

Disability as Difference

Sociologist Erving Goffman's 1963 book *Stigma: Notes on the Management of Spoiled Identity* is still the most influential description of the processes of stigmatization. Goffman frequently uses disabilities as examples of stigmas, which has increased the influence of his book on those attempting to understand the social devaluing of people with disabilities. Although Goffman's work contains significant insights that apply to the experience of disability, I believe that his lumping together all sources of stigma, which causes him to overgeneralize, prevents him from seeing some crucial aspects of the stigmas of illness and disability. In addition, because he does not question the social 'norms' that stigmatize people with disabilities, he tends to adopt a patronizing tone in speaking of people who do not meet them, and to belittle and underestimate their efforts to live by different 'norms.'

Let us look first at how Goffman characterizes stigma:

Three grossly different types of stigma may be mentioned. First there are the abominations of the body—the various physical deformities. Next there are the blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty. . . . Finally there are the tribal stigma of race, nation, and religion, these being stigma that can be transmitted through lineages and equally contaminate all members of a family. In all of these various

instances of stigma, however, . . . the same sociological features are found: an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us. He possesses a stigma, an undesired differentness from what we had anticipated. (Goffman 1963, 4–5)

Here Goffman misses the importance of the specific symbolic meanings people with disabilities have for others in a society. It is interesting that his own language reflects those meanings. He refers unself-consciously to “physical deformities,” even though the examples he uses throughout the book include all sorts of disabilities, including deafness and stuttering; then he calls them “abominations of the body,” the strongest expression he uses for any of the types of stigma. Dishonesty, in contrast, is called a “blemish” of character. Elsewhere in the book, he uses such terms as “affliction,” “victim,” and “cripple,” and introduces people as “cases.” Of course he was writing in 1963, when such language was still widely used, so I am not drawing attention to it to criticize his personal attitudes toward disability. My point is that he exhibited subscription to the cultural stereotypes and meanings of disability far more than he examined it.

Later in his book, Goffman says of stigma that it “involves not so much a set of concrete individuals who can be separated into two piles, the stigmatized and the normal, as a pervasive two-role social process in which every individual participates in both roles, at least in some connections and in some phases of life” (Goffman 1963, 138). But then he says that “[t]he lifelong attributes of a particular individual may cause him to be type-cast; he may have to play the stigmatized role in almost all of his social situations” (138). He makes no attempt to explain why some attributes typecast a person and others do not; I do not see how he could explain it without considering the symbolic meanings of stigmatizing characteristics. I will return to the subject of symbolic meanings of disability later.

Goffman did contribute to the understanding of disability by bringing to public attention some of the social and psychological burdens of living as a person with a disability in the United States and places with similar cultures. He is particularly good on some of the dynamics of ‘passing’ as non-disabled (42), the obligation placed on ‘different’ individuals to ‘manage’ social situations with ‘normals’ in such a way as to protect the ‘normals’ from discomfort (especially 21–23 and 115–16), and the propensity of stigmatized people to place themselves along with others like

them in hierarchies of value (107). Moreover, by comparing the stigmas of disability to those of race and ethnic origin, he at least implies, although he never explicitly supports, the possibility of seeing disability as a civil rights issue.

Nevertheless, Goffman repeatedly fails to appreciate the possibility that having at least some disabilities may be, like membership in some other groups that are stigmatized, as good as or better than ‘normality.’ He discusses valuing one’s difference only as a coping strategy of the stigmatized, without calling into question the objectivity or permanence of the values that regard them as less than ‘normal.’ On the contrary, he rates valuing one’s difference and identifying closely with those who share it rather low, even as a coping strategy:

The first set of sympathetic others is of course those who share his stigma. Knowing from their own experience what it is like to have this particular stigma, some of them can provide the individual with instruction in the tricks of the trade and with a circle of lament to which he can withdraw for moral support and for the comfort of feeling at home, at ease, accepted as a person who really is like any other normal person. . . .

Among his own, the stigmatized individual can use his disadvantage as a basis for organizing life, but he must resign himself to a half-world to do so. Here he may develop to its fullest his sad tale accounting for his possession of the stigma. . . .

On the other hand, he may find that the tales of his fellow-sufferers bore him, and that the whole matter of focusing on atrocity tales, on group superiority, on trickster stories, in short, on the “problem,” is one of the large penalties for having one. (1963, 20–21)

The possibility of genuinely felt group pride (such as Deaf pride) seems to escape Goffman’s imagination. He can see solidarity among the different only as poor compensation for the acceptance as ‘normals’ that is denied them. He even seems to miss the genuineness of pride among stigmatized ethnic groups. Consequently, Goffman also misses an important difference between people with disabilities and other stigmatized people. Most stigmatized people are members of stigmatized groups that have subcultures within which the stigma may be made irrelevant or at least ameliorated by the group’s own values. Most (but not all) people with disabilities grow up with non-disabled people and/or are constantly surrounded by them, absorbing their values and assumptions; they have little or no contact with a

subculture that destigmatizes or positively values their difference from the non-disabled (Zola 1993, 167).¹ Perhaps Goffman's inability to imagine group pride is caused partly by his overgeneralizing from examples of people with disabilities.

Nevertheless, inability or unwillingness to imagine taking real (as opposed to defensive, self-deceptive) pride in a difference that is stigmatized by the majority indicates a failure to question the values of the majority; in effect, Goffman represents those values rather than examining them. Insofar as he holds out any collective hope for stigmatized people, he places it in the possibility that their differences may someday be ignored or at least considered unimportant relative to their other characteristics, not in the possibility that they might be revalued and appreciated. Difference remains a curse.

People with Disabilities as 'the Other'

In many ways, the concept of 'the Other' as developed in feminist theorizing is more fruitful than stigma for understanding the social position of people with disabilities. When Simone de Beauvoir used this term to elucidate men's views of women (and women's views of themselves), she emphasized that Man is considered essential, Woman inessential; Man is the Subject, Woman the Other. (Beauvoir 1952, xvi) In *Pornography and Silence* (1981), Susan Griffin expands upon this idea by showing how we project rejected aspects of ourselves onto groups of people who are designated 'the Other.' Thus, as I understand the concept of 'the Other,' it involves two essential processes: When we make people 'Other,' we group them together as the objects of our experience instead of regarding them as subjects of experience with whom we might identify, and we see them primarily as symbolic of something else—usually, but not always, something we reject and fear and project onto them. To the non-disabled, people with disabilities and people with dangerous or incurable illnesses symbolize, among other things, imperfection, failure to control the body, and everyone's vulnerability to weakness, pain, and death.

