climate legislation like the ADA yields doctrine and results that are in conflict with the underlying political and ideological components of the disability rights movement, namely the social model of disability and the goal of political equality. This conflict manifests itself when the ADA is viewed either as an

appropriate and adequate legal remedy for rights violations or, more broadly, as a constructive social response to the inequality that people with disabilities experience.

THE ADA AS A REMEDY FOR RIGHTS VIOLATIONS

The ADA sets out detailed legal and administrative mechanisms for determining, adjudicating and remedying complaints of discrimination on the basis of disability as explicitly defined by its provisions. This role is accomplished by means of provisions that provide adjudicators with the legal tools for distinguishing discriminatory from nondiscriminatory treatment within protected sectors represented by the four primary titles of the act: Employment, Public Services, Public Accommodations, and Telecommunications. And the purposes of the act are clear-namely, to provide "clear, strong, consistent, enforceable standards" that address discrimination against individuals with disabilities, such as will establish a clear and comprehensive mandate for the elimination of that discrimination. 18

The governing assumptions of the act are nowhere better expressed than in the "finding" that individuals with disabilities are a: "discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society. . . . "19 The cause of discrimination is here portraved as "purposeful unequal treatment" founded on "stereotypic assumptions" directed at a "discrete and insular minority." These salient phrases, adopted directly from the developed law on racial discrimination, firmly root the ADA in a conception of discrimination that informs not only the substantive provisions that follow but also the jurisprudence that has developed.

The ADA presumes that people with disabilities see themselves and are seen by others as a minority group analogous to a racial minority who have historically suffered discriminatory treatment that is fundamentally irrational and prejudicial. Unfortunately, the analogy between disability and race is forced and awkward. The social stigma and stereotyping that undoubtedly exist in the case of disability vary widely between mental and physical impairments. People with disabilities do not have common experiences, nor, the Deaf community notwithstanding, is there a unifying culture or language that people with disabilities can point to in order to establish transdisability solidarity. One does not have to be an anthropologist to observe that the leaders of the disability movement have tended to be highly educated, white, middle-class males with late onset physical disabilities and minimal medical needs, a group that is hardly representative of the population of people with disabilities around the world.

But even if the minority model fitted the facts, and people with disabilities did constitute a "discrete and insular minority," there is a fundamental dilemma in relying on this characterization. Unlike race and gender, in the case of disability adverse labeling is a justifiable concern on its own. Yet in order to benefit from the protections of the ADA, one is required to embrace a label and a minority group status which is explicitly described to be socially discredited.

But surely, it might be argued, the ADA and its operation over the years have helped to destigmatize the label of "person with disability," perhaps even infusing it with new and invigorated positive value. There is little evidence that this has occurred, nor is it clear how it could happen since the purpose of the ADA is explicitly negative, namely to eliminate

discrimination against persons with disabilities. Given that purpose, the essence of the ADA as a legal tool rests on its conception not of the minority group nor of an individual with a disability but on discriminatory treatment based on disability.

The key to the ADA's characterization of discriminatory treatment flows from a legal protocol that has gained wide acceptance across jurisdictions that adopted antidiscrimination legislation in the last decade. 20 The protocol, most clearly applied in the employment sector, envisages an individual who is "otherwise qualified" to perform a job, but who is prevented from doing so-or denied some other opportunity or benefit-solely because of a disability (or perceptions that others have of the individual's disability or presumed disability). Such treatment is discriminatory, subject to the conditional defence that no reasonable way exists of accommodating the disability, that is of providing an accommodation, modification, or other alteration that would enable the individual to perform the essential functions of the job. Accommodations are "reasonable" only if their provision would not constitute an "undue hardship" for those charged with providing them.

Inevitably, legislation such as the ADA will lead to proactive or anticipatory responses by individuals and agencies to avoid potential ADA complaints. This is undoubtedly a good thing, but this social response depends entirely on the primary function of the ADA to deal post hoc with instances of putatively discriminatory treatment. In short, the ADA is designed to be reactive and complaint-driven. It is legislation that seeks to protect human rights by giving people a legal tool to use when they feel that their rights to equal participation and equal respect are being infringed. Antidiscrimination is, in the first instance, "individualistic" legislation, inasmuch as the onus is on the individual to take the initiative to use the power it provides.

