PART

2 The Meaning and Experience of Illness

Our commonsense understandings of the world tell us that illness is a purely biological condition, definable by objectively measured biological traits. As we will see in Part Two, however, definitions of illness vary considerably over time and space and across social groups. In Chapter 5, we explore the social meanings of illness and consider how ideas about the nature and causes of illness have changed historically, from biblical explanations that attributed illness to punishment for sin to modern New Age explanations that attribute illness to lack of self-love. We also examine how defining something as an illness can act as a form of social control.

Whereas Chapter 5 discusses the meaning of illness in the abstract, Chapter 6 looks at the consequences of chronic illness and disability for individuals. Beginning with a discussion of how Western society historically has treated those who have chronic illnesses and disabilities, we then consider the modern experience of illness, from responding to initial symptoms to searching for mainstream or alternative therapies to coming to terms with a changed body and self-image.

In Chapter 7, we examine parallel questions regarding mental illness. That chapter explores what people mean when we say something is a mental illness. Then we look at how and why mental illness is distributed among social groups; how Western society historically has treated persons with mental illnesses; and how individuals experience mental illness, from initial symptoms, to treatment, to social status following treatment.

CHAPTER 5

The Social Meanings of Illness

All Marco Oriti has ever wanted, ever imagined, is to be taller. At his fifth birthday party at a McDonald's in Los Angeles, he became sullen and withdrawn because he had not suddenly grown as big as his friends who were already five: in his simple child's calculus, age equaled height, and Marco had awakened that morning still small. In the six years since then, he has grown, but slowly, achingly, unlike other children. "Everybody at school calls me shrimp and stuff like that," he says.

"They think they're so rad. I feel like a loser. I feel like I'm nothing." At age 11, Marco stands 4 feet 1 inch—4 inches below average—and weighs 49 pounds. And he dreams, as all aggrieved kids do, of a sudden, miraculous turnaround: "One day I want to, like, surprise them. Just come in and be taller than them."

Marco, a serious student and standout soccer player, more than imagines redress. Every night but Sunday, after a dinner he seldom has any appetite for, his mother injects him with a hormone known to stimulate bone growth. The drug, a synthetic form of naturally occurring human growth hormone (HGH) produced by the pituitary, has been credited with adding up to 18 inches to the predicted adult height of children who produce insufficient quantities of the hormone on their own—pituitary dwarfs. But there is no clinical proof that it works for children like Marco, with no such deficiency. Marco's rate of growth has improved since he began taking the drug, but his doctor has no way of knowing if his adult height will be affected. Without HGH, Marco's predicted height was 5 feet 4 inches, about the same as the Nobel Prize–winning economist Milton Friedman and . . . Masters golf champion, Ian Woosnam, and an inch taller than the basketball guard Muggsy Bogues of the Charlotte Hornets. Marco has been taking the

shots for six years, at a cost to his family and their insurance company of more than $15,000 a year [$21,000 in 2005 dollars]. . . .

A Cleveland Browns cap splays Marco Oriti's ears and shadows his sparrowish face. Like many boys his age, Marco imagines himself someday in the NFL. He also says he'd like to be a jockey—making a painful incongruity that mirrors the wild uncertainty over his eventual size. But he is unequivocal about his shots, which his mother rotates nightly between his thighs and upper arms. "I hate them," he says.

He hates being short far more. Concord, the small Northern California city where the Oriti family now lives, is a high-achievement community where competition begins early. So Luisa Oriti and her husband, Anthony, a bank vice president, rationalize the harshness of his treatment. "You want to give your child that edge no matter what," she says, "I think you'd do just about anything." (Werth, 1991)

Does Marco have an illness? According to his doctors, who have recommended that he take an extremely expensive, essentially experimental, and potentially dangerous drug, it would seem that he does. To most people, however, Marco simply seems short.

In the first part of this chapter, we look at the medical and sociological models of illness—two opposing ways of thinking about what illness means. Then we will explore how the public in general thinks about illness, and some of the consequences of these views. In the second part of this chapter, we consider how medicine can act as an institution of social control, highlighting the process through which behaviors or conditions become defined as illnesses and the consequences of these definitions.