Griffin, in a characteristically insightful passage from "The Way of All Ideology" (1982), illustrates the dynamics of making another person symbolic to oneself:

As I was composing the notes toward this writing, I was forced to confront my own self-denial and projection. Waiting in line to be served in a restaurant, I began to notice an older woman who was sitting at a table alone. She was not eating, and she seemed to be miserable. I assumed she was waiting to be met. Her expression, the paleness of her skin, something in her posture all indicated to me that she might be ill, perhaps even seriously ill, perhaps dying. I imagined that she was nauseous. I was hungry. Yet as I looked at her I felt my appetite begin to ebb, a nausea seemed about to invade me by virtue of her presence. I was afraid that I might be seated at a table next to her, so that I might become more nauseous, or be contaminated. Slowly, despite another voice in me that urged reason and compassion, I felt an anger toward her. Why was she sick in this restaurant? Why force people who are eating to participate in her misery? I wanted to shout at her that she should go home, but of course, I did not. I was deeply ashamed of my feelings. And because of this shame I hid them away.

... And now as I looked at my imagined portrait of her son I saw myself. For according to my ideological explanation of male hostility toward women, men are afraid of women, and most particularly of their mothers, because they fear death. And was not that precisely what I had projected on her, my own fear of death, of the possibility that my body might fail me, and instead of giving me hunger, give me nausea? (1982, 648-49)

This sort of projection is something we can all do to each other, but the process is often not symmetrical, because one group of people has more power than another to call itself the paradigm of humanity and to make the world suit its own needs and validate its own experiences; the non-disabled are such a group in relation to people with disabilities. Non-disabled people may sometimes be 'the Other' to people with disabilities (as when disabled people refer to them as TABS, Temporarily Able-Bodieds), but the consequences of this 'Othering' for the able-bodied are minor. Most non-disabled people can afford not to notice that they might be 'the Other' to people with disabilities. The reverse is not true.

However, people with disabilities can and sometimes do make each other 'the Other,' for example by despising those who have less control over their bodily functions. There are often hierarchies of power and value in rehabilitative institutions, with those who act most like the non-disabled at the top, and those who have least control of their bodies at the bottom (Frank 1988). This suggests that failure to control the body is one of the most powerful symbolic meanings of disability.

The Symbolic Meanings of Illnesses and Disabilities

The symbolic meanings that disabilities and dangerous or incurable illnesses have are both products of and contributors to making people with them 'the Other.' Of course different disabilities and illnesses can have different meanings within a society (consider the different meanings of epilepsy and AIDS, or bipolar disorder and paraplegia), and the same disability or illness may have different meanings in different societies or in the same society at different times (tuberculosis is no longer considered romantic in Western societies, as it once was). Moreover other characteristics of a person, such as race, age, gender, class, or sexual identity, may alter the meaning of her/his disability. For example, Fine and Asch (1988, 3) point out that cultural associations of disability with dependency, childlikeness, and helplessness clash with cultural expectations of masculinity but overlap with cultural expectations of femininity, so that a disabled man is perceived as a "wounded male," while a disabled woman is redundantly fulfilling cultural expectations of her.

Susan Sontag has described in detail and with a critical eye the symbolic meanings of having tuberculosis, cancer, and AIDS in Western cultures: excess passion (in the past, for TB), repression of feeling, especially rage (for cancer), invasion by an alien force (cancer and AIDS), pollution (AIDS), cosmic punishment for immorality (AIDS) or for living unhealthy lives (cancer and AIDS), the possibility of moral or spiritual contagion with evil (cancer and AIDS), and so forth. (Sontag 1977, 1988) I find it interesting that myalgic encephalomyelitis, or chronic fatigue immune dysfunction syndrome, was for a while described in the media primarily in terms of the symbolic meanings that were created for it in the mid 1980s; it was the "yuppie flu," a punishment of nature visited upon the ambitious, especially ambitious women. Even now, few people realize that it occurs in many children, old people, and people in all socioeconomic classes, or that it can be a chronic, debilitating illness; the mythic descriptions are more exciting and more reassuring to the healthy than the reality. Moreover, a disease that causes profound fatigue was perfect for symbolizing the fatigue that many people experienced or feared when attempting to meet the demands of the 1980s for higher performance at a faster pace in all aspects of life. It is interesting that the words "Immune Dysfunction" are usually omitted from its name (which was given to it by the Centers for Disease Control) in popular reference. I find that friends and acquaintances often forget that the

primary symptom of my disease now is chronic pain; the extreme fatigue that dominated the first few years of my illness captured people's imaginations, and they still tell me that their own experiences of exhaustion make them realize what it must be like for me.

Although different illnesses carry different symbolic meanings, there are, I think, meanings associated with being chronically ill with anything. In my society, acceptance of the chronicity of one's illness is generally perceived as 'giving up hope,' which clearly implies that the chronically ill person is not good enough as s/he is but needs hope of getting better. Chronic illness also seems to mean chronic misery or unhappiness. I have the impression that people expect me to be miserable as long as I am ill. If I say I am doing well, they tend to assume that my health has improved. I have experimented with saying, in answer to "How are you?," "I'm sick but happy,"² but so far it has produced a lot of silence and puzzled looks. Most people who know me are aware that I live a complex life of work and relationships, just as they do, but it seems to be hard to reconcile that fact with the fact that I have a disabling illness. I understand the difficulty all too well; for most of the first few years of my illness, I could not imagine having a good life with it. I wonder frequently if some people think I am not as ill as I say I am, and others think I am putting on a brave face. I feel the weight of a social obligation to be either healthy or miserable. Nevertheless, I have concluded that I am always sick and often happy, and that this seems very peculiar in my culture.

As with illnesses, although different disabilities have different meanings within a society, there seem to be meanings associated with having any physical disability. (See Mason 1987 and Morris 1991 on England; Vargas 1989 and Dahl 1993 on Canada; Zola 1993 on the United States.) There also seem to be some similarities in the meanings of having a physical disability across societies and over time.³ Disability tends to be associated with tragic loss, weakness, passivity, dependency, helplessness, shame, and global incompetence.⁴ In the societies where Western science and medicine are powerful culturally, and where their promise to control nature is still widely believed, people with disabilities are constant reminders of the failures of that promise, and of the inability of science and medicine to protect everyone from illness, disability, and death. They are 'the Others' that science would like to forget. In the societies where there are strong ideals of bodily perfection to which everyone is supposed to aspire, people with disabilities are the imperfect 'Others' who can never come close enough to the ideals; identifying with them would remind the non-disabled that their ideals imply a degree of control that must eventually elude them too.⁵

Some people with disabilities, the 'disabled heroes,' symbolize heroic control against all odds, and their public images comfort non-disabled people by reaffirming the possibility of overcoming the body. Disabled heroes are people with readily apparent disabilities who receive public attention because they accomplish things that are unusual even for the able-bodied. It is revealing that, with few exceptions (Helen Keller and, recently, Stephen Hawking are among them), disabled heroes are recognized for performing feats of physical strength and endurance. While disabled heroes can be inspiring and heartening to the disabled, they may give the non-disabled the false impression that anyone can 'overcome' a disability. Disabled heroes usually have extraordinary social, economic, and physical resources that are not available to most people with those disabilities. In addition, many disabled people are not capable of performing physical heroics, because many (perhaps most) disabilities reduce or consume the energy and stamina of people who have them and do not just limit them in some particular kind of physical activity. The image of the disabled hero may reduce the 'Otherness' of a few people with disabilities, but because it creates an ideal that most people with disabilities cannot meet, it *increases* the 'Otherness' of the majority of people with disabilities.

