CHAPTER **6**

The Experience of Disability, Chronic Pain, and Chronic Illness

Nancy Mairs is a writer, teacher, social activist, mother, and wife who has multiple sclerosis (MS). She writes:

I am a cripple. I choose this word to name me. . . . People—crippled or not—wince at the word "crippled," as they do not at "handicapped" or "disabled." Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates/gods/viruses have not been kind, but who can face the brutal truth of her existence squarely. As a cripple, I swagger. . . .

I haven't always been crippled. . . .When I was 28 I started to trip and drop things. What at first seemed my natural clumsiness soon became too pronounced to shrug off. I consulted a neurologist, who told me that I had a brain tumor. A battery of tests, increasingly disagreeable, revealed no tumor. About a year and a half later I developed a blurred spot in one eye. I had, at last, the [symptoms] . . . requisite for a diagnosis: multiple sclerosis. I have never been sorry for the doctor's initial misdiagnosis, however. For almost a week, until the negative results of the tests were in, I thought that I was going to die right away. Every day for the past nearly ten years, then, has been a kind of gift. I accept all gifts.

Multiple sclerosis is a chronic degenerative disease of the central nervous system. . . . During its course, which is unpredictable and uncontrollable, one may lose vision, hearing, speech, the ability to walk, control of bladder and/or bowels, strength in any or all extremities, sensitivity to touch, vibration, and/or pain, potency, coordination of movements—the list of possibilities is lengthy and, yes, horrifying. One may also lose one's sense of humor. That's the easiest to lose and the hardest to survive without. . . .

I don't like having MS. I hate it. My life holds realities—harsh ones, some of them—that no right-minded human being ought to accept without

grumbling. One of them is fatigue. I know of no one with MS who does not complain of bone-weariness. . . . As a result, I spend a lot of time in extremis and, impatient with limitation, I tend to ignore my fatigue until my body breaks down in some way and forces rest. Then I miss picnics, dinner parties, poetry readings, the brief visits of old friends from out of town. . . My life often seems a series of small failures to do as I ought. . . .

[Over time], I [have] learned that one never finishes adjusting to MS. I don't know now why I thought one would. One does not, after all, finish adjusting to life, and MS is simply a fact of my life—not my favorite fact, of course—but as ordinary as my nose and my tropical fish and my yellow Mazda station wagon. It may at any time get worse, but no amount of worry or anticipation can prepare me for a new loss. My life is a lesson in losses. I learn one at a time. (1986: 9–12, 19)

Nancy Mairs's story illustrates some of the central tasks faced by those who live with **chronic illness**, chronic pain, or disability—searching for an accurate diagnosis, coming to terms with a body that does not meet social expectations for behavior or appearance, nurturing social relationships despite a contrary body, and constructing a viable and life-sustaining sense of self. In this chapter, we look at these and other issues in the lives of people who have chronic illnesses, chronic pain, or disabilities. We also consider the social context in which these individuals live and see how that context can affect individuals' lives at least as much as the bodily changes Mairs describes.

This chapter begins with an exploration of the meaning and history of disability. We then examine the extent and social distribution of disability in the United States. After that, we look at chronic pain, which falls on the borders between disability and illness, and then consider the experience of living with these conditions.

Understanding Disability

Defining Disability

As explained in Chapter 5, the meaning of the term *illness* is far from obvious. The same is true for the term **disability.** Competing definitions of disability reflect competing stances in an essentially political struggle. The **World Health Organization (WHO)** definition is probably the most widely used. WHO defines disability in terms of impairments: "disturbances in body structures or processes which are present at birth or result from later injury or disease . . . [and which cause] loss or abnormality of psychological, physiological, or anatomical structure or function" (1980: 47). WHO defines disability as "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." Disability, then, includes some but not all persons who have chronic illnesses (the majority of those with disabilities) as well as, for example, persons who are born deaf, become paralyzed in an auto accident, or experience chronic pain that limits their ability to function.

As many disability activists and social scientists have noted, this definition reflects a **medical model,** which locates impairments—and thus disabilities—solely within the individual mind or body. At first glance, such a definition seems perfectly reasonable. After all, isn't a disability something that an individual has, a defect in his or her body? According to many people with disabilities, the answer is no. Instead, they argue, their disabilities primarily stem not from their physical differences but from the way others respond to those differences and from the choices others have made in constructing the social and physical environment. For example, a man whose energy waxes and wanes unpredictably during the day might be able to work forty hours per week on a flexible schedule but not within a rigid 9-to-5 schedule. Similarly, a woman who uses a wheelchair might find it impossible to work in an office where furniture can fit only persons who walk and are of average height, but she might have no problems in an office with more adaptable furniture. Disability activists argue that making an office accessible to wheelchair users does not mean providing special benefits for the disabled, but rather compensating for the unacknowledged benefits that existing arrangements offer those who walk, such as chairs to sit in, stools for reaching high shelves, and carpeted floors that make walking easier but wheeling more difficult.

This approach reflects a **sociological model of disability** in its emphasis on social forces and public issues rather than on individual physical variations and troubles. In the rest of this chapter, the term *disability* refers to restrictions or lack of ability to perform activities resulting largely or solely from either (1) social responses to bodies that fail to meet social expectations or (2) assumptions about the body reflected in the social or physical environment.

These two models of disability—the medical model and the more sociological model used by disability activists—have strikingly different implications. As Paul Higgins (1992: 31) notes, "To individualize disability [as the medical model does] is to preserve our present practices and policies that produce disability. If disability is an internal flaw to be borne by those 'afflicted,' then we do not question much the world we make for ourselves. Our actions that produce disability go unchallenged because they are not even noticed." Individualizing disability, therefore, exemplifies the broader process of **blaming the victim,** through which individuals (in this case, people with disabilities) are blamed for causing the problems from which they suffer (Ryan, 1976); an example is the common belief that women would not be battered if they did not provoke their husbands in some way (Dobash and Dobash, 1998). In contrast, the sociological model of disability challenges us to look at the problem of disability from a very

different perspective. If we conclude that the problem resides primarily in social attitudes and in the social and built environment, then we can solve the problem most efficiently by changing attitudes and environments, rather than by "rehabilitating" people with disabilities.

People with Disabilities as a Minority Group

Once we start thinking of disability as primarily based on social attitudes and built environments rather than on individual deficiencies, strong parallels emerge between people with disabilities and members of minority groups (Hahn, 1985). A **minority group** is defined as any group that, because of its cultural or physical characteristics, is considered inferior and subjected to differential and unequal treatment and that therefore develops a sense of itself as the object of collective discrimination (Wirth, 1985). Few would argue with the assertion that we differentiate disabled persons from others on the basis of physical characteristics. But can we also argue, as the definition of a minority group requires, that people with disabilities are considered inferior and subject to differential and unequal treatment?

Unfortunately, yes. Even a cursory look at the lives of people with disabilities reveals widespread prejudice and discrimination. **Prejudice** refers to unwarranted suspicion, dislike of, or disdain toward individuals because they belong to a particular group, whether defined by ethnicity, religion, or some other characteristic. Prejudice toward disabled persons is obvious in the fact that, throughout history, most societies have defined those who are disabled as somehow physically or even morally inferior and have considered disabilities a sign that either the individual or his or her parents behaved sinfully or foolishly (Albrecht, 1992).

Prejudice typically expresses itself through **stereotypes,** or oversimplistic ideas about members of a given group. Nondisabled people typically stereotype those who are disabled as either menacing and untrustworthy or as childlike—asexual, dependent, mentally incompetent, the passive "victims" of their fate, and suitable objects for pity (Zola, 1985). These attitudes permeate the health care world as well as the general public. In one study, for example, researchers divided a large sample of health care students and practitioners into two groups and showed each group a videotape of a job interview. Both videotapes used the same actors and scripts, but in one the actor playing the job applicant walked, and in the other he used a wheelchair. Those who saw the videotape with the "disabled" applicant rated the applicant significantly more cruel, selfish, incompetent, weak, dependent, and mentally unstable than did those who saw the same actor portraying a nondisabled applicant (Gething, 1992).

Stereotypes about people with disabilities are so strongly held that obvious evidence regarding the falsity of those stereotypes scarcely affects social attitudes. For example, attorney Marylou Breslin, executive director of the Berkeley-based Disability Rights Education and Defense Fund and a

wheelchair user, tells of waiting at the airport for a flight in her dressed-for-success businesswoman's outfit, sipping from a cup of coffee. "A woman walked by, also wearing a business suit, and plunked a quarter into the plastic cup Breslin held in her hand. The coin sent the coffee flying, staining Breslin's blouse, and the well-meaning woman, embarrassed, hurried on" (J. Shapiro, 1993: 19).

