We need a feminist theory of disability, both because 16 percent of women are disabled, and because the oppression of disabled people is closely linked to the cultural oppression of the body. Disability is not a biological given; like gender, it is socially constructed from biological reality. Our culture idealizes the body and demands that we control it. Thus, although most people will be disabled at some time in their lives, the disabled are made "the other," who symbolize failure of control and the threat of pain, limitation, dependency, and death. If disabled people and their knowledge were fully integrated into society, everyone's relation to her/his real body would be liberated.

In 1985, I fell ill overnight with what turned out to be a disabling chronic disease. In the long struggle to come to terms with it, I had to learn to live with a body that felt entirely different to me—weak, tired, painful, nauseated, dizzy, unpredictable. I learned at first by listening to other people with chronic illnesses or disabilities; suddenly able-bodied people seemed to me profoundly ignorant of everything I most needed to know. Although doctors told me there was a good chance I would eventually recover completely, I realized after a year that waiting to get well, hoping to recover my healthy body, was a dangerous strategy. I began slowly to identify with my new, disabled body and to learn to work with it. As I moved back into the world, I also began to experience the world as structured for people who have no weaknesses. The process of encountering the able-bodied world led me gradually to identify myself as a disabled person, and to reflect on the nature of disability.

Some time ago, I decided to delve into what I assumed would be a substantial philosophical literature in medical ethics on the nature and experience of disability. I consulted The Philosopher's Index, looking under "Disability," "Handicap," "Illness," and "Disease." This was a depressing experience. At least 90% of philosophical articles on these topics are concerned with two questions: Under what conditions is it morally permissible/right to kill/let die a disabled person and how potentially disabled does a fetus have to be before it is permissible/right to prevent its being born? Thus, what I have to say here
about disability is not a response to philosophical literature on the subject. Instead, it reflects what I have learned from the writings of other disabled people (especially disabled women), from talking with disabled people who have shared their insights and experiences with me, and from my own experience of disability. It also reflects my commitment to feminist theory, which offers perspectives and categories of analysis that help to illuminate the personal and social realities of disability, and which would, in turn, be enriched by a greater understanding of disability.

We need a theory of disability. It should be a social and political theory, because disability is largely socially-constructed, but it has to be more than that; any deep understanding of disability must include thinking about the ethical, psychological and epistemic issues of living with disability. This theory should be feminist, because more than half of disabled people are women and approximately 16% of women are disabled (Fine and Asch 1988), and because feminist thinkers have raised the most radical issues about cultural attitudes to the body. Some of the same attitudes about the body which contribute to women's oppression generally also contribute to the social and psychological disablement of people who have physical disabilities. In addition, feminists are grappling with issues that disabled people also face in a different context: Whether to stress sameness or difference in relation to the dominant group and in relation to each other; whether to place great value on independence from the help of other people, as the dominant culture does, or to question a value-system which distrusts and de-values dependence on other people and vulnerability in general; whether to take full integration into male dominated/able-bodied society as the goal, seeking equal power with men/able-bodied people in that society, or whether to preserve some degree of separate culture, in which the abilities, knowledge and values of women/the disabled are specifically honoured and developed.²

Disabled women struggle with both the oppressions of being women in male-dominated societies and the oppressions of being disabled in societies dominated by the able-bodied. They are bringing the knowledge and concerns of women with disabilities into feminism and feminist perspectives into the disability rights movement. To build a feminist theory of disability that takes adequate account of our differences, we will need to know how experiences of disability and the social oppression of the disabled interact with sexism, racism and class oppression. Michelle Fine and Adrienne Asch and the contributors to their 1988 volume, Women and Disabilities, have made a major contribution to our understanding of the complex interactions of gender and disability. Barbara Hillyer Davis has written in depth about the issue of dependency/independence as it relates to disability and feminism (Davis 1984). Other important contributions to theory are scattered throughout the extensive, primarily experiential, writing by disabled women;³ this work offers vital insights into the nature of embodiment and the experience of oppression.
Unfortunately, feminist perspectives on disability are not yet widely discussed in feminist theory, nor have the insights offered by women writing about disability been integrated into feminist theorizing about the body. My purpose in writing this essay is to persuade feminist theorists, especially feminist philosophers, to turn more attention to constructing a theory of disability and to integrating the experiences and knowledge of disabled people into feminist theory as a whole. Toward this end I will discuss physical disability from a theoretical perspective, including: some problems of defining it (here I will criticize the most widely-used definitions—those of the United Nations); the social construction of disability from biological reality on analogy with the social construction of gender; cultural attitudes toward the body which oppress disabled people while also alienating the able-bodied from their own experiences of embodiment; the "otherness" of disabled people; the knowledge that disabled people could contribute to culture from our diverse experiences and some of the ways this knowledge is silenced and invalidated. Along the way, I will describe briefly three issues discussed in disability theory that have been taken up in different contexts by feminist theory: sameness vs. difference, independence vs. dependency and integration vs. separatism.

