

Disability and Institutional Change: A Human Variation Perspective on Overcoming Oppression

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For at least three decades, disability rights activists have challenged exclusionary and stigmatizing social processes that constrain people with disabilities, an effort highlighted by the 1990 enactment Of the Americans with Disabilities Act. However, all environmental barriers to participation by people with disabilities may not be eliminated by a policy strategy that focuses on discrimination and fails to address many forms of oppression that do not fall under legal definitions of discrimination. The human variation model of disability defines disability as the systematic mismatch between physical and men-tal attributes of individuals and the present (but not the potential) ability of social institutions to accommodate those attributes. Although rights•based approaches remain necessary to overcome the barriers facing many Americans with disabilities' a policy strategy that builds on a human variation approach may further efforts to eliminate disability oppression.

The effectiveness of any strategy for addressing the current sta-tus of Americans with disabilities depends on identifying the nature of the problems they face. Different conceptions of the problem are necessarily linked to different solutions, either through legally imposed remedies or through broader social and political action (Hahn, 1985b). For example, a medical model of disability typically views the disadvantage associated with having disability as inherent in an individual's impair-ment; the solution to this problem is individual rehabilitation or, when necessary, income support to compensate for the dis-abled individual's inability to function.

For over three decades, disability rights activists and organizations linked to the disability rights and independent living movements have challenged exclusionary and stigma-tizing social processes that constrain people with disabilities (Barnartt, Schriener, & Scotch, in press). According to the ide-ology underlying these protests, disability is defined in socio-political terms, identifying barriers faced by people with disabilities as imposed and subject to change, rather than in-trinsically linked to the presence of an impairment (Hahn, 1985b). Disability rights activists have rejected the assumption that having a disability inevitably means that someone is unable to live independently or participate in everyday eco-nomic, political, or social life, an assumption that has become a self•fulfilling prophecy embedded in employment practices, the design and operation of public accommodations, and in-centives in public benefit systems.

The Americans with Disabilities Act of 1990 (ADA; see Note) characterizes the disadvantaged social and economic po-sition of people with disabilities through a sociopolitical lens in which individuals who have physical or mental impair-ments face stigmatization, exclusion, and marginalization and because of assumptions about incapacity that are embedded in a wide variety of cultural, organizational, and physical manifestations (Hahn, 1985a). One key rationale for the ADA was that many of the problems associated with having a dis-ability were not inevitable products of impairment, but rather were the result of a socially constructed environment that arbitrarily and perniciously excluded or limited social par-ticipation. The social environment determines the extent to which an

impairment results in incapacity or exclusion from mainstream social processes, rather than merely the impairment itself. Assumptions about normality of human functioning become built into technology, architecture, spatial organization, and institutional processes. These physical and social structures become reinforced by social belief and cultural expression.

Thus the social environment has enforced the social isolation and dependency of people with disabilities, substantially limiting participation. Until recently, building construction standards did not allow for wheelchair access, and public programs contained assumptions about minimum mobility needed for participation. Communication technologies still require certain levels of visual and hearing acuity. Almost invariably, these arrangements are not inextricably linked to the nature of the activity involved, but rather represent choices that are often arbitrary, and once made, become institutionalized and difficult to challenge without a commitment to change.

Some of the experiences and characteristics of people with disabilities are like those of other groups commonly recognized as minorities, such as racial and ethnic minorities, women, or gays and lesbians. These groups are subject to prejudiced attitudes, discriminatory behavior, and institutional and legal constraints that parallel those experienced by African Americans and other disadvantaged and excluded groups. People with disabilities are victimized by negative stereotypes of dependence and incapacity associated with discriminatory attitudes and practices that result in exclusion and social isolation. Disabled people may lack access to employment, public facilities, voting, and other forms of civic involvement due to barriers of stigma, fear, and disabling assumptions, and thus are denied the opportunity to participate fully in society (Hahn, 1985a).

