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The Social Construction of Disability

In chapter 1, I argued that neither impairment nor disability can be defined purely in biomedical terms, because social arrangements and expectations make essential contributions to impairment and disability, and to their absence. In this chapter, I develop that argument further. I maintain that the distinction between the biological reality of a disability and the social construction of a disability cannot be made sharply, because the biological and the social are interactive in creating disability. They are interactive not only in that complex interactions of social factors and our bodies affect health and functioning, but also in that social arrangements can make a biological condition more or less relevant to almost any situation. I call the interaction of the biological and the social to create (or prevent) disability "the social construction of disability."[1]

Disability activists and some scholars of disability have been asserting for at least two decades that disability is socially constructed.[2] Moreover, feminist scholars have already applied feminist analyses of the social construction of the experience of being female to their analyses of disability as socially constructed (Hannaford 1985). (Fine and Asch (1988, 6) were among the first to compare the two kinds of social construction explicitly.) Thus I am saying nothing new when I claim that disability, like

gender, is socially constructed. Nevertheless, I understand that such an

assertion may be new and even puzzling to many readers, and that not everyone who says that disability is socially constructed means the same thing by it. Therefore, I will explain what I mean in some detail.

I see disability as socially constructed in ways ranging from social conditions that straightforwardly create illnesses, injuries, and poor physical functioning, to subtle cultural factors that determine standards of normality and exclude those who do not meet them from full participation in their societies. I could not possibly discuss all the factors that enter into the social construction of disability here, and I feel sure that I am not aware of them all, but I will try to explain and illustrate the social construction of disability by discussing what I hope is a representative sample from a range of factors.

Social Factors That Construct Disability

First, it is easy to recognize that social conditions affect people's bodies by creating or failing to prevent sickness and injury. Although, since disability is relative to a person's physical, social, and cultural environment, none of the resulting physical conditions is necessarily disabling, many do in fact cause disability given the demands and lack of support in the environments of the people affected. In this direct sense of damaging people's bodies in ways that are disabling in their environments, much disability is created by the violence of invasions, wars, civil wars, and terrorism, which cause disabilities not only through direct injuries to combatants and noncombatants, but also through the spread of disease and the deprivations of basic needs that result from the chaos they create. In addition, although we more often hear about them when they cause death, violent crimes such as shootings, knifings, beatings, and rape all cause disabilities, so that a society's success or failure in protecting its citizens from injurious crimes has a significant effect on its rates of disability.[3]

The availability and distribution of basic resources such as water, food, clothing, and shelter have major effects on disability, since much disabling physical damage results directly from malnutrition and indirectly from diseases that attack and do more lasting harm to the malnourished and those weakened by exposure. Disabling diseases are also contracted from contaminated water when clean water is not available. Here too, we usually learn more about the deaths caused by lack of basic resources than the (often lifelong) disabilities of survivors.

Many other social factors can damage people's bodies in ways that are disabling in their environments, including (to mention just a few) tolerance of high-risk working conditions, abuse and neglect of children, low public safety standards, the degradation of the environment by contamination of air, water, and food, and the overwork, stress, and daily grinding deprivations of poverty. The social factors that can damage people's bodies almost always affect some groups in a society more than others because of racism, sexism, heterosexism, ageism, and advantages of class background, wealth, and education.[4]

Medical care and practices, traditional and Western-scientific, play an important role in both preventing and creating disabling physical damage. (They also play a role in defining disability, as described in chapter 1.) Lack of good prenatal care and dangerous or inadequate obstetrical practices cause disabilities in babies and in the women giving birth to them. Inoculations against diseases such as polio and measles prevent quite a lot of disability. Inadequate medical care of those who are already ill or injured results in unnecessary disablement. On the other hand, the rate of disability in a society increases with improved medical capacity to save the lives of people who are dangerously ill or injured in the absence of the capacity to prevent or cure all the physical damage they have incurred. Moreover, public health and sanitation measures that increase the average lifespan also increase the number of old people with disabilities in a society, since more people live long enough to become disabled.

The *pace of life* is a factor in the social construction of disability that particularly interests me, because it is usually taken for granted by non-disabled

people, while many people with disabilities are acutely aware of how it marginalizes or threatens to marginalize us. I suspect that increases in the pace of life are important social causes of damage to people's bodies through rates of accident, drug and alcohol abuse, and illnesses that result from people's neglecting their needs for rest and good nutrition. But the pace of life also affects disability as a second form of social construction, the social construction of disability through expectations of performance.[5]

When the pace of life in a society increases, there is a tendency for more people to become disabled, not only because of physically damaging consequences of efforts to go faster, but also because fewer people can meet expectations of 'normal' performance; the physical (and mental) limitations of those who cannot meet the new pace become conspicuous and disabling, even though the same limitations were inconspicuous and irrelevant to full participation in the slower-paced society. Increases in the pace

of life can be counterbalanced for some people by improvements in accessibility, such as better transportation and easier communication, but for those who must move or think slowly, and for those whose energy is severely limited, expectations of pace can make work, recreational, community, and social activities inaccessible.

