

## POLICY FORUM

### Perspectives on the Meaning of “Disability”

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#### Abstract

The meaning of “disability” has shifted with changes in public policy. Half a century ago, Congress was convinced that narrow determinations of disability are easy for physicians to make. But with the advent of universal civil rights protection against disability discrimination in the US, deciding whether particular individuals are disabled became increasingly contentious, until Congress intervened. What should now be addressed in each case is not whether the functionally compromised person is severely disabled enough to exercise a right, but whether mitigating interventions and reasonable accommodations can together achieve equitable access for that person.

#### Introduction

“Disability” is a term of art with different specialized meanings, each developed for the particular policy or program that uses it. How we conceptualize disability shifts relative to the methodologies used to learn about it and the contexts in which it is addressed. The criteria for judging people to be disabled likewise fluctuate over time and across different social and cultural contexts.

#### A Medical Perspective

The history of the concept of disability illuminates its evolution. Before the nineteenth century, being disabled meant being disadvantaged by laws preventing participation in some areas of a community’s social, political, or economic life. For example, according to legal theory of that day, successful domestic arrangements required husband and wife to be as one person, permitting only one decision-maker—the male. So married women were explicitly disabled by law from the management or disposition of property [1].

While legal disability’s imposition of disadvantage was a result of a social arrangement, by the late nineteenth century, another kind of disabling disadvantage—associated with compromised health rather than legislative mandate—came to be portrayed as a natural fact. During this era, healthy and pathological states of organisms began to be distinguished through statistical investigation, with species typical functioning being conceived as a “[norm](#)” conducive to individual and species success [2]. As the nineteenth century turned to the twentieth, anomalous biological functioning began to be equated

as a general matter with disabling defectiveness that not only disadvantages the individual but also, unless ameliorated or eliminated, detracts from social stability and species survival [3, 4]. We examine social welfare and disability rights legislation in the US to consider additional shifts in views of disability during the twentieth century.

### **A Pre-Civil Rights Perspective**

A generalized characterization of persons with disabilities as functionally abnormal enabled them to be addressed collectively for purposes of policy formulation. On the one hand, persons with such anomalies could be discriminated against by policies denying them access to common services or by segregating them into institutions [5, 6]. On the other hand, aggregation of various kinds of biological dysfunction enabled a more positive policy effect: income-related benefits to individuals with impairments who, due to their past or potential social contribution, were judged deserving. For example, after the Civil War, Congress gave veterans with a variety of injuries and illnesses preference as a group for government employment [7]. Later, assistance programs such as the 1920 Civil Vocational Rehabilitation Act [8] were devised to return citizens with the potential to overcome their functional disabilities to the workforce, regardless of how the disability was acquired.

Between 1954 and 1964, a series of amendments to the 1935 Social Security Act added payment of benefits to persons with illness or injury too severe to work [9-11]. According to a US Social Security Advisory Board report, *The Social Security Definition of Disability* [12], "When the Social Security Disability Insurance (DI) program was enacted in 1956, it was intended for the 'totally and permanently disabled,' a population for whom work was not an option" [13]. To the Social Security Administration (SSA), persons with disabilities were people permanently unable to perform substantial gainful activity due to severe impairment. During Congressional hearings on the Social Security Act amendments, controversies arose about the definition of disability and its implementation through physicians' testimony [14]. Despite testimony from American Medical Association (AMA) leadership and many other physicians about their doubts that practitioners could deliver objective judgments about disability, as the amendments to the 1935 Social Security Act apparently presumed, federal legislators remained unshakably optimistic. As Georgia Senator Walter F. George declared, "[M]any American doctors are afraid that they cannot determine when a man or a woman is disabled, when the plain requirement is that the disability must be a medically determined physical or mental impairment. .... I think more of the medical profession in this country than to believe that they cannot determine when a man or a woman worker has a permanent and total disability" [15].

As the SSDI program functions today, to qualify for Social Security disability benefits, applicants' conditions must be severe enough to interfere with basic work-related activities. The SSA maintains a list of medical conditions that are so severe they

automatically mean that the person is disabled [16]. If the applicant's diagnosis is not on the list, there is a Social Security process that decides "if it is of equal severity to a medical condition that is on the list" [16]. To receive benefits if the condition is not considered as severe as those on the list, the applicant must demonstrate that the condition prevents executing both previous types of employment and other types of employment in the relevant labor market [16]. Demonstrating such inability to work in the relevant labor market is thus a critical aspect of [disability determinations](#) today for people whose conditions do not fall within the SSA list.