Some Consequences of Being 'the Other'

For people with disabilities, the consequences of being 'the Other' to non-disabled people include all those aspects of the social construction of disability that result from the failure of non-disabled people to identify with people with disabilities, or to identify themselves as potentially disabled, including planning and structuring society for a narrow range of abilities, refusing to take responsibility for creating ability, rigid and unimaginative expectations of performance, and false or inadequate cultural representation. This is a self-perpetuating social system, since the exclusion of people with disabilities from many aspects of life in a society prevents non-disabled people from getting to know them, and also prevents people with disabilities from making their own mark on culture, both of which contribute to their remaining the symbolic 'Other' to non-disabled people.

Like other people who are made 'Other,' people with disabilities are subjected to high rates of verbal, physical, and sexual abuse (Matthews 1983; Ridington 1989; Sobsey 1989).⁶ For people whose disabilities are readily

apparent, every appearance in the public world means risking insult, ridicule, and embarrassment, but also physical assault. Diane DeVries, who was born with short arms, no hands, and no legs, describes an incident in her childhood:

I just knew I was different. Certain things could happen during the day to make me sad or mad, 'cause I could go . . . weeks without it bothering me at all, because nothing happened. But something could happen, like once when I was a little kid. I was in the wagon and we were in this trailer park, and some kid came up to me with a knife. He said, "Aw, you ain't got no arms, you ain't got no legs, and now you're not gonna have no head." He held me right there, by the neck, and had a little knife. It was one of those bratty kids that did weird things. (Frank 1988, 48)

As Anne Finger points out (Fellows and Razack 1994, 1055), people with disabilities are also subjected to forms of abuse, such as public stripping in hospitals, which are extremely damaging to their self-esteem and sexual identity, but which might not even be recognized as abuse by people who regard them as 'Other.' One has to be aware of the subjectivity of a person to imagine her/his experience of events and how s/he might be affected by one's actions.

'Otherness' is maintained by culture but also limits culture profoundly. Canadian and United States culture rarely include people with disabilities in their depictions of ordinary daily life, and they exclude the struggles, thoughts, and feelings of people with disabilities from any shared cultural understanding of human experience. This tends to make people with disabilities feel invisible (except when they are made hypervisible in their symbolic roles as heroes or tragic victims), and it deprives the non-disabled of the knowledge and perspectives that people with disabilities could contribute to culture, including knowledge of how to live well with physical and mental limitations and suffering. Because disabled people's experience is not integrated into the culture, most newly disabled people know little or nothing about how to live with long-term or life-threatening illness, how to communicate with doctors and nurses and medical bureaucrats about their problems, how to live with limitation, uncertainty, pain, and other symptoms when doctors cannot make them go away. Nor do they have any idea that they might gain something from their experiences of disability. There is a cultural gulf between the disabled and the non-disabled; to become disabled is to enter a different world. Yet experiences of living with

a disability are not by their nature private, separable from the rest of life and the rest of society. They can and should be shared throughout the culture as much as we share experiences of love, work, and family life.

I have found that people who realize concretely and vividly their own physical and mental limitations, or who understand from their own lives that they cannot control everything, not even the things that are most important to them, are more open to identifying with people with disabilities, less inclined to regard and treat them as 'the Other.' On the other hand, I am uncomfortable with efforts to undermine the 'Otherness' of people with disabilities by overextending the category of disability, for example by claiming that everyone is 'disabled' in some way because everyone has some limitations and 'imperfections'; this can lead to underestimating the struggles of people whose limitations or sufferings are much greater because of their physical and/or mental conditions and because of the many socially constructed obstacles in their lives besides their 'Otherness.'

Disability as Difference

Disability may be looked at as a form of difference from what is considered normal or usual or paradigmatic in a society. Difference is a more general concept than either 'Otherness' or stigmatization, both of which are forms of difference. Difference is also more value-neutral than either stigmatization or 'Otherness,' and it is therefore possible and necessary to ask whether a particular kind of difference is as good as or better than 'normality.' Because it leaves open the question of value, I prefer to speak of disability as a form of difference, while recognizing that both stigma and being 'the Other' are aspects of the social oppression of people with disabilities.

It is not uncommon for a difference to be valued for being exotic and interesting, even as the people who embody it or are associated with it are kept on the outskirts of society (Fiedler 1984). People with disabilities are subject to this double-edged form of appreciation, which plays a role in their token cultural representation. Since their difference is what is seen to make them interesting, it is highlighted, and their similarity to people without disabilities is minimized or else commented upon as amazing or amusing in order to maintain focus upon the difference. Of course, to those with a disability, their difference is not exotic, and it may be valued for itself, or for the different knowledge, perspective, and experience of life it

gives them. Among people without disabilities, it is somewhat more unusual to view disabilities as valuable forms of difference without treating the people who have them as curiosities, but this attitude is repeatedly demonstrated in the writings of the neurologist Oliver Sacks.

Sacks's appreciation of difference is shown in his descriptions of the lives of people with diagnoses of major neurological 'disorders.' First, he explores respectfully the meanings that their 'symptoms' have for the people who experience them. Second, although Sacks does not minimize the suffering of his patients, he is very willing to see the intrinsic value (and sometimes extrinsic advantages) of some of the forms of consciousness that are consequences of pathology. Third, he makes us aware of the contextuality of disability by describing situations in which his patients' differences from the 'normal' are not disadvantages.

For example, Sacks discusses the complex situation of "Witty Ticky Ray," a man with Tourette's syndrome who was "almost incapacitated by multiple tics of extreme violence coming in volleys every few seconds" (Sacks 1987, 97). Ray had been fired from a dozen jobs because of his tics, was frequently embroiled in crises because of "his impatience, his pugnacity, and his coarse, brilliant 'chutzpah,'" and had marital difficulties caused by his loud, involuntary outbursts of obscenities, all of which were manifestations of Tourette's. On the other hand, Tourette's was also the source of his famous, wild improvisations as a weekend jazz drummer and his extraordinary ability at Ping-Pong.