I do not presume to speak for disabled women. Like everyone who is disabled, I have a particular standpoint determined in part by both my physical condition and my social situation. My own disability may be temporary, it could get better or worse. My disability is usually invisible (except when I use a walking stick). I am a white university professor who has adequate medical and long-term disability insurance; that makes me very privileged among the disabled. I write what I can see from my standpoint. Because I do not want simply to describe my own experience but to understand it in a much larger context, I must venture beyond what I know first-hand. I rely on others to correct my mistakes and fill in those parts of the picture I cannot see.

**WHO IS PHYSICALLY DISABLED?**

The United Nations 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. (U.N. 1983: I.c. 6-7)

These definitions may be good-enough for the political purposes of the U.N. They have two advantages: First, they clearly include many conditions that are not always recognized by the general public as disabling, for example, debilitating chronic illnesses that limit people's activities but do not necessarily cause any visible disability, such as Crohn's Disease. Second, the definition of "handicap" explicitly recognizes the possibility that the primary cause of a disabled person's inability to do certain things may be social—denial of opportunities, lack of accessibility, lack of services, poverty, discrimination—which it often is.

However, by trying to define "impairment" and "disability" in physical terms and "handicap" in cultural, physical and social terms, the U.N. document appears to be making a shaky distinction between the physical and the social aspects of disability. Not only the "normal" roles for one's age, sex, society, and culture, but also "normal" structure and function, and "normal" ability to perform an activity, depend on the society in which the standards of normality are generated. Paradigms of health and ideas about appropriate kinds and levels of performance are culturally-dependent. In addition, within each society there is much variation from the norm of any ability; at what point does this variation become disability? The answer depends on such factors as what activities a society values and how it distributes labour and resources. The idea that there is some universal, perhaps biologically or medically-describable paradigm of human physical ability is an illusion. Therefore, I prefer to use a single term, "disability," and to emphasize that disability is socially constructed from biological reality.

Another objection I have to the U.N. definitions is that they imply that women can be disabled, but not handicapped, by being unable to do things which are not considered part of the normal role for their sex. For example, if a society does not consider it essential to a woman's normal role that she be able to read, then a blind woman who is not provided with education in Braille is not handicapped, according to these definitions.

In addition, these 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 a society which provides few resources to allow disabled people to participate in it will be likely to marginalize all the disabled,
including the old, and to define the appropriate roles of old people as very limited, thus handicapping them. Aging is disabling. Recognizing this helps us to see that disabled people are not "other," that they are really "us." 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 an understanding of disability that does 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 liberating those who are disabled now.

Ultimately, we might eliminate the category of "the disabled" altogether, and simply talk about individuals' physical abilities in their social context. For the present, although "the disabled" is a category of "the other" to the able-bodied, for that very reason it is also a politically useful and socially meaningful category to those who are in it. Disabled people share forms of social oppression, and the most important measures to relieve that oppression have been initiated by disabled people themselves. Social oppression may be the only thing the disabled have in common; our struggles with our bodies are extremely diverse.

Finally, in thinking about disability we have to keep in mind that a society's labels do not always fit the people to whom they are applied. Thus, some people are perceived as disabled who do not experience themselves as disabled. Although they have physical conditions that disable other people, because of their opportunities and the context of their lives, they do not feel significantly limited in their activities (see Sacks 1988); these people may be surprised or resentful that they are considered disabled. On the other hand, many people whose bodies cause them great physical, psychological and economic struggles are not considered disabled 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 people when they cannot and refuses to acknowledge and support their struggles. Of course, no one wants the social stigma associated with disability, but social recognition of disability determines the practical help a person receives from doctors, government agencies, insurance companies, charity organizations, and often from family and friends. Thus, how a society defines disability and whom it recognizes as disabled are of enormous psychological, economic and social importance, both to people who are experiencing themselves as disabled and to those who are not but are nevertheless given the label.

There is no definitive answer to the question: Who is physically disabled? Disability has social, experiential and biological components, present and recognized in different measures for different people. Whether a particular
physical condition is disabling changes with time and place, depending on such factors as social expectations, the state of technology and its availability to people in that condition, the educational system, architecture, attitudes towards physical appearance, and the pace of life. (If, for example, the pace of life increases without changes in other factors, more people become disabled simply because fewer people can keep up the "normal" pace.)

THE SOCIAL CONSTRUCTION OF DISABILITY.

If we ask the questions: Why are so many disabled people unemployed or underemployed, impoverished, lonely, isolated; why do so many find it difficult or impossible to get an education (Davis and Marshall 1987; Fine and Asch 1988, 10-11); why are they victims of violence and coercion; why do able-bodied people ridicule, avoid, pity, stereotype and patronize them?, we may be tempted to see the disabled as victims of nature or accident. Feminists should be, and many are, profoundly suspicious of this answer. We are used to countering claims that insofar as women are oppressed they are oppressed by nature, which puts them at a disadvantage in the competition for power and resources. We know that if being biologically female is a disadvantage, it is because a social context makes it a disadvantage. From the standpoint of a disabled person, one can see how society could minimize the disadvantages of most disabilities, and, in some instances, turn them into advantages.

Consider an extreme case: the situation of physicist Stephen Hawking, who has had Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease) for more than 26 years. Professor Hawking can no longer speak and is capable of only the smallest muscle movements. Yet, in his context of social and technological support, he is able to function as a professor of physics at Cambridge University; indeed he says his disability has given him the advantage of having more time to think, and he is one of the foremost theoretical physicists of our time. He is a courageous and talented man, but he is able to live the creative life he has only because of the help of his family, three nurses, a graduate student who travels with him to maintain his computer-communications systems, and the fact that his talent had been developed and recognized before he fell seriously ill (Newsweek 1988).