The ADA envisages a situation in which an individual is prevented from achieving goals that he or she could plausibly achieve solely because of artificial barriers founded on irrational beliefs, stereotypes or prejudice about disability. Each individual is presumed to have the motivational and other merit-creating abilities required for full participation in a protected area of social life, so as to plausibly argue that he or she would succeed but for these artificial and irrational obstacles. If nothing else, this presumption in practice clearly favors intelligent people with late-onset mobility or sensory or mild psychiatric impairments that have not affected either their motivation or their general capacity to work. The largest class of complainants under the ADA employment provisions have been from people with lower-back pain—a classic late-onset debilitating condition—and the upper range of compensation awards involve damages such as those awarded against a law firm that failed to accommodate an attorney with depression.

Arguably, the paradigm instance of disability discrimination presumed by the ADA is not representative of the condition of social inequality faced by persons with disabilities. But even if it were, the process of determining whether an individual qualifies for ADA protection has become entangled in complex and subtle legal argumentation and distinction-drawing as the intentionally vague components of the protocol just described are applied to concrete cases. The growing complexity and legal subtlety of ADA case law are clearly seen in the voluminous detail of the Equal Employment Opportunity Commission's (EEOC) ADA Compliance Manual and related interpretative guidelines.²¹

THE ADA AND THE DEFINITION OF DISABILITY

One might suggest that ever-increasing complexity and subtlety are a common characteristic of the maturation of legal concepts and rules as they are modified by application in

particular cases. The cynic might suggest that this trend is just a by-product of the legal profession creating work for itself. What is ironic, however, is the message this growing complexity seems to embody. It is as if the moral clarity expressed in the opening sections of the ADA needs to be reconsidered: we thought that it was obvious that people with disabilities "continually encounter" discrimination and are "severely disadvantaged," but now we cannot be so sure. This message is, of course, considerably reinforced by recent Supreme Court cases such as Sutton v. United Airlines, Inc., in which the scope of ADA coverage has been significantly restricted, in part on the basis of the claim, reinforced by the ADA itself, that disability can affect only "a discrete and insular minority."24

Indeed, the practical value of the ADA as a response to rights violation is cast into doubt by the clear direction that the legal interpretation of disability has taken. It is understandable that the ADA should define the term "disability" consistent with its purpose of eliminating discrimination and so, perhaps, very differently from legislation that, for example, determines eligibility for disability pensions or workers' compensation. Yet the ADA's statutory definition of "disability" and subsequent interpretations are arguably inconsistent with the social model of disability that underwrote the disability rights movement and generated the political will to enact the ADA in the first place.

There are two components of the statutory definition of "disability" in the ADA—the first from the act itself, and the second from the regulations:

- sec. 3 (2) Disability.—The term "disability" means, with respect to an individual a physical or mental impairment that substantially limits one or more of the major life activities of such individual:23
 - (A) a record of such an impairment; or
 - (B) being regarded as having such an impairment.

sec. 1630. 2(h) A physical or mental impairment means:

any physiological disorder, or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genito-urinary, hemic and lymphatic, skin, and endocrine; or any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities.24

There is as well a third component, namely a list of exceptions to what qualifies as a disability or an impairment:

sec. 510. Illegal Use of Drugs.

In General.—For purposes of this Act, the term "individual with a disability" does not include an individual who is currently engaging in the illegal use of drugs. . . .

sec. 511 Definitions.

Homosexuality and bisexuality.—For purposes of the definition of "disability" in section 3(2), homosexuality and bisexuality are not impairments and as such are not disabilities under this Act.

Certain Conditions.—Under this Act, the term "disability" shall not include transvestitism, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, or other sexual behavior disorders;

compulsive gambling, kleptomania, or pyromania; or psychoactive substance use disorders resulting from current illegal use of drugs.

Setting aside the exclusions for the moment, the primary definition of "disability" accords well with the antidiscrimination mandate of the act. In particular, it is perfectly appropriate that there be three prongs to the definition of disability—namely, having a disability, having a record of a disability, and being regarded as having a disability. Since prejudice, stigma and other adverse and discriminatory attitudes are based on perception rather than reality, it is perfectly sensible to define the protected class of people both in terms of physical conditions that they have as well as those they no longer have or never had. Discrimination on the basis of the perception of a disability is as much a social ill as discrimination on the basis of an actual disability. As well, it is surely defensible to separate the determination of disability from that of eligibility to bring a complaint, that is, the determination that one is a "qualified individual with a disability." That said, these statutory definitions reveal a conception of disability that is surprisingly at odds with the social model, as characterized by the four basic principles noted above.