When Sacks treated Ray with Haldol, Ray eventually became free of tics and able to work steadily. His marriage improved, and he had children and many friends. But he also lost something:

During his working hours, and working week, Ray remains 'sober, solid, square' on Haldol—this is how he describes his 'Haldol self.' He is slow and deliberate in his movements and judgments, with none of the impatience, the impetuosity, he showed before Haldol, but equally, none of the wild improvisations and inspirations. . . . He is less sharp, less quick in repartee, no longer bubbling with witty tics or ticky wit. He no longer enjoys or excels at ping-pong or other games . . . he is less competitive . . . and also less playful; and he has lost the impulse, or the knack, of sudden 'frivolous' moves which take everyone by surprise. He has lost his obscenities, his coarse chutzpah, his spunk. . . .

Most important, and disabling, because this was vital for him—as a means of support and self-expression—he found that on Haldol he was musically 'dull,' average, competent, but lacking energy, enthusiasm,

extravagance and joy. He no longer had tics or compulsive hitting of the drums—but he no longer had wild and creative surges. (Sacks 1987, 100–101)

Eventually Sacks and Ray worked out a solution. Ray took Haldol during the working week, and stopped taking it at weekends, so that he could still experience the “wildness” of Tourette’s syndrome while having the rest of the life he wanted.

Another of Sack’s patients, Natasha K., came to him at the age of ninety, explaining that shortly after her eighty-eighth birthday she began to notice a change in her state of mind. “I felt more energetic, more alive—I felt young once again.” (Sacks 1987, 102) This change was, as she suspected, caused by the advent of neurosyphilis after a latent period of seventy years following a primary, uncured infection with syphilis. She knew that it could progress to a severe dementia, which she did not want, but she did not want it ‘cured’ either, since she felt better with the neurosyphilis than she had in twenty years. Sacks treated her with penicillin, which halted the progress of infection but fortunately did nothing to reverse the changes that had already occurred in her brain. She was well satisfied with the treatment. Sacks says of Natasha K., Ray, and related examples:

We are in strange waters here, where all the usual considerations may be reversed—where illness may be wellness, and normality illness, where excitement may be either bondage or release, and where reality may lie in ebriety, not sobriety. It is the very realm of Cupid and Dionysus. (Sacks 1987, 107)

In Western scientific-medical culture, it is far more common to assume that states of mind that are caused by or associated with pathological states of the body are themselves pathological, and to dismiss both their perspective and their content as illusory. This attitude, which seems to be based on a model of temporary illness, total recovery, and complete return to one’s former self, makes it unlikely that we will be open to regarding illness and disability as either sources of knowledge or valuable ways of being.⁹

Yet as Sacks’s work demonstrates, if one looks at disabilities as forms of difference and takes seriously the possibility that they may be valuable, one begins to notice the lived reality of people one may have assumed were simply less able and less fortunate versions of oneself. Then it becomes obvious that people with disabilities have experiences, by virtue of their

disabilities, which non-disabled people do not have, and which are sources of knowledge that is not directly accessible to non-disabled people. Some of this knowledge, for example, how to live with a suffering body, would be of enormous practical help to most people, as I have already pointed out. Much of it would enrich and expand our culture, and some of it has the potential to change our thinking and our ways of life profoundly.

For example, because people with disabilities cannot do or be many things that non-disabled people feel they themselves must do or be in order to be ‘normal,’ sane, and happy, people with disabilities are in better positions to notice and criticize cultural myths about the body and mind,¹⁰ as well as such matters as self-worth, intimacy, sexuality, dependency, and independence. When people cannot ground their self-worth in their conformity to cultural body-ideals or social expectations of performance, the exact nature of those ideals and expectations and their pervasive, unquestioning acceptance become much clearer. So does the fact that most people must fail eventually to conform to them, a fact that those who can currently conform do not usually want to face. When people’s genitals are numb or paralyzed, they may discover things about the nature of intimacy and sexuality that remain unknown to people who can participate in cultural obsessions with goal-oriented, genital sex. (See Bullard and Knight 1981; Morris 1989.) And an adult who needs someone else’s daily help to eat, wash, dress, and use the toilet may see very clearly how a culture despises this kind of dependency, but also how the same culture promotes the self-deception that ‘independent’ adults do not need each other’s help, that we are not all profoundly dependent on one another.¹¹

A Standpoint Epistemology for People with Disabilities?

These observations about the knowledge of people with disabilities raise questions that have been disputed extensively in feminist theory, questions about the epistemic advantages of oppressed groups and the plausibility of standpoint epistemologies. In *The Science Question in Feminism* (1986), Sandra Harding describes the feminist standpoint epistemologies, that is, feminist descriptions of the nature of knowledge and the processes of creating knowledge, thus:

The logic of the standpoint epistemologies depends on the understanding that the “master’s position” in any set of dominating social

relations tends to produce distorted visions of the real regularities and underlying causal tendencies in social relations—including human interactions with nature. The feminist standpoint epistemologies argue that because men are in the master's position vis-à-vis women, women's social experience—conceptualized through the lenses of feminist theory—can provide the grounds for a less distorted understanding of the world around us. (Harding 1986, 191)

Harding (1986, chapter 7) and others have pointed out the questionable assumptions of the standpoint epistemologies: that women, or even feminists, are a social group in the sense required by these epistemologies; that identities/social positions that cut across gender, such as race, class, and culture, are not as important to knowledge as gender; that other identities/social positions, and also historical contexts, do not profoundly affect how gender is experienced. Harding and others have labelled the critiques of these assumptions “postmodernist.” They include the critiques of “universalization” and “essentialism” that have been very influential in feminist theory since the early 1980s.¹² These point out, among other things, that efforts to describe ‘women’ as a social group and to honour ‘women’s experiences’ ignored and made invisible differences among women, including differences of race, class, sexual identity, age, ethnicity, and (dis)ability, often falsely universalizing the social positions and experiences of small groups of relatively privileged women (Spelman 1988; Fine and Asch 1988; Higginbotham 1992).

I want to avoid making the same mistakes with the category “people with disabilities” that were, and still are, frequently made with the category “women.” We now know, from the extensive writings of women with disabilities, that living with similar disabilities is different for females and males. An emerging literature also reveals that living with similar disabilities is different for women of different races, classes, sexual identities, and ethnicities. (See, for example, Rooney and Israel 1985; *Canadian Woman Studies* 1993.) Moreover, we know that living with disabilities is different for people with different disabilities, such as paraplegia and blindness, and different for people whose disabilities are readily apparent compared to those whose disabilities can be hidden (Todoroff and Lewis 1992). It is therefore important not to assume that people with disabilities identify with all others who have disabilities or share a single perspective on disability (or anything else), or that having a disability is the most important aspect of a person's identity or social position.