Let me give a straightforward, personal illustration of the relationship between pace and disability. I am currently just able (by doing very little else) to work as a professor three-quarter time, on one-quarter disability leave. There has been much talk recently about possible increases in the teaching duties of professors at my university, which would not be accompanied by any reduction in expectations for the other two components of our jobs, research and administration. If there were to be such an increase in the pace of professors' work, say by one additional course per term, I would be unable to work more than half-time (by the new standards) and would have to request half-time disability leave, even though there had been no change in my physical condition. Compared to my colleagues, I would be more work-disabled than I am now. Some professors with less physical limitation than I have, who now work full-time, might be unable to work at

the new full-time pace and be forced to go on part-time disability leave. This sort of change could contribute to disabling anyone in any job.

Furthermore, even if a person is able to keep up with an increased pace of work, any increase in the pace of work will decrease the energy available for other life activities, which may upset the delicate balance of energy by which a person manages to participate in them and eventually exclude her/him from those activities. The pace of those other activities may also render them inaccessible. For example, the more the life of a society is conducted on the assumption of quick travel, the more disabling are those physical conditions that affect movement and travel, such as needing to use a wheelchair or having a kind of epilepsy that prevents one from driving a car, unless compensating help is provided. These disabling effects extend into people's family, social, and sexual lives and into their participation in recreation, religious life, and politics.

Pace is a major aspect of expectations of performance; non-disabled people often take pace so much for granted that they feel and express impatience with the slower pace at which some people with disabilities need to operate, and accommodations of pace are often crucial to making an activity accessible to people with a wide range of physical and mental abilities. Nevertheless, expectations of pace are not the only expectations of performance that contribute to disability. For example, expectations of indi-

vidual productivity can eclipse the actual contributions of people who cannot meet them, making people unemployable when they can in fact do valuable work. There are often very definite expectations about *how* tasks will be performed (not the standards of performance, but the methods). For example, many women with disabilities are discouraged from having children because other people can only imagine caring for children in ways that are impossible for women with their disabilities, yet everything necessary could be done in other ways, often with minor accommodations (Matthews 1983; Shaul, Dowling and Laden 1985). Furthermore, the expectation that many tasks will be performed by individuals on their own can create or expand the disability of those who can perform the tasks only in cooperative groups or by instructing a helper.

Expectations of performance are reflected, because they are assumed, in the social organization and physical structure of a society, both of which create disability. Societies that are physically constructed and socially organized with the unacknowledged assumption that everyone is healthy, non-disabled, young but adult, shaped according to cultural ideals, and, often, male, create a great deal of disability through sheer neglect of what most people need in order to participate fully in them.

Feminists talk about how the world has been designed for the bodies and activities of men. In many industrialized countries, including Canada and the United States, life and work have been structured as though no one of any importance in the public world, and certainly no one who works outside the home for wages, has to breast-feed a baby or look after a sick child. Common colds can be acknowledged publicly, and allowances are made for them, but menstruation cannot be acknowledged and allowances are not made for it. Much of the public world is also structured as though everyone were physically strong, as though all bodies were shaped the same, as though everyone could walk, hear, and see well, as though everyone could work and play at a pace that is not compatible with any kind of illness or pain, as though no one were ever dizzy or incontinent or simply needed to sit or lie down. (For instance, where could you rest for a few minutes in a supermarket if you needed to?) Not only the architecture, but the entire physical and social organization of life tends to assume that we are either strong and healthy and able to do what the average young, non-disabled man can do or that we are completely unable to participate in public life.

A great deal of disability is caused by this physical structure and social organization of society. For instance, poor architectural planning creates

physical obstacles for people who use wheelchairs, but also for people who can walk but cannot walk far or cannot climb stairs, for people who cannot open doors, and for people who can do all of these things but only at the cost of pain or an expenditure of energy they can ill afford. Some of the same architectural flaws cause problems for pregnant women, parents with strollers, and young children. This is no coincidence. Much architecture has

been planned with a young adult, non-disabled male paradigm of humanity in mind. In addition, aspects of social organization that take for granted the social expectations of performance and productivity, such as inadequate public transportation (which I believe assumes that no one who is needed in the public world needs public transportation), communications systems that are inaccessible to people with visual or hearing impairments, and inflexible work arrangements that exclude part-time work or rest periods, create much disability.

When public and private worlds are split, women (and children) have often been relegated to the private, and so have the disabled, the sick, and the old. The public world is the world of strength, the positive (valued) body, performance and production, the non-disabled, and young adults. Weakness, illness, rest and recovery, pain, death, and the negative (devalued) body are private, generally hidden, and often neglected. Coming into the public world with illness, pain, or a devalued body, people encounter resistance to mixing the two worlds; the split is vividly revealed. Much of the experience of disability and illness goes underground, because there is no socially acceptable way of expressing it and having the physical and psychological experience acknowledged. Yet acknowledgement of this experience is exactly what is required for creating accessibility in the public world. The more a society regards disability as a private matter, and people with disabilities as belonging in the private sphere, the more disability it creates by failing to make the public sphere accessible to a wide range of people.