Many people consider providing resources for disabled people a form of charity, superogatory in part because the disabled are perceived as unproductive members of society. Yet most disabled people are placed in a double-bind: they have access to inadequate resources because they are unemployed or underemployed, and they are unemployed or underemployed because they lack the resources that would enable them to make their full contribution to society (Matthews 1983; Hannaford 1985). Often governments and charity organizations will spend far more money to keep disabled people in institutions where they have no chance to be productive than they will spend to en-
able the same people to live independently and productively. In addition, many of the "special" resources the disabled need merely compensate for bad social planning that is based on the illusion that everyone is young, strong, healthy (and, often, male).

Disability is also frequently regarded as a personal or family problem rather than a matter for social responsibility. Disabled people are often expected to overcome obstacles to participation by their own extraordinary efforts, or their families are expected to provide what they need (sometimes at great personal sacrifice). Helping in personal or family matters is seen as supererogatory for people who are not members of the family.

Many factors contribute to determining whether providing a particular resource is regarded as a social or a personal (or family) responsibility. One such factor is whether the majority can identify with people who need the resource. Most North Americans feel that society should be organized to provide short-term medical care made necessary by illness or accident, I think because they can imagine themselves needing it. Relatively few people can identify with those who cannot be "repaired" by medical intervention. Sue Halpern makes the following observation:

Physical health is contingent and often short-lived. But this truth eludes us as long as we are able to walk by simply putting one foot in front of the other. As a consequence, empathy for the disabled is unavailable to most able-bodied persons. Sympathy, yes, empathy, no, for every attempt to project oneself into that condition, to feel what it is like not to be ambulatory, for instance, is mediated by an ability to walk (Halpern 1988, 3).

If the able-bodied saw the disabled as potentially themselves or as their future selves, they would be more inclined to feel that society should be organized to provide the resources that would make disabled people fully integrated and contributing members. They would feel that "charity" is as inappropriate a way of thinking about resources for disabled people as it is about emergency medical care or education.

Careful study of the lives of disabled people will reveal how artificial the line is that we draw between the biological and the social. Feminists have already challenged this line in part by showing how processes such as childbirth, menstruation and menopause, which may be represented, treated, and therefore experienced as illnesses or disabilities, are socially-constructed from biological reality (Rich 1976; Ehrenreich and English 1979). Disabled people's relations to our bodies involve elements of struggle which perhaps cannot be eliminated, perhaps not even mitigated, by social arrangements. But, much of what is disabling about our physical conditions is also a consequence of social arrangements (Finger 1983; Fine and Asch 1988) which could, but
do not, either compensate for our physical conditions, or accommodate them so that we can participate fully, or support our struggles and integrate us into the community and our struggles into the cultural concept of life as it is ordinarily lived.

Feminists have shown that the world has been designed for men. In North America at least, 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 made for them, but menstruation cannot. Much of the world is also structured as though everyone is physically strong, as though all bodies are "ideally shaped," as though everyone can walk, hear and see well, as though everyone can work and play at a pace that is not compatible with any kind of illness or pain, as though no one is ever dizzy or incontinent or simply needs to sit or lie down. (For instance, where could you sit down in a supermarket if you needed to?) Not only the architecture, but the entire physical and social organization of life, assumes that we are either strong and healthy and able to do what the average able-bodied person can do, or that we are completely disabled, unable to participate in life.

In the split between the public and the private worlds, women (and children) have been relegated to the private, and so have the disabled, the sick and the old (and mostly women take care of them). The public world is the world of strength, the positive (valued) body, performance and production, the able-bodied and youth. Weakness, illness, rest and recovery, pain, death and the negative (de-valued) body are private, generally hidden, and often neglected. Coming into the public world with illness, pain or a de-valued body, we encounter resistance to mixing the two worlds; the split is vividly revealed. Much of our experience goes underground, because there is no socially acceptable way of expressing it and having our physical and psychological experience acknowledged and shared. A few close friends may share it, but there is a strong impulse to protect them from it too, because it seems so private, so unacceptable. I found that, after a couple of years of illness, even answering the question, "How are you?" became a difficult, conflict-ridden business. I don't want to alienate my friends from my experience, but I don't want to risk their discomfort and rejection by telling them what they don't want to know.

Disabled people learn that many, perhaps most, able-bodied people do not want to know about suffering caused by the body. Visibly disabled women report that curiosity about medical diagnoses, physical appearance and the sexual and other intimate aspects of disability is more common than willingness to listen and try to understand the experience of disability (Matthews 1983). It is not unusual for people with invisible disabilities to keep them entirely secret from everyone but their closest friends.
Contrary to what Sue Halpern says, it is not simply because they are in able bodies that the able-bodied fail to identify with the disabled. Able-bodied people can often make the imaginative leap into the skins of people physically unlike themselves; women can identify with a male protagonist in a story, for example, and adults can identify with children or with people much older than themselves. Something more powerful than being in a different body is at work. Suffering caused by the body, and the inability to control the body, are despised, pitied, and above all, feared. This fear, experienced individually, is also deeply embedded in our culture.