ADA disabilities and impairments exist on a continuum, in the sense that a disability is defined as an impairment that meets a threshold of severity. Since impairments are viewed as exclusively biomedical phenomena-disorders, conditions, losses or diseases-on this definition, so too are disabilities. In practical terms, this means that, where it is not obvious, some form of medical documentation of impairment is essential to qualify as a person with a disability. But this is to fall back on the medical model of disability that was explicitly rejected by disability rights advocates. And it was rejected for a good reason, since disability is not a personal trait but an outcome of an interaction between an impairment and the physical and social environment in which the individual lives. Disabilities are not severe instances of impairment; they are categorically different enrities.

Does this matter for the aims of the ADA? There is, of course, the blatant inconsistency between the first and the third prongs of the definition. Why demand medical evidence that one has a severe enough impairment to qualify for protection against stigma, stereotyping and prejudice, when no such evidence is needed to qualify as being "regarded as having a disability"? If the social issue is discrimination, that is a matter of how other people treat a person with disabilities, and that treatment is not directly correlated with the medical status of a person or the range and extent of that individual's functional capabilities in real-life situations. Making a determination of whether a person's rights have been violated by others in terms of that individual's medical condition seems perverse and utterly beside the point.

This is precisely why disability theorists and activists rejected the medical model of disability. On the social model, disability is entirely context- or environment-dependent, in the sense that the existence of a disability or its quality as a limitation on a person's range of social roles and activities is as much a function of features of the world as of his or her physical or mental condition. This fact has been recently recognized by the World Health Organization and embodied in its revised international classification of disability, the ICIDH-2.25 Although traditionally viewed as an international organization devoted to the provision of medical assistance and advice, the WHO has, consistent with its own very broad definition of "health," stated that health is not merely a matter of the absence of disease but also the extent and range of an individual's functioning. In the ICIDH-2, disability is modeled as a limitation in the range or extent of a person's activity performance. Yet, as activities are always performed in the context of a world shaped by

features of the physical and human-made environment, the ICIDH-2 recognizes that the outcome of extent of participation will typically be the product of an interaction between the individual, his or her health status, and the physical and social world. Thus two people may have the same impairment with the same severity, but because of different occupational demands, social supports or climatic conditions, one may have a disability and the other may not. Disabilities are rarely directly inferable from impairments precisely because disabilities are context-dependent and impairments are medical abstractions from context.

There are many reasons why the ADA, contrary to the intentions of its advocates, seems always to be belabored by a medicalized version of disability. But prominent among these reasons is the fact that the ADA is an evolutionary development from the Rehabilitation Act of 1973, an act which deals primarily with provision for and access to medical and rehabilitation services. Medically based services presumed genuine medically determined needs, so a medical qualification for eligibility is appropriate. As mentioned, the ADA is also influenced by the Civil Rights Act of 1964, in which membership in a "discrete and insular minority" is the rationale for protection. In order to qualify for membership in a minority group, some objective determination is required and, for well-known reasons, 26 medical determination has always been the administrative approach taken in matters involving disability.

The result has been an inordinate expenditure of judicial time and energy on ever more precise rules for determining the medically based qualifications for disability. And this has invariably been at the expense of illuminating the genuine issue of whether a person has been treated in a discriminatory fashion. Perhaps the more notorious examples of misplaced energy and injustice have been in ADA complaints founded on obesity.

On the social model, obesity is understood as a common impairment that is amenable to a relatively uncontentious medical definition—namely, a state of weighing more than a statistically defined normal range for height and sex. 27 Whether or not obesity can lead to disabilities is entirely a matter of whether a person's weight limits the performance of activities, which in turn is a question of what activities a person wants or needs to do, and, more importantly, the environmental context in which those activities are to be performed. If activities are limited, these are the disabilities, not the obesity, which is the underlying impairment. Except in very extreme cases, it would be impossible to predict, without knowing details about the physical and social environment of an obese individual, what disabilities he or she experiences, if any. One thing is sure: if a person is ridiculed for being overweight, assumed to be slothful, gluttonous or unintelligent, or denied employment or other opportunities, then these reactions are prima facie discriminatory. And we can be sure of this whether or not the person involved is obese (rather than merely at the upper bounds of normal weight) and without having to be concerned about why he or she is overweight or obese.

