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THE DEFINITION OF DISABILITY:
PERSPECTIVE OF THE DISABILITY COMMUNITY

Deborah Kaplan, J.D.*

Introduction

The questions of the definition of "person with a disability" and how persons with disabilities perceive themselves are knotty and complex. It is no accident that these questions are emerging at the same time that the status of persons with disabilities in society is changing dramatically. The Americans with Disabilities Act (ADA) is the cause of some of these changes, as well as the result of the corresponding shift in public policy. Questions of status and identity are at the heart of disability policy. One of the central goals of the disability rights movement, which can claim primary political responsibility for the ADA, is to move American society to a new and more positive understanding of what it means to have a disability.

Part I of this Article describes the four historical and social models of disability, as defined by disability policy scholars. Part II includes an analysis of the ADA definition of disability and case law interpreting that definition. Part III describes the United States Supreme Court's recent interpretation of disability under the ADA and the reaction of the disability community to this interpretation.

I. Disability Models

Disability policy scholars describe four different historical and social models of disability: (1) a moral model of disability which regards disability as the result of sin; (2) a medical model of disability which regards disability as a defect or sickness which must be cured through medical intervention; (3) a rehabilitation model, an offshoot of the medical model, which regards the disability as a deficiency that must be fixed by a rehabilitation professional or other helping professional; and (4) the disability model, under which the problem is defined as a dominating attitude by professionals and others, inadequate support

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services when compared with society generally, as well as attitudinal, architectural, sensory, cognitive, and economic barriers, and the strong tendency for people to generalize about all persons with disabilities overlooking the large variations within the disability community.3

The moral model is historically the oldest and is less prevalent today.4 However, there are still many cultures that associate disability with sin and shame,5 and disability is often associated with feelings of guilt, even if such feelings are not overtly based in religious doctrine.6 For the individual with a disability, this model is particularly burdensome. This model has been associated with shame on the entire family that has a member with a disability.7 Families have hidden away the disabled family member, keeping them out of school and excluding them from any chance at having a meaningful role in society.8 Even in less extreme circumstances, this model has resulted in general social ostracism and self-hatred.

The medical model came about as modern medicine and the enhanced role of the physician in society began to develop during the nineteenth century.9 Due to the fact that many disabilities have medical origins, people with disabilities were expected to benefit from the direction of the medical profession.10 Under this model, the problems that are associated with disability are deemed to reside within the individual.11 In other words, if the individual is “cured” then these problems will not exist.12 Society has no underlying responsibility to make a “place” for persons with disabilities, since they live in an outsider role waiting to be cured.13

The individual with a disability is in the sick role14 under the medical model. When people are sick, they are excused from the nor-

4. See Drimmer, supra note 2, at 1346.
5. See Pfeiffer, supra note 3, at 2.
6. See Drimmer, supra note 2, at 1346 n.14; Pfeiffer, supra note 3, at 2.
7. See Drimmer, supra note 2, at 1346 n.14; Pfeiffer, supra note 3, at 2.
9. See Drimmer, supra note 2, at 1361; Pfeiffer, supra note 3, at 2.
10. See Mary Crossley, The Disability Kaleidescope, 74 Notre Dame L. Rev. 621, 650 (1999); Drimmer, supra note 2, at 1347; Pfeiffer, supra note 3, at 2-3.
11. See Crossley, supra note 10, at 649; Pfeiffer, supra note 3, at 3.
12. See Crossley, supra note 10, at 650.
13. See id. at 650-52; Drimmer, supra note 2, at 1348.
mal obligations of society: going to school, getting a job, taking on family responsibilities, etc. They are also expected to come under the authority of the medical profession in order to get better. Thus, until recently, most disability policy issues have been regarded as health issues, and physicians have been regarded as the primary authorities in this policy area.