It is worth noting that some of the most influential tendencies toward false universalizing about disability arise from the medical model of disability. Doctors, researchers, and rehabilitation specialists tend to universalize the experience of a given disease or disability because they are trying to fit people's experiences into ‘scientific’ descriptions of the disease or disability. It is true that people with the same physical condition, such as osteoarthritis of roughly the same severity affecting the same joints, will usually have quite a lot of bodily experiences and struggles in common. Nevertheless, their social experiences, their opportunities, their economic welfare, and their status in their communities may be very different, and these will have profound effects on how disabling their arthritis is (i.e., how it limits their participation in major aspects of life in their societies) and on how they experience their disability. The medical model, with its tendency to over-generalize in this particular way, still has a very strong presence in most people's thinking about disability.

Nevertheless, much of the risk of obscuring differences among people with disabilities also comes from choosing categories upon which to build analyses or politics. As Jane Roland Martin points out (1994, 637), all categories mask some differences, although some categories mask fewer differences than others. “People with disabilities” masks all differences but disability. “Disabled women” does not mask gender differences, but does mask differences of race, class, sexual identity, age, and different disabilities, among others. “Working-class African-Canadian heterosexual middle-aged women with rheumatoid arthritis” masks fewer differences, but even this category masks differences; for example, it does not say whether the women are mothers, whether they are employed, whether they are labelled as “former mental patients,” and many other things that might be relevant to understanding their situations and their perspectives. Yet it is impossible to engage in social analysis without choosing some categories with which to work, or to engage in political activity without choosing categories around which to organize, and all categories mask differences. Martin suggests: “The question of which categories we should choose cannot be answered in advance of inquiry or decided upon once and for all because the contexts of our investigations change over time and so do our interests and purposes” (Martin 1994, 637–38).

Categories must be chosen, but they need not be chosen forever, and they need not be used in all contexts. The categories that mask the fewest differences contain the fewest people, which is an important consideration for both social analysis and political activity. Differences can be unmasked

by choosing a category for a particular context or purpose, working with it, and listening carefully to those who do not identify with it or who disagree with generalizations made about members of the category and their experience. The question whether everyone in the category has anything significant (for analytical or political purposes) in common is an open question, which can only be answered by learning about all the people in a category. Practically speaking, it is answered by attempting to work with the category and remaining aware of its possible inadequacies, and by unmasking the differences it is found to mask.

A second important concern remains. Insofar as identities/social positions are interactive, rather than additive, we cannot arrive at an understanding of a person's epistemic perspective or social position by creating understandings of the effects of (dis)ability, the effects of race, the effects of gender, the effects of sexual identity, and so forth, and adding together the relevant ones for each person (Spelman 1988). The interaction of identities/social positions means that we will not have an accurate understanding of what it is to be disabled until we hear from everyone who is disabled. It also means that their stories may or may not have anything in common; that remains an open question, to be kept constantly under investigation.

Although the feminist standpoint epistemologies Harding originally discussed made some false and damaging assumptions, the idea that some groups of people have access to experiences that are not directly available to others, and that those experiences could give them, not only a different, but a truer and more complete perspective on some aspects of the world still seems plausible to many people, and standpoint epistemologies have not been abandoned. Patricia Hill Collins has developed a standpoint epistemology of Black feminist thought (Collins 1989; 1991), which she defines as follows:

Black feminist thought consists of theories or specialized thought produced by African-American women intellectuals designed to express a Black women's standpoint. The dimensions of this standpoint include the presence of characteristic core themes, the diversity of Black women's experiences in encountering these core themes, the varying expressions of Black women's Afrocentric feminist consciousness regarding the core themes and their experiences with them, and the interdependence of Black women's experiences, consciousness, and actions. (Collins 1991, 32)

Collins builds the expectation of diversity into her standpoint epistemology of Black women and into her definitions of Black feminist thought. She

does not assume that all Black women, or even all Black feminists, think alike. She looks and listens to discover how much similarity there is. She identifies the core themes of Black women's standpoint by investigating the writings and sayings of Black women and discovering the themes, such as the legacy of struggle, that are central in their thought. She starts with the assumption that experience affects consciousness, including how and what people know, but she does not assume that similar experiences always produce similar points of view.

Black women's work and family experiences and grounding in traditional African-American culture suggest that African-American women as a group experience a world different from that of those who are not Black and female. Moreover, these concrete experiences can stimulate a distinctive Black feminist consciousness concerning that material reality. Being Black and female may expose African-American women to certain common experiences, which in turn may predispose us to a distinctive group consciousness, but it in no way guarantees that such a consciousness will develop among all women or that it will be articulated as such by the group. (Collins 1991, 25)

Does having a disability in itself give a person a particular point of view or a less distorted and more complete perspective on certain issues? No. Following in the footsteps of Patricia Hill Collins, I want to say that having a disability usually gives a person experiences of a world different from that of people without disabilities, and that being a woman with a disability usually gives a person different experiences from those of people who are not female and disabled, and that these different experiences create the possibility of different perspectives which have epistemic advantages with respect to certain issues.¹³ I do not want to claim that all people with disabilities, or all women with disabilities, have the same epistemic advantages, or that they all have the same interpretations of their experiences, or even that they all have similar experiences. We are just beginning to investigate how much we have in common. But (and here I am following Collins's empirical approach to epistemological issues), having read and listened a great deal to the thoughts of people with disabilities, I do want to claim that, collectively, we have accumulated a significant body of knowledge, with a different standpoint (or standpoints) from those without disabilities, and that that knowledge, which has been ignored and repressed in non-disabled culture, should be further developed and articulated.

The Politics of Similarities and Differences

While questions of similarities and differences among people with disabilities are still open, many people with disabilities are, of course, already engaged in political work on behalf of people with disabilities.¹⁴ The problems of being 'the Other' to a dominant group are always politically complex. Many of them tend to centre around the question of whether to emphasize similarities to the dominant group or differences from them.

Emphasizing similarities between people with and people without disabilities seems to hold the promise of reducing the 'Otherness' of those who are disabled by enabling the non-disabled to identify with them, recognize their humanity and their rights, paving the way to increasing their assimilation into all aspects of social life. Many people with disabilities are tired of being symbols to the non-disabled, visible only or primarily for their disabilities, and they want nothing more than to be seen as individuals rather than as members of the group, 'the disabled.'

