consider medicine's greatest failures to be unrecognized, unsupported, meaningless, or hopeless suffering. I conclude by pointing out that philosophers of biomedical ethics have tended not to question the authority of medicine and to adopt medicine's preoccupation with life-and-death issues. I give reasons for hoping that the emerging field of feminist medical ethics will produce a critique of medicine that speaks to the concerns of people with disabilities and people with unrecognized or incurable illnesses.

In chapter 6 I argue that the experiences and interests of both people with disabilities and those who care for people with disabilities are vitally relevant to the projects and issues of feminist ethics, including the attempt to develop an ethic of care and to balance it with a morality of justice, the critical re-examination of the ethical ideals of autonomy and independence, and feminist ethical approaches to abortion, euthanasia, and health care reform. By discussing the analyses and concerns of people who have some experience with disability, especially those with feminist perspectives, I attempt to show how they must be included in any adequate treatment of these projects and issues. I maintain that feminist ethics needs the insights of people with disabilities, that people with disabilities need feminist ethics, that some people involved in disability ethics and politics are already practicing feminist ethics, and that more feminist ethicists should be practicing disability ethics.

Chapter 7 is devoted to what might seem like an esoteric subject—transcendence of the body. In fact, for many people with disabilities, it is a practical matter of immediate daily concern. Ideas of transcending the body have generally been rejected by feminists, partly in reaction to philosophies and religions that derogate the body (especially women's bodies) and partly because feminist theorizing about the body has not fully confronted the experience of bodily suffering. I describe some strategies for living with pain, sickness, and physical limitation gathered from my own experience and the writings of other people with disabilities, and argue that a more complete feminist understanding of the body might include some concept of transcendence.

Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York: Routledge, 1996.

1 ◈

Who Is Disabled?
Defining Disability

The question of how we should define disability is not merely the beginning of an analytic exercise. We encounter the problem of definition as soon as we take an interest in disability. For example, how many people have disabilities? Estimates of the incidence of disability worldwide and within countries vary greatly among the estimators, because not only methods of gathering information about disabilities, but also understandings of what constitutes disability, vary greatly among those gathering the information. Questions of definition arise in countless practical situations, influence social policies, and determine outcomes that profoundly affect the lives of people with disabilities.

Definitions of disability officially accepted by government bureaucracies and social service agencies determine people's legal and practical entitlement to many forms of assistance, where assistance is available. This may include economic help for such purposes as: education, training, and retraining; obtaining equipment, such as wheelchairs for basic mobility or computers for basic communication; modifying a home or a vehicle to enable a person with a disability to use it; hiring assistants to help with bodily maintenance and household tasks; even obtaining medical supplies such as medications and bandages. For people with disabilities who are unemployed, it includes the basic support to buy food and shelter. It also

includes eligibility for accessible housing and special forms of transportation, and even for such seemingly minor (but actually major) means of access as a disabled parking sticker.

Socially accepted definitions of disability determine the recognition of disability by friends, family members, and co-workers. Recognition of a person's disability by the people s/he is closest to is important not only for receiving their help and understanding when it is needed, but for receiving the acknowledgement and confirmation of her/his reality, so essential for keeping a person socially and psychologically anchored in a community. It is not uncommon for friends and even family members to desert a person who has debilitating symptoms that remain undiagnosed. They may insist that the ill person is faking, or mentally ill and unwilling to get appropriate treatment. People whose disability is unrecognized are frequently pressured to keep up a pretense of normality, to continue to work as if nothing were wrong, and/or to undergo unnecessary psychiatric treatment.

Definitions of disability are important to those who are organizing people with disabilities for political purposes, for example, to press for fuller recognition of their rights, for increased accessibility to public places, or for better opportunities to work. There have been struggles within political groups of people with disabilities, especially in recent years, to include more categories of people. For example, people with AIDS and with debilitating chronic illnesses like ME fought within disability groups for the recognition that they too are disabled, share similar needs and struggles, and suffer similar forms of insult, discrimination, distrust, and exclusion.

Definitions of disability affect people's self-identity. Recognizing yourself as disabled and identifying with other people who are disabled and learning about their experiences can all contribute to understanding and interpreting your own experiences, and to knowing that you are not alone with problems that you may have believed were unique to you. But being identified as disabled also carries a significant stigma in most societies and usually forces the person so identified to deal with stereotypes and unrealistic attitudes and expectations that are projected on to her/him as a member of this stigmatized group.[1]

A careful effort to define disability can clarify our conceptions of disability and reveal misconceptions and false stereotypes. For example, for many people the paradigmatic disabled person is a young, healthy, paraplegic man who has been injured in an accident but continues to be athletic, or a young, healthy, professionally successful blind woman who has 'overcome' her handicap with education. In fact, arthritis, rheumatism, heart and respi-

ratory disease, stroke, Parkinsonism, hypertension, and epilepsy are major causes of disability in Canada, the United States, and Great Britain, and many people with disabilities in these countries are also ill and/or old (Health and Welfare Canada and Statistics Canada 1981; Statistics Canada 1986 and 1991; Pope and Tarlov 1991; LaPlante 1991; Bury 1978).

The United Nations Definitions

The United Nations definition of disability (UN 1983: I.c. 6–7) is widely used and tends to be favoured by disability activists and other advocates of greater opportunities for people with disabilities (Wright 1983, 10–12; Fine and Asch 1988, 5–6). It offers the following definitions of and distinctions among impairment, disability, and handicap:

> "Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure or function. Disability: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. Handicap: A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors, for that individual."
>
> Handicap is therefore a function of the relationship between disabled persons and their environment. It occurs when they encounter cultural, physical or social barriers which prevent their access to the various systems of society that are available to other citizens. Thus, handicap is the loss or limitation of opportunities to take part in the life of the community on an equal level with others. (UN 1983: I.c. 6–7)

There are two things I like about the UN definitions. First, they are general enough to include many conditions that are not always recognized by the general public as disabling, for example, debilitating chronic illnesses, such as Crohn's disease, which limit people's activities but do not necessarily cause any immediately observable disability. I shall return to this aspect of the definitions later in this chapter. Second, the definition of handicap explicitly recognizes the possibility that the primary causes of a disabled person's inability to do certain things may be social; they may be lack of opportunities, lack of accessibility, lack of services, poverty or discrimination, and they often are. It is this latter aspect of the definitions that makes them appealing to advocates for people with disabilities.

Nevertheless, there are several criticisms I have of the UN definitions that may throw some light on the nature of disability and the problems associated with defining it. First, the definitions of "impairment" and "disability" seem to imply that there is some universal, biologically or medically describable standard of structure, function, and human physical ability. As we shall see, there would be important advantages to employing some universal standards, should we be able to agree on them. Yet surely what are "normal" structure, function, and ability to perform an activity all depend to some degree on the society in which the standards of normality are generated. For example, I, who can walk about half a mile several times a week but not more, am not significantly disabled with respect to walking in my society, where most people are not expected to walk further than that in the course of their daily activities. But in some societies, in Eastern Africa for example, where women normally walk several miles twice a day to obtain water for the household, I would be much more severely disabled. It is not just that I would be considered more disabled in those societies but that I would in fact need constant assistance to carry on the most basic life activities. What is normal ability in urban Western Canada is neither normal nor adequate ability in rural Kenya.