One can see the influence of the medical model in disability public policy today, most notably in the Social Security system, in which disability is defined as the inability to work. This is consistent with the role of the disabled person as sick. It is also the source of enormous problems for persons with disabilities who want to work but who would risk losing all related public benefits, such as health care coverage or access to Personal Assistance Services (for in-home chores and personal functioning), since a person loses his or her disability status by going to work.

The rehabilitation model is similar to the medical model; it regards the person with a disability as in need of services from a rehabilitation professional who can provide training, therapy, counseling, or other services to make up for the deficiency caused by the disability.

Parsons describes the sick person role as institutionally defined. He defines four specific elements of the role of the "sick person." First, the individual is not held responsible for the illness, as it is beyond his or her control. See id. at 176. Second, the sick person is "exempt" from performing his or her normal societal obligations and tasks, at least for the duration of the illness. See id. Third, the sick person is in a conditionally legitimated state but only if the individual realizes that he or she has an obligation to get well. See id. at 176-77. Finally, in order to attain that "socially legitimated state," the sick person must make an effort to seek competent medical assistance with the intent to become well. See id. at 177; see also Crossley, supra note 10, at 650; Drimmer, supra note 2, at 1347-48; Pfeiffer, supra note 3, at 3.

15. See Pfeiffer, supra note 3, at 3, 5.
17. See Crossley, supra note 10, at 650-51.
19. See Help the Disabled Work, L.A. TIMES, Dec. 13, 1998, at M4; see also COMMITTEE ON WAYS AND MEANS, TICKET TO WORK AND WORK INCENTIVES IMPROVEMENT ACT OF 1999, H.R. DOC. No. 106-393, pt. 1 at 51, 54-55, 79-80 (1999). The Ticket to Work and Work Incentives Improvement Act of 1999 was designed in order to ease the transition of disabled SSI recipients into the workforce by expanding access to vocational rehabilitation and employment support services and extending health care coverage for disabled beneficiaries who return to work. See id. at 4. The Committee on Ways and Means reported that prior to creation of the Act, Social Security disability beneficiaries faced losing health care coverage, cash benefits, and other support services upon returning to work. See id. at 51, 54-55, 79-80.
20. See Crossley, supra note 10, at 650; Drimmer, supra note 2, at 1361; McBride, supra note 16, at 13; Pfeiffer, supra note 3, at 3.
Historically, it gained acceptance after World War II when many disabled veterans needed to be re-introduced into society. The current Vocational Rehabilitation system is designed according to this model.

Persons with disabilities have been very critical of both the medical model and the rehabilitation model. While the individual can require medical intervention at times, it is naïve and simplistic to regard the medical system as the appropriate locus for disability-related policy matters. A cure for many disabilities and chronic medical conditions will never be found. Persons with disabilities are quite capable of participating in society, and the practices of confinement and institutionalization that accompany the sick role are simply not acceptable.

The disability model has taken hold as the disability rights and independent living movements have gained strength. This model regards disability as a normal aspect of life, not as a deviance, and rejects the notion that persons with disabilities are in some inherent way "defective." As Professor David Pfeiffer has put it:

It depends upon the concept of normal. That is, being a person with a disability which limits my mobility means that I do not move about in a (so-called) normal way. But what is the normal way to cover a mile . . . ? Some people would walk. Some people would ride a bicycle or a bus or in a taxi or their own car. Others would use a skate board or in line roller blades. Some people use wheelchairs. There is, I argue, no normal way to travel a mile.

Most people will experience some form of disability, either permanent or temporary, over the course of their lives. Given this reality, if disability were more commonly recognized and expected in the way that we design our environments or our systems, it would not seem so abnormal.

The disability model recognizes social discrimination as the most significant problem experienced by persons with disabilities and as the cause of many of the problems that are regarded as intrinsic to the disability under the other models.