Stereotypes about people with disabilities are reflected and perhaps reinforced in the popular media, which often portray disabled individuals as pitiful, maladjusted, or evil (Higgins, 1992: 80–97; Safran, 1998). In book and film characters from Captain Hook in *Peter Pan* to Freddie Krueger in *Nightmare on Elm Street* and the Penguin in Batman comics and films, the media have equated physical deformity with moral deformity. Moreover, when the media do not portray persons with disabilities as horrifying, they often portray them as pitiful—whether depicting Tiny Tim in Charles Dickens's classic novel, *A Christmas Carol,* or Maggie Fitzgerald in *Million Dollar Baby,* for whom death was preferable to life. Although contemporary media sometimes do present more positive images, such as stories about people with disabilities who have "heroically" compensated for their physical disabilities, who have chosen to live "saintly" lives, or whose innocence can help the rest of us learn to live better lives (*Riding the Bus with My Sister,* for instance), these stories, too, typically ignore the social nature of disabilities and instead offer simplistic stories about individual character. Exceptions to these rules—films such as *The Station Agent, Murderball,* and *Children of a Lesser God*—remain rare, although they have become far more common in the last 20 years.

All too often, these prejudices against persons with disabilities result in **discrimination,** or unequal treatment grounded in prejudice. As recently as the first decades of the twentieth century, American laws forbade those with epilepsy, leprosy, Down syndrome, and other conditions from marrying and mandated their institutionalization or sterilization (J. Schneider and Conrad, 1983: 32–33; J. Shapiro, 1993: 197). During the 1930s and 1940s, doctors working for the government of Nazi Germany murdered about 100,000 disabled children and adults as *Lebensunwertes Leben*—"life unworthy of life" (Lifton, 1986). Partly due to discrimination, 68 percent of working-age disabled Americans are unemployed, even though two-thirds of these individuals say they could and would work if given the opportunity (National Organization on Disability, 2001).

To fit the definition of a minority group, a group must not only experience prejudice and discrimination but also consider themselves objects of collective discrimination. This is the weakest link in defining disabled people as a minority group (Higgins, 1992: 39–44). Unlike members of other minority groups, disabled individuals are rarely born to disabled parents. As a result, they might have little contact with, let alone sense of connection to, other people with disabilities. Moreover, fewer than 15 percent of people with disabilities are born disabled (J. Shapiro, 1993: 7). Therefore, most

establish their sense of individual and group identity before they become disabled, and not all will change their sense of identity following disability. In addition, those who develop a sense of community with others who share their disability do not necessarily feel a connection to persons with other disabilities; deaf people, for example, might identify with others who are deaf, but not with those who have arthritis. Nevertheless, the sense of belonging to a broader group is surprisingly strong. In a national survey conducted in 2001, 47 percent of disabled persons reported feeling a sense of community with other disabled persons (National Organization on Disability, 2001). Thus disabled Americans increasingly have come to believe that they deserve not charity—as exemplified by the Muscular Dystrophy telethon, with its implications of inferiority and pity—but the same rights as other citizens to live, work, study, and play in the community.

These rights have been reinforced by the federal Education for All Handicapped Children Act, which requires school districts to educate all children regardless of disability in the least restrictive environment feasible, and the **Americans with Disabilities Act (ADA),** which outlaws discrimination and requires accessibility in employment, public services, and public accommodations (including restaurants, hotels, and stores). Box 6.1 describes the work of Disability Rights Advocates, an organization that fights to enforce these legal rights.

To explore how the ADA has affected the work environment, sociologists Sharon Harlan and Pamela Robert (1998) interviewed a nonrandom but diverse sample of disabled, nonmanagerial civil service workers in one state. One-third of their subjects (32 percent) had never requested an accommodation, either because they were not familiar with the procedures or because they assumed that doing so would call attention to their disabilities and threaten their jobs rather than result in meaningful accommodations. Instead, they tried to compensate for their disabilities by working longer hours, working even when sick, refusing promotions that would leave them with more difficult work conditions, and so on.

Of those workers who had requested accommodations, 69 percent had been granted those requests or were still awaiting their resolution. Requests were most often granted for men, for whites, and for persons in higher-status jobs. Employers were more likely to grant requests for changes in the physical environment, such as providing adaptable furniture or disabled parking, than for changes in the social environment, such as offering flexible work schedules or personal assistance. These findings led the authors to conclude that employers will offer accommodations only if those accommodations do not threaten the authority structure of the workplace by suggesting that workers should be granted more flexibility or autonomy.

When employers refuse requests for accommodation, workers have the option of bringing lawsuits or filing complaints with the federal Equal Employment Opportunity Commission (EEOC). Of the 107,000 workers whose complaints were resolved in the first five years after the ADA went into

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Box 6.1   *Making a Difference: Disability Rights Advocates*

Disability Rights Advocates (DRA) is a nonprofit law firm that uses individual lawsuits, class action lawsuits, and the threat of lawsuits to fight for the rights of persons with disabilities (www.dralegal.org). Its staff consists of a few paid lawyers (some of whom have disabilities) and numerous volunteer lawyers and law students. In recognition of its excellent work, DRA has received ongoing funding from various foundations and associations, including the Kaiser Family Foundation, the San Francisco Foundation, and various Bay Area bar associations.

Although initially DRA worked solely on California cases, it grew rapidly into a national organization. In addition, since 1995, when DRA received a grant from the private, nonprofit Soros Foundation and matching funds from the U.S. State Department, it has run an advocacy program for disabled persons in Hungary, as well as leadership training programs open to disabled persons from across Eastern Europe.

Some of DRA's successes include advocating for greater access to California public schools, including educating disabled students and their parents about their rights and helping school administrators remove barriers; settling a statewide lawsuit against Denny's restaurants, as a result of which all California Denny's are being made accessible; and initiating the first lawsuit in the country against a city building department for failure to enforce laws requiring the removal of architectural barriers

in public and private buildings. The lawsuit was dropped when the city pledged to hire more building inspectors, train its inspectors in disability access laws, and hire a consulting firm to handle the backlog of complaints from disabled persons against the city. In addition, in the last few years legal pressure was used to convince Greyhound Bus Lines to provide accessible rest stops and assist riders with disabilities, to convince a major national car rental company to make vehicles with hand controls reasonably available, to convince a hospital to provide sign language interpreters for patients and their relatives who are deaf, to convince several hotels to increase the number of accessible guest rooms and to remove physical barriers, and to convince a major supermarket chain to begin providing assistance to disabled shoppers.

Finally, to support those who proactively work to advance the rights of disabled Americans, rather than doing so only when threatened with lawsuits, each year DRA gives out its ADA Eagle Awards. For example, awards have been given to Nordstrom, Inc., for its commitment to making its stores accessible to persons with disabilities and its use of models with disabilities; to Marriott International and Noah's Bagels for their efforts to hire and accommodate employees with disabilities; and to NBC's "Dateline" show for its coverage of housing and employment discrimination against people with disabilities.

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effect, only 11.4 percent both won their cases and received benefits as a result (Equal Employment Opportunity Commission, 1999). Similarly, during approximately the same time period, workers won only 8 percent of cases that went to trial (American Bar Association, 1998). Unfortunately, the impact of the ADA has been limited because most courts have narrowly defined who qualifies for its protection (Gostin, Feldblum, and Webber, 1999).

For example, courts have ruled that the ADA does not apply to individuals whose diabetes is controlled by insulin or whose spinal cord injuries keep them from working rigid hours but do not otherwise interfere with their work.

The Social Distribution of Disability

According to U.S. government researchers, approximately 12 percent of non-institutionalized persons living in the United States have a disability, defined by these researchers as a chronic health condition that makes it difficult to perform one or more activities generally considered appropriate for persons of a given age—play or study for children, work for adults, or basic activities needed to maintain an independent life (shopping, dressing, bathing, and so on) for the elderly (National Center for Health Statistics, 2004).

The proportion of the population living with disabilities has grown significantly over time (Kaye et al., 1996). Only a few decades ago most paraplegics, babies born prematurely or with serious birth defects, persons with serious head or spinal injuries, and soldiers with major wounds died quickly. Now most live, although often with serious disabilities. During the Iraq war, for example, new body armor that protects soldiers' torsos plus advances in military medical care have resulted in far fewer deaths but far more survivors with brain damage or multiple amputations (Glasser, 2005). In addition, average survival times for various common chronic conditions, such as hypertension and cardiovascular disease, have increased. Finally, as the proportion of the population over age 65 has increased—and in the absence of meaningful attempts to remove the social and physical barriers that can prevent individuals from living independent lives—so has the proportion living with disabilities. As Table 6.1 shows, the percentage of Americans with activity limitations (i.e., unable to perform some basic life activity such as shopping or dressing oneself) increases as age increases, for longer lives translate into more years in which to have accidents or develop degenerative diseases. Even among persons above age 75, however, more than half report no disabilities.

As the table also shows, poorer persons are more likely than wealthier persons to report activity limitations. Not surprisingly, ethnicity also affects rates of disabilities, largely because of its relationship to poverty. By their early thirties, about 12 percent of Native American men have been unable to work or are limited in the work they can do because of illness or injury for at least six months (Hayward and Heron, 1999). In contrast, disability does not become equally common among African American men until their late thirties. Even more startling, white and Hispanic men do not reach this rate of disability until their early fifties, and Asian American men do not reach it until their early sixties. Similar patterns emerge when white, Hispanic, African American, Asian American, and Native American women are compared. However, largely because women live longer than men do, most disabled persons are women.