Failure to recognize that standards of structure, function, and ability are socially relative could be dangerous to people with disabilities. If the standards employed are generated by people in highly industrialized societies, many people in less industrialized societies and in rural areas where there are fewer technological resources will be considered non-disabled when they are in fact in need of special assistance to survive and participate in life where they are.

On the other hand, definitions of impairment and disability could be relativized too much to some societies. If most people in a particular society are chronically undernourished, that society's standards of "normal" functioning might become so low as to mask the widespread disability among its citizens that starvation is causing. Another particularly disturbing example is the genital mutilation of girls. In societies where the majority of people approves of the practice and the vast majority of girls has been mutilated, the girl who has a clitoris (and other external sexual organs, depending on the form of mutilation practiced) is considered abnormal. Yet because genital mutilation often causes severe infections, shock, hemorrhage, and chronic physical and mental health problems, in addition to reducing or destroying some women's capacities for sexual pleasure, I cannot believe that the rest of the world should accept uncritically those societies' standards of normal structure and function for women. To do so seems a betrayal of the girls and women whose lives, health, and sexuality are endangered by mutilation.[2]

Iris Marion Young's statement that "women in sexist society are physically handicapped,"[3] and her arguments in support of it present another strong challenge to the idea that culturally relative standards of physical structure, function, and ability should be accepted. Young argues that lack of opportunities and encouragement to develop bodily abilities, rigid standards of feminine bodily comportment, and constant objectification and threat of invasion of their bodies combine to deprive most women in sexist societies of their full physical potential. In these societies, a "normal" woman is expected to lack strength, skills, and the range of movement that "normal" men are expected to possess and that she might have developed had she grown up in a less sexist society. If we accept these standards uncritically, we will tend to overlook the ways that those societies create physical disadvantages for women.

Thus there seem to be problems both in denying the social and cultural relativity of impairment and disability (as used in the UN definitions) and in accepting it. The UN definitions seem to recognize the relativity of standards of ability while attempting to universalize them by using the phrase "in the manner or within the range considered normal for a human being." Unfortunately, that does not amount to a practical recognition of the relativity of disability. A woman in Kenya who can walk only as much as I can will still not be considered disabled with respect to walking, because her ability falls within the worldwide *range* considered normal. Nor does it universalize standards enough to create the basis for criticizing societies whose standards of health and good functioning fall too low for some or all of their members. The standards of such societies could still be seen to fall, by definition, in the "range considered normal for a human being."

Philosopher Ron Amundson suggests that we define disabilities as "the absences of basic personal abilities." (Amundson 1992, 108) "Basic personal abilities" enable us to perform such actions as "moving one's arms, standing, seeing and hearing things in the environment," and also to remain alert for several hours a day and to remain active without unreasonable fatigue. The actions they enable us to perform are "biomedically typical of the human species (suitably relativized to age and perhaps sex)." This is an attractive attempt to universalize the concept of disability via an appeal to common sense (with some additional appeal to biomedical standards). Yet the idea of a basic personal ability seems less clear when we ask,

"How well?" or "How much?" How well must one see or hear in order to have the basic personal ability? How long must one be able to stand or how fast must one be able to walk? Is running a basic personal ability? I find myself unable to answer these questions without first asking about the circumstances of the person whose abilities are being discussed. How much ability is basic, like how much ability is normal, seems to depend on how much is necessary to perform the most common tasks of daily living in a particular physical and social environment. For example, far more strength and stamina are necessary to live where there is no water on tap, where it gets cold and there is no central heating, where a fire has to be built every time a meal is cooked, and all the clothes are washed by hand. In such an environment I would be considered a helpless invalid, and indeed I would lack most of the personal abilities I would need.

Appeal to what is biomedically typical of the human species would not seem to help settle the question, since people who are biomedically identical have different personal abilities, and people who have the same personal abilities are biomedically different. Eyeglasses, hearing aids, good prostheses, and other products of medical technology optimize the abilities of some people, while others, who have identical physical conditions but do not have access to the technology, lack the same abilities. People who use strong but completely effective corrective lenses may have the same personal ability to see as people with uncorrected good eyesight; do we want to call them or their seeing biomedically identical? Of course, in asking whether a person is disabled we could consider only whether a person's biology is typical of the human species, but Amundson would not like that, since, as he points out, atypical and even pathological biology is not necessarily disabling, that is, it does not necessarily affect a person's abilities adversely. I think we are stuck with the problem that the question of what abilities are basic, like that of what abilities are normal, is to a significant extent relative to the environment in which the abilities are exercised.

This is not the same point as claiming that a person's physical structure, function, or ability may or may not be *disadvantageous* in a given environment. Like the authors of the UN definitions and others (e.g., see Wright 1983), Amundson distinguishes "disability" from "handicap." He defines "handicap" as "an opportunity loss sustained by an individual resulting from the interaction between that individual's (biomedical) disability and the specific environment in which the individual's opportunities exist" (Amundson 1992, 111). So, applying this to my most recent example, I might lack most of the basic personal abilities required in my environment, but I still might live quite well, participate actively in my community, and have many valuable opportunities if I could buy the services most people perform for themselves. For reasons I will explain shortly, I like Amundson's definition of "handicap" better than that offered by the United Nations.

Nevertheless, we still need some recognition of the relativity of standards of structure, function, and ability to the customs and conditions of different societies so that what the UN calls "impairment" and "disability" will be concepts that are useful and accurate in identifying those individuals who may need adjustments in their environment or direct assistance in order to survive and participate in their societies. On the other hand, we also need some cross-cultural comparisons and criticism of societies' standards of structure, function, and ability to perform activities. Such comparisons could contribute to raising the standards and, eventually, the levels of health in a society and help to protect people whose ill health or disability might serve the interests of others within their society.

My other criticisms of the UN definitions concern how they define "handicap." Because that definition refers to "a role that is normal, depending on age, sex, social and cultural factors, for that individual," the definitions imply that women can be disabled, but not handicapped, by being unable to do things which are not part of the "normal" roles of women in their societies. Thus, for example, if it is not considered essential to a woman's role in a given society that she be able to read, then a blind woman who is not provided with education in Braille or good alternatives to printed material is not handicapped by that lack of assistance, according to these definitions. In general, where the expectations for women's participation in social and cultural life are considerably lower than they are for men, disabled women's opportunities will be severely constrained, and the UN has, through its own definitions, robbed itself of the ability to criticize the circumstances in which many disabled women live.

Moreover, disability in women often goes unrecognized and rehabilitation of women is often minimal because of the expectation that women need only be able to function well enough to perform household duties (Fine and Asch 1988; Russo and Jansen 1988; Driedger and Gray 1992). On the other hand, because women's unpaid work in the home (and in volunteer activities) is not publicly valued, and because disability is still defined in many places as the inability to earn wages, women's inabilities to perform their traditional unpaid labour often go unrecognized as disability (Reisine and Fifield 1988).