Social Institutions and Oppression

The conditions affecting people with disabilities are not static, and the disadvantages imposed by these conditions are not immutable. Changes in employment practices, social attitudes, or the built environment may begin to remedy existing disadvantages for some individuals with impairments but may impose them on others. Some social trends appear to favor greater inclusion of people with disabilities. Technological changes, activism by the disability rights and independent living movements, and policies that have promoted greater public participation have helped to give people with disabilities more visibility, and have advanced public understanding of the experience of disability. Nevertheless, people with disabilities are still disproportionately unemployed and underemployed, and their incomes are below those of people without disabilities (Bruyere, 2000). For example, despite the ADA, the employment situation faced by most persons with disabilities has not improved in the past decade, and labor force participation by working-age persons with disabilities has declined since the early 1990s (Schwochau & Blanck, 2000). Older disabled individuals and disabled people of color have particularly low levels of work force participation, reflecting general trends in the economy for middle-aged and minority workers (Yelin, 1992).

More disconcerting for the future, the below-average educational attainment of people with disabilities makes them vulnerable to labor market trends in the emerging knowledge-based economy that favor high levels of education and technical training (Scotch & Schriener, 1997). Many people with disabilities also are discouraged from seeking employment by persistent work disincentives built into benefit and insurance programs and by inadequate systems of social support (National Council on Disability [NCD], 1996). Inadequate health insurance coverage for chronic conditions creates barriers

to employment, as do difficulties with transportation (NCD, 1996). Although policy initiatives such as the 1999 Work Incentives Improvement Act are first steps in reducing such barriers, we believe they have only modest potential for expanding workforce participation for most disabled people.

As one of the most vulnerable groups in the labor force, people with disabilities also may be affected by the economic turbulence associated with globalization, rapid technological change, geographic displacement, and Web-based economic activity. Heightened competition, continuing deregulation, and the growth of the service sector have led to ongoing changes in work relationships, job longevity, and the organizational, geographic, and spatial settings in which work is done (Scotch & Schriener, 1997). These changes present many opportunities for entrepreneurship, telecommuting, and nonstandard forms of employment among individuals with disabilities, such as those with mobility or communication-related impairments.

However, they also represent heightened risk for disruption in employment that some people with disabilities may find particularly difficult due to general lack of economic resources and their reliance on interpersonal and community systems of support. The social isolation experienced by many people with disabilities may create difficulties in adjustment to the culture of work. Although new technologies may de-emphasize working in adjacent space, the increasing interconnectedness and "just-in-time" nature of many work tasks may limit the flexibility of work scheduling, and this may have consequences for individuals with certain physical and mental impairments. For example (according to an anonymous corporate executive), one prominent high-technology firm routinely expects employees to engage in so-called "death marches" at the final stage of product development that require a sustained intensity of around-the-clock effort that may be incompatible with certain needed accommodations (personal communication, September 10, 1999).

The work-related challenges raised by rapid and complex economic and social change exemplify the shifting circumstances that can pose barriers to equal participation of people with disabilities. The disadvantages faced by individuals with disabilities are inherent in a combination of factors that affect different people differently. Overtly discriminatory conduct and associated attitudes are only one element in the disadvantaged employment situation for many people with disabilities, for which anti-discrimination laws such as the ADA are only one part of the solution.

Although overt discrimination remains widespread and pernicious, the commonly held notion of discrimination must be so stretched to include the various barriers faced by people with disabilities that the concept loses some of its precision and thus its utility as a guide to policy. The nature of disadvantage faced by people with disabilities is so pervasive and, in many instances, the unintended consequence of routine or novel practices, that the concept of discrimination is insufficient to encompass these processes and effects. It may be useful for public policy to focus broadly on the systematic failure of social institutions to accommodate the human variation represented among people with disabilities, regardless of whether that failure might be considered to be the result of discrimination. Where disability-based disadvantage is wide-spread and systematic in a social institution, occurring and recurring in constantly changing relationships and arrangements, it might be characterized as oppression.

Disability and Institutional Change

The ADA is based primarily upon the minority group model of disability. Legislatively, it is built upon the Civil Rights Act of 1964, which prohibited discrimination on the bases of race, religion, and gender, and Section 504 of the Rehabilitation Act of 1973. The ADA was intended to eliminate through established civil rights remedies to discrimination the marginalization of people with disabilities. In the conceptual foundation of the ADA, failure to provide accommodation that enables social, economic, and political participation is characterized as discrimination, whether it is the result of deliberate animus or of institutional practices that constructively block participation without a reasonable rationale. Conversely, equity is equated with elimination of discrimination, often through provision of reasonable accommodation.