Table 6.1	*Percentage of Americans With Chronic Activity Limitation, 2002*

	% WITH LIMITATION
AGE	
Under 18 years	7.1
18–44 years	6.3
45–54 years	13.7
55–64 years	21.1
65–74 years	25.2
75 years and over	45.1
ETHNICITY	
Hispanic	10.7
White non-Hispanic	12.4
Black non-Hispanic	15.0
INCOME	
Poor	22.9
Near Poor	17.5
Not Poor	9.5

Source: National Center for Health Statistics (2004: 214).

Understanding Chronic Pain

Chronic pain, which affects about 50 million Americans (Bradshaw, Nakamura, and Chapman, 2005), falls on the border between disability and chronic illness. Chronic pain is a symptom, not an illness in itself. Sometimes it can be attributed to an injury or an illness, such as arthritis or cancer, but in other cases no specific cause can be identified; doctors often lack explanations for chronic headaches or back pain, the two most common types of chronic pain. Finally, chronic pain may be attributed to conditions whose existence and diagnosis remains contested within the medical world; examples are irritable bowel syndrome, fibromyalgia, and chronic fatigue syndrome.

Although the causes of chronic pain are often unclear, its consequences are obvious. Chronic pain is the most common underlying reason for disability among working-age adults (American Pain Society, 2000). In addition to its physical toll (which includes sleep deprivation and exhaustion), chronic pain damages social relationships; increases depression, anxiety, and the risk of suicide; and costs the nation $61 billion yearly in reduced productivity alone (W. Stewart et al., 2003).

Treating chronic pain is notoriously difficult, and there is no medical consensus on how to do so (American Pain Society, 2000). Few truly new treatments are available: Most pain medications derive from either morphine or aspirin, both of which were first commercially produced in the 1800s. Although morphine-related drugs such as OxyContin are often the safest and most effective treatments for chronic pain (American Academy of Pain Medicine and American Pain Society, 1996), American doctors are reluctant to use them, both because doctors share popular American beliefs about opiates and addiction and because they fear arrest under strict U.S. drug trafficking laws. Meanwhile, the most popular aspirin-related drugs (including Celebrex and Vioxx) have recently been found both less effective and more dangerous than initially claimed (Abramson, 2004). To make matters worse, few American doctors are specially trained in pain management.

Obtaining appropriate treatment is particularly unlikely for minorities, poorer persons, children, the elderly, and women (Hoffman and Tarzian, 2001). Women—representing the majority of those living with chronic pain—are significantly more likely than men to encounter doctors who ascribe their pain to psychiatric causes and prescribe sedatives or psychotherapy rather than effective pain medications (Barker, 2005; Hoffman and Tarzian, 2001; Werner and Malterud, 2003). To avoid this fate, women with chronic pain must tread a fine line, striving to appear neither too sick nor too well and neither too assertive nor too passive, in order to receive proper treatment and avoid being labeled hysterical or pushy, malingerers or whiners (Werner and Malterud, 2003). Not surprisingly, women consumers have been at the forefront of the movements to medicalize chronic fatigue syndrome, multiple chemical sensitivity, fibromyalgia, and other similar conditions (Barker, 2005).

Living with Disability and Chronic Illness

Living with disability or chronic illness, whether or not it results in chronic pain, is a long-term process that includes responding to initial symptoms, injuries, or diagnoses; making sense of one's situation; and continually reconceptualizing one's future. In this section, we examine this process and explore how illness, pain, and disability affect individuals' lives, relationships with others, and sense of self.

Initial Symptoms and Diagnosis

Becoming a chronically ill or disabled person begins with recognizing that something about the body is troubling. This recognition does not always come easily. Health problems often build gradually, allowing individuals and their families slowly and almost unconsciously to adapt to them and to

minimize their importance (Bury, 1982; Charmaz, 1991: 24–28; J. Schneider and Conrad, 1983; D. Stewart and Sullivan, 1982). In addition, the signs of illness and disability often do not differ greatly from normal bodily varia-tions. A child who doesn't walk by 12 months might have a disability or might simply be a slow developer. Similarly, children with epilepsy, for example, can for many years experience "strange feelings," "headaches," "spaciness," "blackouts," and "dizzy spells" before they or their families rec-ognize these as signs of epilepsy. As one man recalled:

> I'd always had the tendency to roll my eyes back in my head . . . to kind of fade out for a while. But I thought that was nothing, but . . . I guess they call them petit mal [epileptic seizures]? I'd lose consciousness for a while. I wasn't really con-scious of it and [the only] time anybody would notice it was when the family was all together at the dinner table and I, I'd be like daydreaming for a while and then I'd roll my eyes back and they'd go, "Stop that!" and I'd go "Stop what?," y'know, I didn't know what I was doin'. (J. Schneider and Conrad, 1983: 57–58)

Social scientists refer to this process of defining, interpreting, and other-wise responding to symptoms and deciding what actions to take as **illness behavior** (Mechanic, 1995). A review article by anthropologists Vuckovic and Nichter (1997), summarizing 20 years of research studies, concluded that U.S. residents treat between 70 and 95 percent of all illness episodes without a doctor's assistance. Individuals typically begin by medicating themselves or those under their care with nonprescription medications rec-ommended by friends, families, store clerks, or pharmacists or, more rarely, with prescription medicines left over from previous illnesses.

Research results are mixed regarding whether gender or ethnicity affects use of self-medication, but age clearly has an impact: Persons over age 65 are considerably more likely than others are to self-medicate, with the majority of older persons using one or more nonprescription drugs regularly (Vuckovic and Nichter, 1997). Social class does not affect the *use* of self-medication, but does affect the *reasons* for doing so: Affluent persons are more likely to self-medicate to save time, whereas poorer persons are more likely to do so to save money. For all Americans, however,

> cultural demands to be productive and practical contingencies related to job/household responsibilities make time off for illness a luxury few Americans can afford. As popular commercials for cold and flu remedies remind mothers, construction workers, and teachers, there is simply no time to be ill. Pressures of the clock inherent in modern life often prohibit taking time for the extra sleep necessary to care for a cold or for the relaxation required to relieve a "stress" headache. In the past, individuals who were ill might "tough it out," waiting for symptoms to subside. Today, Americans can avoid delays by taking products "strong enough to tackle even the toughest cold." Medicines obviate the need to devote time and energy to healing activities, or to the "down time" necessitated by ill health. (Vuckovic and Nichter, 1997: 1289)

Key Concepts 6.1	*Some Factors Predicting Illness Behavior*	
	INDIVIDUALS ARE *LIKELY* TO DEFINE THEMSELVES AS ILL AND SEEK MEDICAL CARE WHEN:	INDIVIDUALS ARE *UNLIKELY* TO DEFINE THEMSELVES AS ILL AND SEEK MEDICAL CARE WHEN:
	Symptoms appear frequently or persistently (e.g., coughing blood once per day for a week).	Symptoms appear infrequently (e.g., coughing blood every few months).
	Symptoms are very visible (e.g., rash on face).	Symptoms are not very visible (rash on lower back).
	Symptoms are severe enough to disrupt normal activities (e.g., epileptic convulsions).	Symptoms are mild (annoying but tolerable headaches).
	Illness is only likely explanation for physical problems.	Alternative explanations are available (e.g., recent stresses may explain headaches).
	They have ready access to health care (e.g., good health insurance).	They have poor access to health care (e.g., no health insurance).
	They have a positive attitude to health care providers (e.g., trust doctors' abilities and motives).	They have a negative attitude to health care providers (e.g., distrust doctors' abilities and motives).

When and whether individuals seek formal diagnosis for acute or chronic medical problems depends on a variety of factors. According to the illness behavior model developed by David Mechanic (1995) and summarized in Key Concepts 6.1, the likelihood of seeking medical care depends, first, on the presence of alternative explanations for symptoms and the frequency, visibility, and severity of those symptoms (including most importantly how much they interfere with usual daily activities). In turn, how individuals interpret these factors depends on the social context; symptoms that seem serious to a middle-class professional who generally enjoys good health might seem quite minor to a homeless or elderly person who expects a certain amount of bodily discomfort. Social networks of friends and relatives also play a large role in determining how individuals will interpret and respond to symptoms because those networks can reinforce either a medical or a nonmedical interpretation of the problem and of how to treat it (Pescosolido, 1992). Finally, access to care and attitude toward health care providers also affect how quickly individuals seek care; those who can afford care only from public clinics and whose experience of clinics has taught them to expect long waits and rude treatment often put off seeking care for some time.

Eventually, however, if symptoms persist—and especially if they progress—individuals and their families are likely to reach a point where they

cannot avoid recognizing that something is seriously wrong. As their previous interpretations of their symptoms crumble, individuals find themselves in an intolerable situation, torn by uncertainty regarding the changes in their bodies and their lives. Once they reach this point, the incentive grows to seek diagnosis and treatment because any diagnosis can become preferable to uncertainty.