In addition, the UN definitions suggest that we can be disabled, but not handicapped, by the normal process of aging, since although we may lose some ability, we are not "handicapped" unless we cannot fulfill roles that are normal for our age. Yet the fates of old people and of people with disabilities tend to be linked in a society because aging is disabling. A society that provides few resources to allow disabled people to participate in its activities will be likely to marginalize all people with disabilities, including the old, and to define the appropriate roles of old people as very limited, thus disadvantaging them. I think the UN should recognize that old people can be handicapped unnecessarily by their societies, but its definitions seem to prevent that recognition.

Realizing that aging is disabling helps non-disabled people to see that people with disabilities are not 'Other,' that they are really themselves at a later time. Unless we die suddenly, we are all disabled eventually. Most of us will live part of our lives with bodies that hurt, that move with difficulty or not at all, that deprive us of activities we once took for granted, or that others take for granted—bodies that make daily life a physical struggle. We need understandings of disability and handicap that do not support a paradigm of humanity as young and healthy. Encouraging everyone to acknowledge, accommodate, and identify with a wide range of physical conditions is ultimately the road to self-acceptance as well as the road to increasing the opportunities of those who are disabled now.

Ron Amundson objects to Norman Daniels's classifying the disabled with the group Daniels calls the "frail elderly," that is, those who, according to Daniels, are experiencing a normal reduction in biomedical functioning associated with aging. Amundson says of this: "To the extent that frailty and opportunity reduction is a natural consequence of aging, classifying disability with age-frailty again falsely depicts handicaps as a natural and expected part of human existence" (Amundson 1992, 115).

I appreciate Amundson's concern that grouping the "frail elderly" together with nonelderly people with disabilities will lead most people to assume that the opportunities of the latter are reduced by nature and not by the failures of society. But I prefer challenging the underlying assumption about what is natural to pressing the distinction between the two groups. It is not obvious to me that the reduction of opportunities experienced by the elderly are any more attributable to nature than the reduction of opportunities experienced by nonelderly people with disabilities.[4] True, there may be many physical feats they will never accomplish again, but this is also true of nonelderly people with disabilities, and it does not imply for either group that their opportunities to do other things must be diminished. In fact, many elderly people who used to take too many limitations on their activities for granted now take advantage of improvements in accessibility, such as ramps and lowered curbs, that were made with nonelderly people with disabilities in mind. I imagine that if we did not construct our environment to fit a *young* adult, non-disabled, male paradigm of humanity, many obstacles to nonelderly people with disabilities would not exist.[5]

When disability is carefully distinguished from the expected frailties of old age, we lose the main benefit of the insight that aging is disabling. That insight enables non-disabled people to realize that they are temporarily non-disabled, and that in turn enables them to see that it is in their own direct interest to structure society so that people with disabilities have good opportunities to participate in every aspect of social life. Therefore, I do not think that for most social and political purposes it is a good idea to make distinctions among disabilities according to whether they were brought on by aging.[6] It is partly for this reason, and partly because it does not relativize handicaps to sex roles, that I prefer Amundson's less qualified definition of "handicap" to the UN definition.

Is Illness Disability?

Amundson proposes that we make a strong distinction between illness and disability. Although he defines "disabilities" as "absences of basic personal abilities," which would seem to apply to the conditions of many people who are ill, he says : "In paradigm cases of disability, a blind man or a paraplegic woman require nothing special in the way of medical care," and "Unlike ill people, disabled people are not (typically) globally incapacitated *except insofar as the environment helps to make them so*" (Amundson 1992, 21, 22). Amundson has two purposes in distinguishing illness and disability. First, he wants to correct a common mistaken impression, sometimes encountered in the literature of medical ethics, that people with disabilities require extraordinary medical care. His second and major concern is to change the widespread false belief that people with disabilities are "globally incapacitated" by their physical conditions. He believes that "the social devaluation of people with disabilities derives in large part from the image of the globally incapacitated disabled person" (Amundson 1992, 22).

How concerned should we be to distinguish disability from chronic illness? From life-threatening illness (such as AIDS or cancer)?[7] Of course, even when chronic or life-threatening, illness need not always be disabling, and it may be useful to distinguish those who have some disability due to illness from those who do not, such as people with epilepsy whose seizures are completely controlled by medication or people with multiple sclerosis (MS) whose disease is in remission and therefore presents no disabling symptoms during a given period of time (always keeping in mind that they may nevertheless share in the handicapping social stigma of other people with 'imperfect' or devalued bodies).

It is also true that many people with disabilities are healthy. Nevertheless, I think Amundson's paradigm cases of disability may lead him to underestimate the proportion of people with disabilities who are either disabled by what we would all recognize as illness or ill as a consequence of disability. If we consider that many more people in North America are disabled by arthritis, heart or respiratory disease, or diabetes[8] than by blindness or paraplegia, we are compelled to adopt very different paradigms of disability. In addition, some disabilities not caused by disease, such as paraplegia and quadriplegia due to spinal cord injury, have significant tendencies to cause health problems, including chronic pain, circulatory difficulties leading to skin breakdown, and recurring bladder infections (Morris 1989; Murphy 1990, 178).

Perhaps most important, we must recognize that, like healthy people with disabilities, most people who have disabilities due to chronic or even life-threatening illnesses are not "globally incapacitated." The inclination to keep those who are more than temporarily ill out of the stream of work and social activity is based as much on ignorance and prejudice as is the inclination to keep other people with disabilities hidden in the private realm. Thus there are issues of access for people with chronic and life-threatening illnesses that need to be addressed.

For people with chronic illnesses, access to the workplace often includes the ability to work part-time, with some flexibility to accommodate periods of greater or lesser illness. Disability leave and insurance schemes frequently make the assumption that workers are either fully disabled from working or able to work full-time, leaving people with chronic illnesses, or people with progressive life-threatening illnesses, in impossible positions. Either they must push themselves beyond endurance to appear to be capable of working full-time or dishonestly declare themselves unable to work at all, often when they want very much to continue working. The desire of their co-workers to avoid the realities of illness, especially potentially fatal illness, often contributes to their difficulties in finding a way to work. Some of these problems have been made more visible recently by people with AIDS who have had to fight for their right to continue to work as much as they are able. I will discuss these problems at more length in the next chapter. Here it is important to note that although issues of time flexibility may not be important to that group we might call the "healthy disabled," so many people with disabilities also have health problems, and so many people with illnesses are disabled by their illnesses, that it seems to make sense to make common cause on these issues by recognizing them as aspects of access to opportunities for people with disabilities.