The treatment of obesity under the ADA is quite different. Obesity is conceptualized as a "disability" rather than an impairment, and counts as a disability only if (a) the condition is truly one of obesity rather than merely high but normal weight; and (b) there are underlying medical causes for it (often termed "morbid obesity"). 28 In short, the etiology of the obesity is the crucial issue. If obesity is a "physiological disorder," it qualifies as a disability; otherwise, not. This issue dominates the judicial scrutiny.29 The question of what activities were limited by the excess weight, if any, and the issue of how employers, coworkers or others treated the complainant are pushed into the background. Despite constant academic

criticism, it is unlikely that courts will move away from this approach. 30 Canadian human rights tribunals mirror this approach.31

To be sure, in some cases, courts have been sympathetic to the argument that, though not disabled, the obese individual who was denied employment or presumed to be unintelligent qualifies under the third prong of the definition and was "regarded as having a disability." Though effective in the result, this ploy is not a satisfactory solution to the core problem: the "regarded as" prong of the definition is appropriate when either the complainant has no impairment or his or her impairment does not in fact substantially limit his or her activities. So argued, the complainant cannot point to a failure to make reasonable accommodations at the workplace, since the complaint is founded on the premise that there are no actual activity limitations caused by the impairment. Although reliance on the third prong can save the day for a few, it does not address the central problem that obesity may lead to disabilities, irrespective of its causes or medical etiology.

At bottom, the problem represented by the obesity cases—involving not only the ADA but many other state antidiscrimination acts—is a failure to adhere to the social model of disability. Disabilities are not simply severe impairments; to identify a disability, it is essential to contextualize the discussion and to understand how environmental factors contribute to the disadvantage at the core of the complaint. The compulsive line-drawing that invariably medicalizes the discussion ignores the fact that disability is not a categorical or "bipolar" phenomenon, but context-dependent and continuous. 32 Moreover, the concern with disability ought to be discriminatory disadvantage associated with disability, and this issue (which ought to be the core of antidiscrimination law) has nothing to do with the etiology of the disability.

The obesity cases are emblematic of yet another current of ADA jurisprudence: that discrimination is not legally possible for individuals whose disabilities were "voluntarily induced." Despite a clear rejection of this proposition in the EEOC Compliance Manual,33 judicial remarks in a variety of contexts make it clear that part of the reason courts insist on an underlying medical cause of obesity is to ensure that the condition was not the product of voluntary overeating.³⁴ Similarly, the consistent refusal to recognize as impairments adverse personality traits such as poor judgment, irresponsible behavior and poor impulse control—unless the result of a psychological disease or disorder—can be traced to the assumption that these conditions are voluntary.³⁵ Finally, and most blatantly, the ADA's treatment of illegal drug and alcohol use indicates a presumption that, however much these practices may contribute to disability (as they plainly do), they will not be so considered because these conditions are voluntary. The Supreme Court has made this last point abundantly clear in a Veterans' Administration case in which two honorably discharged veterans were denied educational assistance benefits because, as alcoholics, they had "engaged with some degree of wilfulness in the conduct that caused them to become disabled."36 By contrast, there is law in Canada to the effect that alcohol dependency is itself a disability, whether wilful or not.³⁷

The twin motivations of moralism and paternalism at work here may also be responsible for the explicit legislative exclusions listed above. Being a transvestite, voyeur or compulsive gambler does not mean that all adverse treatment that one experiences is discriminatory or not. It all depends. Although there is more than enough judicial affirmation of the principle that ADA discrimination must be determined on a individual basis, in full apprisal of the particular circumstances involved, these exclusions simply rule out an individualized, context-sensitive determination.

It would be naïve to ignore the fact that antidiscrimination legislation is invariably the product of a political compromise in which irrelevant ideological positions can leave their imprint. In the cases of the ADA this has yielded the peculiar result that some classes of persons with disabilities are excluded, not because they do not have medically ascertained impairments, or are believed to have, but because their conditions are perceived to be indicative of moral fault or weakness of character. There are also instances where this attitude has spilled over to conditions that are not excluded. There are, for example, several cases of the denial of ADA protection to students with learning disabilities on the grounds that their proposed accommodation of more time and a quiet room for exam-taking is compatible with lack of motivation or weakness of the will to overcome stress and nervousness.38

All of these features of the statutory definition of "disability" distance the ADA from the social model of disability; if anything, judicial interpretations, especially in recent years, have further emphasized this conceptual gap. This can only limit the effectiveness, or indeed relevance, of antidiscrimination law as a remedy to the violation of basic rights inherent in the unequal treatment that people with disabilities experience in all sectors of social life. Viewing disability as a severe form of an impairment, determined by etiology and categorical, is a persistent and perhaps inevitable flaw in the legal definition used in the ADA and most other antidiscrimination legislation. More troubling is the failure to acknowledge the essential role that the environmental context plays in creating or worsening disability. The ADA appears to undermine the very model of disability that created its rationale.