The cultural habit of regarding the condition of the person, not the built environment or the social organization of activities, as the source of the problem, runs deep. For example,

21. See Drimmer, supra note 2, at 1363-65.
23. See generally Pfeiffer, supra note 3, at 6-8.
24. Id. at 8.
it took me several years of struggling with the heavy door to my building, sometimes having to wait until a person stronger came along, to realize that the door was an accessibility problem, not only for me, but for others as well. And I did not notice, until one of my students pointed it out, that the lack of signs that could be read from a distance at my university forced people with mobility impairments to expend a lot of energy unnecessarily, searching for rooms and offices. Although I have encountered this difficulty myself on days when walking was exhausting to me, I interpreted it, automatically, as a problem arising from my illness (as I did with the door), rather than as a problem arising from the built environment having been created for too narrow a range of people and situations.  

The United Nations uses a definition of disability that is different from the ADA:

**Impairment**: Any loss or abnormality of psychological, or anatomical structure or function.

**Disability**: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

**Handicap**: A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.

Handicap is therefore a function of the relationship between disabled persons and their environment. It occurs when they encounter cultural, physical or social barriers which prevent their access to the various systems of society that are available to other citizens. Thus, handicap is the loss or limitation of opportunities to take part in the life of the community on an equal level with others.

This definition reflects the idea that to a large extent, disability is a social construct. Most people believe they know what is and is not a disability. If you imagine "the disabled" at one end of a spectrum and people who are extremely physically and mentally capable at the other, the distinction appears to be clear. However, there is a tremendous amount of middle ground in this construct, and it is in the mid-


dle that the scheme falls apart. What distinguishes a socially "invisible" impairment—such as the need for corrective eyeglasses—from a less acceptable one—such as the need for a corrective hearing aid, or the need for a walker? Functionally, there may be little difference. Socially, some impairments create great disadvantage or social stigma for the individual, while others do not. Some are considered disabilities, and some are not.

The following examples further illustrate the difficulty of defining disability without consideration of social factors:

- A person who has a cochlear implant;
- A person who has a digestive disorder that requires following a very restrictive diet and following a strict regime of taking medications and could result in serious illness if such regime is not adhered to;
- A person with serious carpal tunnel syndrome;
- A person who is very short.

It is likely that different people could have different responses to the question of whether any of the above-listed characteristics would result in "disability," and some might say, "It depends." This illustrates the differences in the terms "disability" and "handicap" as used by the United Nations. Any of the above traits could become a "handicap" if the individual were considered disabled and also received disparate treatment as a result.

Another example of the social construction of disability that is especially relevant for determining whether a genetic predisposition to disease is a disability is when society discriminates against an individual who may have an "impairment" (in the sense of the United Nations definition) without a corresponding functional limitation.

The power of culture alone to construct a disability is revealed when we consider bodily differences—deviations from a society's conception of a 'normal' or acceptable body—that, although they cause little or no functional or physical difficulty for the person who has them, constitute major social disabilities. An important example is facial scarring, which is a disability of appearance only, a disability constructed totally by stigma and cultural meanings. Stigma, stereotypes, and cultural meanings are also the primary components of other disabilities, such as mild epilepsy and not having a 'normal' or acceptable body size.27

27. Wendell, supra note 25, at 44.
II. The ADA Definition of Disability

The definition of disability in the ADA reflects a recognition of the social construction of disability, especially by including coverage for persons who are perceived by others as having a disability.28 The U.S. Equal Employment Opportunity Commission’s ADA Title I Technical Assistance Manual provides the following explanations of how this prong of the definition is to be interpreted:

The individual may have an impairment which is not substantially limiting, but is treated by the employer as having such an impairment.

For example: An employee has controlled high blood pressure which does not substantially limit his work activities. If an employer reassigns the individual to a less strenuous job because of unsubstantiated fear that the person would suffer a heart attack if he continues in the present job, the employer has “regarded” this person as disabled.

The individual has an impairment that is substantially limiting because of attitudes of others toward the condition.

For example: An experienced assistant manager of a convenience store who has a prominent facial scar was passed over for promotion to store manager. The owner believed that customers and vendors would not want to look at this person. The employer discriminated against her on the basis of disability, because he perceived and treated her as a person with a substantial limitation.