Some of the initial opposition in disability rights groups to including people with illnesses in the category of people with disabilities may have come from an understandable desire to avoid the additional stigma of illness (see Gill 1994, 7), especially such heavily stigmatized ones as AIDS and cancer. People with physical disabilities often insist that they are not mentally disabled, because of the additional stigma of psychological or developmental disabilities in most societies. Of course, in both cases there is the valuable point to be made that a person with a disability is not disabled in all respects, that a deaf person or someone with paraplegia may be otherwise healthy, and that someone with cerebral palsy may not be developmentally disabled. Nevertheless, many people with disabilities are also ill, and many people with physical disabilities also have developmental or psychological disabilities.

Perhaps having ME makes me sensitive to the limitations of these distinctions. I am chronically ill, partially "globally" disabled in that the amount of any activity I can engage in is much more restricted than it is for a healthy person, and specifically disabled sometimes and in some contexts (for example, some days my arms are too weak and painful to write on the blackboard, open heavy doors, or carry anything). I have also experienced some psychological disability in that my disease causes profound mental as well as physical fatigue and has caused depression (primarily in the first two years), inability to concentrate, and short-term memory problems, including trouble finding the right words in conversation and remembering the names of even close friends. The psychological symptoms occasionally reappear in less severe form during periods of increased illness. Some people with ME, many of whom share these recurring symptoms, emphasize that they have a physical rather than a psychiatric cause. This is not (or not just) to avoid the stigma of psychiatric disability,

but to avoid psychiatric diagnoses, which are no help to us, since attempts to cure our symptoms by psychotherapy are ineffective and may prevent us from receiving the care we need. Nevertheless, ME does combine physical and psychological disability, and experiencing that complex combination has led me to believe that what matters most in identifying disability is identifying the difficulties people face in surviving and contributing to their societies.

How Should Disability Be Defined?

I am not going to recommend specific definitions that I would like to see adopted by the United Nations. The definitions they use have to serve specific political purposes of the World Health Organization and other agencies, and they have to be arrived at by a complex process of political compromise, of which I know virtually nothing. My purpose in criticizing the UN definitions is to bring to light issues that may be glossed over or missed altogether if we accept them too readily and try to apply them in all contexts.

Nevertheless, I think that on the basis of the discussion so far, I can summarize some characteristics that good definitions, for both educational and practical purposes, should have: Good definitions of impairment and disability should recognize that normal (i.e., unimpaired) physical structure and function, as well as normal (i.e., non-disabled) ability to perform activities, depend to some extent on the physical, social, and cultural environment in which a person is living, and are influenced by such factors as what activities are necessary to survival in an environment and what abilities a culture considers most essential to a participant. However, they should also take into account the possibility that some members of a society may have a vested interest in defining 'normal' structure, function, and ability for other members in ways that disadvantage those other members and/or mask ill treatment of them. Thus it is important before accepting a society's standards of normality to compare them to those of other societies; if they are lower than, or markedly different from, many others, or if they are different for different groups (e.g., sexes, races, classes, or castes), the possibility that disability is more widespread in that society than its standards would recognize should be carefully examined.

In addition, some terms, such as *handicap*, may be useful to refer specifically to any loss of opportunities to participate in major aspects of the life of a society that results from the interaction of a disability with the physical,

social, and cultural environment of the person who has it. The fact that a society does not consider an opportunity necessary or appropriate for a person belonging to some particular group (e.g., age, sex, class) may[9] be irrelevant to whether the person is handicapped, since it is not unusual for a society to handicap large groups of its own people. On the other hand, not every loss of opportunity is a handicap, despite the fact that one often hears or reads the observation that everyone is disabled or handicapped in some way (for example, see Murphy 1990, 66). I will not go into detail here about how much loss of opportunity constitutes a handicap but will discuss this as an aspect of the social creation of disability in the next chapter.

In general usage, the distinction between "disability" and "handicap" is not usually maintained. Introducing it does have an educational function, reminding people that many of the obstacles faced by people with disabilities are not necessary consequences of their physical conditions. On the other hand, it also tends to create the mistaken impression that disability is purely biological and handicap is social, when in fact both are products of biological and social factors. In this book, I will most often use the term "disability" to refer to any lack of ability to perform activities to an extent or in a way that is either necessary for survival in an environment or necessary to participate in some major aspect of life in a given society. I will assume that disability has biological, social, and experiential components.

Who Defines Disability and for What Purposes?

I believe that discussion of how disability *should* be defined is essential for clarifying our understanding of disability and, ultimately, for formulating policies. But defining disability and identifying individuals as disabled are also social practices that involve the unequal exercise of power and have major economic, social, and psychological consequences in some people's lives. To ignore these practices would leave us with an idealized picture of the problems of definition. To understand how the power of definition is exercised and experienced, we have to ask who does the defining in practice, for what purposes and with what consequences for those who are deemed to fit the definitions.

On the subject of defining race, Evelyn Brooks Higginbotham says:

> Like gender and class, then, race must be seen as a social construction predicated upon the recognition of difference and signifying the simulta-

neous distinguishing and positioning of groups vis-à-vis one another. More than this, race is a highly contested representation of relations of power between social categories by which individuals are identified and identify themselves. The recognition of racial distinctions emanates from and adapts to multiple uses of power in society. Perceived as "natural" and "appropriate," such racial categories are strategically necessary for the functioning of power in countless institutional and ideological forms, both explicit and subtle. (Higginbotham 1992, 253–54)

Much of what Higginbotham says about race is also true for disability, although the positioning of groups (disabled versus non-disabled, those with acceptable bodies versus those with rejected bodies) and the contesting of representations (e.g., pitiful cripple, inspiring example) are, I think, in earlier stages of development in disability politics than they are in racial politics. Despite the fact that there is sometimes more biological reality underlying distinctions between the non-disabled and the disabled than there is underlying distinctions between races, the belief that 'the disabled' is a biological category is like the belief that 'Black' is a biological category, in that it masks the social functions and injustices that underlie the assignment of people to these groups.

Charlotte Muller (1979, 43) points out that the providers of health care and of benefits and services to people with disabilities generally define who needs their help. This is an important reminder that the power to define is not necessarily in the hands of those who are most affected by the definitions. Later in this book, I will discuss more fully the cognitive authority (Addelson 1983) of medical professionals and bureaucrats to describe us to ourselves and others, and the practical consequences of that authority. Here perhaps it is sufficient to note that there may be important differences between the definitions of disability employed by so-called 'providers' and the definitions of disability employed by people with disabilities. It is in the interest of many providers to define disability narrowly, so that fewer people are seen to be entitled to the benefits they are supposed to provide than if disability were defined more broadly. Many examples of this can be seen when insurance companies are involved as providers; clearly it is in their direct financial interest to define disability as narrowly as they can without risking costly litigation.[10] The multiplicity of providers can create confusion about who is disabled; it is not uncommon for people with disabilities to find themselves fitting some bureaucracies' definitions of disability and not others.[11]

Who Identifies Herself/Himself as Disabled?

It is important to keep in mind that some people who consider themselves disabled are not identified as disabled by everyone else, and that not everyone who is identified by other people as disabled (either for purposes of entitlement, purposes of discrimination, or others) considers herself or himself disabled.