Seeking a diagnosis, however, does not necessarily mean receiving one. Although some problems are relatively easy to diagnose—a 45-year-old white man who complains to his doctor of pains in the left side of his chest will probably quickly find himself getting tested for a heart attack—others are far less obvious. Persons with multiple sclerosis, for example, often find that doctors initially dismiss their symptoms as psychosomatic or trivial (Register, 1987; D. Stewart and Sullivan, 1982). In addition, the same symptoms may more rapidly produce a diagnosis for some than for others. For example, and as mentioned earlier, doctors more often ascribe women's than men's complaints to emotional problems rather than to physical illness (Council on Ethical and Judicial Affairs, 1991; Steingart, 1991).

Initially, both women and men can find these alternative diagnoses comforting and welcome—after all, it is far easier to hear that you are suffering from stress than that you have a serious illness. When symptoms persist, however, individuals find themselves torn by ambiguity and uncertainty, suffering anxiety about their failing health but receiving little sympathy or help from relatives and colleagues (Bury, 1982; J. Schneider and Conrad, 1983; D. Stewart and Sullivan, 1982; Waddell, 1982). As a result, eventually most people seek more accurate diagnoses. Some go from doctor to doctor, seeking a more believable diagnosis; others research their symptoms, diagnose themselves, and then press their doctors to confirm their self-diagnoses through testing. In the end, even those diagnosed with life-threatening conditions typically conclude that this certainty is preferable to continued uncertainty.

Responding to Illness or Injury

Once newly diagnosed or newly disabled individuals learn the nature of their conditions, responses vary widely. Some individuals with **HIV disease,** for example, find it easiest to cope by immediately considering their diagnosis a "death sentence," thus eliminating any uncertainty from their minds (Weitz, 1991). Others initially assume they can "beat" their illness, refusing to take seriously any dire predictions about their future. Still others cope by accepting their diagnoses intellectually but denying them emotionally. For example, one young man told how, two months after learning he had AIDS, he thought that he had picked up someone else's medical file when he noticed that his file read, "Caution: Patient has AIDS" (Weitz, 1991). Similarly, following traumatic injuries, some individuals refuse to participate in rehabilitation because they consider their situation hopeless; others refuse because they consider their injuries temporary.

Faced by the uncertainties and loss of control that accompany chronic illness and disability, individuals must reconstruct their images of their futures. Two basic strategies are available to these individuals, as to all who confront uncertainty—**avoidance** and **vigilance** (Janis and Mann, 1977; Weitz, 1989). Some cope by avoiding knowledge about their conditions so they can maintain previous images of their futures and ward off depression. Others cope by seeking knowledge vigilantly so that they can feel prepared to respond appropriately to any changes in their bodies. Both strategies reduce uncertainty and give individuals ways of understanding and, thus, responding to their health problems.

Although learning the nature of one's condition answers some questions, it raises new questions about why this has happened. Those who experience serious illness or injury therefore must reconceptualize not only their futures but also their pasts. Only by doing so can individuals make their situations comprehensible and, consequently, tolerable.

This search for explanations is often a painful one, set as it is in the context of a culture that continues at least partially to believe that individuals deserve their illnesses and disabilities. Nevertheless, some individuals do manage to avoid allocating blame to themselves. For example, one gay man with HIV disease stated in an interview: "Nobody deserves it [HIV disease]. I have friends that say 'Well, hey, if we weren't gay, we wouldn't get this disease.' That's bullshit. I mean, I don't want to hear that from anybody. Because no germ has mercy on anybody, no matter who they are—gay, straight, babies, adults" (Weitz, 1991: 68).

Other individuals, however, readily conclude—whether accurately or not—that they caused their own health problems by acting in ways that either contravened "divine laws" or put them at risk (such as smoking tobacco, having multiple sexual partners, or driving fast). As another man with HIV disease stated, "I should have helped people more, or not have yelled at somebody, or been better to my dad even though we have never gotten along. . . . Maybe if I had tried to get along better with him, maybe this wouldn't be happening" (Weitz, 1991: 68). Increasingly, too, individuals conclude that they caused their health problems through their psychological conflicts. As described in Chapter 5, this theory has gained considerable public exposure through the writings of Bernie Siegel and others, who have theorized that individuals become ill because they "need" their illnesses.

Interruptions, Intrusions, and Immersions

According to sociologist Kathy Charmaz, who interviewed more than one hundred chronically ill people, illness can be experienced as an interruption, an intrusion, or something in which an individual is immersed (Charmaz, 1991). Although Charmaz's research addressed only chronic illness, similar patterns undoubtedly apply to at least some individuals with disabilities, especially those that worsen over time.

When illness or disability is an **interruption,** it remains only a small and temporary part of a person's life (Charmaz, 1991: 11–40). Viewing it as an interruption means regarding it essentially as an acute problem—something to be dealt with at the moment, but not something that will have a significant long-term impact. This strategy can work as long as episodes of illness are minor or rare, or the disability is a mild one. For example, because of unexpected physical problems, someone with multiple sclerosis may need to change plans for a given day but not necessarily for the next week.

If the illness or disability progresses, however, it can become an **intrusion,** demanding time, accommodation, and attention and requiring that a person "live day to day" (Charmaz, 1991: 41–72). For example:

> I just take each day as it comes and I don't worry about tomorrow. I know that when I'm feeling good I should try to do as much as I can without overdoing, because sometimes I won't be able to do that. (Register, 1987: 190)

If the illness or disability progresses still further, people can find themselves immersed in their bodily problems (Charmaz, 1991: 73–104). Upon reaching this stage of **immersion,** they must structure their lives around the demands of their bodies rather than structuring the demands of their bodies around their lives. Social relationships often wither, and people often withdraw into themselves. Dealing with the body and illness can take most of a person's day and require the assistance of others. One woman, for example, told Charmaz that her kidney dialysis

> just about takes up the day. . . . I'm supposed to be on at 12:30, but sometimes don't get on until 1:00, then I'm dialyzed for four and a half hours and then it takes approximately half an hour to be taken off the machine and to have it clot. So quite often it's 6:00 or 6:30 before I ever leave there. So the day is shot. (1991: 83)

This chapter's ethical debate (Box 6.2), on the international trade in human organs, discusses one of the extreme solutions some individuals adopt to avoid such overwhelming illness.

Managing Health Care and Treatment Regimens

Persons who live with chronic illness and disability can turn to both conventional and alternative health care for help. And increasingly, they use the Internet to help them in these decisions.

Using Conventional Health Care

Living with chronic illness or disability often means living a life bound by health care regimens. However, in the same manner that, following injury or diagnosis with a chronic illness, some individuals seek and some avoid knowledge, some will strictly follow prescribed regimens of diet, exercise, or medication and others will not. Researchers traditionally have framed this

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Box 6.2   ***Ethical Debate: The Sale of Human Organs***

One of the most extreme situations an ill individual can face is the failure of a major organ, be it heart, lung, kidney, or liver. Such situations are death sentences unless the organ can be replaced either with a mechanical substitute or with a donated human organ. But mechanical replacements can severely restrict individuals' lives by tethering them to machines, and human organs can be difficult or even impossible to obtain legally; 85,000 Americans were on waiting lists for organs as of 2004, with an average wait of five years (during which time many on the list will die). As a result, a multi-million-dollar international market in human organs has emerged (Rohter, 2004).

Most commonly, the organs sold through this market are kidneys, although livers, lungs, corneas, and other organs also are sold. Because (almost) every human is born with two kidneys, and only one is needed to live, an individual can sell one kidney and still hope to live a normal and healthy life.

Selling an organ carries great risks, but can seem worth it if an individual is poor enough. In Brazil, for example, a person can earn $80 per month working at minimum wage—if work is available—or can sell his or her kidney for $3,000. Such sales are illegal in many countries, but those laws are rarely enforced.

To some observers, the trade in human organs is a natural and reasonable market response, in which supply (organs for sale) develops to fill an obvious need (organs required). These observers see no difference between selling organs and selling any other valued commodity, be it drugs, cars, or food. Similarly, they argue, people should have at least as much right to buy an organ that will save their life as they have to buy a television or a face-lift, and as much right to risk their health by selling an organ as they have to risk their life by selling their labor in dangerous occupations (Cherry, 2005).

Other observers, however, compare the trade in human *organs* to the trade in *humans,*

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issue as a matter of compliance—whether individuals do as instructed by health care workers.

The most commonly used framework for studying compliance is the **health belief model.** As we saw in Chapter 2, this model was developed to explain why healthy individuals adopt preventive health behaviors. The same model is also used to understand why people who have acute or chronic health problems comply with medical advice regarding treatment (see Key Concepts 6.2). The model suggests that individuals will be most likely to comply if they believe they are susceptible to a health problem that could have serious consequences, believe compliance will help, and perceive no significant barriers to compliance. For example, people who have diabetes will be most likely to comply with their prescribed diet if they believe that they face substantial risks of blindness due to diabetes-induced glaucoma, that blindness would substantially decrease their quality of life, that the prescribed diet would substantially reduce their risk of blindness, and that the diet is neither too costly nor too inconvenient.