Models of Illness

The Medical and Sociological Models of Illness

What do we mean when we say something is an illness? As Marco's story suggests, the answer is far from obvious. Most Americans are fairly confident that someone who has a cold or cancer is ill. But what about the many postmenopausal women whose bones have become brittle with age, and the many older men who have bald spots, enlarged prostates, and urinary problems? Or the many young boys who have trouble learning, drink excessively, or enjoy fighting? Depending on who you ask, these conditions may be defined as normal human variations, as illnesses, or as evidence of bad character. As these questions suggest, defining what is and is not an illness is far from a simple task. In this section we explore the **medical model of illness:** what doctors typically mean when they say something is an illness. This medical model is not accepted in its entirety by all doctors—those in public health, pediatrics, and family practice are especially likely to question it—and is not rejected by all

sociologists, but it is the dominant conception of illness in the medical world. The **sociological model of illness** summarizes critical sociologists' retort to the medical model of illness. This sociological model reflects sociologists' view of how the world currently operates, not how it ideally should operate. Key Concepts 5.1 compares these two models, using as an example female sexual dysfunction (FSD), a recently developed and still contentious diagnosis.

The medical model of illness begins with the assumption that illness is an *objective* label given to anything that deviates from normal biological functioning (Mishler, 1981). Most doctors, if asked, would explain that polio is caused by a virus that disrupts the normal functioning of the neurological system, that menopause is a "hormone deficiency disease" that, among other things, impairs the body's normal ability to regenerate bone, and that men develop urinary problems when their prostates grow excessively large and unnaturally compress the urinary tract. Doctors might further explain that, because of scientific progress, all educated doctors can now recognize these problems as illnesses, even though they were not considered as such in earlier eras.

In contrast, the sociological model of illness begins with the statement that illness (as the term is actually used) is a *subjective* label, which reflects personal and social ideas about what is normal as much as scientific reasoning (Weitz, 1991). Sociologists point out that ideas about normality differ widely across both individuals and social groups. A height of 4 feet 6 inches would be normal for a Pygmy man but not for an American man. Drinking three glasses of wine a day is normal for Italian women but could lead to a diagnosis of alcoholism in American medical circles. In defining normality, therefore, we need to look not only at individual bodies but also at the broader social context. Moreover, even within a given group, "normality" is a range and not an absolute. The median height of American men, for example, is 5 feet 9 inches, but most people would consider someone several inches taller or shorter than that as still normal. Similarly, individual Italians routinely and without social difficulties drink more or less alcohol than the average Italian. Yet medical authorities routinely make decisions about what is normal and what is illness based not on absolute, objective markers of health and illness but on arbitrary, statistical cutoff points—deciding, for example, that anyone in the fifth percentile for height or the fiftieth percentile for cholesterol level is ill. Culture, too, plays a role: Whereas the American Society of Plastic and Reconstructive Surgeons recommends breast enlargement for small breasts, which it considers a disease ("micromastia") and believes "results in feelings of inadequacy, lack of self-confidence, distortion of body image and a total lack of well-being due to a lack of self-perceived femininity" (1989: 4–5), in Brazil large breasts are denigrated as a sign of African heritage and breast *reduction* is the most popular cosmetic surgery (Gilman, 1999).

Because the medical model assumes illness is an objective, scientifically determined category, it also assumes there is no *moral* element in labeling a condition or behavior as an illness. Sociologists, on the other hand, argue that illness is inherently a moral category, for deciding what is illness always means

Key Concepts 5.1 ***Medical and Sociological Models of Illness***

MEDICAL MODEL	SOCIOLOGICAL MODEL
Illness is an *objective* label: All educated people agree on what is normal and what is illness.	Illness is a *subjective* category: Educated people sometimes disagree on what should be labeled illness.
Example: Female sexual dysfunction (FSD) is a biological disease characterized by lack of sexual responsiveness.	*Example: Female sexual dysfunction (FSD) is a* label *given to women who are distressed by their lack of sexual responsiveness with their* current *sexual partner.*
Illness is *nonmoral*: Conditions and behaviors are labeled *illness* scientifically, without moral considerations or consequences.	Illness is a *moral* category: Conditions and behaviors are labeled *illness* when they are considered bad (deviant).
Example: Labeling FSD an illness and labeling individuals as having FSD are neutral biological statements that do not reflect moral judgments of the condition or individual.	*Example: We label sexual nonresponsiveness an illness because we find it repugnant, and we typically look down on those who have FSD.*
Illness is an *apolitical* label.	Illness is a *political* label: Some groups have more power than others to decide what is an illness and who is ill.
Example: FSD was first identified by doctors through scientific research.	*Example: The concept of FSD was promoted by pharmaceutical companies to sell drugs.*

deciding what is good or bad. When, for example, doctors label menopause a "hormonal deficiency disease," they label it an undesirable deviation from normal. In contrast, many women consider menopause both normal and desirable and enjoy the freedom from fear of pregnancy that menopause brings (E. Martin, 1987). In the same manner, when we define cancer, polio, or diabetes as illnesses, we judge the bodily changes these conditions produce to be both abnormal and undesirable, rather than simply normal variations in functioning, abilities, and life expectancies. (Conversely, when we define a condition as healthy, we judge it normal and desirable.)