On the one hand, many people who identify themselves as disabled because their bodies cause them great physical, psychological, and economic struggles are not considered disabled by others because the public and/or the medical profession do not recognize their disabling conditions. These people often long to be perceived as disabled, because society stubbornly continues to expect them to perform as healthy non-disabled people when they cannot, and refuses to acknowledge and support their struggles. For example, pelvic inflammatory disease (PID) causes severe prolonged disability in some women. Women with PID are often given psychiatric diagnoses and have to endure the skepticism of families and friends, in addition to living with intense and unrelenting abdominal pain (Moore 1985).

Of course, no one wants the social stigma associated with disability, but, as I have already pointed out, social recognition of disability determines the practical help a person receives from doctors, government agencies, insurance companies, charity organizations, and often from families and friends. Moreover, if you are correctly identified by others as disabled, your experience of your own body is (at least to some extent) recognized by your society and the people who surround you; denial of their experience is a major source of loneliness, alienation, and despair in people with unrecognized disabilities (Jeffreys 1982). In addition, for many people with disabilities, identity as a person with a disability has a vital political meaning; they are members of a group of people who share the social oppressions of disability and struggle together against them.

On the other hand, there are many reasons for not identifying yourself as disabled, even when other people consider you disabled. First, disability carries a stigma that many people want to avoid, if at all possible. For newly disabled people, and for children with disabilities who have been shielded from knowledge of how most non-disabled people regard people with disabilities, it takes time to absorb the idea that they are members of a stigmatized group. Newly disabled adults may still have the stereotypes of

disability that are common among non-disabled people. They may be in the habit of thinking of disability as total, believing that people who are disabled are disabled in all respects. Since they know that they are not themselves disabled in all respects, they may resist identifying themselves as people with disabilities. They may fear, with good reason, that if they identify themselves as disabled, others will see them as wholly disabled and fail to recognize their remaining abilities or, perhaps worse, see their every ability and achievement as 'extraordinary' or 'courageous' (Wright 1983).

For some people, having hoped or expected to recover from accident or injury, or having hoped for a 'cure' since childhood, identifying themselves as disabled may mean giving up on being healthy, or being able to walk, see, or hear (for example, deaf children often expect to grow up into hearing adults), and accepting the prospect of the rest of one's life with the body and abilities one currently has (Wright 1983). Canadian filmmaker Bonnie Klein describes how, sixteen months after a debilitating stroke, she did not accept herself as disabled. Even though she used a wheelchair, she chose "a glamorous cinema with inaccessible bathrooms" for the premier of one of her films (Klein 1992).

For people who identify themselves strongly with their work and fear (or know) that they cannot continue the same work with their new bodies, accepting disability means making a deep change of identity. Barbara Rosenblum, who became ill with cancer in midlife, wrote:

> My work identity runs through my very cellular structure. For me, work is like a religion. I have devoted my life to it. Being a sociologist has been central to my identity and now I am giving that up. I was frightened when I thought of going on disability. Would they write "disabled professor" on my records at the hospital? (Butler and Rosenblum 1991, 63)

Recognizing myself as disabled certainly required that I change my self-identity and adopt a radically new way of thinking about myself. This included accepting the reality (though not the justice) of the stigma of being chronically ill,[12] especially the shame of being unable to do many things that people still expected me to do. It also required reimagining my life with a new, much more limited, and perpetually uncomfortable body, and then reorganizing my work, home, and relationships to make this different life possible. All of this was difficult, but another very important part of changing my identity helped me through the rest. I found that I could make sense of what was happening to me by talking with other people

with disabilities and reading books and articles by them. They already knew how the stigma of disability works, and how to live well with illness and physical limitations. In the process of learning what I needed to know from them, I recognized myself as one of them. When I identified myself as a person with a disability, I no longer felt I was struggling alone.

It was easier to identify myself as disabled to myself than it was to identify myself as disabled to others. For me, this was not primarily because I was afraid of the stigma; I had already encountered the most profound ways that the stigma of chronic illness would affect me. The problem was that when I had recovered enough strength to return to work part-time, I no longer looked very ill although I still fought a daily battle with exhaustion, pain, nausea, and dizziness, and I used a cane to keep my balance. I was struggling, and since people could not see that I was struggling, I was constantly explaining to them that I was struggling, that I could no longer do things that I had done before, and that I did not know when or even if I would ever be able to do them again. I simply wanted my friends and the people I worked with to recognize my limitations and to accept, as I had, that they might be permanent, but it is hard to describe the invisible reality of disability to others without feeling that you are constantly complaining and asking for sympathy. Then too, others resisted believing that I might never regain my previous health and ability. They tried to talk me out of attitudes and actions that they saw as "giving up hope" and that I saw as acceptance and rebuilding my life.

In addition, there was another obstacle to identifying myself to others as disabled. Although I felt that the struggles of people with disabilities, especially women with disabilities, were my struggles (and I still do), I also felt a kind of unworthiness to count myself among people with disabilities, because I was so much better off than they were.

I have heard other people with disabilities, some of them in terrible circumstances, say that they do not consider themselves disabled because "others are so much worse off than I am." I think it is sometimes a way of minimizing one's own difficulties in order not to feel frustration, grief, or shame. Or it can be a way of clinging to one's right to pity others, and therefore to feel stronger, healthier, and more 'normal' than them. I think it is sometimes based on the stereotype of disability that pictures people with disabilities as totally disabled, unable to do anything for themselves or others, and therefore in need of charity; as long as they can do anything, people who have this stereotype in mind refuse to think of themselves as disabled out of pride and to avoid charity.

Something else was also bothering me. My reluctance came partly from awe of people who lived with more disabling conditions than mine; after all, I had learned most of what I knew about how to cope from them. It also came from guilt and shame that while I was able-bodied I had barely noticed, and certainly had not begun to understand, the struggles of people with disabilities or the privileges I had because I was not disabled. I realized too how lucky I was to have built a professional life before I became ill that provided not only adequate disability insurance but also the possibility of continuing my work with my new limitations.

Bonnie Klein describes feelings similar to mine, which occurred the first time she attended a meeting of the DisAbled Women's Network, Canada:

> I feel apologetic, illegitimate, because I was not born disabled, and I am not as severely disabled as many other people. I feel guilty about my privileges of class, profession (including my disability pension), and family. I am a newcomer to the disability movement; I have not paid my dues. (Klein 1992, 73)

My own embarrassment and fear of rejection gave way to the reality of shared work, shared experiences, and mutual understanding. When I began teaching a course on women and disability and meeting a lot of women with disabilities, I found that they treated me as one of them, welcomed my contribution to disability movement, and taught me about their lives with great generosity, regardless of the severity of their own disabilities and disadvantages. Although I am still very aware of my privileges, I no longer feel unworthy to call myself a disabled woman.