The health belief model is a useful but limited one for understanding compliance with medical treatment because it largely reflects the medical model of

and consider selling organs no more ethical than selling slaves. They argue that no one truly sells their bodily organs freely, but rather does so because they are coerced by poverty. They also argue that whenever a highly profitable commodity is for sale, and that sale is unregulated by laws, unscrupulous individuals will find ways to profit from the sale and vulnerable individuals will be exploited—whether they are buyers or sellers. Individuals who purchase black-market organs have no guarantees that the donor was healthy or that the organ will be a good match for them; and those who sell organs have no guarantee that the surgery will be conducted safely, that it will not harm their health, and that they will receive needed health care afterward. A study conducted in the Indian state of Tamil Nadu found that virtually all who (illegally) sell their kidneys did so to pay crippling debts. Yet because most (86 percent) were in worse health in the years following surgery, their average family incomes declined by one-third, even though average income in the state increased during the same period (Goyal et al., 2002). Despite these problems, though, the trade in organs is likely to continue so long as demand continues to outstrip supply.

Sociological Questions

1. What social views and values about medicine, society, and the body are reflected in this policy? Whose views are these?

2. Which social groups are in conflict over this issue? Whose interests are served by the different sides of this issue?

3. Which of these groups has more power to enforce its view? What kinds of power do they have?

4. What are the intended consequences of this policy? What are the unintended social, economic, political, and health consequences of this policy?

illness and disability. First, the health belief model assumes that noncompliance with medical recommendations stems primarily from psychological processes internal to the patient. Although this is sometimes true, in other cases patients do not comply because health care workers did not sufficiently explain either the mechanics of the treatment regimen or the benefits of following it (Conrad, 1985). Patients also might not comply because they lack the money, time, or other resources needed to do so.

Second, the health belief model implicitly assumes that compliance is always good (that is, that health care workers always know better than patients what patients should do). Yet, although health care workers often can help their patients considerably, this is not always the case, especially with chronic conditions (and it is one reason the **sick role** model does not fit chronic illnesses well). Bodies rarely respond precisely as medical textbooks predict. Nor can those textbooks determine whether an individual will consider a given treatment worth the impact it has on his or her quality of life. For example, persons with bipolar disorder (manic depression) often resist taking medications because the medications leave them feeling sedated and deprive them of the sometimes pleasurable highs of mania.

Key Concepts 6.2	*The Health Belief Model and Medical Compliance*		
PEOPLE ARE MOST LIKELY TO COMPLY WITH MEDICAL ADVICE WHEN THEY:	EXAMPLE: COMPLIANCE LIKELY	EXAMPLE: COMPLIANCE UNLIKELY
Believe they are susceptible.	Fifty-year-old man with hypertension who believes he is at risk for a heart attack	Fifteen-year-old boy diagnosed with epilepsy who has had only minor problems. Does not believe he is at risk for convulsions.
Believe risk is serious.	Believes that heart attack could be fatal	Believes that convulsions would not be physically dangerous
Believe compli-ance will reduce risk.	Believes he can reduce risk through taking medication regularly	Believes he doesn't really have a problem, so doesn't see how medica-tion could help
Have no signifi-cant barriers to compliance.	Medication is affordable and has no serious or highly unpleasant side effects.	Medication makes the boy feel drowsy, dull, and set apart from his peers.

Moreover, for numerous chronic conditions, the only available treatments are disruptive to normal routines, experimental, only marginally effective, unpleasant, or potentially dangerous. As a result, many people who at first diligently follow prescribed regimens eventually abandon them and lose some of their faith in mainstream health care (Conrad, 1985). Meanwhile, health care providers who do not understand why their patients did not respond to treatment as expected will often blame the problem on patient noncompliance, further eroding relationships between patients and providers and leading to future noncompliance.

As people's faith in mainstream medicine declines, some begin experi-menting with their treatment regimens, learning through trial and error what works best for them not only physically but also socially, psychologi-cally, and economically (Conrad, 1985). Others begin using **alternative** or **complementary therapies** (defined broadly as treatments not widely inte-grated into medical training or practice in the United States).

Using Alternative Therapies

Interest in alternative therapies has grown rapidly in the United States, both among healthy persons interested in avoiding illness and among those with

chronic or acute illnesses. The most widely cited data on use of alternative therapies comes from three national, random surveys of English-speaking U.S. residents, conducted by a Harvard-based research team in 1990, 1997, and 2002 (Eisenberg et al., 1998; Tindle et al., 2005). The researchers looked at use of fifteen alternative therapies, including chiropractic, acupuncture, megavitamins, "folk" remedies, and biofeedback. Thirty-five percent of respondents reported using at least one alternative therapy in 2002, with more than 40 percent of these individuals using more than one therapy.

Users of alternative therapies are disproportionately likely to be female, upper income, below age 65, college educated, white, and suffering from chronic health problems (Astin, 1998; Kessler et al., 2001; Tindle et al., 2005). Currently, the most commonly used therapies are relaxation techniques and herbal medicine (used by 19 percent and 14 percent of Americans, respectively). Chiropractic, massage, and yoga are next most popular (used by 5 to 7 percent of Americans).

Most who use alternative therapies do so because conventional treatments have not helped them (most commonly, for dealing with chronic pain). Individuals typically use alternative therapies to complement rather than to replace mainstream medicine: Whereas 32 percent of those who sought help from a medical doctor also used an alternative therapy, virtually all—96 percent—of those who visited an alternative therapist also visited a medical doctor (Eisenberg et al., 1998). However, more than 60 percent of those who use alternative therapies do not tell their doctors that they have done so (Tindle et al., 2005). Moreover, 95 percent of those who use herbal medicine—the category that grew most rapidly between 1997 and 2002—choose their herbs without advice from a practitioner of any sort.

The popularity of alternative therapies rests on belief—or at least hope—in the efficacy of these treatments. These beliefs are supported both by personal experience and by recommendations from friends and acquaintances who believe alternative therapies have helped them. In some of these cases the therapies no doubt did help, either because of the biological effects of the therapies or because consumers' belief in the therapy helped the body to heal itself, as happens in about 30 percent of all persons treated with **placebos** (drugs known to have no biological effect). In other cases, individuals attribute cures to alternative therapies when actually the problem went away on its own, as happens with 70 to 80 percent of health problems (Lundberg, 2001: 123). Finally, people sometimes convince themselves that the therapies helped them even though their health did not actually improve.

Use of alternative therapies also rests on the belief that "natural" treatments are unlikely to do harm. This can be a dangerous assumption. For example, the Chinese herb, ma huang, helps dieters but can cause heart attacks and strokes. Kava kava tea can reduce anxiety but also can cause liver damage, and gingko biloba both stimulates circulation and increases bleeding during surgery (McNeil, 2002). Moreover, whereas the federal Food and Drug Administration is responsible for regulating the safety, potency, and effectiveness of prescription drugs, no governmental agency regulates

herbal remedies or supplements. Current law does not permit manufacturers to claim that alternative herbs and supplements are cures, but does allow them to claim that their products *might* help.

To convince people to try alternative therapies and to believe in their efficacy and safety, manufacturers and retailers now spend millions yearly on promotion. For example, GNC, which sells nutritional supplements and other alternative and natural products, contracted with the Rite Aid drugstore chain to open outlets in 1,500 Rite Aid stores and to jointly run an Internet website where consumers can learn about and purchase their products. The two companies agreed to spend $30 million during the first year to market the stores and website (Janoff, 1999).

Other, less obvious, means are also now used to promote alternative therapies. Mainstream supermarkets routinely devote large sections in prime locations to "wellness products" and alternative therapies, and newsstands are filled with magazines devoted to informing consumers of the reputed health benefits of various alternative therapies and laced with advertisements for those products. Mainstream media, too, regularly run articles and advertisements promoting alternative therapies; a review for this textbook of articles on chiropractors indexed in the *Reader's Guide to Periodical Literature* during 1998 found 64 that described the potential benefits of chiropractic treatment, but only 4 that adequately described its risks.

The huge amounts corporations spend promoting alternative therapies are justified by the even larger amounts of money consumers spend on such services and products. Eisenberg and his colleagues (1998) conservatively estimated that Americans spent $21.2 billion in 1997 on alternative practitioners; $8.9 billion for herbal therapies and megavitamins; and $7.7 billion on books, classes, and equipment related to alternative therapies, for a total of $44.5 billion in 2005 dollars.

A fascinating study by Matthew Schneirov and Jonathan David Geczik (1996) suggests that neither marketing campaigns nor the potential health benefits of alternative therapies can fully explain the appeal of these therapies. Instead, the authors suggest, alternative healing appeals to individuals as a **new social movement,** a term first coined by German sociologist Jürgen Habermas (1981). Habermas argued that whereas older social movements arose out of discontent with material social conditions such as poverty, the new social movements stem from discontent with modern society's emphasis on science and rationality and its devaluing of the **lifeworld** of everyday human interaction, identity, and needs. Because new social movements focus on the lifeworld, they are less concerned with political strategies for social change and more concerned with creating ways of living that reflect their values. Thus new social movements depend less on formal organizations and more on "submerged networks" (Melucci, 1995) in which likeminded individuals can trade resources and obtain social support for adopting nonnormative ways of life. Although more recent writers tend to argue that movements cannot be neatly dichotomized into "new" versus "old,"

Habermas's insight regarding the importance of the lifeworld to social move-
ment growth is nonetheless an important one.