Disability is also socially constructed by the failure to give people the amount and kind of help they need to participate fully in all major aspects of life in the society, including making a significant contribution in the form of work. Two things are important to remember about the help that people with disabilities may need. One is that most industrialized societies give non-disabled people (in different degrees and kinds, depending on class, race, gender, and other factors) a lot of help in the form of education, training, social support, public communication and transportation facilities, public recreation, and other services. The help that non-disabled people receive tends to be taken for granted and not considered help but entitle-

ment, because it is offered to citizens who fit the social paradigms, who by definition are not considered dependent on social help. It is only when people need a different kind or amount of help than that given to 'paradigm' citizens that it is considered help at all, and they are considered socially dependent. Second, much, though not all, of the help that people with disabilities need is required because their bodies were damaged by social conditions, or because they cannot meet social expectations of performance, or because the narrowly-conceived physical structure and social organization of society have placed them at a disadvantage; in other words, it is needed to overcome problems that were created socially.

Thus disability is socially constructed through the failure or unwillingness to create ability among people who do not fit the physical and mental profile of 'paradigm' citizens. Failures of social support for people with disabilities result in inadequate rehabilitation, unemployment, poverty, inadequate personal and medical care, poor communication services, inadequate training and education, poor protection from physical, sexual, and emotional abuse, minimal opportunities for social learning and interaction, and many other disabling situations that hurt people with disabilities and exclude them from participation in major aspects of life in their societies.

For example, Jongbloed and Crichton (1990, 35) point out that, in Canada and the United States, the belief that social assistance benefits should be less than can be earned in the work force, in order to provide an incentive for people to find and keep employment, has contributed to poverty among people with disabilities. Although it was recognized in the 1950s that they should receive disability pensions, these were set, as were other forms of direct economic help, at socially minimal levels. Thus, even though unemployed people with disabilities have been viewed by both governments as surplus labour since at least the 1970s (because of persistently high general rates of unemployment), and efforts to increase their employment opportunities have been minimal, they are kept at poverty level incomes[7] based on the 'incentive' principle. Poverty is the single most disabling social circumstance for people with disabilities, since it means that they can barely afford the things that are necessities for non-disabled people, much less the personal care, medicines, and technological aids they may need to live decent lives outside institutions, or the training or education or transportation or clothing that might enable them to work or to participate more fully in public life.

Failure or unwillingness to provide help often takes the form of irrational rules governing insurance benefits and social assistance,[8] long

bureaucratic delays, and a pervasive attitude among those administering programs for people with disabilities that their 'clients' are trying to get more than they deserve. In her semiautobiographical novel, *The Body's Memory* (1989), Jean Stewart describes the cluster of assumptions a woman discovers behind the questions of her social worker when she first applies for some 'vocational rehabilitation,' that is, the money to buy a basic wheelchair:

> (1) The client-applicant is ineligible for services until proven eligible. (2) The client-applicant's Vocational Goals are outlandish, greedy, arrogant, must be trimmed down to appropriately humble scale. (3) The client-applicant's motive in seeking services is, until proven otherwise, to rip off the system. (4) The function of the Agency is to facilitate (favorite word) adaptation (second favorite) of client to job (client to world), not the reverse. (5) The client is a fraud. (6) The client is helpless. (Stewart 1989, 190)

I do not want to claim or imply that social factors alone cause all disability. I do want to claim that the social response to and treatment of biological difference constructs disability from biological reality, determining both the nature and the severity of disability. I recognize that many disabled people's relationships to their bodies involve elements of struggle that perhaps cannot be eliminated, perhaps not even mitigated, by social arrangements. But many of the struggles of people with disabilities and much of what is disabling, are the consequences of having those physical conditions under social arrangements (Finger 1983; Fine and Asch 1988) that could, but do not, either compensate for their physical conditions, or accommodate them so that they can participate fully, or support their struggles and integrate those struggles into the cultural concept of life as it is ordinarily lived.

Cultural Construction of Disability

Culture makes major contributions to disability. These contributions include not only the omission of experiences of disability from cultural representations of life in a society, but also the cultural stereotyping of people with disabilities, the selective stigmatization of physical and mental

limitations and other differences (selective because not all limitations and

differences are stigmatized, and different limitations and differences are stigmatized in different societies), the numerous cultural meanings attached to various kinds of disability and illness, and the exclusion of people with disabilities from the cultural meanings of activities they cannot perform or are expected not to perform.

The lack of realistic cultural representations of experiences of disability not only contributes to the 'Otherness' of people with disabilities by encouraging the assumption that their lives are inconceivable to non-disabled people but also increases non-disabled people's fear of disability by suppressing knowledge of how people live with disabilities. Stereotypes of disabled people as dependent, morally depraved, superhumanly heroic, asexual, and/or pitiful are still the most common cultural portrayals of people with disabilities (Kent 1988; Dahl 1993). Stereotypes repeatedly get in the way of full participation in work and social life. For example, Francine Arsenault, whose leg was damaged by childhood polio and later by gangrene, describes the following incident at her wedding:

> When I got married, one of my best friends came to the wedding with her parents. I had known her parents all the time I was growing up; we visited in each other's homes and I thought that they knew my situation quite well.
>
> But as the father went down the reception line and shook hands with my husband, he said, "You know, I used to think that Francine was intelligent, but to put herself on you as a burden like this shows that I was wrong all along." (Arsenault 1994, 6)