THE OPPRESSION OF DISABLED PEOPLE IS THE OPPRESSION OF EVERYONE'S REAL BODY.

Our real human bodies are exceedingly diverse—in size, shape, colour, texture, structure, function, range and habits of movement, and development—and they are constantly changing. Yet we do not absorb or reflect this simple fact in our culture. Instead, we idealize the human body. Our physical ideals change from time to time, but we always have ideals. These ideals are not just about appearance; they are also ideals of strength and energy and proper control of the body. We are perpetually bombarded with images of these ideals, demands for them, and offers of consumer products and services to help us achieve them. Idealizing the body prevents everyone, able-bodied and disabled, from identifying with and loving her/his real body. Some people can have the illusion of acceptance that comes from believing that their bodies are “close enough” to the ideal, but this illusion only draws them deeper into identifying with the ideal and into the endless task of reconciling the reality with it. Sooner or later they must fail.

Before I became disabled, I was one of those people who felt “close enough” to cultural ideals to be reasonably accepting of my body. Like most feminists I know, I was aware of some alienation from it, and I worked at liking my body better. Nevertheless, I knew in my heart that too much of my liking still depended on being “close enough.” When I was disabled by illness, I experienced a much more profound alienation from my body. After a year spent mostly in bed, I could barely identify my body as my own. I felt that “it” was torturing “me,” trapping me in exhaustion, pain and inability to do many of the simplest things I did when I was healthy. The shock of this experience and the effort to identify with a new, disabled body, made me realize I had been living a luxury of the able-bodied. The able-bodied can postpone the task of identifying with their real bodies. The disabled don’t have the luxury of demanding that their bodies fit the physical ideals of their culture. As Barbara Hillyer Davis says: “For all of us the difficult work of finding (one’s) self includes the body, but people who live with disability in a society that glorifies fitness and physical conformity are forced to understand more fully what bodily integrity means” (Davis 1984,3).
In a society which idealizes the body, the physically disabled are marginalized. People learn to identify with their own strengths (by cultural standards) and to hate, fear and neglect their own weaknesses. The disabled are not only de-valued for their de-valued bodies (Hannaford 1985), they are constant reminders to the able-bodied of the negative body—of what the able-bodied are trying to avoid, forget and ignore (Lessing 1981). For example, if someone tells me she is in pain, she reminds me of the existence of pain, the imperfection and fragility of the body, the possibility of my own pain, the inevitability of it. The less willing I am to accept all these, the less I want to know about her pain; if I cannot avoid it in her presence, I will avoid her. I may even blame her for it. I may tell myself that she could have avoided it, in order to go on believing that I can avoid it. I want to believe I am not like her; I cling to the differences. Gradually, I make her “other” because I don’t want to confront my real body, which I fear and cannot accept.  

Disabled people can participate in marginalizing ourselves. We can wish for bodies we do not have, with frustration, shame, self-hatred. We can feel trapped in the negative body; it is our internalized oppression to feel this. Every (visibly or invisibly) disabled person I have talked to or read has felt this; some never stop feeling it. In addition, disabled women suffer more than disabled men from the demand that people have “ideal” bodies, because in patriarchal culture people judge women more by their bodies than they do men. Disabled women often do not feel seen (because they are often not seen) by others as whole people, especially not as sexual people (Campling 1981; Matthews 1983; Hannaford 1985; Fine and Asch 1988). Thus, part of their struggle against oppression is a much harder version of the struggle able-bodied women have for a realistic and positive self-image (Bogle and Shaul 1981). On the other hand, disabled people who cannot hope to meet the physical ideals of a culture can help reveal that those ideals are not “natural” or “normal” but artificial social creations that oppress everyone.

Feminist theorists have probed the causes of our patriarchal culture’s desire for control of the body—fear of death, fear of the strong impulses and feelings the body gives us, fear of nature, fear and resentment of the mother’s power over the infant (de Beauvoir 1949; Dinnerstein 1976; Griffin 1981). Idealizing the body and wanting to control it go hand-in-hand; it is impossible to say whether one causes the other. A physical ideal gives us the goal of our efforts to control the body, and the myth that total control is possible deceives us into striving for the ideal. The consequences for women have been widely discussed in the literature of feminism. The consequences for disabled people are less often recognized. In a culture which loves the idea that the body can be controlled, those who cannot control their bodies are seen (and may see themselves) as failures.

When you listen to this culture in a disabled body, you hear how often health and physical vigour are talked about as if they were moral virtues. Peo-
people constantly praise others for their "energy," their stamina, their ability to work long hours. Of course, acting on behalf of one's health can be a virtue, and undermining one's health can be a vice, but "success" at being healthy, like beauty, is always partly a matter of luck and therefore beyond our control. When health is spoken of as a virtue, people who lack it are made to feel inadequate. I am not suggesting that it is always wrong to praise people's physical strength or accomplishments, any more than it is always wrong to praise their physical beauty. But just as treating cultural standards of beauty as essential virtues for women harms most women, treating health and vigour as moral virtues for everyone harms people with disabilities and illnesses.