Using Habermas's model, Schneirov and Geczik argue that the rise of
alternative healing reflects dissatisfaction with the lack of match between
doctors' concerns and patients' concerns: Whereas doctors typically are con-
cerned with solving the puzzle of diagnosis and identifying a specific body
part that requires treatment, patients are primarily concerned with the impact
of illness on their lives (Mechanic, 1995). This mismatch can leave patients
feeling like depersonalized objects and deeply dissatisfied with the care
they receive, even if it is technically competent. In contrast, Schneirov and
Geczik argue, alternative healing offers patients the opportunity to work as
collaborators with health care providers and the promise to look holisti-
cally at the sources of their health problems and the consequences of any
treatments.

Using interviews, ethnographic observations, and focus groups, Schneirov
and Geczik uncovered two slightly overlapping submerged networks linked to
alternative healing in the Pittsburgh area: one made up of working-class con-
servative Christians, the other of college-educated followers of spiritual,
Eastern, or New Age philosophies. The researchers conclude that

> at the core of alternative health is a commitment to an ecological conception of
> the body, in which biochemical processes, emotional states, beliefs, lifestyle prac-
> tices (especially nutrition), and spiritual phenomena are thought to be intercon-
> nected. Beyond this emphasis on holism is also a commitment to low-tech care;
> individualized treatment regimes (treating the person not the symptom), in
> which the patient's intuitions and perceptions of his or her illness are an impor-
> tant part of diagnosis and treatment; an emphasis on the self-healing capacities
> of the body; a commitment to something more than the absence of disease—to
> "wellness" or some positive conception of health; a desire to narrow the power
> imbalances between practitioner and patient; and finally an effort to critically
> appropriate healing traditions that lie outside of Western allopathic medicine.
> (Schneirov and Geczik, 1996: 630–631)

Most members joined these networks when confronted by a chronic ill-
ness and dissatisfied with the treatment they received from mainstream
health care providers, and most of the rest joined while going through some
other sort of life crisis. Network members were united by several beliefs:
that modern medicine focuses too much on treating symptoms through
surgery and medication rather than on preventing illness through lifestyle
changes, that government regulation of health care endangers both personal
freedom and health, that individuals should take responsibility for their
own health, and that doing so means adopting stringent behavior regimens,
such as restrictive diets and regular use of laxatives. Through these shared
beliefs, users of alternative healing constructed not only a philosophy of health
care but also a shared sense of identity and community. Thus, Schneirov
and Geczik conclude, "the alternative health movement may be seen as part

of a larger wave of discontent with the bureaucratic-administrative state, its reliance on expert systems, and the way it coordinates people's health care practices 'behind their backs'—without their knowledge and participation" (1996: 642).

Seeking Information on the Internet

Whether individuals rely primarily on mainstream or alternative therapies, many seek information about their conditions on their own, rather than relying solely on information provided by health care professionals. In the last few years, public access to information has exploded due to the exponential growth of Internet use. A national random survey conducted in December 2004 found that 51 percent of all Americans have used the Internet to seek health information, and 35 percent did so during the month preceding the poll (*Harris Poll,* 2004a).

Unfortunately, there are no controls on the quality of materials posted on the Internet, and its vast size makes it impossible to police for fraudulent information, such as claims that herbs can cure cancer or AIDS. Moreover, more often than not, popular websites such as Yahoo.com and MSN.com take readers seeking health-related information to websites run by individuals or corporations that have vested economic interests in selling certain drugs or treatments (Green, Kazanjian, and Helmer, 2004). Partly in response to concerns about misleading websites, the U.S. Department of Health and Human Services now runs its own website (www.healthfinder .gov) to link consumers to reliable online sources of health information.

Despite limitations in most people's ability to effectively search the Internet or evaluate the information they find there, the Internet has proven enormously beneficial to those living with chronic health problems. The Internet has allowed individuals to find others who share their troubles and to find information far beyond what they otherwise could access. As a result, those who use the Internet are now better able to negotiate with health care providers regarding appropriate treatment and to navigate the daily difficulties of living with illness or disability.

Dealing with Service Agencies

For those who experience disabilities, whether or not they are chronically ill, dealing with social service agencies can become a major part of life. Unfortunately, and despite the best intentions of many social service providers, the philosophies and structures of those agencies create systems that sometimes harm more than help those they serve (Albrecht, 1992; Higgins, 1992: 151–187).

Typically, social service agencies adopt a medical model of disability, focusing on how individuals can compensate for their individual deficiencies rather than on how social arrangements handicap them (Phillips, 1985). This approach has several **unintended negative consequences.** First, to accept someone as a client, agencies must define him or her as disabled. As a result,

workers spend much of their time certifying individuals as disabled—identifying internal individual problems rather than looking for individual strengths. Through this process, individuals learn to think of themselves as disabled. According to Paul Higgins (1992: 132), "When service agencies evaluate, place, categorize, transfer, educate, rehabilitate, and so much more, the agencies are informing people who they are and who they are becoming." At the same time, because agencies receive funding based on how many clients they serve, agencies sometimes unintentionally encourage individuals to remain dependent on their services.

Second, because agencies use a medical model that defines people with disabilities as inherently flawed, agencies typically define "progress" as making those with disabilities as much like the nondisabled as possible (Albrecht, 1992; Higgins, 1992). Therefore rehabilitation workers might, for example, encourage someone to use a false leg even though the individual could move more quickly and less painfully on crutches or in a wheelchair. Box 6.3 describes how this philosophy has affected the education of deaf persons.

Third, the medical model encourages agencies to adopt a hierarchical pattern of care. This pattern of care is based on the premise that social service providers understand clients' needs, desires, problems, and strengths better than the clients themselves do and that social service providers are thus better equipped than clients to make decisions regarding clients' lives. Like other health care professionals, those who work in service agencies "evaluate, plan, treat, monitor, revise, discharge, and in other ways manage people. Disabled people (and their families) are expected to do what they are told" (Albrecht, 1992: 178). Thus, unwittingly, agencies encourage dependency.

Social Security, the major governmental program for persons with disabilities, further encourages dependency by economically penalizing those who obtain paid employment. Persons with disabilities who accept paid employment risk losing their government benefits, including both financial assistance and health care. Yet the costs of living with a disability are high; for example, as of 2005, modifying a van for a wheelchair-using driver costs anywhere from $10,000 to $27,000. Thus, unless individuals can get well-paid professional jobs with full health benefits, they may find employment unaffordable (Burns, Batavia, and DeJong, 1993).

Illness, Disabilities, and Social Relationships

For better or worse, chronic illness and disability alter relationships not only with health care providers and service agencies but also with friends, relatives, and colleagues. Illness and disability can strengthen social relationships, as families pull together to face health problems, old wounds are healed or put aside, and individuals realize how much they mean to each other. Illness and disability, however, can also strain relationships. Friends and family might help each other willingly during acute illnesses or the first few months of a chronic illness or traumatic injury, but they might become more loath to do so over time. This is especially true for male friends and family, who less often

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Box 6.3   ***American Sign Language and the Education of Deaf Children***

American Sign Language (ASL) is the native language of the U.S. deaf community. (English Sign Language is quite different.) Until recently, nonsigners considered ASL little more than a crude collection of gestures. In fact, however, ASL is a fully functioning language with a coherent and unique grammatical structure that allows people to communicate complex ideas as quickly and fluently as any spoken language (Klima and Bellugi, 1979). The history of ASL and its place in the education of deaf children demonstrates the disabling impact of prejudice (Lane, 1992; Neisser, 1983; J. Shapiro, 1993).

Before the nineteenth century, no national American sign language existed, although deaf individuals, scattered around the country, typically developed their own "home signs." European schools had begun teaching deaf children, but American educators considered them incapable of learning. In 1813, Thomas Gallaudet, a Congregationalist minister, distressed by the isolation of a neighbor's deaf child, decided to travel to Europe to observe deaf education there.

In France, Gallaudet for the first time saw sign language used to teach deaf children. He became convinced that deaf children could learn if taught in a language they could understand. Gallaudet returned to the United States accompanied by Laurent Clerc, a deaf teacher who communicated via French Sign Language.

Once back in the United States, Gallaudet and Clerc opened a school in Hartford, Connecticut. Most of the teachers were deaf, and all could sign fluently in the new language—American Sign Language—that developed naturally out of the combination of French Sign Language and American home signs. The school boasted impressive results as deaf children, taught to communicate in ASL, learned a wide variety of academic skills, including reading and writing English.

This "golden age" of ASL was brief, however. In 1867, the Clarke School for the Deaf was established to promote "oralism," the philosophy that deaf children would learn to speak English and lip-read only if forbidden to use ASL. In 1880, the International Congress of Educators of the Deaf—a Congress that included only one deaf educator—voted to make oralism the sole method for teaching

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than women are socialized to be caregivers (Cancian and Oliker, 2000; Fine and Asch, 1988b). Moreover, the growing burden of gratitude can make those who have chronic illnesses or disabilities reluctant to ask for needed help. Problems are especially acute among elderly persons, who have outlived their close relatives and friends and thus must rely on more distant social connections. For all these reasons, relationships may wither.