The political and legal limitations of the ADA now being realized are due in part to differences between disability and other statuses, such as race and gender, which are associated with social and economic disadvantage. In order to eliminate discrimination based on race, a color-blind standard of nondiscrimination is achievable (although the goal will be achieved sooner through affirmative action, which has been proposed as a remedy to past discrimination). A disability-blind standard will not eliminate discrimination against people with disabilities, because it is typically necessary to recognize the disability in order to accommodate it.

Further, it is not necessary to distinguish among various subgroups among racial minorities. Similarly, there are a limited range of legitimate circumstances in which gender-conscious remedies for discrimination may be necessary (Brandwein & Scotch, in press), and these fail to require subtle distinctions among subgroups within the protected class of women. Yet, the diversity of physical and mental impairments and their consequences for function require recognition of different categories of disabilities (e.g., blindness, deafness, mobility, mental, emotional.)

If disability discrimination were directly analogous to racial and gender discrimination, it would be technically, if not politically, easy to identify and eliminate. Because of the diversity of disabling conditions and the variety of coping strategies of individuals who have them, however, many accommodations under the ADA must be tailored to the individual involved, and may require periodic alterations to reflect changes in the individual's impairment or changes in the environment in and outside of the workplace. Accommodating people with disabilities may require an ongoing willingness to change; the restructuring of expectations, tasks, and techniques; and a constructive communication between persons with disabilities and those responsible for their environments such as employers.

The concept of disability represents a wide and diverse variety of conditions, each with its own idiosyncrasies that may require unique accommodations. To be effective, accommodations may even need to differ for different individuals with similar impairments. Some deaf people may require sign language interpretation, whereas others may not. Some blind people read Braille, others do not. And because impairments are rarely constant over time, individuals may require varying accommodations over the course of their employment.

Although there are occasionally individual difficulties to be worked out, racial and gender discrimination can typically be eliminated through "wholesale" changes in policy and practice. The ADA, however, must be implemented primarily at the "retail" level of individually crafted solutions to

problems of accessibility. According to past experience, most accommodations are easily achievable and involve only modest costs (Bruyere, 2000). Nevertheless, the transaction costs to identify and negotiate such changes may be considerable for those institutions that traditionally have been procedurally rigid and unresponsive to employee or customer needs. If one accepts the premise that the elimination of disability discrimination requires providing reasonable opportunities appropriate to each individual's circumstances, then some fundamental institutional changes may be required.

If the logic underlying the ADA is followed to its conclusion, the Act would require that workplaces, public facilities, and the infrastructures that support them institutionalize flexibility and responsiveness to individualized needs. This would require a long-term transformation that would be beneficial to people with disabilities and many others. It would also require a commitment of effort beyond other civil rights mandates of the ADA and the Rehabilitation Act. To what extent can the ADA promote humane, responsive, and individualized environments in work and public life?

Disability community advocates had hoped that the ADA would be an important step in redefining how disability is constructed in public policy, and ultimately in public life. A decade after its enactment, the direct impact of the ADA on discriminatory practices remains unclear. Although a tremendous effort was made to educate affected parties about the Act, many employers and providers of public accommodation have been slow to respond to its mandates (NCD, 1996). Although some of this delayed response may have been due to the perceived ambiguity of several statutory provisions, many affected entities appear to have continued to resist any changes promoted by the ADA (Russell, 2000). Of course it is impossible to assess how many proactive initiatives have been taken in the absence of direct legal duress. It is clear that many employers and providers of public accommodation have made their facilities more accessible, and there appears to be a public commitment to ensuring access.

There is some good news in that the systematic transformation envisioned in the ADA is consistent with other workplace and societal trends and more easily achieved with emerging technologies. There are multiple pressures on social institutions to accommodate the range of individual needs, increasing the likelihood that individuals with disabilities will be accommodated as well. Labor shortages in high technology industries have led many employers to create more humane and supportive workplaces. Corporate concierge services, flexible working hours, on-site childcare and retail services, and the promotion (or at least toleration) of telecommuting are not qualitatively different from the kinds of accommodations needed by many disabled workers. As employees and communities increasingly demand family-friendly workplaces, they will find it conceptually similar to offer disability-friendly workplaces as well.