THE ADA AS A RESPONSE TO INEQUALITY

There remains a deeper concern.³⁹ Even if the ADA and antidiscrimination law in general could be made to work effectively and without these drawbacks, the advocacy strategy that sets its sights entirely on responding to discrimination may be of limited value to people with disabilities. Although undoubtedly there is discrimination against people with disabilities, and this should be corrected, the condition of inequality that people with disabilities face cannot always fit into the conceptual mold or legal test of discrimination. People with disabilities internationally face nonaccommodating physical and organizational environments; lack of educational or training programming; impoverished or nonexistent employment prospects; inadequate income-support programs founded on insulting eligibility requirements; limited access to assistive technologies; a general lack of resources to meet impairment-related needs; neglect; and minimal political influence. These are all social ills brought about by a maldistribution of power and resources. But they are not forms of discrimination.

But why not discrimination? Because that is not what is going on. Discrimination is a wrongful limitation of someone's freedom; it is the creation of an obstacle or barrier to full participation or benefit, to which the wronged party has a claim, based on a feature of that individual that is, in the context of the treatment, irrelevant. A discriminatory action is offensive because it is disrespectful and assaults the dignity of an individual or a group.⁴⁰ Because discrimination is an indignity, compensation to the victim of the insult is meaningful and appropriate. But first the complainant needs to show that he or she has been denied a benefit or opportunity available to others and that the disadvantage followed from perceptions about disability that are irrational and unjustifiable. But for reasons already mentioned, this is a difficult case to make out, even in clear cases.

In practice, of course, antidiscrimination law has moved considerably beyond this core meaning. It is common in this jurisprudence to speak of derivative forms of discrimination—"indirect," "adverse effect," or "constructive"—which often serves the important legal function of applying legislative remedies where there is no clear evidence of a discriminatory intent or even a discriminator. In the hands of rights advocates, the term "discrimination" has often been extended to encompass any social injustice whatsoever. The term has become elastic and threatens to be stripped of concrete meaning. Judicial backlash was inevitable. In order to sustain the distinction between those disadvantages that are and those that are not discriminatory, judges will, since they have little option, rely on the core notion of "discrimination" in order to recenter their intuitions about when and why discriminatory distinction-drawing violates antidiscrimination law.

But why pursue the dubious tactic of stretching the meaning of discrimination beyond its natural bounds? Unemployment undoubtedly makes life harder for people with disabilities; but why assign the responsibility for these complex, multifactorial and systemic phenomena to some discriminator? Undoubtedly people with disabilities do face discrimination in this central sense; and for that reason, antidiscrimination legislation is justifiable and important. But that is not all there is to a recognition of human rights. Especially when economic factors create real disadvantages for persons with disabilities, there is no insult, because there is no insulter. There is a social evil; there is injustice and inequality. But it is an evil of a different sort.

The characteristic feature of the inequality and denial of human rights suffered by people with disabilities around the world is the unjust limitation of their equal right to participate in the full range of social roles and ways of living. This may be the consequence of neglect, lack of political clout or a systemic social failure to provide the resources and opportunities needed to make participation feasible. Inequality is exemplified in concrete and practical terms by the absence of resources and opportunities that make it realistically possible for a person to achieve what he or she wishes to achieve.

The denial of opportunities and resources is an issue not of discrimination but of distributive injustice—an unfair distribution of society's resources and opportunities that results in limitations of participation in all areas of social life. Opportunities and resources respond to needs, and a key disadvantage linked to disability is an inequality in the satisfaction of human needs. Impairment-related needs, variable across the population, are met for some people but not others. Some needs are catered to, while others are ignored. Resources are allocated to satisfy the repertoire of functional capacities of some people, but not others. These allocations create a distributive imbalance unfairly disadvantaging some people. This accounts for the fact that the most accurate indicator of the social status of being a person with disabilities is poverty. The social construction of disability creates inequality of access to social resources.

Distributive injustice persists because of the variation in impairment-related needs and disability accommodations. Statistically, the higher the level of impairment need, the smaller the population cohort, with the result that more trivial and more common impairment needs (such as glasses for mild visual impairment) tend to be catered to, while more complex and less common needs (say those for spina bifida) are more likely to be underserved. Overlying this is the arbitrary allocation of socially constructed disadvantages distributed across the population of impairments. Generally speaking, there are far more disadvantages associated with mental and psychiatric impairments than the actual needs linked to those impairments would predict. Many of the complaints against managed care as a mode of distribution of health care reflect these same injustices. In the end,

distributional injustice is the product of structural and impersonal economic forces, forces that cannot be explained in terms of discrimination in any of its many senses.

