

**Transforming the Culture:
The Visibility of Disability in the Humanities**
Anita Silvers

RECONCEPTUALIZING DISABILITY

Over the past quarter century, the advantage of contextualizing disability socially instead of medically has become increasingly apparent. From a disability rights perspective, the highlight of this period of profound and progressive social change is the Americans with Disabilities Act. Departing from all previous American legislation, the A.D.A. explicitly portrays disability as being socially constructed.

Reconceptualizing disability so as to understand it to be a condition of society which artificially and unfairly disadvantages certain individuals, not a condition of those individuals that naturally abridges their social participation, thus has had an impact on public policy similar to the more widely discussed social analyses of race and gender. But the public has yet to respond to transformative disability policy as it did to the earlier policy revolutions that abated social exclusions attendant on race and gender. For example, relatively little recognition of the significance of the lives of people with disabilities has transfused into the general culture, nor have we enjoyed a major breakthrough in public acceptance and appreciation of our differences. As a class, we are no more embraced and little better integrated than in the pre-social-model era.

CHANGING THE CULTURE

This is so in large part because we have not yet created a programmatic educational approach to disseminate the cultural components of the social analysis of disability. The characteristic neglect of disability at both pre-collegiate and university levels of the general educational curriculum cannot help but curtail the influence of the disability policy revolution. We cannot awaken the masses of young people we educate to what individuals with disabilities have contributed, let alone to how much more society would benefit were the impediments to their full participation erased, absent such a vehicle for education.

In particular, disability is not very visible in those areas of study that traditionally transform social attitudes by elevating personal and public values. It is little discussed in the cultural educational programs that explore and redraw, and ultimately transmit and secure, our traditions, namely, what we sanctify and celebrate, as well as the institutions we rely on for challenging and changing infelicitous, exclusionary, or threatening social arrangements. As a consequence, disability does not often appear as an authorized topic in courses designed to satisfy the diversity requirements now familiar in universities' general education programs. Even at those universities where diversity includes disability, relatively few faculty are prepared to address it.

Both the structure and the content of cultural education typically originate in scholarship conducted in the disciplines of the humanities and the humanistic social sciences. These arts and letters disciplines include, according to the legislation establishing the National Endowment for the Humanities, the study of classical and modern languages and literature, history, philosophy, linguistics, the history and theory of art and architecture, cultural anthropology, and

jurisprudence. Themes that promise to facilitate interest in disability are not unfamiliar to these disciplines.

DISABILITY THEMES

Feminism already has proven to be an important point of entry for the study of disability in the arts and letters disciplines, especially because the cultural construction of corporeal differences is a central concern of feminism. Concurrently, social constructionism is edging out naturalism as a methodological presupposition in many humanities disciplines. This transformation promises to fortify the social model of disability by exploring how deficits which appear to be natural, unalterable inferiorities of individuals actually are artificial and reversible because they are the product of flawed social arrangements.

Also of importance is the romantic tradition, for two centuries a major influence in our interpretation and appreciation of literature and the arts. Romanticism famously prizes those individuals whose perspective is heightened and privileged by the experience of disability. In this regard, it is regrettable that an influential segment of the disability community currently seems uncomfortable with discourses of achievement, apparently feeling these to be coercive instrumentalities used only to chide people with disabilities for not overcoming their limitations. By celebrating hero(in)ic individuals, romanticism may seem antithetical to the interests of ordinary people with disabilities. But this is to misunderstand romanticism which insists that people with disabilities excel because of, rather than despite, their special situations. In sum, romanticism extols embracing difference.

In order to enhance the general culture's respect for people with disabilities, it may well be advisable to compose a canon of admirable accomplishments by people with disabilities in the arts, humane letters, and in leadership and public life. To be not just excellent, but also exemplary, these achievements should speak to disability in ways that people with disabilities find enlightening, but also should engage the imaginations of people without direct experience of disability. Given our romantic tradition, which is replete with artists, scholars, and civic leaders with disabilities, the disability community should not hesitate to encourage interpretive scholarship designed to reveal the positive influences of being disabled as these are manifested in admirable conduct and creative work.