Emphasizing similarities to the non-disabled, attempting to make people's disabilities unnoticeable in comparison to their other human qualities, may be a good strategy for bringing about assimilation one-by-one.¹⁵ It does not directly challenge the non-disabled paradigm of humanity, just as women emphasizing their similarities to men and moving into traditionally male arenas of power does not directly challenge the male paradigm of humanity, although both may produce a gradual change in the paradigms. Moreover, assimilation of most people with disabilities may be very difficult to achieve. Although the non-disabled like disabled tokens who do not seem very different from themselves and who seem to confirm the possibility of 'overcoming' great adversity, they may need someone to carry the burden of the negative body as long as they continue to idealize and try to control the body; the subject needs 'the Other' to carry the subject's fears and rejected qualities. People without disabilities may therefore resist the assimilation of most disabled people.

Emphasizing differences from the dominant group, on the other hand, often creates a strong sense of solidarity among those who share them and makes it easier to resist the devaluation of those differences by the dominant group. In addition, some people with disabilities do not particularly want to be assimilated into non-disabled social life or non-disabled political groups, either because they fear that unless social values are changed quite

radically, they will always be at a disadvantage in integrated settings, or because they value qualities of their separate lives and organizations.¹⁶

In separate groups of people with disabilities, powerful 'givens' of the larger culture that put them at a disadvantage, such as the non-disabled paradigm of humanity, the idealization of the body, and the demand for control of the body, can be challenged openly and even made irrelevant. Values that are highly esteemed in non-disabled culture, such as the value of independence from the help of others, can be more safely questioned and debated in a context where the stereotype of all people with disabilities as dependent and incompetent is known to be false.¹⁷ Where these values have been questioned and debated in relation to the lives of people with disabilities, they are not as likely to be used unthinkingly to the detriment of those who cannot conform to them. Why should people who need a great deal of physical or mental help from others, for example, seek the company of those who take naive pride in their own imagined 'independence,' when they can have the company of those whose values and understanding are more sophisticated?

The desire to preserve culture is another powerful motive for avoiding assimilation into non-disabled society. Many of the Deaf do not want to be assimilated into 'hearing' society because they want to preserve the separate culture Deaf people have created. Oliver Sacks quotes the message of a Deaf student at the California School for the Deaf, who signed on television: "We are a unique people, with our own culture, our own language (American Sign Language, which has just recently been recognized as a language in itself), and that sets us apart from hearing people" (Sacks 1988, 28).

It would be hard to claim that disabled people as a whole have their own culture. Nevertheless, there is an extensive and growing literature on disability by people with disabilities, as well as drama, poetry, and art that express experiences of disability and the ideas that arise from them. Moreover, people with disabilities have both knowledge and ways of knowing that are not available to the non-disabled. Although I hope that their knowledge will ultimately be integrated into all culture, I suspect that any culture that stigmatizes and fears disability would rather ignore and suppress that knowledge than make the changes necessary to absorb it. It may have to be cultivated separately until non-disabled society is transformed enough to receive and integrate it.

Despite the advantages, emphasizing differences from the non-disabled in disability politics and organizing separately from the non-disabled carry

perils that should not be underestimated. First, when we do so, we identify ourselves by the categories of those who stigmatize us and to whom we are 'the Other.' Second, proclaiming and valuing one's difference may contribute to the dominant group's assumptions that they are the paradigm human beings and that they have a valid basis for discriminatory actions. Feminist politics and theory have struggled a long time with the problems created by valuing difference from a group that has greater power to describe the differences and to control their consequences (Snitow 1990; Kimball 1995). It would be good to avoid these problems, but can they be avoided? How can people fight collectively an oppression based on a category without using that category, without organizing around it? But then, if they do use it, do they not build a collective interest in maintaining the category? How can people preserve their valuable differences from dominant groups without proclaiming them and asserting their importance? But then, if they do proclaim their valuable differences, do they not increase the likelihood of remaining 'the Other' indefinitely? Is it possible to use a collective identity, preserve the differences we value, and undermine our 'Otherness' too? Questions like these, to which I do not know the answers, lead me to value a diversity of political groups and strategies in disability politics (and in feminist politics), including both groups and strategies that emphasize similarities to the non-disabled and those that emphasize differences.

Perhaps the type of disability I have also influences my appreciation of diversity in disability politics. Because my disability is no longer readily apparent, and because it is an illness whose symptoms vary greatly from day to day, I live between the world of the disabled and the world of the non-disabled. I am often very aware of my differences from healthy, non-disabled people, and I often feel a great need to have my differences acknowledged when they are ignored. Moreover, I identify strongly with people with disabilities, and thinking about disability issues has become the centre of my intellectual life. On the other hand, I am very aware of how my social, economic, and personal resources, and the fact that I can 'pass' as non-disabled among strangers, allow me to live a highly assimilated life among the non-disabled; I have more choices in this respect than many other people with disabilities. Because of these circumstances, I repeatedly experience in my daily life advantages and disadvantages of both emphasizing similarities to the non-disabled and emphasizing differences from them.

The Politics of Language

Not surprisingly, disputes over whether to emphasize similarities or differences in relation to people without disabilities are reflected in disagreements over what we should call ourselves—"handicapped," "disabled," "differently abled," "challenged?" I have my own preferences, some of which I have explained, and some of which I will explain soon, but first I want to discuss why the issue of labels tends to have so much importance to people with disabilities. I believe it is because our own languages so often betray us—by offering so many ways of derogating us, by containing the assumption that we are 'Other,' and by failing to describe our experiences¹⁸—and because both deliberate verbal abuse and unintentional insult of people with disabilities is so common. Part of asserting our similarities to people without disabilities is demanding that we not be set apart by disparaging and/or unnecessary labels, and that the words used to describe or refer to us be as respectful as the words used to describe or refer to non-disabled people. Part of asserting the value of our differences is taking control of language to describe ourselves, adopting realistic and positive self-descriptions.

There is a large number of terms (not all of which were originally derogatory) in English that are used for insulting people with disabilities, such as "cripple," "gimp," "spastic," "retard," "invalid," and "psycho." Some of these terms, as well as relatively neutral terms for describing disabilities, are used to insult people without disabilities, by way of implying insultingly that they have disabilities, as in, "What, are you blind (spastic, deaf, etc.?)?" They are also used to refer to defects in physical objects. (Once, when I was shopping with my cane, a store clerk advised me not to buy a piece of clothing with a sewing mistake she noticed because, she said, "It's gimp.") Thus, even people with disabilities who are lucky enough not to encounter much direct insult are exposed frequently to uses of language that remind them that they are stigmatized and/or 'the Other.'