Here the stereotype of a woman with a disability as a helpless, dependent burden blots out, in the friend's father's consciousness, both the reality that Francine simply has one damaged leg and the probability that her new husband wants her for her other qualities. Moreover, the man seems to take for granted that the new husband sees Francine in the same stereotyped way (or else he risks incomprehension or rejection), perhaps

because he counts on the cultural assumptions about people with disabilities. I think both the stigma of physical 'imperfection' (and possibly the additional stigma of having been damaged by disease) and the cultural meanings attached to the disability contribute to the power of the stereotype in situations like this. Physical 'imperfection' is more likely to be thought to 'spoil' a woman than a man by rendering her unattractive in a culture where her physical appearance is a large component of a woman's

value; having a damaged leg probably evokes the metaphorical meanings of being 'crippled,' which include helplessness, dependency, and pitifulness.[9] Stigma, stereotypes, and cultural meanings are all related and interactive in the cultural construction of disability. I will discuss them, and some of their social consequences, more extensively in chapter 3.

The power of culture alone to construct a disability is revealed when we consider bodily differences—deviations from a society's conception of a 'normal' or acceptable body—that, although they cause little or no functional or physical difficulty for the person who has them, constitute major social disabilities. An important example is facial scarring, which is a disability of appearance only, a disability constructed totally by stigma and cultural meanings.[10] Stigma, stereotypes, and cultural meanings are also the primary components of other disabilities, such as mild epilepsy and not having a 'normal' or acceptable body size.

I believe that culture plays a central role in constructing (or not constructing) disability. However, I want to distinguish this view from approaches to cultural construction of 'the body' that seem to confuse the lived reality of bodies with cultural discourse about and representations of bodies, or that deny or ignore bodily experience in favour of fascination with bodily representations.[11] For example, this approach troubles me in Donna Haraway's "The Biopolitics of Postmodern Bodies: Constitutions of Self in Immune System Discourse" (Haraway 1991), where Haraway discusses the biomedical construction of "immune system discourse" as though discourse and its political context are all there is, without acknowledging either the reality of physical suffering (for example, by people with

edging either the reality of physical suffering (for example, by people with AIDS, ME, MS, Amyotrophic Lateral Sclerosis (ALS), rheumatoid arthritis), which surely has *some* relationship to the development of immune system discourse, or the effects of this discourse on the lives of people who are thought to be suffering from immune disorders.

I do not think my body *is* a cultural representation, although I recognize that my experience of it is both highly interpreted and very influenced by cultural (including medical) representations. Moreover, I think it would be cruel, as well as a distortion of people's lives, to erase or ignore the everyday, practical, experienced limitations of people's disabilities simply because we recognize that human bodies and their varied conditions are both changeable and highly interpreted. That I can imagine having an energetic, pain-free body or living in a society where my body is considered acceptable or normal and its limitations are compensated by social and physical arrangements does not make it any easier to get out of bed or to

function as an academic in my present circumstances. In most postmodern cultural theorizing about the body, there is no recognition of—and, as far as I can see, no room for recognizing—the hard physical realities that are faced by people with disabilities. (Or would postmodernists deny that there are such 'realities,' suggestive as they are of something that is not constructed or constituted by discourse? I cannot tell, because nothing like it is discussed.) The experiences of people with disabilities are as invisible in the discourses of postmodernism, which has the virtue of being critical of idealized, normalized, and universalized representations of bodies, as they are in discourses which employ concepts of bodily 'normality' uncritically.[12]

I believe that in thinking about the social construction of disability we need to strike a balance between, on the one hand, thinking of a body's abilities and limitations as given by nature and/or accident, as immutable and uncontrollable, and, on the other hand, thinking of them as so constructed by society and culture as to be controllable by human thought, will, and action. We need to acknowledge that social justice and cultural change can eliminate a great deal of disability while recognizing that there may be much suffering and limitation that they cannot fix.

In my view, then, disability is socially constructed by such factors as social conditions that cause or fail to prevent damage to people's bodies; expectations of performance; the physical and social organization of societies on the basis of a young, non-disabled, 'ideally shaped,' healthy adult male paradigm of citizens; the failure or unwillingness to create ability among citizens who do not fit the paradigm; and cultural representations, failures of representation, and expectations. Much, but perhaps not all, of what can be socially constructed can be socially (and not just intellectually) deconstructed, given the means and the will.

A great deal of disability can be prevented with good public health and safety standards and practices, but also by relatively minor changes in the built environment that provide accessibility to people with a wide range of physical characteristics and abilities. Many measures that are usually regarded as helping or accommodating people who are now disabled, such as making buildings and public places wheelchair accessible, creating and respecting parking spaces for people with disabilities, providing American Sign Language translation, captioning, and Telephone Devices for the Deaf,

and making tapes and Descriptive Video services available for people who are visually impaired, should be seen as preventive, since a great deal of disability is created by building and organizing environments, objects, and activities for a too-narrow range of people. Much more could be done along the same lines by putting people with a wide variety of physical abilities and characteristics in charge of deconstructing disability. People with disabilities should be in charge, because people without disabilities are unlikely to see many of the obstacles in their environment. Moreover, they are likely not to see them *as obstacles* even when they are pointed out, but rather as 'normal' features of the built environment that present difficulties for 'abnormal' people.