Current humanistic scholarship already reflects post-modernism's signature commitment to defend pluralism, deviation, and difference against the hegemony of homogeneity. During the last decade, post-modernist methodologies supported an impressive deployment of intellectual resources for the study of ethnicity, race, and gender. Within humanistic scholarship, disability recently has been added to this list of attributes as another category of "oppression." People with disabilities sometimes are seen to stand as the ultimate test of the inclusiveness of post-modern theory and of its claims to embrace and celebrate difference.

Moreover, inherent in the fashioning of civil rights for people with disabilities, that singular achievement of the A.D.A., is the extension to them of the core philosophical concepts of our liberal tradition. That people with disabilities also are equal, that they rightly command justice as well as solicit care, urges reconstruction of the fundamentals of how we think about humans and their communities. Of course, it also may urge people with disabilities to rethink how they wish to position themselves in respect to autonomy and (in)dependence.

THE HUMANITIES DISCIPLINES

All these developments have intersected to help disability emerge as a recognized topic in the scholarship of members of the professional organizations which belong to the American Council of Learned Societies (A.C.L.S.). Disability is the subject of a variety of recent books in core humanities disciplines from classical historian Robert Garland's very useful The Eye of the Beholder, a study of disability in the Graeco-Roman world which investigates the elaborate variety of social roles assigned in antiquity to persons with disabilities, to contemporary cultural critic Michael Berube's Life As We Know It, where the experience of developmental disability triggers exploration of the kind of individuality we value and of our ability to imagine other people's lives. And several collections of readings, both of primary sources and of commentaries, will become available for use in the classroom over the next few months.

As a topic, disability now is appearing more frequently on programs of humanities organizations' professional meetings and of humanities conferences. Subjects run from 17th and 18th Century imagery of disability and deformity (UCLA Center for 17th & 18th Century Studies) to feminist philosophical approaches to disability (American Philosophical Association) to the history of deafness (Organization of American Historians). In addition to the history of deafness, the annual meeting of the Organization of American Historians has included individual papers on such subjects as "Disability and Technology." The '95, '96, and '97 programs of the American Philosophical Association all feature symposia that fall within the purview of disability studies: the A.D.A. and its intersect with medicine (1995 - Atlanta); disability law and disability rights (1996 - Chicago); and the rejected body (1997 - Berkeley). And the Modern Language Association has an ongoing section devoted to disability topics.

To mention these few examples should not be taken to exclude the many smaller, specialized associations that also are beginning to see disability as a topic relevant to their subject matter. For instance, several papers which assumed the social model of disability were presented at the conjoint 1996 meetings of the International Association of Bioethics, American Association of Bioethics, and Feminist Approaches to Bioethics. Nor should we ignore social science associations, such as the American Sociological Association, which regularly arrange panels on disability. Readers of this journal undoubtedly can contribute many more examples.

BROADENING INTERESTS

So there is initial interest in disability as a topic of humanistic study. The A.C.L.S. organizations have the potential to broaden this audience and to strengthen the humanities' contributions to disability studies and to the way our society thinks about disability. But at present, far more arts and letters scholars are acquainted with the research in women's and ethnic studies than with the much newer work in disability studies. This will remedy itself in time, but only if two conditions obtain.

One is that more scholars in these disciplines come to see disability as a category relating to and extending the fundamental questions that shape research in their fields. To thrive as women's and ethnic studies have done, disability studies will need to engage with and create exemplary treatments of intellectual themes that command broad interest in contemporary arts and letters scholarship. Pursuing such themes can develop disability studies without distorting their subject matter. The material is readily at hand.

Take a recent comment made by David Pfeiffer in reviewing Michael Oliver's Understanding Disability: From Theory to Practice. Pfeiffer disagrees with Oliver's diagnosis that

"society" disadvantages people with disabilities, arguing instead that it is other people, exercising their power in the allocation of scarce resources, who do. This seems to me to engage with a critically important methodological debate over whether the source of our oppression should be traced to impersonal social structures or personal motivational structures. That is, should we socialize or should we psychologize the oppression of people with disabilities? The question is clearly of a piece with current methodological discussions about other kinds of oppression.

We need to acknowledge the importance of encouraging dialogues such as the one Pfeiffer and Oliver might pursue in comparing both the theoretical and the concrete implications of their different methodological assumptions. And taking one more step would be of enormous help: namely, to draw from this kind of dialogue wide-ranging illumination about how not just psychology and social structure, but concept and culture as well, shape group identity.