Relationships also suffer if individuals no longer can participate in previous activities. How do you maintain a relationship with a tennis partner once you no longer can hold a racket? How do you maintain a relationship with a friend when architectural and transportation barriers keep you from going to movies or restaurants? And how do you maintain a relationship with a spouse or lover when your sexual abilities and interests have changed dramatically—or when your partner no longer finds you sexually attractive?

deaf children. This decision remained in force for more than a century.

The decision to adopt oralism reflected the times (Neisser, 1983). With immigration rising in the United States, many Americans feared (as some do now, more than 100 years later), that "inferior" languages would soon replace English. The movement to eliminate ASL from the classroom paralleled the movement to ban these other languages. ASL seemed especially foreign and even sinister because its reliance on gestures made it seem less like English and more like the stigmatized languages of low-status Jewish and Italian immigrants. In addition, ASL seemed heretical to many because it seemed to refute the popular belief that God had separated humans from animals through speech.

Following the adoption of oralism, schools removed deaf teachers from the classrooms and in some cases began punishing children caught using ASL. Yet, except for the very small proportion of deaf children and adolescents who lose their hearing after learning English—and even for many of those—communicating in English usually remained an empty promise. Students would now spend hours each day practicing lip-reading and forming sounds they could not hear. Despite this, by the time they graduated, the vast majority could lip-read only a small fraction of spoken English and spoke English so poorly even their teachers could not understand them (Lane, 1992: 129). Moreover, the hours devoted to studying oral skills left little time for scholarly subjects, which, at any rate, were taught in incomprehensible spoken English. It was as if U.S. public schools taught children mathematics in Japanese! As a result, most deaf people remained functionally illiterate (Lane, 1992: 130). Since the 1970s, the ban on manual communication in the classroom has eased. In its place, though, most educators have adopted not ASL but artificially developed systems that substitute signs for words within grammatically English sentences. Whether deaf students are best taught in English-based systems or in ASL remains a highly contentious subject among educators and the deaf community, while the average reading level of 18- to 19-year-old deaf students remains no better than that of 9- to 10-year-old hearing students (Paul, 1998: 23).

Declines in financial standing also strain relationships. An individual might, for example, have the physical ability to go to a movie with a friend but lack the price of admission. Women and minorities are especially hard hit because they typically earned lower wages and had more erratic work histories before becoming ill or disabled, and so qualify for lower Social Security benefits, if any (DeJong, Batavia, and Griss, 1989). At the same time, the stress caused by financial pressures can damage relationships with children, lovers, and spouses.

Managing Stigma

Illness and disability affect not only relationships with friends and family but also less intimate relationships. Most basically—and despite the predictions of the sick role model—living with illness or disability means living

with **stigma.** Stigma refers to the social disgrace of having a deeply discrediting attribute, whether a criminal record, a gay lifestyle, or a socially unacceptable illness. The term *stigma* does not imply that a condition *is* immoral or bad, only that it is commonly viewed that way.

Some illnesses, especially acute illnesses such as influenza or streptococcal infections, produce relatively little stigma; but others, such as leprosy or HIV disease, are so stigmatized that they can affect even relationships with health care providers. Individuals whose illnesses carry a heavy burden of stigma can manage that stigma in various ways. First, individuals can attempt to **pass,** or to hide their illnesses or disabilities from others (Charmaz, 1991: 68–70, 110–119; Goffman, 1963: 73–91; J. Schneider and Conrad, 1983; Weitz, 1991: 128–132). For example, an elderly man who bumps into furniture because of failing eyesight might try to convince others that he is merely clumsy, and one who sometimes does not respond to questions because of hearing problems might try to convince others that he is merely absentminded. Similarly, those who have chronic illnesses can choose to go out only on days when their symptoms are least noticeable.

Although passing offers some protection against rejection, it carries a high price. Fear of disclosure means constant anxiety. Relationships with friends and families suffer when disabled or ill individuals lie about their conditions. In addition, those individuals forfeit the emotional or practical support they might receive if others understood their situations. Individuals also risk losing jobs or flunking courses when they cannot explain their reduced productivity and increased absences.

Those who cannot tolerate the stresses of passing can instead adopt a strategy of **covering**—no longer hiding their condition but instead trying to deflect attention from it (Goffman, 1963: 102–104). A woman with a visible leg brace can wear eye-catching jewelry, and persons with mobility limitations can arrive early to social gatherings to accustom themselves to the setting, identify potential physical hazards, and find accessible seats. Similarly, elderly persons who no longer see well enough to drive at night can schedule their social activities during daylight hours.

Conversely, those who have invisible disabilities sometimes find advantages in **disclosing** their disability to elicit sympathy or aid (Charmaz, 1991: 119–133). For example, a woman might choose to wear a leg brace or tell co-workers about her arthritis in order to avoid being labeled lazy when she cannot do certain tasks.

Other people deal with the potential for stigma through a process of **deviance disavowal,** that is, convincing others that they are the same as "normal" people (Davis, 1961). These individuals do not try to pass or cover their deviance, but instead try to prove that their illnesses or disabilities make them no different from others. Such "supercrips"—in the slang of disabled activists—often appear in the pages of popular magazines: the quadriplegic who paints holding a brush between her teeth, the blind man who is a champion skier, the participants in Special Olympics, and so on.

Each of these strategies can ease ill or disabled people's lives in an intolerant society. None, however, challenges the basis of that intolerance. Those who pass or cover in no way threaten the prejudices of those who would reject them. Even those who attempt to disavow their deviance do not challenge social prejudices regarding disabilities as much as proclaim they are not like others who have disabilities.

In contrast, other people take the more radical step of rejecting their rejecters and **challenging** the stigma of illness and disability. These individuals reject the social norms that denigrate them and refuse to adopt the accommodative strategies of passing, covering, or disavowing deviance. Instead, they argue that their deviations from bodily norms should not limit their civil rights or social status. Rather than accepting the stigma of illness and disability, these individuals attempt instead to label those who discriminate against them as foolish or immoral (Weitz, 1991: 132–133). They disclose their illness or disability not to elicit sympathy or aid but to affirm their dignity and pride in the lives they have made for themselves despite—or perhaps because of—the ways their bodies differ from social expectations. For example, a woman born without a hand who, after a year of wearing a hot, uncomfortable, and functionally useless artificial hand, decided to switch to a metal hook told an interviewer about her habit of looking at herself when passing store windows:

> I never failed to get a reaction from people, so I always looked too. What the hell are they looking at? I looked and I saw a woman with a *surprisingly* short arm! But when I got the [cosmetic] hand, I looked and I thought, oh my God, that's what I would have looked like [if I had been born with a hand]! And I saw this person that I would have been. But maybe I would have been an asshole just like all the rest of them [the nondisabled]. . . . And [now] when I see the hook, I say, boy, what a *bad* broad. And that's the look I like the best. (Phillips, 1990: 855)

This quote illustrates how individuals can construct an alternative view of both themselves and "normals"—in this case, redefining the self as feisty, independent, and rebellious and defining "normals" as voyeuristic "assholes."

Similar sentiments help explain the 1998 student rebellion at Gallaudet University (Lane, 1992: 186–191). Although Gallaudet is the only American college or university devoted to serving deaf and hearing-impaired students, all its presidents before 1988 had been hearing. That year, when the college's board of trustees (80 percent of whom were hearing) once again chose as president a hearing person who could not communicate in sign language, the students, along with many faculty, staff, and others, rose in protest. To these students, there was nothing wrong with deaf people, only with those who considered them inferior; many referred to themselves as "Deaf" rather than "deaf" to signify that they are linked by a minority culture rather than by a physical deficit. The protesters' anger grew after the board's chairperson reportedly told a group of students that the university needed a hearing president because "deaf people are incapable of functioning in a hearing world" (Lane, 1992: 188); the chairperson's later disclaimer that her remark had been

mistranslated into sign language only highlighted the incongruity of allow-
ing hearing people who knew no sign language to run Gallaudet. The stu-
dents' protests and the groundswell of support they received from alumni,
staff, faculty, and the general public led to the resignation of the chairper-
son, the appointment of a new board with a majority of deaf and hard-of-
hearing people, and the appointment of a deaf president who knew sign
language.

Health Social Movements

Like the Gallaudet students, others who live with or are at risk of illness or
disability increasingly have turned to collective political action to address
their grievances. Like other social movements, **health social movements** are
collective (rather than individual) efforts to change something about the
world that movement members believe is wrong (P. Brown et al., 2004).

Health social movements have a variety of goals. Many are organized
around obtaining equal access to health care. For example, both doctors and
consumers have fought to loosen health insurers' restrictions on what they
will cover or for the adoption of a national health insurance system that will
provide coverage to all citizens. Other health social movements are primar-
ily concerned with meeting the needs (including access to health care) of a
particular group. For example, the women's health movement, through
organizations such as the National Women's Health Network, has fought to
obtain for women the same access to heart disease treatments that men
have, to halt the unnecessary use of cesarean sections and hysterectomies,
and to increase the number of women physicians. Finally, a growing
number of health social movements have as their goal challenging medical
understandings of diseases based at least in part on their personal experi-
ences with illness or disability. For example, few doctors believe in the exis-
tence of "multiple chemical sensitivity" (MCS), which is theorized to make
some individuals ill whenever they contact any of the many chemicals that
are part of everyday modern life. Persons who believe they have this condi-
tion have organized to lobby for medical recognition of their condition and
to sue insurance companies that refuse to cover their treatment.