Such changes were not, and likely could not, be forced by legal protections against disability-based discrimination. An antidiscrimination strategy using the ADA, therefore, cannot serve as a sufficient policy basis for promoting participation by people with disabilities. It may be more useful to look beyond discrimination in addressing the needs of such individuals.

Although eliminating discrimination is necessary to promote the empowerment of people with disabilities, it falls short of offering a comprehensive approach to the development of policy solutions to the problems associated with disability. The goal of expanding participation will require efforts on multiple fronts. An antidiscrimination strategy does not provide adequate guidance in developing

cost-effective, politically defensible policies that meet the employment and other needs of people with disabilities.

Disability and Human Rights

Given the uniquely American history of civil rights discourse and policymaking, framing the concerns of people with disabilities in terms of equal protection/equal opportunity calculations until recently has been politically both promising and palatable. But now, with the court's limited understanding and occasional hostility to the ADA, and a less reliable political environment, it may be necessary to reevaluate the theories and discourse on which the ADA is based.

One attractive alternative for policy debates is based on human rights theories, which seek to establish positive rights to economic, social, and political justice for all. These theories are very broadly conceived; indeed, they are the broadest of all approaches to defining equality for persons with disabilities and other disadvantaged groups. They are implicitly based on an understanding of oppression by encompassing the various forms of potential disadvantage that governments and other social institutions can impose. Human rights theories go beyond negative rights by establishing minimal criteria for achieving social, political, and economic equality.

Human rights theories are multifaceted, addressing rights ranging from political and civil rights to cultural, social, and economic rights and serve as the basis for various documents of the United Nations. For example, the Universal Declaration of Human Rights (adopted in 1948), the International Covenant on Civil and Political Rights (1966) and the International Covenant on Economic, Social and Cultural Rights (1976), are broad statements concerning the rights of individuals to these categories of rights with profound implications for governing the relationships between states and their citizens. Each elevates the individual's rights to a high plane and thus creates potential claims on governments to adopt policies that promote equality of opportunity and results. These instruments establish an international commitment to democratic governance, strong civil societies, and social justice. Although the potential import of these commitments is still unrealized in most countries, the moral imperative they represent is significant.

Several United Nations documents already have targeted the needs of people with disabilities, including the 1971 Declaration on the Rights of Mentally Retarded Persons, the 1975 Declaration on the Rights of Disabled Persons, and the recently developed Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Degener & Koster-Dreese, 1995).

Human rights theories have been a galvanizing moral force in countries around the world in establishing standards for promoting democracy, social and economic development, and individual rights. Many nations, particularly those established since 1948, include parts or all of the Universal Declaration of Human Rights in their constitutions (United Nations, 1995). Yet, the full force of human rights theories is far from being realized for a variety of cultural, political, and economic reasons. In many parts of the world, the realities of tradition and economic pressures impose impediments to progress.

As with many good and proper ends, constructing the conditions in which human rights are ensured

for all has proven difficult. This is just as true for people with disabilities as other historically oppressed groups. The disadvantages imposed by modern public-sector bureaucracies and economic arrangements in the private sector are entrenched and stubborn. In any scenario, these disadvantages will not be removed without fundamental social change of the sort that threatens powerful interests.

In this respect, human rights theories are as potentially limited as the antidiscrimination theories on which the ADA rests, although in different ways. The ADA's limitations arise from the legal and political resistance to stretching the discrimination definition as far as necessary to address disability-based disadvantage. In human rights theories, disadvantage is the result of oppressive structures and practices (which also oppress other groups). Compared with anti-discrimination theories, the breadth of analysis available using human rights theories permits a more systemic and far-reaching critique of the political and economic sphere.