The myth that the body can be controlled is not easily dispelled, because it is not very vulnerable to evidence against it. When I became ill, several people wanted to discuss with me what I thought I had done to "make myself" ill or "allow myself" to become sick. At first I fell in with this, generating theories about what I had done wrong; even though I had always taken good care of my health, I was able to find some (rather far-fetched) accounts of my responsibility for my illness. When a few close friends offered hypotheses as to how they might be responsible for my being ill, I began to suspect that something was wrong. Gradually, I realized that we were all trying to believe that nothing this important is beyond our control.

Of course, there are sometimes controllable social and psychological forces at work in creating ill health and disability (Kleinman 1988). Nevertheless, our cultural insistence on controlling the body blames the victims of disability for failing and burdens them with self-doubt and self-blame. The search for psychological, moral and spiritual causes of illness, accident and disability is often a harmful expression of this insistence on control (see Sontag 1977).

Modern Western medicine plays into and conforms to our cultural myth that the body can be controlled. Collectively, doctors and medical researchers exhibit very little modesty about their knowledge. They focus their (and our) attention on cures and imminent cures, on successful medical interventions. Research, funding and medical care are more directed toward life-threatening conditions than toward chronic illnesses and disabilities. Even pain was relatively neglected as a medical problem until the second half of this century. Surgery and saving lives bolster the illusion of control much better than does the long, patient process of rehabilitation or the management of long-term illness. These latter, less visible functions of medicine tend to be performed by nurses, physiotherapists and other low-prestige members of the profession. Doctors are trained to do something to control the body, to "make it better" (Kleinman 1988); they are the heroes of medicine. They may like being in the role of hero, but we also like them in that role and try to keep them there, because we want to believe that someone can always "make it better." As long as we cling to this belief, the patients who cannot be "repaired"—the chronically ill, the disabled and the dying—will symbolize the
failure of medicine and more, the failure of the Western scientific project to control nature. They will carry this stigma in medicine and in the culture as a whole.

When philosophers of medical ethics confine themselves to discussing life-and-death issues of medicine, they help perpetuate the idea that the main purpose of medicine is to control the body. Life-and-death interventions are the ultimate exercise of control. If medical ethicists looked more closely at who needs and who receives medical help, they would discover a host of issues concerning how medicine and society understand, mediate, assist with and integrate experiences of illness, injury and disability.

Because of the heroic approach to medicine, and because disabled people's experience is not integrated into the culture, most people know little or nothing about how to live with long-term or life-threatening illness, how to communicate with doctors and nurses and medical bureaucrats about these matters, how to live with limitation, uncertainty, pain, nausea, and other symptoms when doctors cannot make them go away. Recently, patients' support groups have arisen to fill this gap for people with nearly every type of illness and disability. They are vitally important sources of knowledge and encouragement for many of us, but they do not fill the cultural gulf between the able-bodied and the disabled. The problems of living with a disability are not private problems, separable from the rest of life and the rest of society. They are problems which can and should be shared throughout the culture as much as we share the problems of love, work and family life.

Consider the example of pain. It is difficult for most people who have not lived with prolonged or recurring pain to understand the benefits of accepting it. Yet some people who live with chronic pain speak of "making friends" with it as the road to feeling better and enjoying life. How do they picture their pain and think about it; what kind of attention do they give it and when; how do they live around and through it, and what do they learn from it? We all need to know this as part of our education. Some of the fear of experiencing pain is a consequence of ignorance and lack of guidance. The effort to avoid pain contributes to such widespread problems as drug and alcohol addiction, eating disorders, and sedentary lives. People with painful disabilities can teach us about pain, because they can't avoid it and have had to learn how to face it and live with it. The pernicious myth that it is possible to avoid almost all pain by controlling the body gives the fear of pain greater power than it should have and blames the victims of unavoidable pain. The fear of pain is also expressed or displaced as a fear of people in pain, which often isolates those with painful disabilities. All this is unnecessary. People in pain and knowledge of pain could be fully integrated into our culture, to everyone's benefit.

If we knew more about pain, about physical limitation, about loss of abilities, about what it is like to be "too far" from the cultural ideal of the body,
perhaps we would have less fear of the negative body, less fear of our own weaknesses and “imperfections,” of our inevitable deterioration and death. Perhaps we could give up our idealizations and relax our desire for control of the body; until we do, we maintain them at the expense of disabled people and at the expense of our ability to accept and love our own real bodies.

DISABLED PEOPLE AS “OTHER”

When we make people “other,” we group them together as the objects of our experience instead of regarding them as fellow subjects of experience with whom we might identify. If you are “other” to me, I see you primarily as symbolic of something else—usually, but not always, something I reject and fear and that I project onto you. We can all do this to each other, but very often the process is not symmetrical, because one group of people may have more power to call itself the paradigm of humanity and to make the world suit its own needs and validate its own experiences. Disabled people are “other” to able-bodied people, and (as I have tried to show) the consequences are socially, economically and psychologically oppressive to the disabled and psychologically oppressive to the able-bodied. Able-bodied people may be “other” to disabled people, but the consequences of this for the able-bodied are minor (most able-bodied people can afford not to notice it). There are, however, several political and philosophical issues that being “other” to a more powerful group raises for disabled people.