Some Politics of Disability Identity

Whether to identify oneself as disabled can be a contentious political issue. For example, there is a lively debate among the Deaf[13] about whether to include themselves in disability rights groups, since many Deaf people do not consider themselves disabled. Because the Deaf have sign language and a rich culture separate from hearing people, it is very clear that the Deaf are not disabled in all contexts. As Roger J. Carver puts it:

> Indeed, as one enters into the world of the Deaf, disability as a factor in their lives ceases to exist. A hearing person unfamiliar with the language and customs of the Deaf community will instantly find himself handicapped in such a context, arising from his disability in the area of communication. In the same vein, a Deaf person will feel the same way when he [sic] is among speaking hearing persons. This handicap is no different from that incurred by visiting a foreign country in which a different language is spoken. It explains in large part why the Deaf do not feel at home among other disabled persons; they do not share the same communications system. Put "wheelies" together into a group; they are still confronted by the reality of their disability. The same is true for the blind or even the hard of hearing. (Carver 1992)

From medical and rehabilitative practitioners' point of view (which is also the point of view of most hearing people), a deaf child is disabled by her inability to hear, and so the child becomes the focus of efforts to 'normalize' her as far as possible within the hearing community. But from another, equally valid point of view, the same child is handicapped by hearing people's (often including her parents') ignorance of Sign. In a Deaf, signing community, she is already normal, assuming that she has signing ability appropriate for her age. The validity of this second point of view is weakened or even forsaken when the Deaf identify themselves as people with disabilities and join disability rights groups to work for their own welfare.

On the other hand, since most medical and rehabilitative authorities, as well as the hearing majority, consider the Deaf disabled, the Deaf must often identify themselves as people with disabilities in order to obtain the equipment and services they need. Carver says, "In the eyes of the Hearing, our technical devices are medical devices or 'assistive living aids;' in the eyes of the Deaf, they are mundane, everyday instruments in much the same way the Hearing regard their telephones, TV sets, alarm clocks, and doorbells" (Carver 1992).

Moreover, since the Deaf are widely regarded as disabled, they are treated in some of the same ways as (other) people with disabilities, and therefore they have some common causes with (other) people with disabilities, including the goal of being accepted as different rather than rejected as defective (Vlug 1992). For this reason, some of the Deaf identify themselves as people with disabilities and/or want to work within organizations of people with disabilities.

Many of the same things Carver says about the Deaf are true of most people with disabilities: We are disabled in some, but not all, contexts; the

disability in a given situation is often created by the inability or unwilling-
ness of others to adapt themselves or the environment to the physical or
psychological reality of the person designated as 'disabled'; and people
with disabilities often regard the accommodations they make to their physi-
cal conditions as ordinary living arrangements and their lives as ordinary
lives, despite their medicalization by professionals and most people's insis-
tence that they are unusually helpless or dependent. These facts are more
obvious in the case of the Deaf, because the contexts in which the Deaf are
not disabled are more readily available, more total, and more public than
for most people with disabilities. Thus Carver says that other people with
disabilities are still confronted with their disabilities when they are in each
other's company; but that is not entirely true. It is true that people who use
wheelchairs still have the same difficulty walking when they are in the
exclusive company of other people who use wheelchairs, but walking is
out of the question for the whole group, and so it is not an issue or an
obstacle to participating fully in the group's activities. Disability is contex-
tual for everyone, not only for the Deaf.[14]

Nevertheless, many of the concerns raised by the Deaf are important
general concerns for political organizations of people with disabilities.
What, if anything, do people with disabilities have in common? Do those
with similar disabilities have more in common, or do other factors such as
gender, class, race, age, or sexual identity have a more profound effect on
the experience of disability? Does identifying ourselves as disabled rein-
force the very perception of us as radically 'different,' which is a source of
stereotypes and assumptions that stand in our way? Does it perpetuate the
practice of regarding our different bodies, rather than the inaccessible and
unaccommodating environment, as the source of our problems? Should we
emphasize our similarities to non-disabled people or our differences from
them, including our different strengths and abilities? Should our political
goals emphasize full integration of people with disabilities among people
without disabilities, or should people with disabilities maintain some sepa-
rate organizations and perhaps nurture separate cultures based on our
different experiences and knowledge?

These concerns in turn raise questions about the meaningfulness of the
category, "people with disabilities," the subject of this chapter. Is that cate-
gory a product of false universalization, as some feminist writers claim is
true of the category "women?"[15] Is it not likely that living with disabilities
is very different for people with different disabilities, and different for
males and females, people of different ages, races, classes, occupations—

perhaps so different that to lump them all together in a single category
serves no useful purpose? Does the category obscure the differences and
perhaps even swallow up the diversity of experiences, absorbing them into
the experiences of articulate, relatively privileged white males with certain
disabilities?

Researchers working on disability have, as Fine and Asch put it, "focused
on disability as a unitary concept and have taken it to be not merely the
'master' status but apparently the exclusive status for disabled people"[16]
(Fine and Asch 1988, 3). One consequence is that gender differences in the
experience of disability have only recently been brought to light, primarily
in the writings of women with disabilities. Nevertheless, there is already
strong evidence that there are major gender differences in the experience of
disability (Fine and Asch 1988, 1–4). This gives us reason to suspect that
further research will reveal the importance of other factors, such as race
and class, to the experience of disability. Does this mean that we should be
suspicious of the category, "people with disabilities?" Yes. Does it mean we
should discard it, or does it retain some meaning and usefulness? Fine and
Asch suggest an answer when they consider similar questions about the cat-
egory "women with disabilities," the subject of their book:

> It is ironic to note that the very category that integrates this text, "dis-
> abled girls and women," exists wholly as a social construct. Why should a
> limb-deficient girl, a teenager with mental retardation, or a blind girl
> have anything in common with each other, or with a woman with breast
> cancer or another woman who is recovering from a stroke? What they
> share is similar treatment by a sexist and disability-phobic society. This is
> what makes it likely that they will be thrown together in school, in the
> unemployment line, in segregated recreational programs, in rehabilita-
> tion centers, and in legislation. (Fine and Asch 1988, 6)

Widespread perceptions that people with disabilities are similar in very
significant ways create the category, "people with disabilities." Thus it is
various aspects of their treatment by their societies that people with disabil-
ities are most likely to have in common; these will often be aspects of social
oppression. In North America, they include: verbal, medical, and physical
abuse; neglect of the most basic educational needs; sexual abuse and
exploitation; enforced poverty; harassment by public and private sector
bureaucracies; job discrimination; segregation in schools, housing, and
workshops; inaccessibility of buildings, transportation, and other public

facilities; social isolation due to prejudice and ignorant fear; erasure as a sexual being; and many more subtle manifestations of disability-phobia, experienced as daily stress and wounds to self-esteem. As in every oppressed group, not everyone will have experienced all aspects of the oppression, but the pattern of oppression produces overlapping patterns of experience among group members. This overlap, combined with the awareness that many things happened to them because they are identified *by others* as members of the group, can motivate people of diverse experiences to work together for their common welfare, to identify themselves willingly as members of the group, and to redefine for themselves what being one of the group means.[17]

I will discuss issues of diversity among people with disabilities and the dangers of false universalizing at length in chapter 3. For now, it is enough to say that I think "people with disabilities" is not a meaningless category as long as there is social oppression based on disability, even though the forms this oppression takes, and the ways it is experienced, may vary greatly among societies and according to other factors, such as age, gender, race, class, religion, caste, and sexual identity. What the category will mean (if anything) in the future will depend in part on what meanings people with disabilities give it through their cultural interpretations and their political actions. As Audre Lorde says of Black women and men: "[I]t is axiomatic that if we do not define ourselves for ourselves, we will be defined by others—for their use and to our detriment" (Lorde 1984, 45).