Also, compared with antidiscrimination theories, there would be even greater resistance to implementing policies based on human rights theories. This is the issue that advocates for people with disabilities will have to face. No matter what theory of equality and definitions of oppression are relied on, it must be recognized that the public and its political and legal establishments seldom enthusiastically embrace the idea of remedying the inequities that exist in American society. This is especially true with respect to class issues, which are at the core of many disability issues. Poverty and its consequences have not been a centerpiece of political discourse for many years, and when poverty is discussed, it is usually in terms of "extending the prosperity," not adjusting the structural characteristics that continuously sort the winners from the losers. Although there are clearly avenues for socio-economic advancement (and many individuals who benefit from them), without the political will to keep pursuing more equitable outcomes for America's disadvantaged populations, disability policy is not likely to have a significant effect on the quality of life for people with disabilities in this country.

Even when disability policy protects the subsistence rights of people with disabilities (as in disability insurance schemes that provide an income floor and at least minimal health-care benefits), it does so at the discretion of the legislature. The "deserving poor" are usually offered this assistance, but those who are not considered deserving may not be. In fact, the current legislative and judicial stance toward more subsistence rights is often hostile or at least resistant. The federal entitlement to welfare for poor families (among which are many individuals with disabilities) was abolished in the most recent Congress, and the bill was signed into law by a Democratic president. Before that, the Supreme Court's hostility to subsistence rights spanned the terms of the liberal Chief Justice Earl Warren and the conservative Chief Justice William Rehnquist (Bussiere, 1997).

More expansive benefits, and access to the education and social and rehabilitation services that many people with disabilities need to take advantage of the opportunities available to them, maybe more vulnerable than the historically minimal social insurance programs available to people with disabilities. Further, requirements for accommodating individuals with disabilities in the private sector continue to be resisted by business interests, and it seems unlikely that the legislature and the courts will take decisive action to strengthen their application. Such initiatives require public investments and private obligations at odds with traditional U.S. notions of individualism, property rights, and limited government.

This analysis suggests that disability rights advocates and other interested parties face substantial challenges in addressing the inequalities that affect the ability of people with disabilities to participate fully in American society. It may be that human rights theories will offer some promise in this effort. However, we would like to suggest that even a successful rights-oriented strategy would fall short of creating the substantive equality of participation sought by the disability rights movement. Although creating formal claims on equity regardless of impairment is important and worth pursuing, the nature of environmental adaptation required to accommodate people with disabilities may be best achieved through an approach based on a different conceptual model, such as the human variation model we have proposed (Scotch & Schriener, 1997).

Disability as Human Variation

In the human variation model, disability is defined situationally as a mismatch between physical and mental attributes and the present (but not the potential) ability of social institutions to incorporate those attributes. Institutions affected are those involved in economic, social, cultural, and political life, such as the family, the community, the economy, and the polity. Included are organizations that provide employment, education, health care, transportation and communication, and the full range of public services.

By focusing attention on how systems respond to the variation introduced by disability, a new model of disability might help us address issues of how to design institutional responses to such variation. Such a human variation model assumes that within any population, physical and mental attributes vary. Disability occurs where the environment within which an individual is situated can only accommodate a limited range of characteristics. Thus, some environments demand from individuals the capacity to read print, climb stairs, or work for eight hours without a break, and those individuals who lack that capacity are defined as disabled.

Certain environments are associated with high levels of disability because of their physical design or their institutional rules and routines which have the effect of limiting participation. In some cases, such restrictions are intrinsic to the essential functions of the work or other activity that is being taking place, and in those cases they may be unavoidable. For example, given the current nature of transportation technology, a certain level of visual acuity is necessary to operate a transit bus or an airplane. However, in many other cases, alternative strategies for accomplishing the same tasks may be available. In those cases, restrictions on participation by a person with an impairment may be fairly arbitrary, and the failure to adopt the alternative might be seen as oppressive. The position of copyeditor, for example, may be inaccessible to a blind person if text is only available in print, yet completely accessible with the now virtually costless conversion of print to electronic text that is readily readable by that same person.

The concept of universal design suggests the creation of environments that can accommodate the needs of virtually any individual, regardless of impairment (Zola, 1989). According to this conception, the problems faced by people with disabilities might be seen as the consequences of the failure of social institutions (and their physical and cultural manifestations) that can be attributed to having been constructed to deal with a narrower range of variation than is in fact present among any given population). Thus, those individuals whose mobility, communication, vision, cognition, or medical

needs differ from social norms find themselves confronting institutions not well suited for their abilities and potential.