The individual may have no impairment at all, but is regarded by an employer as having a substantially limiting impairment.

For example: An employer discharged an employee based on a rumor that the individual had HIV disease. This person did not have any impairment, but was treated as though she had a substantially limiting impairment.

This part of the definition protects people who are “perceived” as having disabilities from employment decisions based on stereotypes, fears, or misconceptions about disability. It applies to decisions based on unsubstantiated concerns about productivity, safety, insurance, liability,

“(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
(B) a record of such an impairment; or
(C) being regarded as having such an impairment.”
Id. § 12102(2)(A)-(C).
attendance, costs of accommodation, accessibility, workers' compensation costs or acceptance by co-workers and customers.

Accordingly, if an employer makes an adverse employment decision based on unsubstantiated beliefs or fears that a person's perceived disability will cause problems in areas such as those listed above, and cannot show a legitimate, nondiscriminatory reason for the action, that action would be discriminatory under this part of the definition.29

The definitions within a statute are related to the purpose of the statute. This is especially relevant in the field of disability policy, as one can find many different statutes, all with different definitions of the term disability.30 The purpose of the ADA is to prevent discrimination and to provide a remedy for people who have experienced it.31 This is consistent with the disability model of understanding disability, which places great importance on discrimination as a major cause of disadvantage. In order to provide an appropriate remedy to the full range of individuals who experience discrimination based on disability, it is necessary to explicitly recognize that there are people who would not consider themselves "disabled," nor would they be considered so by most others, but who receive the same disparate treatment as "the disabled." Another important issue related to the topic of the definition of disability has to do with disability identity. There are many persons who arguably fit within the first prong of the ADA definition32 who do not consider themselves disabled.

[T]here are many reasons for not identifying yourself as disabled, even when other people consider you disabled. First, disability carries a stigma that many people want to avoid, if


30. The Social Security Act defines "disability" as the:
(A) inability to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months; or
(B) in the case of an individual who has attained the age of 55 and is blind (within the meaning of "blindness" as defined in section 416 (i)(1) of this title), inability by reason of such blindness to engage in substantial gainful activity requiring skills or abilities comparable to those of any gainful activity in which he has previously engaged with some regularity and over a substantial period of time.


31. See id. § 12101(b) (1994).

32. See id. § 12102(2)(A) (1994).
at all possible. For newly disabled people, and for children with disabilities who have been shielded from knowledge of how most non-disabled people regard people with disabilities, it takes time to absorb the idea that they are members of a stigmatized group. Newly disabled adults may still have the stereotypes of disability that are common among non-disabled people. They may be in the habit of thinking of disability as total, believing that people who are disabled are disabled in all respects.... They may fear, with good reason, that if they identify themselves as disabled, others will see them as wholly disabled and fail to recognize their remaining abilities, or perhaps worse, see their every ability and achievement as 'extraordinary' or 'courageous.'

The reason that so many people reject the label "disabled" is that they seek to avoid the harsh social reality that is still so strong today. Having a disability, even though the ADA has been in place for almost a decade, still carries with it a great deal of stigmatization and stereotyping. It is ironic that those who could benefit from the law choose not to do so because they wish to avoid the very social forces that this law seeks to redress and eradicate.

People who might fall under the coverage of the ADA because of the presence of a genetic marker are certainly not likely to think of themselves as disabled. While there may be discomfort at the thought of coming under this label, it is worthwhile to recognize that no one with a disability, visible or otherwise, wants to experience the stigma and discrimination that is still all too common for those who society considers disabled. There are many others who do not consider themselves to be disabled but who do experience discrimination. The ADA ought to provide a legal remedy when this occurs. Since the ADA definition seems to recognize the social construction of disability, whether it could apply to a person ought to be a function of the social treatment that the individual receives. In other words, the question of whether a person with a genetic marker is covered by the definition should not arise in the abstract. If the individual has experienced discrimination based on the individual's physical or mental characteristics, then that individual should be able to take advantage of the ADA to redress that discrimination.