Disability cannot be deconstructed by consulting a few token disabled rep-

resentatives. A person with a disability is not likely to see all the obstacles to people with disabilities different from her/his own, although s/he is likely to be more aware of potential inaccessibility. Moreover, people with disabilities are not always aware of the obstacles in our environment *as obstacles*, even when they affect us. The cultural habit of regarding the condition of the person, not the built environment or the social organization of activities, as the source of the problem, runs deep. For example, it took me several years of struggling with the heavy door to my building, sometimes having to wait until someone stronger came along, to realize that the door was an accessibility problem, not only for me, but for others as well. And I did not notice, until one of my students pointed it out, that the lack of signs that could be read from a distance at my university forced people with mobility impairments to expend a lot of energy unnecessarily, searching for rooms and offices.[13] Although I have encountered this difficulty myself on days when walking was exhausting to me, I interpreted it, automatically, as a problem arising from my illness (as I did with the door), rather than as a problem arising from the built environment having been created for too narrow a range of people and situations. One of the most crucial factors in the deconstruction of disability is the change of perspective that causes us to look in the environment for both the source of the problem and the solutions.

It is perhaps easiest to change perspective by thinking about how people who have some bodily difference that does not impair any of their physical functions, such as being unusually large, are disabled by the built environment—by seats that are too small and too close together, doors and aisles and bathroom stalls that are too narrow, desks and tables that are too low (or chairs that cannot be adjusted for height), the unavailability or expense of clothing that fits or of an automobile that they can operate comfortably. Of

course, many people regard large people as unfortunate or (if they are fat) weak individuals whose abnormality creates their problems, which in itself illustrates the strength of the cultural demand that everyone meet body ideals. Nevertheless, although they are subjected to stigma, stereotypes, and cultural judgements, they are not surrounded by the same aura of hopelessness and pathology that many cultures project onto people with illnesses and

injuries, nor does it seem as plausible that they should be kept out of public life. This makes it somewhat easier to see how the built and social environments create disability by failing to accommodate bodily difference.

How much difference can be practically accommodated? How large a group must find a public place, a product, or an activity inaccessible before we must accept a social obligation to change it? These are reasonable questions that are sometimes difficult to answer.[14] Although a great deal of disabling structure and organization can be prevented by creative, relatively inexpensive planning or correction,[15] sometimes it is quite costly to make an environment or activity accessible to a relatively small number of people, especially if it was planned originally to accommodate a narrow range of human beings (an example is equipping city buses with wheelchair lifts). Some increases in accessibility—such as making public places accessible to people with severe allergies to perfumes, solvents, cleaners, smoke, and a multitude of other chemicals—would require many changes and significant sacrifices by many individuals. I do not want to offer an ethical formula for making decisions about how much to change existing structures, objects, and ways of doing things in order to accommodate how many people. But I would like to suggest that in thinking about these questions, it is important to remember three things: First, it is likely that the number of people who will benefit from an improvement in accessibility is greater than expected, since many people are hidden in the private sphere because of assumptions that they belong there and because public spaces and facilities are inaccessible to them. Second, rates of disability increase dramatically with age, so that as populations age, improvements in accessibility will benefit larger proportions of the population, and those who work to increase accessibility now may very well benefit from it later. Third, the public presence of people with disabilities has many potential benefits for people without disabilities, including better knowledge of the forms of difference among people, better understanding of the realities of physical limitations and/or suffering, and a lessening of the fear of becoming disabled, which is exacerbated by the assumption that disability means exclusion from major aspects of social life.

Architectural changes and expansions of communication are the best known, and probably the most often recognized, efforts to deconstruct disability, along with 'changing the attitudes' of non-disabled people, which I will come to later. But it must be recognized that other changes and accommodations would make it possible for more people with disabilities to participate in all the major aspects of life in a society. Among these are accommodations of pace and expectations, which I discussed earlier in this chapter. Many more people with disabilities would be able to work, for example, if they could work part-time or flexibly, so that they could manage their work despite having more fatigue, pain, and/or interruptions for medical procedures than the average non-disabled worker.[16] People with disabilities are often forced to work less than they could, or at less creative and demanding jobs than they are capable of doing, because of inflexible workplaces. Those who acquire chronic illnesses often have to fight to continue working at a slower pace or with fewer hours. I was shocked to discover that the major insurer who administered disability insurance at my university had no policy to cover workers who remain 'partially disabled'[17] (i.e., able to work part-time, but not full-time) more than two years after returning to work. After two years, the insurance company expected workers to be "fully rehabilitated," that is, working full-time, or "fully disabled." Given the choice between the impossible (working full-time) and the undesirable (being on full disability leave), surely many people are forced to stop working altogether. This bad choice must cost insurers and employers a lot of money. Whether it is a price they choose to pay rather than making the organizational changes that would accommodate disabled workers, or simply the product of a cultural assumption that disabled people cannot work, I do not know. I do know that, when my university created a policy to cover ongoing 'partial disability' of professors, someone at the insurance company was said to have warned that, with this new policy, all the professors would want to be disabled.[18]