I have said that for the able-bodied, the disabled often symbolize failure to control the body and the failure of science and medicine to protect us all. However, some disabled people also become symbols of heroic control against all odds; these are the “disabled heroes,” who are comforting to the able-bodied because they re-affirm the possibility of overcoming the body. Disabled heroes are people with visible disabilities who receive public attention because they accomplish things that are unusual even for the able-bodied. It is revealing that, with few exceptions (Helen Keller and, very recently, Stephen Hawking are among them), disabled heroes are recognized for performing feats of physical strength and endurance. While disabled heroes can be inspiring and heartening to the disabled, they may give the able-bodied the false impression that anyone can “overcome” a disability. Disabled heroes usually have extraordinary social, economic and physical resources that are not available to most people with those disabilities. In addition, many disabled people are not capable of performing physical heroics, because many (perhaps most) disabilities reduce or consume the energy and stamina of people who have them and do not just limit them in some particular kind of physical activity. Amputee and wheelchair athletes are exceptional, not because of their ambition, discipline and hard work, but because they are in better health than most disabled people can be. Arthritis, Parkinsonism and
stroke cause severe disability in far more people than do spinal cord injuries and amputations (Bury 1979). The image of the disabled hero may reduce the "otherness" of a few disabled people, but because it creates an ideal which most disabled people cannot meet, it increases the "otherness" of the majority of disabled people.

One recent attempt to reduce the "otherness" of disabled people is the introduction of the term, "differently-abled." I assume the point of using this term is to suggest that there is nothing wrong with being the way we are, just different. Yet to call someone "differently-abled" is much like calling her "differently-coloured" or "differently-gendered." It says: "This person is not the norm or paradigm of humanity." If anything, it increases the "otherness" of disabled people, because it reinforces the paradigm of humanity as young, strong and healthy, with all body parts working "perfectly," from which this person is "different." Using the term "differently-abled" also suggests a (polite? patronizing? protective? self-protective?) disregard of the special difficulties, struggles and suffering disabled people face. We are dis-abled. We live with particular social and physical struggles that are partly consequences of the conditions of our bodies and partly consequences of the structures and expectations of our societies, but they are struggles which only people with bodies like ours experience.

The positive side of the term "differently-abled" is that it might remind the able-bodied that to be disabled in some respects is not to be disabled in all respects. It also suggests that a disabled person may have abilities that the able-bodied lack in virtue of being able-bodied. Nevertheless, on the whole, the term "differently-abled" should be abandoned, because it reinforces the able-bodied paradigm of humanity and fails to acknowledge the struggles disabled people face.

The problems of being "the other" to a dominant group are always politically complex. One solution is to emphasize similarities to the dominant group in the hope that they will identify with the oppressed, recognize their rights, gradually give them equal opportunities, and eventually assimilate them. Many disabled people are tired of being symbols to the able-bodied, visible only or primarily for their disabilities, and they want nothing more than to be seen as individuals rather than as members of the group, "the disabled." Emphasizing similarities to the able-bodied, making their disabilities unnoticeable in comparison to their other human qualities may bring about assimilation one-by-one. It does not directly challenge the able-bodied paradigm of humanity, just as women moving into traditionally male arenas of power does not directly challenge the male paradigm of humanity, although both may produce a gradual change in the paradigms. In addition, assimilation may be very difficult for the disabled to achieve. Although the able-bodied like disabled tokens who do not seem very different from themselves, they may need someone to carry the burden of the negative body as long as they
continue to idealize and try to control the body. They may therefore resist the assimilation of most disabled people.

The reasons in favour of the alternative solution to "otherness"—emphasizing difference from the able-bodied—are also reasons for emphasizing similarities among the disabled, especially social and political similarities. Disabled people share positions of social oppression that separate us from the able-bodied, and we share physical, psychological and social experiences of disability. Emphasizing differences from the able-bodied demands that those differences be acknowledged and respected and fosters solidarity among the disabled. It challenges the able-bodied paradigm of humanity and creates the possibility of a deeper challenge to the idealization of the body and the demand for its control. Invisibly disabled people tend to be drawn to solutions that emphasize difference, because our need to have our struggles acknowledged is great, and we have far less experience than those who are visibly disabled of being symbolic to the able-bodied.

Whether one wants to emphasize sameness or difference in dealing with the problem of being "the other" depends in part on how radically one wants to challenge the value-structure of the dominant group. A very important issue in this category for both women and disabled people is the value of independence from the help of others, so highly esteemed in our patriarchal culture and now being questioned in feminist ethics (see, for example, Sherwin 1984, 1987; Kittay and Meyers 1987) and discussed in the writings of disabled women (see, for example, Fisher and Galler 1981; Davis 1984; Frank 1988). Many disabled people who can see the possibility of living as independently as any able-bodied person, or who have achieved this goal after long struggle, value their independence above everything. Dependence on the help of others is humiliating in a society which prizes independence. In addition, this issue holds special complications for disabled women; reading the stories of women who became disabled as adults, I was struck by their struggle with shame and loss of self-esteem at being transformed from people who took physical care of others (husbands and children) to people who were physically dependent. All this suggests that disabled people need every bit of independence we can get. Yet there are disabled people who will always need a lot of help from other individuals just to survive (those who have very little control of movement, for example), and to the extent that everyone considers independence necessary to respect and self-esteem, those people will be condemned to be de-valued. In addition, some disabled people spend tremendous energy being independent in ways that might be considered trivial in a culture less insistent on self-reliance; if our culture valued interdependence more highly, they could use that energy for more satisfying activities.