The courts have had a difficult time interpreting the ADA's complex definition. There are numerous cases in which judges have treated the ADA definition as though the purpose of the law is to provide a social benefit, rather than protect an individual from discrimi-

In some cases, the courts have placed an individual with a disability in a catch-22 situation: if the individual has held a job, then this is proof that the individual is not disabled and therefore cannot use the ADA to seek a remedy for employment discrimination.

III. The Disability Community's Reaction to the United States Supreme Court Interpretation of Disability Under the ADA

The U.S. Supreme Court decided three cases on the definition of disability under the ADA at the end of the 1998-99 term: Sutton v. United Air Lines, Inc., Murphy v. United Parcel Service Inc., and Albertsons, Inc. v. Kirkingburg. Each of these was an employment discrimination case in which the Court was presented with the question of whether an individual with a medical condition that is correctable or ameliorated with medicine or technology can find protection under the ADA. The Court was persuaded that the definition should be interpreted narrowly, thereby excluding these plaintiffs from ADA

34. See, e.g., Van Sickle v. Automatic Data Processing Inc., 166 F.3d 1216 (6th Cir. 1998); Gilday v. Mecosta County, 124 F.3d 760 (6th Cir. 1997).
39. Sutton v. United Air Lines, Inc. brought before the Court the issue of whether United's minimum vision requirement violated the ADA. The Court held that corrective or mitigating measures, such as eyeglasses or contact lenses, should be considered in determining whether an individual is disabled under the ADA. See Sutton, 119 S. Ct. at 2148. As a result, the Court held that the applicants were not disabled under the ADA definition. See id. at 2149. In addition, the Court found that applicants failed to state a claim regarding their contention that the airline had violated the ADA by regarding them as disabled. See id. at 2150.

In Murphy v. United Parcel Service, Inc., the Court addressed whether United Parcel Service, Inc. violated the ADA by firing an employee because his blood pressure was in excess of the limits set for commercial drivers by the Department of Transportation. Again, the Court stated that the determination of whether a person is disabled under the ADA is made with consideration of mitigating or corrective measures taken by the individual. See Murphy, 119 S. Ct. at 2137. The Court did not consider whether the petitioner was disabled because of limitations that persisted while on blood pressure medication. See id. The Court stated that Murphy demonstrated that he was regarded as being substantially limited in the major life activity of working. See id. at 2138.

Albertsons, Inc. v. Kirkingburg again raised the issue of whether firing an employee for failing to meet minimum Department of Transportation vision requirements was a violation of the ADA. The Court held that vision below the standards required by one employer does not make a person disabled; rather, such decisions should be made on a case-by-case basis, focusing on substantial limitation of major life activities, as required by the ADA definition of disabled. See Albertsons, 119 S. Ct. at 2168-69.
coverage. The Court noted that Congress had expressly found that there are forty-three million Americans with disabilities, and if that figure was meant to include all individuals with medical conditions or limitations, even those that are correctable or can be ameliorated, the number would have been much higher.

The disability advocacy and legal communities were stunned by these decisions. The notion that the ADA should be used to protect only persons who are somehow "truly" disabled, reflected in these opinions, can be argued to be an unsophisticated or naive understanding of the nature of disability. Given the significance of social and cultural influences in determining who is regarded as disabled, it makes little sense to refuse to take these same influences into account. Nevertheless, the Court strained to keep the definition under control and rejected such arguments.

These decisions make it questionable whether a person with genetic markers could seek the protection of the ADA to redress discrimination. From a policy perspective, there are two possible options that could be pursued to create a secure legal right to such protection: (1) an amendment to the ADA to explicitly state that persons with genetic markers are included within the definition; and/or (2) separate legislation to redress discrimination based on genetic characteristics.