It is probably best to face this sort of objection squarely. Much disability policy and practice makes the assumption that disability must have enormous economic disadvantages, or else large numbers of people will want to be, or to pretend to be, disabled, presumably because they would not be expected or forced to work with a disability. Of course, if workplaces and the organization of work were fully accessible, or even considerably more accessible than they are now, and if employers stopped discriminating against people with disabilities, but hired them for their abilities, then many more people with disabilities could reasonably be expected to work. In the

best circumstances, only people with the severest physical and mental impairments would be unable to work, and it is not plausible that many people would be motivated to acquire or pretend to such severe impairments in order to avoid work. So, even if the motivation argument were correct, improving access to work would seem to be an effective way of preventing the alleged desire for disability, which would make it unnecessary to impoverish people with disabilities in order to make disability undesirable. Of course, the motivation argument does not take adequate account of the disadvantages of pretending to have a disability, much less the disadvantages of having a disability, including the social burden of stigma.

Advocates for people with disabilities tend to argue for accessibility on the basis of rights, perhaps because rights, once recognized, can be written into laws. A rights-based approach to thinking about social assistance for people with disabilities is also appealing because it so clearly opposes the charity-based approach, and because it requires the recognition that people with disabilities are full citizens who belong in the realm of public rights and duties.

In "Disability and the Right to Work," the philosopher Gregory S. Kavka argued that people with disabilities in advantaged societies[19] have a right "not only to receive a basic income, but to *earn* incomes at—or above—the basic maintenance level" (Kavka 1992, 265). He described this right as follows:

> What specific sorts of treatment or "special opportunities" are entailed by handicapped people's right to work? First, a right of nondiscrimination in employment and promotion—that people not be denied jobs on the basis of disabilities that are not relevant to their capacities to carry out the tasks associated with those jobs. Second, a right to compensatory training and education, funded by society, that will allow disabled people the opportunity to overcome their handicaps and make themselves qualified for desirable employment. Third, a right to reasonable investments by society and employers to make jobs accessible to otherwise qualified people with disabilities. Fourth, and most controversially, a right to minimal (or tie-breaking) "affirmative action" or "preferential treatment": being admitted, hired, or promoted when in competition with other equally qualified candidates. Spelled out in this way, the right of handicapped persons to work is seen to be, in its various elements, a right against society, government, and private employers. (Kavka 1992, 265)

This sounds like a good beginning to me. However, I am wary of being satisfied with "desirable employment." People with disabilities should have

opportunities equal to those of non-disabled people to develop their talents and work at the things they could do best, not just at any "desirable employment." How many potential Stephen Hawkings[20] might we have already condemned to lives of idleness, or boring, trivial labour in 'sheltered workshops?' In thinking about providing training and education, why not start with the assumption that people should receive a reasonable amount of help to make significant contributions to society according to their potential, both for their sakes and for the benefit of society? If schools, colleges, universities, and workplaces were designed or modified to be fully accessible, and if discriminatory practices were ended, the extra help that a person with a disability would need to meet her/his potential would not be very much greater than that needed by a non-disabled person.

Of course, help in achieving one's goals often has to be a compromise between what an individual wants to do and what a society is willing and able to offer. For instance, societies cannot reasonably be expected to restore all opportunities that are lost due to lack of ability. Some inabilities are widespread in the population, such as the inability to dance gracefully or to perform complex mathematical operations. Although these inabilities do result in lost opportunities, and although we might say that a dancer who *lost* her ability to dance or a mathematician who *lost* her ability to do mathematics had been disabled,[21] it would be wrong to consider them disabilities in any sense that would imply a social obligation to give those particular opportunities to the people who lack the abilities. Many other inabilities are not particularly important to full participation in the life of a society, and it would be inappropriate to consider them disabilities, even though they do deprive people of opportunities. Thus, I want to say that preventing disability requires providing the help necessary to create, wherever possible,[22] the ability to participate in all *major aspects* of life in a society, in which I would include (for Canada and the United States) at least work, social life, political life, religious life, cultural life, personal relationships, and recreation.

Yet I am not satisfied with this description either. I feel strongly that the

Yet I am not satisfied with this description either. I feel strongly that the ultimate goal of social assistance for people with disabilities should be to enable them to fulfill their potentials, enjoy their lives, and make as full a contribution to society as they can, not merely to enable them to participate. But here I encounter a conflict. Should the goals of social help for people with disabilities be higher than those currently operating for most people without disabilities? Yes, because they should be higher for everyone. But I do not want the just claims of people with disabilities to be drowned in a general discussion of social justice and political economy.

There are still so many obstacles to thinking clearly and accurately about the needs and claims of people with disabilities that it seems to me too early to attempt to weigh them in relation to the needs and claims of others.