In her excellent discussion of the issue of dependency and independence, Barbara Hillyer Davis argues that women with disabilities and those who care for them can work out a model of reciprocity for all of us, if we are willing to
learn from them. “Reciprocity involves the difficulty of recognizing each other’s needs, relying on the other, asking and receiving help, delegating responsibility, giving and receiving empathy, respecting boundaries” (Davis 1984, 4). I hope that disabled and able-bodied feminists will join in questioning our cultural obsession with independence and ultimately replacing it with such a model of reciprocity. If all the disabled are to be fully integrated into society without symbolizing failure, then we have to change social values to recognize the value of depending on others and being depended upon. This would also reduce the fear and shame associated with dependency in old age—a condition most of us will reach.

Whether one wants to emphasize sameness or difference in dealing with the problems of being “other” is also related to whether one sees anything valuable to be preserved by maintaining, either temporarily or in the long run, some separateness of the oppressed group. Is there a special culture of the oppressed group or the seeds of a special culture which could be developed in a supportive context of solidarity? Do members of the oppressed group have accumulated knowledge or ways of knowing which might be lost if assimilation takes place without the dominant culture being transformed?

It would be hard to claim that disabled people as a whole have an alternative culture or even the seeds of one. One sub-group, the deaf, has a separate culture from the hearing, and they are fighting for its recognition and preservation, as well as for their right to continue making their own culture (Sacks 1988). Disabled people do have both knowledge and ways of knowing that are not available to the able-bodied. Although ultimately I hope that disabled people’s knowledge will be integrated into the culture as a whole, I suspect that a culture which fears and denigrates the real body would rather silence this knowledge than make the changes necessary to absorb it. It may have to be nurtured and cultivated separately while the able-bodied culture is transformed enough to receive and integrate it.

**THE KNOWLEDGE OF DISABLED PEOPLE AND HOW IT IS SILENCED**

In my second year of illness, I was reading an article about the psychological and philosophical relationship of mind to body. When the author painted a rosy picture of the experience of being embodied, I was outraged at the presumption of the writer to speak for everyone from a healthy body. I decided I didn’t want to hear anything about the body from anyone who was not physically disabled. Before that moment, it had not occurred to me that there was a world of experience from which I was shut out while I was able-bodied.

Not only do physically disabled people have experiences which are not available to the able-bodied, they are in a better position to transcend cultural mythologies about the body, because they cannot do things that the able-bodied feel they must do in order to be happy, “normal” and sane. For
example, paraplegics and quadriplegics have revolutionary things to teach about the possibilities of sexuality which contradict patriarchal culture's obsession with the genitals (Bullard and Knight 1981). Some people can have orgasms in any part of their bodies where they feel touch. One man said he never knew how good sex could be until he lost the feeling in his genitals. Few able-bodied people know these things, and, to my knowledge, no one has explored their implications for the able-bodied.

If disabled people were truly heard, an explosion of knowledge of the human body and psyche would take place. We have access to realms of experience that our culture has not tapped (even for medical science, which takes relatively little interest in people's experience of their bodies). Like women's particular knowledge, which comes from access to experiences most men do not have, disabled people's knowledge is dismissed as trivial, complaining, mundane (or bizarre), less than that of the dominant group.

The cognitive authority (Addelson 1983) of medicine plays an important role in distorting and silencing the knowledge of the disabled. Medical professionals have been given the power to describe and validate everyone's experience of the body. If you go to doctors with symptoms they cannot observe directly or verify independently of what you tell them, such as pain or weakness or numbness or dizziness or difficulty concentrating, and if they cannot find an objectively observable cause of those symptoms, you are likely to be told that there is "nothing wrong with you," no matter how you feel. Unless you are very lucky in your doctors, no matter how trustworthy and responsible you were considered to be before you started saying you were ill, your experience will be invalidated.13 Other people are the authorities on the reality of your experience of your body.

When you are very ill, you desperately need medical validation of your experience, not only for economic reasons (insurance claims, pensions, welfare and disability benefits all depend upon official diagnosis), but also for social and psychological reasons. People with unrecognized illnesses are often abandoned by their friends and families.14 Because almost everyone accepts the cognitive authority of medicine, the person whose bodily experience is radically different from medical descriptions of her/his condition is invalidated as a knower. Either you decide to hide your experience, or you are socially isolated with it by being labelled mentally ill15 or dishonest. In both cases you are silenced.

Even when your experience is recognized by medicine, it is often re-described in ways that are inaccurate from your standpoint. The objectively observable condition of your body may be used to determine the severity of your pain, for instance, regardless of your own reports of it. For example, until recently, relatively few doctors were willing to acknowledge that severe phantom limb pain can persist for months or even years after an amputation. The accumulated experience of doctors who were themselves amputees has begun
to legitimize the other patients’ reports (Madruaga 1979). When you are forced to realize that other people have more social authority than you do to describe your experience of your own body, your confidence in yourself and your relationship to reality is radically undermined. What can you know if you cannot know that you are experiencing suffering or joy; what can you communicate to people who don’t believe you know even this? Most people will censor what they tell or say nothing rather than expose themselves repeatedly to such deeply felt invalidation. They are silenced by fear and confusion. The process is familiar from our understanding of how women are silenced in and by patriarchal culture.