The rise of health social movements reflects a variety of factors (P. Brown
et al., 2004). The civil rights, women's rights, and gay rights movements of
the 1950s through the 1970s set the stage for a broader discussion of rights
and a broader acceptance of political action across American culture.
Health social movements are partly a product of this changed cultural cli-
mate. In addition, the same cultural forces that increased use of alternative
health care and the same technological changes that increased Internet
usage have fostered health social movements, by reinforcing the idea that
individuals have the right and the obligation to challenge medical author-
ity. Individuals are probably most likely to participate in health social move-
ments when they come to believe that medical authorities have failed to

protect them from diseases, to identify their diseases, or to treat their dis-eases appropriately. For example, the environmental breast cancer move-ment was organized primarily by women diagnosed with breast cancer who questioned why medical research has focused almost exclusively on early diagnosis and treatment of breast cancer rather than on its prevention. As this example suggests, people who live with illness and disability are not simply victims of their fate, but may actively work to better their situation and those of others like them.

The Body and the Self

Regardless of a person's political stance toward his or her condition, all dis-abilities and chronic illnesses challenge the self (Brooks and Matson, 1987; Bury, 1982; Charmaz, 1991; Corbin and Strauss, 1987; Fine and Asch, 1988a: 10–11; J. Schneider and Conrad, 1983). Those whose bodies differ in some critical way from the norm must develop a self-concept in the context of a culture that interprets bodily differences as signs of moral as well as physical inferiority. The resulting stigma leads such individuals to feel set apart from others (Conrad, 1987; Kutner, 1987; Weitz, 1991).

Illness and disability threaten self-concept in various ways. People who become physically deformed or less attractive often find it difficult to main-tain their self-images, as do those who lose their financial standing or their social roles as worker, student, spouse, or parent (Brooks and Matson, 1987; Weitz, 1991: 97). In addition, the need to rely on others for assistance can shake individuals' images of themselves as competent adults.

Disability and illness create different problems for women than for men. American society expects men to be emotionally, physically, and financially independent, and the threat to self-esteem when men cannot meet these expectations can be great. Conversely, American society expects women (except for African American women) to be dependent, so disability typi-cally does not threaten women's self-esteem as much as it threatens men's self-esteem. For African American women, however, and for all other American women who cherish their independence, illness or disabilities can hamper the struggle to obtain that independence, because prejudice and discrimination based on illness and disability compound prejudice and dis-crimination based on gender.

The sexual changes accompanying disability and illness also affect women and men differently. Social norms for both persons with and with-out disabilities expect men to be sexually active but regard women's sexual desires with suspicion. Following disability, men can lose esteem in both their eyes and those of their partners if they no longer can perform as before. Women, on the other hand, often find that others assume they have no sexual feelings at all once they no longer meet social norms of sexual attractiveness. This denial of women's sexuality narrows women's lives and diminishes their self-images (Lonsdale, 1990).

To cope with these threats to the self, individuals sometimes attempt intellectually to separate their essential selves from their recalcitrant bodies. Cheri Register (1987: 33), a writer who has a rare, chronic disease, describes

> a need that many of us feel to visualize the illness as smaller than ourselves. Rather than letting the illness overtake our identities, we try to find some confined space within ourselves or our lives to contain it, and then draw boundaries around it: "*Here* is the illness. I will only let it make *this* much difference."

This strategy succeeds best when symptoms follow a predictable course and the problem affects only one part of the body.

Yet the impact of disability and illness on the self is not solely negative. Indeed, disability and illness can bring improved self-esteem and quality of life. Over time, individuals may learn to devalue physical appearances, derive self-esteem from other sources, and focus on the present rather than on an intangible future (Weitz, 1991: 136–140). They may learn to set priorities in their lives so that, often to a greater extent than before, they accomplish their most important goals rather than wasting precious energy on trivial concerns (Charmaz, 1991: 134–166). Finally, they may come to define their condition simply as part of who they are, with good points and bad points, and to recognize that much of their personalities and accomplishments exist not *despite* their physical condition, but *because* of it (Higgins, 1992: 141). As Barbara Rosenblum, a sociologist and artist who died of breast cancer at age 44, wrote:

> I am a very different person now: more open, much more honest, and more self-knowing. . . . I turned it [cancer] into a possibility of opening up to myself, for discovering, and for exploring new areas.
>
> I've realized that I want to list the ways in which cancer can do that. You can get courage to take larger risks than you ever have before. I mean, you're already sick, so what can happen to you? You can have much more courage in saying things and in living than you ever had before. . . .
>
> And you can do things you've always wanted to do. Cancer, by giving you the sense of your own mortality, can entice you into doing those things you have been postponing. . . .
>
> You have this sense of urgency. And you can turn this urgency—you can harness this energy that propels you—so that you go ahead and do these things and discover new parts of yourself. All the things you ever wanted to do, all the dreams you had. And the dreams that you couldn't even dream, because you didn't allow yourself. . . .
>
> Cancer has put me in touch with that. And then also, it has taught me to enjoy the tenderness and the preciousness of every moment. Moments are very important because there may not be any after that—or you may throw up. Cancer exquisitely places you in the moment.
>
> I have become very human to myself in a way that I would never have imagined. I've become a bigger person, a fuller person. This to me is one of the

greatest lessons: just being human. Having cancer doesn't mean that you lose yourself at all. For me it meant that I discovered myself. (Butler and Rosenblum, 1991: 160–161)

Conclusion

Given the progressive aging of the American population and the increasing ability of medical technology to keep alive ill and disabled individuals, many more of us can expect eventually to live with illness, chronic pain, and disability—whether our own, our parents', or our children's. Consequently, understanding what it means to live with these conditions has never been more important.

As both social constructions and social statuses, illness and disability affect all aspects of life. In addition to forcing those who are ill or disabled to interact with health care providers and to manage health care regimens, illness and disability affect relationships with family and friends, work and educational performance and opportunities, and, perhaps most important, one's sense of self and relationship with one's own body. Living with illness and disability also requires people to come to terms—or to refuse to come to terms—with uncomfortable questions and harsh realities regarding their past, present, and future.

Illness and disability can confer social disadvantages similar to those experienced by members of traditionally recognized minority groups. Yet the impact of illness and disability is not always negative, for illness and disability at times can provide individuals with the basis for increased self-esteem and enjoyment of life. Moreover, like other minorities, those who live with illness and disability have in recent years moved from pleas for tolerance to demands for rights. Those demands have produced significant changes in American architecture, education, transportation, and so on, and have laid the groundwork for the changes still needed.

Suggested Readings

Hockenberry, John. 1995. *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence.* New York: Hyperion. A vivid and honest memoir by radio and television correspondent John Hockenberry, who has been a paraplegic since age 19.

Kamen, Paula. 2005. *All In My Head: An Epic Quest to Cure an Unrelenting, Totally Unreasonable, and Only Slightly Enlightening Headache.* Cambridge, MA: Da Capo. Kamen's wry but horrifying story of her decade-long headache illuminates the problem of chronic pain, the stigma attached to it, and the steps needed to improve the situation.

Getting Involved

Disability Rights Education and Defense Fund. 2212 6th Street, Berkeley, CA 94710. (510) 644-2555. www.dredf.org. Activist group promoting independent living and civil rights for persons with disabilities.

Review Questions

How do the medical and sociological models of disability differ?

Are disabled people a minority group?

What is the Americans with Disabilities Act?

How common is disability, and which social groups have the highest rates of disability?

What difficulties do individuals face in responding to initial symptoms of illness or disability, obtaining diagnoses, and coming to terms with their diagnoses?

What is illness behavior?

How can illness serve as an interruption, an intrusion, or something in which a person is immersed?

Why do individuals sometimes ignore medical advice?

Why do individuals use alternative health care?

How can illness or disability affect social relationships and self-image?

How can individuals manage the stigma of illness or disability?

What is a health social movement, and why have they become more common?

Internet Exercises

1. Find the Pharmaceutical Research and Manufacturers of America website. Read and critique their essay on direct-to-consumer advertising. What are the problems with the surveys they cite? What issues are they glossing over?

2. Find three sites devoted to disability rights. (Hint: Each site will probably have links to other sites.) Browse the sites. In what ways are the problems identified by these sites similar to or different from the problems identified in this chapter?

3. Find a website that sells human growth hormone (HGH) direct to the public. (Hint: Search for "purchase HGH.") Critique the website: What kinds of information is the website highlighting? What kinds of necessary information about the drug is either not available on the website, hard to find, or hard to read? What techniques is the website using to convince the viewer to purchase the drug (for example, suggesting that the drug is more "natural" than other available drugs, or recommended by medical "experts")?