There are extended discussions of language and the politics of disability in the work of Irving Kenneth Zola (1993) and Barbara Hillyer (1993, chapter 3).¹⁹ In these discussions, both emphasize the importance of context concerning the acceptability and consequences of using particular expressions. Both draw attention to the fact that even "cripple" has accept-

able uses among people with disabilities (Zola, 169; Hillyer, 23). Zola points out that for some stages of coping with a disability, and for a political coming out as disabled, the personal "ownership" expressed by "I am disabled" may be essential, whereas, on the other hand, "where coalition politics is needed, the concept of 'having' vs. 'being' may be a more effective way of acknowledging multiple identities and kinship. . . ." (Zola, 171). Zola did, however, generally favour the use of prepositions, and I agree with his reasons for this:

'a disabled car' is one which has totally broken down. Could 'a disabled person' be perceived as anything less? Prepositions, on the other hand, imply both 'a relationship to' and 'a separation from'. At this historical juncture the awkwardness in phrasing that often results may be all to the good, for it makes both user and hearer stop and think about what is meant, as in the phrases 'people of color' and 'persons with disabilities'. (Zola 1993, 170)

Zola concluded his discussion of language by expressing his concern that demanding 'politically correct' usage among ourselves and criticizing anyone who deviates from it will damage the unity disability activists need and distract us from the main problem: "Our struggle is necessary because we live in a society which devalues, discriminates against and disparages people with disabilities. It is not our task to prove that we are worthy of the full resources and integration of our society. The fault is not in us, not in our diseases and disabilities but in mythical demands, social arrangements, political priorities and prejudices" (171). While more than twenty-five years of feminist politics have made me wary of calls for unity when there is disagreement, I share Zola's concern that acrimonious divisions over language could weaken our ability to work together and distract us from more central problems.

Hillyer tackles the same issue. I like her honest acknowledgement of political fashions in language and of the difficulties of always speaking/writing acceptably to every group one supports, given that there are conflicting and constantly changing opinions about what language is acceptable.

The politics of both movements (feminist and disability) are such that the implications of each term are constantly reexamined and criticized. The word "disabled" itself was once considered less acceptable than "handicapped," then more acceptable, then acceptable in its noun but not in adjective form (as in "a person with a disability," not "a disabled per-

son"). Language is controversial and political acceptability changes. (Hillyer 1993, 21)

Hillyer provides many examples of changing and conflicting usage. Nevertheless, she is not just complaining about the difficulties this presents. She appreciates the value of political self-consciousness about language usage and of the controversies it generates. She concludes:

What I deduce from all this is the value of a rich, complex language. Instead of creating dichotomies between good and bad words, we can use accurate, individual descriptors. Instead of taking for granted the meanings assigned by one or another political group, we can struggle with distinguishing our own definitions from theirs. The process is awkward; it slows down talk; it is uncomfortable. It slows down thought and increases its complexity. (Hillyer 1993, 46)

Although I do not want to list and defend all my linguistic preferences in relation to disability, and, in agreement with Zola and Hillyer, I think that context is vitally important, I do want to discuss two recent trends in usage that have generated some controversy. I hope they will illustrate some of the perils of attempts to reform language. The first is the introduction of new and (to my mind) euphemistic expressions for disabilities and people with disabilities. One such expression is "differently-abled," which has found favour among feminists since the early 1980s. I assume the point of using this term is to suggest that there is nothing wrong with being the way people with disabilities are, just different. It also seems as though it might have some educational value: It could remind the non-disabled that to be disabled in some respects is not to be disabled in all respects, and it suggests that a person with a disability may have abilities that the non-disabled lack in virtue of not being disabled.

Yet to call someone "differently-abled" is much like calling her "differently-coloured" or "differently-gendered." It says: "This person is not the norm or paradigm of humanity." If anything, it increases the 'Otherness' of people with disabilities, because it reinforces the paradigm of humanity as young, strong, and healthy, with all body parts working 'perfectly,' from which this person is different. Using the term "differently-abled" also suggests a (polite? patronizing? protective? self-protective?) disregard of the special difficulties, struggles, and suffering people with disabilities face. We are *dis-abled*. We live with particular social and physical struggles that are

partly consequences of the conditions of our bodies and/or minds and partly consequences of the structures and expectations of our societies, but they are struggles that only people with bodies and/or minds like ours experience. Expressions that attempt to put a cheerful face on this reality invite denial, placing social pressure on people with and without disabilities to pretend that everything is fine.

Another trend in usage also, to my mind, invites denial. Perhaps so far it is not so much a trend as a demand for change in linguistic practices, which I have now heard in several circumstances, and which Hillyer discusses briefly (Hillyer 1993, 29–30). The demand is that we should avoid metaphoric use of words which refer to abilities which some people lack; I have always heard it in relation to metaphors of sight, such as, “Do you see what I mean?” or, “She can’t see the forest for the trees,” although the same objection would surely apply to metaphors of other abilities that some people lack.

It seems likely that the abundance of sight metaphors in English usage might hurt or at least get on the nerves of anyone who cannot see.¹⁰ Moreover, people who can see often experience sudden awareness of sight metaphors in the presence of blind people, as well as concern about whether they are hurtful. But, while I feel strongly that we should avoid using “blind” as an insult, trying to eliminate sight metaphors from English usage would be setting out on a road that, ultimately, no one will want to travel. For why stop at sight? If metaphors are offensive because they refer to abilities some people do not have, or activities in which some people cannot participate, then metaphors of hearing, walking, running, crawling, swimming, and dancing are offensive for the same reason. There are people who cannot smell, taste, touch, perceive colours, feel pain, talk, read, write, remember anything, or feel love. Metaphors of these abilities must sometimes hurt people who lack them, but we would impoverish language if we stopped using metaphors of all abilities that some people lack. Moreover, do we know that metaphors of abilities are more hurtful to people who lack the abilities than other references to those abilities and their consequences, which we cannot always avoid? Is using the word “insight” really more hurtful than, “Oh, your garden looks beautiful,” said to someone else in the presence of a blind person?

Hillyer presents another objection to this demand to reform language: “To avoid all visual imagery in deference to the blind may discriminate against the deaf for whom visual experience is central, as well as against any sighted person for whom visual ability is very important to her self-con-

cept” (1993, 30). The strength of this objection is obvious when one considers how far it extends. For most people with disabilities, our remaining abilities are extremely important, and for every ability remaining in one person, there is another person who lacks it.

Speaking personally, I would not want people to avoid metaphoric uses of or references to energy, which I lack in abundance, or to running, dancing, hiking, climbing, and opening doors, all of which are difficult or impossible for me. I do sometimes feel bad when people go on at length about someone’s great energy, especially when their attitude seems to be that it is a moral virtue. And I do sometimes feel sad, or envious, hearing about other people’s hiking expeditions or trips to places that are too exhausting for me. But I would not want to be protected from these feelings, and I would not want other people to pretend that they do not have abilities I lack, or that they are not important, even central, in their lives. Both of the attempts to reform language that I have discussed seem to me to invite denial, if not of difference, then of painful consequences of difference. I regard denial as far more dangerous than feeling angry, sad, or envious.