Historically, all societies have adapted to some types of human variation while demanding adjustment of some or marginalizing others, and there is evidence that this marginalization has increased with industrialization and urbanization (Scheer & Groce, 1988). To the extent that society fully accommodates a condition, it ceases to be a disability as defined under the human variation model. Social systems embodying universal design minimize the relevance of impairments at relatively low social or economic cost.

For some individuals and some impairments, discrepancies will persist between individual attributes and the requirements of even universally designed systems. However, where the compatibility between individual variation and societal institutions is limited or strained, secondary effects may ripple through family and community systems as ad hoc or partial adaptations are made, exacting financial, time, and emotional costs from those involved. These customized solutions often involve considerable complexity, due to the institutional inertia of unresponsive systems not geared to generic accommodation.

Building on this perspective of disability as human variation, disability can be viewed as introducing complexity and disequilibrium into individual lives, family relationships, and the various social systems in which people live, learn, play, and work. When a child is born with a severe impairment, for example, more complex support systems may be required to support the child and her family. Additional resources and new approaches to the challenges of daily life may need to be developed because economic, social, and cultural systems are not geared to the needs of the child and the family. In instances where systems have incorporated routinized mechanisms for meeting needs that are associated with different disabilities, systemic strain may never occur, nor will the conflict that can accompany such strain.

Like the sociopolitical model, a conception of disability based on variation highlights and rejects the assumption that stigma and incapacity are inherent to impairment or that disability is solely an individual-level attribute. However, the emphasis of the sociopolitical model on discrimination and discrimination-focused remedies means that the model is of limited help in guiding needed reforms of medical, educational, and human service delivery systems to best promote independence and full social participation by people with disabilities (Batavia & Shriner, in press). By characterizing all barriers faced by people with physical and mental impairments as discrimination, we risk trivializing the still prevalent and often vicious stereotyping and exclusive discriminatory practices by confounding them with the general incapacity of social systems to respond to individual variation.

Disability-related oppression, whether associated with animus and intentional discrimination or not, requires a social response. Many people with disabilities have problems in functioning that will not disappear if prejudice and discrimination are eliminated and may require long-term individualized accommodations that some would question as being justified by the policy goal of nondiscrimination.

Even where productivity for individual firms may be limited by adaptations required for universal design and universal access, society must broadly consider the social costs (i.e., externalities)

imposed by narrow conceptions of the need for short-term profitability by individual firms. Independence and full social participation of people with disabilities entail important multiple gains to society at large, gains that easily justify investment in systems that promote inclusion (Bowe, 1980). Focusing exclusively on discrimination limits our attention to the actions and cost-benefit calculations of individual employers. Focusing on inclusion and universal policies requires cooperative efforts within communities and society at large, broadening the resources that can legitimately be brought to bear on fostering inclusion.

Similarly, a reliance on human rights theories that insist on confronting entrenched economic and political interests raises the possibility that people with disabilities will not be accommodated to the extent necessary because of political resistance to positive rights claims. Here again, arguing for required changes may be more profitable if done from a more cooperative and inclusive stance of universality.

We believe that rights-based approaches prohibiting discrimination on the basis of disability remain necessary to overcome the barriers facing many Americans with disabilities, but that such approaches cannot by themselves lead us to a society in which all people with disabilities will have full opportunities for participation. The human variation may help us to identify further strategies for achieving the goal of integration and suggest how a society would look in which disability was not defined inherently as a handicapping condition. But achieving that goal may be more feasible within a general strategy of working for more responsive institutions, not just on behalf of people with disabilities, but on behalf of everyone. This task may be too daunting to be undertaken by the disability community alone. Now more than ever, the opportunity for overcoming the oppression experienced by many people with disabilities lies in the forging of strong, mutually beneficial alliances with others who analyze the problems they face in the same way as do people with disabilities.

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AUTHORS' NOTES

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2. We would like to express our appreciation to Drew Batavia for his comments as the paper was being revised.

3. 42 U.S.C. § 12101 (1994). The ADA was signed into law on July 26, 1990.

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