Obstacles to the Deconstruction of Disability

As Ron Amundson points out (1992, 115–16), theorists and others tend to worry about potential "social hijacking" of resources by extremely needy people if accessibility is given the status of a civil right. Proposals to provide any assistance to people with disabilities inevitably raise concerns about cost and benefit, and possible drains on resources, partly because most people do not realize that different help could in many instances cut overall costs, partly because most people still think of disability as a personal or family responsibility, and partly because public aid to people with disabilities has long been characterized as pure charity, rather than as social investment in ability and productivity. It is questionable whether making Canada and the United States fully accessible to people with disabilities would be more or less costly than the widespread current approach of providing unearned subsistence incomes or expensive institutionalization for many people with disabilities who would not need them in an accessible society.

There is considerable disagreement among economists and rehabilitation researchers about the net monetary costs of rehabilitation and accessibility, and only a great deal of research (and probably some experimentation) will

and only a great deal of research (and probably some experimentation) will answer the questions.[23] There is also the question of who should pay for rehabilitation and modifications to create greater accessibility—employers, governments, or private insurers? I will make no attempt to offer answers to these questions here. I will, however, draw attention to the fact that the people of Sweden have created a much higher degree of accessibility in their country than we have in Canada or the United States[24] and suggest that they might be looked to for imaginative solutions to problems of rehabilitation and access. The Swedes are leaders in the technological development of aids for people with disabilities, which the Swedish government provides to those who need them (Milner 1989, 193). A 1987 study by Sven E. Olsson found that, in Sweden, "average household income for the severely handicapped was only slightly below that of households without handicapped members" (Milner 1989, 191). Recent statistics for the United States show that fifty-nine percent of adults with disabilities live in house-

holds with incomes of $25,000 or less, compared to thirty-seven percent of non-disabled adults.[25]

In the cost-benefit debates, it is essential to realize that the costs of the current welfare and warehousing approaches to disability are human, as well as economic. They deprive thousands of people of minimally decent lives and millions more of opportunities to participate in aspects of social life that non-disabled people consider essential to the meaningfulness of their own lives. Moreover, they hurt the non-disabled as well as the disabled, not only because many non-disabled people know and love people with disabilities whom these policies hurt, and because many people without disabilities must work much harder on behalf of their disabled friends and family members to make up for the inaccessibility and hardship created by these policies, but also because the non-disabled must live with the fear that illness, accident, or old age will render their own lives or those of their non-disabled loved ones worthless to themselves and society.

Attitudes that disability is a personal or family problem (of biological or accidental origin), rather than a matter of social responsibility, are cultural contributors to disability and powerful factors working against social mea-

sures to increase ability. The attitude that disability is a personal problem is manifested when people with disabilities are expected to overcome obstacles to their participation in activities by their own extraordinary efforts. The public adoration of a few disabled heroes who are believed to have 'overcome their handicaps' against great odds both demonstrates and contributes to this expectation. The attitude that disability is a family matter is manifested when the families of people with disabilities are expected to provide whatever they need, even at great personal sacrifice by other family members. Barbara Hillyer describes the strength of expectations that mothers and other caregivers will do whatever is necessary to 'normalize' the lives of family members, especially children, with disabilities—not only providing care, but often doing the work of two people to maintain the illusion that there is nothing 'wrong' in the family (Hillyer 1993).

These attitudes are related to the fact that many modern societies split human concerns into public and private worlds. Typically, those with disabilities and illnesses have been relegated to the private realm, along with women, children, and the old. This worldwide tendency creates particularly intractable problems for women with disabilities; since they fit two 'private' categories, they are often kept at home, isolated and overprotected (Driedger and Gray 1992). In addition, the confinement of people with disabilities in the private realm exploits women's traditional caregiving

roles in order to meet the needs of people with disabilities (Hillyer 1993), and it hides the need for measures to make the public realm accessible to everyone.

There also seem to be definite material advantages for some people (people without disabilities who have no disabled friends or relatives for whom they feel responsible) to seeing disability as a biological misfortune, the bad luck of individuals, and a personal or family problem. Accessibility and creating ability cost time, energy, and/or money. Charities for people with disabilities are big businesses that employ a great many non-disabled professionals; these charities depend upon the belief that responding to the difficulties faced by people with disabilities is superogatory for people who are not members of the family—not a social responsibility to be fulfilled

through governments, but an act of kindness. Moreover, both the charities and most government bureaucracies (which also employ large numbers of non-disabled professionals) hand out help which would not be needed in a society that was planned and organized to include people with a wide range of physical and mental abilities. The potential resistance created by these vested interests in disability should not be underestimated.

The 'personal misfortune' approach to disability is also part of what I call the 'lottery' approach to life, in which individual good fortune is hoped for as a substitute for social planning that deals realistically with everyone's capabilities, needs and limitations, and the probable distribution of hardship.[26] In Canada and the United States, most people reject the 'lottery' approach to such matters as acute health care for themselves and their families or basic education for their children. We expect it to be there when we need it, and we are (more or less) willing to pay for it to be there. I think the lottery approach persists with respect to disability partly because *fear*, based on ignorance and false beliefs about disability, makes it difficult for most non-disabled people to identify with people with disabilities.[27] If the non-disabled saw the disabled as potentially themselves or as their future selves, they would want their societies to be fully accessible and to invest the resources necessary to create ability wherever possible. They would feel that 'charity' is as inappropriate a way of thinking about resources for people with disabilities as it is about emergency medical care or basic education.