One final caution: As with women’s “special knowledge,” there is a danger of sentimentalizing disabled people’s knowledge and abilities and keeping us “other” by doing so. We need to bring this knowledge into the culture and to transform the culture and society so that everyone can receive and make use of it, so that it can be fully integrated, along with disabled people, into a shared social life.

CONCLUSION

I have tried to introduce the reader to the rich variety of intellectual and political issues that are raised by experiences of physical disability. Confronting these issues has increased my appreciation of the insights that feminist theory already offers into cultural attitudes about the body and the many forms of social oppression. Feminists have been challenging medicine’s authority for many years now, but not, I think, as radically as we would if we knew what disabled people have to tell. I look forward to the development of a full feminist theory of disability. We need a theory of disability for the liberation of both disabled and able-bodied people, since the theory of disability is also the theory of the oppression of the body by a society and its culture.

NOTES

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1. Itzhak Perlman, when asked in a recent CBC interview about the problems of the disabled, said disabled people have two problems: the fact that the world is not made for people with any weaknesses but for supermen and the attitudes of able-bodied people.

2. An excellent description of this last issue as it confronts the deaf is found in Sacks 1988.


4. We also need a feminist theory of mental disability, but I will not be discussing mental disability in this essay.
5. In a recent article in Signs, Linda Alcoff argues that we should define "woman" thus: "woman is a position from which a feminist politics can emerge rather than a set of attributes that are 'objectively identifiable.'" (Alcoff 1988, 435). I think a similar approach may be the best one for defining "disability."

6. For example, Pelvic Inflammatory Disease causes severe prolonged disability in some women. These women often have to endure medical diagnoses of psychological illness and the skepticism of family and friends, in addition to having to live with chronic severe pain. See Moore 1985.

7. Feminism has challenged the distribution of responsibility for providing such resources as childcare and protection from family violence. Increasingly many people who once thought of these as family or personal concerns now think of them as social responsibilities.

8. Some people save me that trouble by telling me I am fine and walking away. Of course, people also encounter difficulties with answering "How are you?" during and after crises, such as separation from a partner, death of a loved one, or a nervous breakdown. There is a temporary alienation from what is considered ordinary shared experience. In disability, the alienation lasts longer, often for a lifetime, and, in my experience, it is more profound.

9. The idealization of the body is clearly related in complex ways to the economic processes of a consumer society. Since it pre-dated capitalism, we know that capitalism did not cause it, but it is undeniable that idealization now generates tremendous profits and that the quest for profit demands the reinforcement of idealization and the constant development of new ideals.

10. Susan Griffin, in a characteristically honest and insightful passage, describes an encounter with the fear that makes it hard to identify with disabled people. See Griffin 1982, 648-649.

11. Thanks to Joyce Frazee for pointing this out to me.

12. When Simone de Beauvoir uses this term to elucidate men's view of women (and women's view of ourselves), she emphasizes that Man is considered essential, Woman inessential; Man is the Subject, Woman the Other (de Beauvoir 1952, xvi). Susan Griffin expands upon this idea by showing how we project rejected aspects of ourselves onto groups of people who are designated the Other (Griffin 1981).

13. Many women with M.S. have lived through this nightmare in the early stages of their illness. Although this happens to men too, women's experience of the body, like women's experience generally, is more likely to be invalidated (Hannaford 1985).

14. Accounts of the experience of relatively unknown, newly-discovered, or hard-to-diagnose diseases and conditions confirm this. See, for example, Jeffreys 1982, for the story of an experience of Chronic Fatigue Syndrome, which is more common in women than in men.

15. Frequently people with undiagnosed illnesses are sent by their doctors to psychiatrists, who cannot help and may send them back to their doctors saying they must be physically ill. This can leave patients in a dangerous medical and social limbo. Sometimes they commit suicide because of it (Ramsay 1986). Psychiatrists who know enough about living with physical illness or disability to help someone cope with it are rare.

16. For more discussion of this subject, see Zaner 1983 and Rawlinson 1983.

17. At this stage of the disability rights movement, it is impossible to anticipate everything that a full feminist theory will include, just as it would have been impossible to predict in 1970 the present state of feminist theory of mothering. Nevertheless, we can see that besides dealing more fully with the issues I have raised here, an adequate feminist theory of disability will examine all the ways in which disability is socially constructed; it will explain the interaction of disability with gender, race and class position; it will examine every aspect of the cognitive authority of medicine and science over our experiences of our bodies; it will discuss the relationship of technology to disability; it will question the belief that disabled lives are not worth living or preserving when it is implied in our theorizing about abortion and euthanasia; it will give us a detailed vision of the full integration of disabled people in society, and it will propose practical political strategies for the liberation of disabled people and the liberation of the able-bodied from the social oppression of their bodies.

REFERENCES