The Future of Difference

The final group of issues I want to consider in this chapter concerns the preservation of difference. If we value the differences of people with disabilities, what implications does that have for efforts to prevent or cure disabilities? Is saying, “Everyone wants a healthy baby,” morally and politically similar to saying, “Everyone wants a white baby?” If not, how is it different? Is there as much reason to preserve the functional impairments and structural imperfections of human bodies as there is to preserve their genetic diversity? Feminist ecologists often urge us to value and protect the vulnerability and imperfections of nature. Should the vulnerability and imperfections of our bodies also be valued and protected, or should we attempt to transcend them?

Some of these questions arise practically now in relation to medical technologies that offer genetic ‘diagnosis’ of potential disabilities in a person’s offspring and prenatal detection of potential disabilities in fetuses. Although I will discuss them again in chapter 6 in relation to a feminist ethics of abortion, I want to point out here that widespread ignorance of the lives of people with disabilities, fear of disablement, and the assumption that dis-

ability is primarily a biologically determined, rather than a socially constructed, phenomenon, contribute to the desire to prevent disability by preventing difference from the physical and mental 'norms' of a society. To people who value disabilities as differences, attempts to prevent disability by preventing the birth of people with disabilities can seem analogous to attempts to guarantee the birth of male babies because they are more highly valued, or to wipe out colour differences by genetic technologies.

It might be argued that it is hard to appreciate disabilities as differences where disabilities have devastating social consequences. The fact is that a child born with spina bifida or Down's syndrome will face many socially created obstacles to living well. Of course the same thing is true for children-of-colour in white-dominated societies, but few people-of-colour would argue that it is a sufficient reason not to bring a child-of-colour into the world. Rather, it would be argued, it is a reason to fight for just treatment of people-of-colour. I think we have to admit that it is the fact of physical and/or mental difference, usually perceived as 'abnormality' or 'pathology,' that makes it seem so much more obvious to many people that potential disability is a sufficient reason not to bring a child into the world. Moreover, unlike children-of-colour in white-dominated societies, who are most often born into families or communities of people-of-colour, children with disabilities are not usually born into a family or community of people with disabilities who are already committed to valuing their differences and fighting for their rights.²¹ At best, adults thinking of parenting a child with disabilities know they will have to find or create a community of support for themselves and their child; at worst, they believe they will have to cope on their own. If they are afraid of the burden of raising a child with a disability in a society where accessibility and help are far from adequate, they have reason to be afraid.

Another consideration enters into questions about the practical implications of valuing disabilities as differences. How much physical and/or mental suffering is inherent in the difference itself, that is, how much suffering that could not be eliminated by any social arrangements, no matter how supportive they might be to the lives of people with disabilities? Part of what is at work in the sentiment, "Everyone wants a healthy baby," is a desire that children be spared suffering. Although ignorance of disability probably exaggerates the physical suffering (and underestimates the social suffering) of most people with disabilities in the minds of people without disabilities, the importance of ineliminable suffering must not be overlooked. Even people with disabilities who identify strongly with being

disabled and have very happy, fulfilling lives might want to be cured, not for social reasons, but because they want to have less pain or physical or mental difficulty.

Who can and who should answer the question: Is the suffering too high a price to pay for the difference? Certainly people with disabilities who have intimate knowledge of the suffering involved in a disability, and who also have sufficient experience to know and value the differences it makes possible, are better qualified to answer this question than others. Yet even for them, this may be a hard question to answer, especially since the social components of the suffering of many people with disabilities, such as loneliness, alienation, poverty, constant blows to self-esteem, and frustration due to lack of accessibility and services are hard to separate clearly from the socially ineliminable physical and/or mental components. Difficult circumstances make both physical and mental suffering worse and harder to bear. These factors are likely to cause error on the "yes" side of the question, but not, I think, as much error in that direction as the ignorance and fear of most people who have little or no experience of disability.

Like the development of technologies to prevent people with disabilities from being born, the drive to find 'cures' for disabilities can be seen, by those who appreciate disabilities as differences, to be as much an attempt to wipe out difference as an effort to relieve suffering. There is so much emphasis on possible 'cures' in biomedical talk and charity talk (and indeed most talk) about disability, and so little recognition of the potential and value of disabled people's actual lives, that this interpretation of motives is justified. The widespread message that they are not good enough until they are 'cured' places the self-respect of people with disabilities in conflict with any desire to be 'cured.'

I find that my own resistance to the attitude that I need to be 'cured' in order to be a whole or fully acceptable person infuses my desire for a 'cure' with ambivalence. I want to have more energy and less pain, and to have a more predictable body; about that there is no ambivalence. Moreover, I feel heartsore when I hear about someone being diagnosed with ME; how could I not want a cure for everyone else who suffers with it? Yet I cannot wish that I had never contracted ME, because it has made me a different person, a person I am glad to be, would not want to have missed being, and could not imagine relinquishing, even if I were 'cured.' For example, I cannot imagine that I would ever stop identifying myself as a person with a disability, and when I think about the probability that others would stop identifying me as one if I were 'cured,' it is hard to imagine how I would deal with the disso-

nance. Perhaps the best summary of my attitude toward 'cure' is this: I would joyfully accept a cure, but I do not need one. If this attitude toward 'cures' were taken for granted in my society, then the search for them would not be accompanied by insulting implications, as it often is now.

People who take it for granted that it would be a good thing to wipe out all biological causes of disability (as opposed to social causes) are far more confident that they know how to perfect nature and humanity than I am. Even supposing that everyone involved in such an effort were motivated entirely by a desire to prevent and alleviate suffering, what else besides suffering might we lose in the process? And would they know where to stop?²² Certainly, those who do not value the differences of people with disabilities cannot be trusted to decide where to stop trying to 'perfect' human beings. Moreover, promises to eliminate the biological causes of disability assume that some culturally neutral, biomedical definition of disability can be agreed upon, and they obscure the fact that disability is socially constructed from physical and mental difference.

What would it mean, then, in practice, to value disabilities as differences? It would certainly mean not assuming that every disability is a tragic loss or that everyone with a disability wants to be 'cured.' It would mean seeking out and respecting the knowledge and perspectives of people with disabilities. It would mean being willing to learn about and respect ways of being and forms of consciousness that are unfamiliar. And it would mean giving up the myths of control and the quest for perfection of the human body.