We have seen that disability is defined, and people are identified as disabled, for many purposes. How a society defines disability and whom it recognizes as disabled are of enormous psychological, social, economic, and political importance, both to people who identify themselves as disabled and to those who do not but are nevertheless given the label. How a society defines disability and whom it recognizes as disabled also reveal a great deal about that society's attitudes and expectations concerning the body, what it stigmatizes and what it considers 'normal' in physical appearance and performance, what activities it takes to be necessary and/or valuable and for whom, and its assumptions about gender, age, race, caste, and class.

In the ethically ideal situation, the only practical reason for defining disability would come from the need to identify people who should receive certain resources in order to have both the necessities of life and good opportunities to develop their potential and to participate in a given community. But this need would apply to everyone, not only to people with

disabilities. Thus, if this need were a society's only concern with disability, the category "people with disabilities" would be useless—too specific to identify those in need of resources and too general to identify what kinds of resources are needed. In such an ideal circumstance, the category itself would probably disappear.

2

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.[6] 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 individual 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 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 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.

Social Deconstruction of Disability

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 representatives. 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 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 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 measures 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 disability 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.

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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

5. Amundson suggests that societies are constructed with the biomedical norm of humanity in mind. Since my social and physical environment is clearly not constructed for the convenience of children, women, elderly people, ill people or people with disabilities, and since these collectively form the vast majority of people living in that environment, I am unwilling to believe that it was constructed for any norm. I think it was constructed for the young non-disabled male paradigm of humanity. I will discuss this more in the next chapter.

6. I do recognize that, for some purposes, it may be appropriate to distinguish old people with disabilities from young and middle-aged people with disabilities. For example, it would make sense for a society with very limited resources to give higher priority to providing expensive medical procedures to those who have more time left to benefit from them, or costly occupational retraining to those who will use it longer.

7. There is a conceptual distinction between the two, as Amundson insisted to me in a personal communication. People may be disabled without being ill, or ill without being disabled. The same illness may cause different disabilities, and different illnesses may cause the same disability. I am not disputing the conceptual distinction here, but I am discussing the politics of emphasizing the practical distinction, as Amundson does in his article.

8. Statistics on causes of disability vary among countries and among age groups within a country, and, of course, according to how disability is defined. Here I am relying on statistics on disability in Canada and the United States, when disability is defined as long-term major activity limitation. (Health and Welfare Canada and Statistics Canada 1981; Statistics Canada 1986 and 1991; Pope and Tarlov 1991; LaPlante 1991.) Worldwide, we would see considerable variation in patterns of disability, with malaria, leprosy, and disease consequences of malnutrition playing major roles in some countries.

9. I say may because some opportunities are not appropriate for children, and some opportunities cannot be given to certain groups by a society, such as the opportunity for men to bear children (not yet, anyway).

10. On the other hand, it is in the financial interest of those who provide health care and therapies for profit to define "health" narrowly so that as many people as possible will see themselves as needing their services. This is apparent in the advertising and operation of 'fitness' centres but also in the attitudes promoted in some of the nonallopathic or alternative medical practices. Here "health" is often a perpetually distant goal. People who consult such providers about a specific problem may come away believing themselves to be much sicker (by their newly acquired standards) than they ever imagined or felt themselves to be before. Nevertheless, I do not think this significantly increases the number of people who are identified by practitioners or identi-

fy themselves as disabled, because the stigma of disability is great enough to make most patients strongly resistant to this identification.

11. One striking example of this was reported by Newsweek (3 February 1992, 57). There is considerable variation, from one school district in the United States to another, in how learning disability is defined, depending partly on the resources that are available for helping children with learning disabilities.

12. The stigma of being ill is very complex, and for the sake of continuity I will not attempt to describe it here. I will describe it at length in chapter 3.

13. The people whose writings I am discussing here refer to themselves as the Deaf.

14. For superb examples of the contextuality of disability, see Sacks 1987 and 1992a.

15. This question is discussed extensively in feminist literature. For an introduction to it, I recommend Spelman 1988, Bordo 1990, and Higginbotham 1992.

16. This is an indication of the strength of the stigma of disability, at least in the minds of social scientists.

17. Linda Alcoff suggests that we should define "woman" thus: "[W]oman is a position from which a feminist politics can emerge rather than a set of attributes that are 'objectively identifiable'" (Alcoff 1988, 435). My approach to defining "people with disabilities" is influenced by Alcoff's suggestion.

2. The Social Construction of Disability

1. Nanette Sutherland pointed out to me that some disabilities may be entirely social. In some instances of psychiatric disability, there may be no relevant biological condition, only a psychiatric label that was originally misapplied and is still disabling to the person who is stuck with it. Nevertheless, the vast majority of disabilities are created by the interaction of biological and social factors.

2. The idea that disability is socially constructed is of such importance in identifying approaches to disability that a recent definition of Disability Studies by Linton, Mello, and O'Neill (quoted in Linton 1994, 46) says that it "reframes the study of disability by focusing on it as a social phenomenon, social construct, metaphor and culture . . ." (my emphasis).

3. For example, a friend who recently spent time on the spinal cord ward of a hospital in a major U.S. city discovered that many people on the ward had been shot.

4. For a discussion of the interactions of race, age, income, education, and marital status in the rates of work disability among women in the United States, see Russo and Jansen 1988.

5. For a discussion of how people with disabilities and those who care for them are affected by social expectations of pace, see Hillyer 1993, chapter 4, "Productivity and Pace."

6. I do not mean to imply that increasing the pace of professors' work would be bad (although it would be bad for me), only to show how expectations of pace have a role in constructing work disability.

7. Here I am speaking about people who do not receive private disability insurance benefits, settlements from accident claims, veterans' disability benefits, or workers' compensation benefits, any of which may be high enough to keep them out of poverty. In Canada, the majority of people with disabilities are not eligible for these more adequate forms of support.

8. An acquaintance of mine who uses a wheelchair and lives on a disability pension discovered recently, when her wheelchair wore out beyond repair, that her insurance company's policy is to pay for only one wheelchair in a lifetime. Wheelchairs are expensive items, and they do wear out. Not only is such a policy stupidly unrealistic, but it reinforces the message (which people who are ill or disabled encounter everywhere) that society expects her to get well or die.

9. For more on the cultural meanings of disabilities and illnesses, see Sontag 1977 and 1988; Fine and Asch 1988; Kleinman 1988; Morris 1991.