More fundamentally, it is crucial to reverse the tendency to analyze disability using theoretical or methodological insights initiated to account for other kinds of phenomena. Disability thereby is approximated to other paradigms rather than itself emerging as a paradigm. (Foucault, who uses disability as a paradigm to explore other kinds of marginalization, is, of course, an exception to this tendency.) To effect the even more profound reconceptualization of disability needed to make it a paradigm calls for civil conversation suffused with respectful, even passionate, curiosity about how others make our common state of being disabled intelligible to themselves.

It also means cultivating more discursive ways of exchanging ideas. Simply issuing conclusions, without permitting attention and time to explore the alternative conceptions that might frame what one believes, is not respectful of the way in which ideas nurture each other so that scholarship flourishes. Conclusions, however accurate they may be, cannot be transformative if there is little opportunity to comprehend the conceptions that inform and energize them. Nor are ideas dynamic unless those whose thinking is framed by divergent conceptions test them with the time, the commitment, and the good will to engage in dialogue.

BROADENING AUDIENCES

This is an intellectual condition for building audiences. There is a second condition for building audiences that is organizational rather than intellectual, namely, increasing the number of scholars who are literate about disability. The majority of humanities scholars who explore disability are either individuals with disabilities or else those who have close ties to individuals with disabilities. This raises the question of whether the scholarly audience for disability studies is limited to those for whom the subject is concrete and personal or for whom the subject has professional interest because it relates to one's clients or consumers.

But building audiences is just part of the problem with which we began: how can appreciation for the lives of people with disabilities become more visible in the general culture? The question here is not "who speaks with authority about disability?" but "who listens when the authorities speak?" In this regard, the Society for Disability Studies might consider facilitating the process of gaining visibility by increasing its affiliations with other professional organizations that promote scholarship in arts and letters.

The American Council of Learned Societies (A.C.L.S.) exists to promote such cross-disciplinary organizational communication. It provides its member organizations with avenues for addressing the nation's cultural and educational policies as well as for promoting

better support for scholarship and research. For instance, it was through the efforts of the A.C.L.S. that the National Endowment for the Humanities was created by the U.S. Congress. The A.C.L.S. also offers its member associations a very wide range of opportunities for acquiring new knowledge and skills from meeting planning advice to projects that assist in electronic publication, to events that explore the most challenging aspects of the contemporary intellectual and educational climate.

Acquiring membership in the A.C.L.S. takes a certain amount of effort because the relation of the scholarship supported by the candidate organization to that of existing A.C.L.S. member groups needs to be articulated informatively. But, in terms of the opportunities it offers the members of the Society for Disability Studies to build audiences so as to increase appreciation of the lives of people with disabilities in the general education curriculum, and subsequently in the general culture, the benefits would time and again repay the effort's costs.

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Health Care Services for Women With Disabilities

Lois J. Shaevel

"There is a puzzling myth that people who are ill or injured (especially women) are obsessed with their health - always talking about their problems, showing off their scars, bragging about their doctors. The reality for women with long-term disability or chronic illness is very different, however. Just as we learned at an early age not to acknowledge disability in others ("Don't ask," "Don't stare"), so too we learned not to confront others with our own disabilities - "Don't tell!"... "And there is much to tell." (Marsha Saxton)

In regard to health care services for women with disabilities there certainly is "much to tell." Much to tell because little has been written to date to guide disabled women through the maze of health care services that even confounds their non-disabled sisters. Much to tell because cultural attitudes towards medicine and towards disability still prevent the ready coordination of health services for disabled women. And much to tell because recent decades have reframed the social issues surrounding disability from old views of charity and care to new views of discrimination, civil rights, and self-directed services.

My purpose here will be to explore these new views of (1) discrimination, (2) civil rights, and (3) self-directed services that are working to shape a new future in health care services for women with disabilities.

(1) Views of Discrimination: Sexuality and Reproduction for Women with Disabilities

"My first period was truly welcome. . . . At last my body had done something right...something every female body is supposed to do." (Ann Cupolo Carillo)

In the "Women and Disability Think Tank" of the Boston-based Project on Women and Disability, a discussion was held regarding the topic of "disability, menstruation, and menopause." The group of women shared stories of their first periods, of adapting menstrual products and