As the AMA warned, however, diagnosing individuals' inability to work has turned out to be much more problematic than Congress initially supposed. Physicians' assessments of the same patient's disability can be surprisingly varied, indicating that the theoretical foundation of this kind of diagnosis is far from robust [17]. Furthermore, clinical judgments of the impact of physiological or psychiatric medical conditions on ability to work can be skewed by implicit bias [18, 19]. Finally, barriers to employment extend beyond actually executing work. To illustrate, having to climb steep stairs to the workplace or restrooms can curtail employment for persons with even modest impairments such as compromised respiration or tendonitis [20].

### **A Civil Rights Perspective**

Recognizing that WWII veterans with disabilities could face exclusion from employment in the communities they had sacrificed to protect, Congress in 1944 gave them preference for government jobs. But such preferences did not prevent government employers' discrimination against workers with disabilities, even those with service-related impairments, so in 1948 Congress prohibited discrimination based on physical handicap in United States civil service employment [21]. Beginning in the 1970s, Congress expanded efforts to give people with disabilities equitable access to the public buildings, public transportation, and education in public schools that other citizens enjoyed. Although by no means abandoning programs entitling some persons with disabilities to various kinds of compensatory support, Congress added legislation with a civil rights perspective aimed at enabling persons with disabilities to combat discrimination that limited opportunity for them. These policies all were framed by an understanding that the [disadvantages of disability](#) emanate, to some degree, from social discrimination rather than biological deficiency.

In 1973, a greatly revised reauthorized Rehabilitation Act expanded civil rights to more meaningfully protect people with disabilities against exclusion from opportunity by prohibiting disability discrimination by federal contractors and in any program receiving federal support. The primary focus of the 1973 legislation was job training and reducing dependency on public funds, so the added language maintained the values and purposes of its origin. Congress defined "handicapped individual"—the language of the day—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” [22]. The civil rights-conferring sections of the 1973 legislation are only a small part of the act, the bulk of which focuses on job training programs and other ways of getting more people with disabilities into the workforce and thus reducing dependency on public funds. In contrast, the 1990 Americans with Disabilities Act (ADA) expands civil rights in recognition of the intrinsic value of people with disabilities and as an expression of personal respect, not just in recognition of the instrumental value of reducing public expenditures.

Nevertheless, the definition of disability that was incorporated into the ADA has roots in the Rehabilitation Act’s definition and remains standard in law today.

The term “disability” means, with respect to an individual—  
(A) a physical or mental impairment that substantially limits one or more major life activities of such individual;  
(B) a record of such an impairment; or  
(C) being regarded as having such an impairment [23].

The ADA aimed to provide “a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities” [24] and “to address the major areas of discrimination faced day-to-day by people with disabilities” [25]. Yet in the decades after enactment of the ADA, the US Supreme Court gradually curtailed the ADA’s reach by adopting a strained and straitened understanding of what it means for a physical or mental impairment to substantially limit a major life activity. In a trilogy of cases in 1999, the Court held that individuals must be assessed in their corrected condition. Corrections may themselves be burdensome, however, such as medication side effects and even the regimen required to administer medication. The Supreme Court’s analysis ignores these and other impacts such as the monetary costs or demands on time that the means of mitigating dysfunctions may impose [26-28]. Ironically, the more medical and mechanical intervention improved the functionality of people with disabilities, the more likely those people were, given the Court’s jurisprudence, to lose protection against well-documented disability discrimination by being denied accommodation for such interventions at work after they have been hired [29]. Further, in 2002 the Court concluded that impairments do not substantially limit a major life activity unless they prevent or severely restrict the ability to execute fundamental activities people normally perform independently in daily life such as fixing simple meals [30], thus denying eligibility for accommodation to individuals who could care for themselves in executing activities of daily life but whose impairments prevented their overcoming barriers erected by an employer’s particular arrangement of work activity or the condition of the work site [31, 29]. The upshot of these decisions was that many people with impairments who were able to engage in personal care for themselves

independently but could not overcome [workplace barriers](#) never cleared the initial hurdle of demonstrating that they were sufficiently disabled to claim the statutory protection of the ADA.