CONCLUSION

Antidiscrimination laws such as the ADA are shaped by social and legal forces that, perhaps inevitably, turn their attention away from distributional issues. In the abstract, this is not a criticism; indeed, the corrective focus of the ADA is the primary source of its strength and relevance to people with disabilities. Yet there are reasons to think that, both in conception and in operation, the ADA conflicts with the fundamental ideological components of the disability rights movement: the social model of disability and the goal of political equality. The conflict is theoretical, to be sure, but there are many concrete instances where the theoretical disequilibrium has produced inexplicable or unjust results. The Canadian approach, with its twin reliance on a fundamental, constitutional guarantee of equality and flexible and conciliation-based antidiscrimination legislation, provides a contrast to the ADA regime. In principle, the Canadian approach offers a stronger protection, since, grounded in constitutional law, the changes a successful complaint could engender would be far-reaching in scope. But precisely because of this, Canadian courts are cautious and, although far less so now than previously, deferential to the objectives of the legislature.

To be sure, none of this provides grounds for moving away from antidiscrimination legislation, either in the ADA model or by means of the more complex Canadian approach. On the contrary, it should be the motivation for supplementing antidiscrimination law with a more vigorous and multisectorial pursuit of equality of participation for persons with disabilities. In the end, perhaps, what is needed is a rethinking not so much of what disability is or who qualifies as a bona fide person with a disability with a valid and enforceable complaint of discrimination, but rather of our social and political commitment to equality.

NOTES

Some examples of legislation closely modeled on the ADA are the Disability Discrimination Act, 1992 (Australia), Disability Discrimination Act, 1995, c 50 (U.K.), Human Rights Act, 1993, No. 82 (New Zealand), Disabled Persons Act (India), and Israel's Disabled Persons Act, 1998. As noted in the text, Canadian human rights acts, at the federal and provincial levels, also follow the pattern set by the ADA and the Vocational Rehabilitation Act 1973, but they must be seen in the context of the constitutional protections found in the Canadian Charter of Rights and Freedoms (enacted as the Canada Act, 1982 (U.K.), c. 11, Schedule B, part I).

²Canadian Charter of Rights and Freedoms, section 15(1) and Antidiscrimination Act (Polahd). ³Severely Disabled Persons Act (Germany), and Israel's Employment (equal opportunities) Law,

⁴Disabled Person's Fundamental Law (Japan); Disability Discrimination Ordinance, 1996 (Hong Kong); and Disabled Persons Act (China).

In particular, Standard Rules on the Equalization of Opportunities for Persons with Disabilities. adopted by the United Nations General Assembly, resolution 48/96 (UN 48th session, 2012.93)

6See, for example, Eaton v. Brant County Board of Education (1997) 1 S.C.R. 241, in which a 12year-old child with cerebral palsy was denied mainstreamed education in part on the ground that the ground of disability differed from those of race and sex, since disability admitted of individual variation, and hence the need on the part of courts to determine what government measures best served the interests of equality in the accommodation of difference. The court felt that specialized but segregated education services mer that test in this case.

⁷Youth Bowling Council of Ontario v. McLeod (1990) 14 C.H.R.R. D/120 (Ont. Div. Ct.).

8 Hines v. Nova Scotia (1990) 73 D.L.R. (4th) 491 (N.S.S.C.), in which the court struck down a provision of the Motor Vehicle Act of Nova Scotia that prevented diabetic truck drivers from getting a license on the ground that there were other ways of securing the objective of highway safety that were less offensive to the values of equality. And see a similar result for flying a plane: Bahlsen v. Canada (1996) 141 D.L.R. (4th) 712 (Fed. C.A.)

⁹Eldridge v. British Columbia (1997) 151 D.L.R. (4th) 577 (S.C.C.).

¹⁰Scotch, R. From Goodwill to Civil Rights. Philadelphia, PA: Temple University Press, 1984; and "Politics and Policy in the History of the Disability Rights Movement" (1989) 67 [Suppl. 2] Milbank Quarterly 380; Driedger, D. The Last Civil Rights Movement. London: Hurst and Co., 1989; Anspach, Renee R. "From Stigma to Identity Politics: Political Activism among the Physically Disabled and Former Mental Patients" (1979) 13 Social Science and Medicine 765.

11 E.g., Safilos-Rothschild, C. The Sociology and Social Psychology of Disability and Rehabilitation. New York: Random House, 1970; Wright, B. Physical Disability—A Psychosocial Approach, 2nd ed. New York: Harper & Row, 1983; Sagarin, E., ed. The Other Minorities: Nonethnic Collectivies Conceptualized as Minority Groups. Toronto: Ginn, 1971; and Bury, M. "Social Aspects of Rehabilitation" (1987) 10 [Suppl. 5] International Journal of Rehabilitation Research 25.

