

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.



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 inability 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 diabetes⁸ 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) may⁹ 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 Deaf¹³ 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 lan-

guage 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 unwillingness 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 physical conditions as ordinary living arrangements and their lives as ordinary lives, despite their medicalization by professionals and most people's insistence 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 contextual 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 reinforce 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 separate 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 category 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 category "women with disabilities," the subject of their book:

It is ironic to note that the very category that integrates this text, "disabled 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 rehabilitation 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 disabilities 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.