In response to these decisions, the ADA Amendments Act (ADAAA) was passed in 2008. Although Congress did not change the statutory definition of disability as substantially limiting a major life activity, it made clear that the ADA was to be construed in favor of broad coverage of individuals. Congress deleted reference to the number of Americans who had disabilities, a finding that had been used by the Court to deny coverage; made clear that the Supreme Court's and the Equal Employment Opportunity Commission's standards for "substantially limits" and "major life activities" were overly strict; rejected the Supreme Court's requirement that the effect of measures to mitigate the effects of the impairment must be weighed in deciding whether an impairment results in a disability; offered broadly construed and diverse examples of major life activities, and eliminated from the "regarded as" prong of the definition the demand that individuals show they are perceived to be substantially limited in a major life activity instead of being merely perceived as disabled [32]. Unlike the objective that prevailed more than half a century earlier when the program for social security disability benefits was devised, Congress's consideration of disability through a civil rights lens aimed to provide broad protections against disability discrimination throughout the community to all individuals who are victimized by it. This is a very different aim than the Social Security objective of providing monetary support, which is offered only to a narrow subset of the population who, due to severe impairment, are unable to work [33].

### **An Ethics Perspective**

As may be expected of terms of art developed to serve specific policy aims, "disability" does not possess a univocal definition. According to the US Census Bureau, changes in context shift the standard for being counted as disabled [34]. By the standard the Census Bureau applies to citizens' self-reports about their functional capacity, approximately one in five US citizens over age 15 has a disability [34]. The same document warns, however, that "health professionals, advocates, and other individuals use the same term in different contexts" [35]. To take an example, in a 1999 Supreme Court case, a stroke patient's physician supported her claim on a Social Security application that she was too disabled to work but testified in an ADA complaint that she would be capable of working if not for her employer's refusal to reasonably accommodate her impairment [36]. According to the Court, testimony that a person is or is not disabled is not always unconditional; both asserting and denying that a person is disabled need not be a contradiction because disability has different meanings in different contexts.

That the standard for having a disability remains so much in flux across contexts reveals a fundamental ethical difficulty that has become embedded in our discourse about

disability. The purported precision of these judgments is illusory, so much so that defining disability to achieve gatekeeping dependent on such judgments too easily devolves into an exercise in stereotyping—for example, by courts defining people with disabilities as unable to work and then by programs and commentators applying the courts' interpretation. By their very nature, such assessments of disability lack epistemic trustworthiness, especially when allocation of opportunity and (dis)advantageous social positioning are at stake [37]. Disregard for lack of epistemic reliability invites deceptively authoritative declarations about who has and does not have a disability, undercuts the effort to increase social participation by biologically anomalous people, and is antithetical to Congress's aim of broad coverage in the ADAAA.

Protection of civil rights under the ADA should not be impeded by difficulties in determining whether a person is sufficiently disabled to qualify. A common misunderstanding is that only those with disabilities, or severe disabilities, can be rights-bearers under that law. The basic issue in each case, however, pertains to whether a person has been subjected to disability discrimination—regardless of the existence or severity of disability—and thus to a violation of the right to equitable social opportunity through accommodations that do not impose undue hardship on other people.

The ADA mandate presents a challenge and an invigorating chance for health care organizations, which are tasked with responding to biological differences related to patients' compromised functioning, to come to grips with more nuanced, proactive, and contextualized understandings of disability. ADA compliance should focus broadly on devising ways for people who, for reasons of biological anomaly, do not function in species-typical ways to nevertheless access opportunities open to others—not on whether it is accurate to call these people disabled. (That is, ADA compliance should be based on whether the functional deficiency can be effectively mitigated by medical means or addressed by the proposed accommodation or by a combination of both.) Such a focus requires flexibility, as well as knowledge and open mindedness, to devise effective approaches for eliminating or reducing harm occasioned by inaccessible practice or other manifestations of disability discrimination.

The ADAAA facilitates shifting skilled medical judgment away from whether the functionally compromised person is severely disabled enough to exercise a right toward bringing medical knowledge and skills to bear on how to implement that right through a process of integrating mitigating interventions and reasonable accommodations to achieve equitable access for that person. This process involves physicians working with persons with disabilities to explore how [workplace accommodations](#) might be designed to allow people with different modes of functioning to perform jobs and otherwise increase their social participation. To do so, both the responsibility and the expertise of physicians should extend beyond improving biological functioning to support assuming a greater role in making progress toward social justice.

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