¹²See, e.g., Imrie, R. *Disability and the City: International Perspectives.* London: Paul Chapman, 1996; Bickenbach, J. Physical Disability and Social Policy. Toronto: University of Toronto Press, 1993; and Barnes, C., and G. Mercer, eds. Exploring the Divide: Illness and Disability. Leeds: Disability Press, 1996. And compare the construct of disability used in the revised International Classification of Functioning and Disability (ICIDH-2). Geneva: World Health Organization, 1999.

13 For a review of the history and development of this definition, see J. Wegner "The Antidiscrimination Model Reconsidered: Ensuring Equal Opportunity without Respect to Handicap under Section 504 of the Rehabilitation Act of 1973" (1983) 69 Cornell Law Review 401.

14UPIAS Fundamental Principles of Disability. London: Union of the Physically Impaired Against Segregation, 1976.

15 The "social model" and "social-political perspective" are examples of social constructivist theories, sometimes called "interactive" or "environmental" approaches; see Imrie, R. "Rethinking the Relationships between Disability, Rehabilitation, and Society" (1997) 19 Disability and Rehabilitation 263, for the former, and Amundson, R. "Disability, Handicap, and the Environment" (1992) 9 Journal of Social Philosophy 105, for the latter. The sociopolitical perspective on disability has a complex history in sociology, tracing its origins both to Parson's notion of the "sick role," Parson, T. "Definitions of Health and Illness in the Light of American Values and Social Structure" in E. Jaco, ed. Patients, Physicians, and Illness. New York: Free Press, 1979; and the work of E. Goffman, in particular Asylums. New York: Doubleday, 1961 and Stigma: Notes on the Management of Spoiled Identity. Englewood Cliffs, NJ: Prentice Hall, 1963, on the process of stigmatizing and the creation of "deviance." In Britain, sociologists sought their explanations outside the more individualistic, American approach, adopting more overtly political theoretical accounts. For a description of some of the history of the sociopolitical perspective (or "paradigm," as it is sometimes called), see Bickenhach, Physical Disability, 135-181, and for the contrasting U.K. history, see Barnes, C. "Theories of Disability and the Origins of the Oppression of Disabled People in Western Society" in Len Barton, ed. Disability and Society. London: Longman, 1996.

¹⁶The phrase is I. Zola's, in "Toward the Necessary Universalizing of a Disability Policy" (1989) 67 The Milbank Quarterly 401.

¹⁷Stone, D. The Disabled State. Philadelphia, PA: Temple University Press, 1984; and Liachowitz, C Disability as a Social Construct: Legislative Roots. Philadelphia, PA: University of Pennsylvania Press, 1988.

18PL. 101-336 Sec. 2 (b) (1), (2).

¹⁹PL. 101-336 Sec. 2 (a) (7).

²⁰Cf. sec. 16 Ontario Human Rights Act, S.O. 181, c. 53; sec. 22 Human Rights Act, 1993, No. 82 (New Zealand); secs. 5,6 Disability Discrimination Act, 1995, c. 50 (U.K.); secs. 8-12 Disability Discrimination Act, 1992 (Australia).

²¹E.g., the comments and analysis on section 1630 of the EEOC's regulations on the implementation of Title I of the ADA run to several hundred pages and are expanding yearly.

²²Sutton v. United Airlines, Inc., 130 F.3d 893 (1999).

²³Like many aspects of the ADA, this definition is closely followed in other jurisdictions In the U.K.'s Disability Discrimination Act, 1995, for example, "disability" is defined as "a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities."

²⁴29 CF.R. sec. 1630.2(h).

²⁵ICIDH-2.

²⁶Stone, The Disabled State.

²⁷"Obesity" is defined by the World Health Organization as being more than 5 percent above the upper range of the "normal" category measured by the body mass index (BMI).

²⁸See Underwood v. Trans World Airlines, 710 F. Supp. 78, 83–84 (S.D.N.Y. 1989) (dealing with obesity under the Rehabilitation Act, 1973) and Cook v. Rhode Island Department of Mental Health, 10 F.3d 17 (1st Cir. 1993).

²⁹E.g. Francis v. City of Merriden, 7 AD Cases 955 (1997). And cf. under state antidiscrimination laws: Cassita v. Community Foods, 2 AD Cases 1188 (Calif. Sup. Ct. 1993); Civil Services Commission v. Penn. Human Relations Commission, 2 AD Cases 1345 (PA Sup. Ct. 1991).