As a result of these decisions, the first option, to seek an amendment to the ADA, is under discussion within disability advocacy and policy coalitions. It is unlikely, however, that this course of action will be followed because of the significant risks of opening the ADA to unfriendly amendments in a potentially hostile political climate in Congress. For this reason, it would be unwise to pursue an amend-

40. See Sutton, 119 S. Ct. at 2147.
41. See id. at 2148. In defending the inclusion of corrective or mitigating factors in determining whether someone is disabled, the Court referred to statistical findings from ADA hearings approximating that 43 million Americans are disabled within the definition included in the ADA. See id. The Court concluded that such a number reflected an intention to narrow the scope of the ADA, as compared with the health conditions approach, which examines all conditions that affect health or functional abilities and which placed the number of Americans who were by definition disabled at approximately 160 million. See id.
43. See Sutton, 119 S. Ct. at 2149; Murphy, 119 S. Ct. at 2137-38; Albertsons, 119 S. Ct. at 2167-69.
44. See Biskupic, supra note 42, at A1; Chemerinsky, supra note 42, at 88; Leonard, supra note 42, at A1.
ment to the ADA that would only address the question of the status of persons with genetic markers if doing so would place other segments of the ADA in jeopardy of amendments designed to narrow its scope.

The second option is also politically and legally fraught with risk. Politically, people with genetic markers are a much smaller group than the very large confederation of disability organizations and individuals who came together to work towards passage of the ADA. Thus, the chances of gaining the strong legal protections that are now available in the ADA are not very high. It could also be expected that well-financed corporate interests would oppose such legislation.\textsuperscript{45} Enactment of any new legislation would be a tough, uphill battle that would probably result in a compromised version of the original proposal. However, this may be the strategy with lesser risk.

From a broad policy perspective, the better course would be to find explicit coverage under the ADA, either through legislative amendments from a relatively friendly Congress or through more favorable court decisions. For those within the disability movement who have no problem being identified as disabled, there are advantages to coming under the coverage of the ADA and, indeed, to being part of a community that is actively working to eradicate the discrimination and stigma that are our legacy. After decades of disparate treatment with no meaningful legal protection or remedy, it is quite satisfying to fight discrimination and to stand together to reject the stigma and stereotypes that are the basis of disability-based discrimination. Most disability activists welcome the inclusion of persons with invisible disabilities, as well as those who have faced discrimination by individuals who regarded them as disabled even though they have no real impairment. This is because we understand that freedom from injustice is not an entitlement to be doled out in small doses. The nature of disability discrimination is that it often has very little to do with the individual’s capabilities and true characteristics. The stigma and stereotypes are the cause of the discrimination, much more than the disability itself. It could be argued that the disability per se is not the cause at all, that the social reaction to disability is the cause.

\textsuperscript{45} See generally Jeremy A. Colby, An Analysis of Genetic Discrimination Legislation Proposed by the 105th Congress, 24 Am. J.L. & Med. 443, 459-63 (1998) (describing the arguments of interest groups, such as insurers and employers, against legislation that would prohibit genetic discrimination).
CONCLUSION

In seeking to avoid the stigma associated with disability, there is a choice of strategies. Social and legal activism that challenge the assumptions behind disability discrimination address the issues head on. The goal is to eradicate the stigma. The decision to disassociate from those who have historically been stigmatized tends to perpetuate the stereotypes and discrimination.

The disability rights movement is working toward a society in which physical and mental differences among people are accepted as normal and expected, not abnormal or unusual. At the beginning of the twenty-first century, we have plenty of methods and tools at our disposal to accommodate human differences should we choose to. The growth of technology in our lives provides us with both the ability to detect more human differences than ever before, as well as the ability to make those differences less meaningful in practical terms. How we react to human differences is a social and a policy choice. The disability community prefers to advocate for a social structure that focuses on including all people in the social fabric, rather than drawing an artificial line that separates “disabled people” from others.