The philosopher Anita Silvers maintains that it is probably impossible for most non-disabled people to imagine what life is like with a disability, and that their own becoming disabled is unthinkable to them (Silvers 1994). Certainly many people without disabilities believe that life with a disability

would not be worth living. This is reflected in the assumption that potential disability is a sufficient reason for aborting a fetus, as well as in the frequent statements by non-disabled people that they would not want to live if they had to use a wheelchair, lost their eyesight, were dependent on others for care, and so on.[28] The belief that life would not be worth living with a dis-

ability would be enough to prevent them from imagining their own disablement. This belief is fed by stereotypes and ignorance of the lives of people with disabilities. For example, the assumption that permanent, global incompetence results from any major disability is still prevalent; there is a strong presumption that competent people either have no major physical or mental limitations or are able to hide them in public and social life.

It seems that the cultural constructions of disability, including the ignorance, stereotyping, and stigmatization that feed fears of disability, have to be at least partly deconstructed before disability can be seen by more people as a set of social problems and social responsibilities. Until that change in perspective happens, people with disabilities and their families will continue to be given too much individual responsibility for 'overcoming' disabilities, expectations for the participation of people with disabilities in public life will be far too low, and social injustices that are recognized now (at least in the abstract), such as discrimination against people with disabilities, will be misunderstood.

To illustrate, let me look briefly at the problem of discrimination. Clearly, when considering whether some action or situation is an instance of discrimination on the basis of ability, the trick is to distinguish ability to do the relevant things from ability to do irrelevant things. But, given that so many places and activities are structured for people with a narrow range of abilities, telling the two apart is not always easy. No one has to walk to be a typist, but if a company is housed in a building that is inaccessible to wheelchairs, and therefore refuses to hire a competent typist who uses a wheelchair because it would be expensive to fix the building, has it discriminated against her on the basis of her disability? Laws may say yes, but people will resist the laws unless they can see that the typist's inability to work in that office is not solely a characteristic of her as an individual. Most people will be ready to recognize refusal to hire her to work in a wheelchair-accessible office, provided she is the most competent typist who applied, as discrimination against her because of her disability; they will regard her disability (like her race) as a personal characteristic irrelevant in the circumstances. But will they be ready to require a company to create wheelchair accessibility so that it can hire her? This is being tested now in

the United States by the 1990 Americans with Disabilities Act. Although I expect the Act to have an invaluable educational function, I predict that it will be very difficult to enforce until more people see accessibility as a public responsibility. Only then will they be able to recognize inabilities that are created by faulty planning and organization as irrelevant.

Consider these sentiments expressed in the Burger King case, as described in *The Disability Rag and Resource* (March/April 1994, 43):

> When deaf actress Terrylene Sacchetti sued Burger King under the ADA for refusing to serve her when she handed the cashier a written order at the pickup window instead of using the intercom, Stan Kyker, executive vice-president of the California Restaurant Association, said that those "people (with disabilities) are going to have to accept that they are not 100 percent whole and they can't be made 100 percent whole in everything they do in life."

Had a woman been refused service because she used a cane to walk up to the counter, her treatment would, I think, have been recognized at once as discrimination. But since Ms. Sacchetti was refused service because she was unable to perform the activity (ordering food) in the way (orally) that the restaurant required it to be performed, the refusal to serve her was not immediately recognized as discrimination. Indeed, the representative of the restaurant association apparently felt comfortable defending it on the grounds that her individual characteristics were the obstacles to Ms. Sacchetti's being served.

When I imagine a society without disabilities, I do not imagine a society in which every physical and mental 'defect' or 'abnormality' can be cured. On the contrary, I believe the fantasy that someday everything will be 'curable' is a significant obstacle to the social deconstruction of disability. Instead I imagine a fully accessible society, the most fundamental characteristic of which is universal recognition that all structures have to be built and all activities have to be organized for the widest practical range of human abilities. In such a society, a person who cannot walk would not be disabled, because every major kind of activity that is accessible to someone who can walk would be accessible to someone who cannot, and likewise with seeing, hearing, speaking, moving one's arms, working for long stretches of time without rest, and many other physical and mental functions. I do not mean that everyone would be able to do everything, but rather that, with respect to the major aspects of life in the society, the dif-

ferences in ability between someone who can walk, or see, or hear, and someone who cannot would be no more significant than the differences in ability among people who can walk, see, or hear. Not everyone who is not disabled now can play basketball or sing in a choir, but everyone who is not disabled now can participate in sports or games and make art, and that sort of general ability should be the goal in deconstructing disability.

I talk about accessibility and ability rather than independence or integration because I think that neither independence nor integration is always an appropriate goal for people with disabilities. Some people cannot live independently because they will always need a great deal of help from caregivers,[29] and some people with disabilities, for example the Deaf, do not want to be integrated into non-disabled society; they prefer their own, separate social life. Everyone should, however, have access to *opportunities* to develop their abilities, to work, and to participate in the full range of public and private activities available to the rest of society.