³⁰See Peterson, S. "Discrimination against Overweight People: Can Society Still Get Away with It?" (1994–1995) 30 Gonzola Law Review 105; Kramer, K., and A. Magerson. "Obesity, Discrimination in the Workplace: Protection through a Perceived Disability Claim under the Rehabilitation Act and the Americans with Disability Act" (1994) 31 California Western Law Review 41; Taussig, W. "Weighing in against Obesity Discrimination" (1994) 35 California Law Review 927; and Hartnett, P. "Nature or Nurturing Lifestyle or Fate: Employment Discrimination against Obese Workers" (1993) 24 Rutgers Law Journal 807.

³¹E.g. Horton v. Niagara (1987) 9 C.H.R.R. D/4611 (Ont. Bd. of Inquiry) and Ontario v. Vogue Shoes (1991) 14 C.H.R.R. D/425 (Ont. Bd. of Inquiry).

³²For a similar critique of the ADA's treatment of disability, see R. Colker *Hybrid—Bisexuals, Multiracials, and Other Misfits under American Law.* New York: New York University Press, 1996.

³³"Voluntariness is irrelevant when determining whether a condition constitutes an impairment" EEOC Compliance Manual, sec. 902.2(e).

³⁴This line of argument can be found arising in earlier Rehabilitation Act, 1973 cases: Greene v. Union Pacific Railroad Co., 548 F. Supp. 3 (1981); and State Division of Human Rights v. Xerox Corp., 480 N.E. (2d.) 695 (1985).

35See Daley v. Koch, 892 F.2d 212 (2nd Cir. 1989).

36 Traynor v. Turnage, 485 U.S. 535.

³⁷Entrop v. Imperial Oil Ltd. (1995) 95 C.L.L.C. 230-022 (Ont. Bd. of Inquiry).

38See Argen v. N.Y. State Board of Law Examiners, 860 F. Supp. 84 (W.D.N.Y. 1994).

³⁹The concern in what follows—that inequality in the case of disability is best conceptualized as a matter of distributive rather than corrective justice—is a large issue that can only be touched on here. See the recent extensive debate on this issue in Silvers, A., Wasserman, D. and Mahowald, M.. Disability, Difference, Discrimination. New York: Rowman & Littlefield Publishers, Inc., 1998.

⁴⁰See David Wasserman, "The Concept of Discrimination," in R. Chadwick, ed. *Encyclopaedia of Applied Ethics*. San Diego, CA: Academic Press, 1997.

The U.K. Disability Discrimination Act

disabling language, justifying inequitable social participation

MAIRIAN CORKER

When I failed basic English on the first attempt, they said that was what was to be expected of the deaf. When I passed it on the second attempt, they were silent. When I passed it at advanced level, they said it was a fluke. Funny how most of the other things they said never got through. Now when I read or write anything, it's my way of continuing to defy them. And now they say I've got it wrong and that I don't understand my own history.

—Notes from a diary, 1974

To be injured by speech is to suffer a loss of context, that is, not to know where you are. Indeed, it may be that what is unanticipated about the injurious speech act is what constitutes its injury, the sense of putting its addressee out of control. To be addressed injuriously is not only to be open to an unknown future, but not to know the time and place of injury, and to suffer the disorientation of one's situation as the effect of such speech. Exposed at the moment of such a shattering is precisely the volatility of one's "place" within the community of speakers; one can be "put in one's place" by such speech, but such a place may be no place.

—Butler 1997, 4

INTRODUCTION

The claim of disabled people to social or civil rights has been high on the agenda of the U.K. disabled people's movement since the publication of the document Fundamental Principles of Disability by the Union of Physically Impaired Against Segregation (UPIAS 1976), although individual disabled people, who drew inspiration from grassroots organizations of disabled people, were writing from a "rights" perspective a decade before (Hunt 1966). Disability rights discourse has traditionally "advocated policies based upon according disabled people full citizenship rights through anti-discrimination legislation." (Oliver 1996b, 123). The pursuit of this goal at the level of national policy has seen no less than thirteen Private Members' Bills pass through the British Parliament, most of which have fallen foul of outdated mechanisms of parliamentary procedure.

This period of intense political mobilization in the U.K. also saw the generation of an increasing body of knowledge and practice which has come to be known as "the social model of disability" (Barnes, Mercer and Shakespeare 1999, 2). There is not the space here to document these developments in detail. For the purposes of this essay, it is important to