10. For a first-person account of living with facial scarring, see Grealy 1994.

11. I like much of Maxine Sheets-Johnstone's criticism of feminist theory of 'the body' and 'embodiment' that does not take account of the body or bodily experience, and in which "the body is simply the place one puts one's epistemology" (Sheets-Johnstone 1992, 43). Nevertheless, I do not accept her notion of the "body simpliciter," which I think takes too little account of the cultural meanings of bodily capabilities and possibilities, and of the cultural relativity of their importance to an individual.

12. For a fuller discussion of the limitations, for understanding disability, of feminist postmodern and other feminist theorizing about the body, see chapter 7.

13. Ellen Frank pointed this out to me.

14. For an interesting discussion of these questions as they apply to designing products, see Vanderheiden 1990.

15. For example, the Canadian-based group, Tetra Development Society, modifies existing equipment and creates new equipment to enable people with severe disabilities to participate in all aspects of life. Volunteers provide the engineering skills, and the capital cost of most projects is minimal.

16. For example, in Isabel Dyck's study of Canadian women with multiple sclerosis who left the paid labour force, several women mentioned the need for flexible, part-time hours, but only one woman had been able to find such a work arrangement (and that only temporarily) (Dyck 1995, 310).

17. I put this expression in quotation marks because, in my view, most people who are disabled are 'partially disabled,' that is, able to do some work under the right conditions.

18. This despite the fact that the new policy did not propose to reimburse us fully for our wage loss, but only at the same rate as wage loss replacement for workers on full disability leave.

19. Kavka explicitly did not describe employment for everyone in advantaged societies or employment for people with disabilities in other societies as a 'right,' since he did not regard these social goals as feasible at the time.

20. Stephen Hawking is one of the world's most influential theoretical physicists. He has had ALS for many years, which has reduced his voluntary muscle movement to the point that he needs a great deal of attendant care and the use of computers to communicate.

21. Moreover, we might consider her deserving of compensation for lost opportunities if someone else's actions deprived her of her ability. Still, we would not, I think, regard her as a person with a disability, if this was the only ability she had lost.

22. I say "wherever possible," because sometimes it is not possible. Not everyone can be given the ability to participate in all the major aspects of life in a society. For example, some people with mental disabilities cannot be given the ability to understand political issues or the voting process.

23. For a good overview of the current state of the debates and many references, see *Disability Studies Quarterly*, Spring 1994.

24. I do not mean to suggest that everything is fully accessible to people with disabilities in Sweden. Bill Bolt reports, based on a visit to Sweden to study conditions for people with disabilities there, that the benefits and practical help are very generous (by US and Canadian standards), but, in his opinion, "they have gained little physical, financial, or psychic mainstreaming, freedom, or productivity" (Bolt 1994, 18).

25. This statistic is from the survey conducted by Louis Harris and Associates for the National Organization on Disability, reported in *Disability Studies Quarterly*, Summer 1994: 13–14.

26. It is ironic that the belief in good luck which seems to underlie people's unwillingness to provide for their possible disablement is not fully balanced by belief in the bad luck of people with disabilities, who are often blamed for their conditions. Perhaps people without disabilities do not really believe it is a matter of luck at all, but a matter of their own control, effort, and moral worthiness. Or perhaps their beliefs are a confused, unexamined mixture of the two. I will discuss the myths of control and their consequences in chapter 4.

27. Gregory Kavka believed that the unpleasantness of thinking about the contingency of disability interferred with people's willingness to plan for long-term disability (Kavka 1992, 277). We find thinking of accident or sudden illness unpleasant too, but we do plan for acute medical care, so I suspect a stronger psychological force—fear so substantial as to prevent identification—is at work in relation to disability.

28. Anita Silvers points out that the suicide rate among people with disabilities is remarkably low considering how often non-disabled people declare that they would rather be dead than "confined to a wheelchair" (Silvers 1994, 159).

29. I realize that this statement violates what Hugh Gallagher calls "the new stereotype" of people with disabilities as basically non-disabled people who just happen to ride around in wheelchairs (Gallagher 1993), but the fact is that many severely disabled people cannot live without frequent daily help from others. For example, imagine telling Stephen Hawking that his goal should be to live independently. I discuss the issue of independence at length in chapter 6.

3. Disability as Difference

1. Fortunately, this is changing. As disability rights organizations and people with disability rights perspectives gain more cultural representation, they create a proud subculture in which one can participate even at a distance.

2. Phyllis Mueller, who was interviewed by Cheri Register, recalled: "The first day I ever realized you could be happy and still sick was a real red-letter day" (Register 1987, 315). Nancy Mairs, seconding Mueller's insight, says, "it is possible to be *both* sick *and* happy. This good news, once discovered, demands to be shared" (Mairs 1994, 127).

3. For example, see Driedger and Gray 1992, an international anthology in which women with disabilities describe their lives.

4. An important exception to these generalizations is that attitudes in some societies differentiate between disability in the elderly and disability in the

nonelderly, with disability being unlikely to affect the respect accorded to the elderly or the recognition of their remaining abilities.

5. I will return to the topic of control and idealization in chapter 4.

6. Sobsey estimates, based on studies in the United States and Canada, that people with disabilities are abused sexually 50 percent more often than people without disabilities.

7. Other 'Others' may also be less inclined to treat people with disabilities as 'the Other.' Robert Murphy, a professor of anthropology at Columbia University who became paralyzed in middle age, reported that students, most women, and black men ("fellow Outsiders,") became more open, relaxed, and friendly to him when he started using a wheelchair (Murphy 1990, 126–28).

8. For an interesting discussion of this issue, see Gill 1994.

9. For a different view of acute illness, see Arthur W. Frank (1991). Frank says, "(t)he healthy can begin to value illness by doubting the standard of productivity by which they measure their lives" (118).

10. I discuss cultural myths of control of the body in chapter 4. In chapter 7 I discuss at length some insights of people with disabilities concerning the value of transcending the body and strategies for doing so.

11. I will take up the theme of dependency and interdependence again in chapter 6.

12. I cannot even begin here to credit everyone I have read on these subjects over the years, much less everyone who has made a major contribution to the debates on universalization and essentialism. I refer in this discussion to only a few feminist intellectuals whose work has been important to my own recent thinking about how these debates apply to issues of disability.

13. It is important to note that most of the original feminist standpoint epistemologists qualified their claims about epistemic advantages in similar ways, that is, they did not claim that social positions by themselves conferred epistemic standpoints on those who occupied them.

14. Women with disabilities are also organizing separately, having found that early organizations of people with disabilities tended to ignore both significant differences between men's and women's experiences and issues of particular importance to women with disabilities. In Canada, women have become leaders in organizations of people with disabilities, which now reflect somewhat better women's experiences and issues, but women with disabilities still organize separately.

15. In a sense, the extreme form of emphasizing similarities is 'passing.' For good discussions of passing as non-disabled, see Todoroff and Lewis 1992; Hillyer 1993, chapter 8.