Similarly, when we label an individual as ill, we also suggest that there is something undesirable about that *person.* By definition, an ill person is one whose actions, ability, or appearance do not meet social **norms,** or expectations

MEDICAL MODEL	SOCIOLOGICAL MODEL
Illness is a *concrete, unchanging reality* that all informed observers agree on. *Example: If Victorian doctors had been more educated, they would have realized that FSD was a disease.*	Illness is a *social construction*: Each cultural group, at each point in time, assigns the label *illness* to whatever it considers both biological and problematic. *Example: Victorians considered women bad—and ill—if they experienced sexual pleasure. Modern society considers women deviant—and ill—if they are sexually unresponsive.*
Each illness has specific, universally recognizable, features, so diagnosis is objective and consistent across doctors and populations. *Example: All women who lack sexual responsiveness share biological markers (such as low testosterone) and will be diagnosed with FSD, regardless of their doctors or their social characteristics.*	Illness is neither specific nor universally recognized, so diagnosis is subjective and culturally bound. *Example: White women are more likely than others to be diagnosed with FSD, and doctors in cultures that consider female sexuality shameful do not consider FSD an illness.*
Each illness is caused by unique biological forces. *Example: Women can become sexually unresponsive when their hormonal balance is awry.*	Illness is caused by a combination of social, psychological, and biological causes. *Example: Women become sexually unresponsive when their cultures deny female sexuality or their partners lack sexual skills, among other reasons.*

within a given culture regarding proper behavior or appearance. Such a person will typically be considered less whole and less socially worthy than those deemed healthy. Illness, then, like virginity or laziness, is a **moral status:** a social condition that we believe indicates the goodness or badness, worthiness or unworthiness, of a person.

From a sociological standpoint, illness is not only a moral status but (like crime or sin) a form of **deviance** (Parsons, 1951). To sociologists, labeling something deviant does not necessarily mean that it is immoral. Rather, deviance refers to behaviors or conditions that socially powerful persons within a given culture *perceive,* whether accurately or inaccurately, as immoral or as violating social norms. We can tell whether behavior violates norms (and, therefore, whether it is deviant) by seeing if it results in

negative social sanctions. This term refers to any punishment, from ridicule to execution. (Conversely, **positive social sanctions** refers to rewards, ranging from token gifts to knighthood.) These social sanctions are enforced by **social control agents** including parents, police, teachers, peers, and doctors. Later in this chapter we will look at some of the negative social sanctions imposed against those who are ill.

For the same reasons that the medical model does not recognize the *moral* aspects of illness labeling, it does not recognize the *political* aspects of that process. Although some doctors at some times are deeply immersed in these political processes—arguing, for example, that insurance companies should cover treatment for newly labeled conditions such as fibromyalgia or multiple chemical sensitivity—they rarely consider the ways that politics underlie the illness-labeling process in general. In contrast, sociologists point out that any time a condition or behavior is labeled as an illness, some groups will benefit more than others, and some groups will have more power than others to enforce the definitions that benefit them. As a result, there are often open political struggles over illness definitions (a topic we will return to later in this chapter). For example, vermiculite miners and their families who were constantly exposed to asbestos dust and who now have strikingly high rates of cancer have fought with insurance companies and doctors, in clinics, hospitals, and the courts, to have "asbestosis" labeled an illness; meanwhile, the mining companies and the doctors they employed have argued that there is no such disease and that the high rates of health problems in mining communities are merely coincidences (A. Schneider and McCumber, 2004).

In sum, from the sociological perspective, illness is a **social construction,** something that exists in the world not as an objective condition but *because we have defined it as existing.* This does not mean that the virus causing measles does not exist, or that it does not cause a fever and rash. It does mean, though, that when we talk about measles as an illness, we have organized our ideas about that virus, fever, and rash in only one of the many possible ways. In another place or time, people might conceptualize those same conditions as manifestations of witchcraft, as a healthy response to the presence of microbes, or as some other illness altogether. To sociologists, then, *illness*, like *crime* or *sin,* refers to biological, psychological, or social conditions subjectively defined as undesirable by those within a given culture who have the power to enforce such definitions.

In contrast, and as we have seen, the medical model of illness assumes that illness is an objective category. Based on this assumption, the medical model of health care assumes that each illness has specific features, universally recognizable in all populations by all trained doctors, that differentiate it both from other illnesses and from health (Dubos, 1961; Mishler, 1981). The medical model thus assumes that diagnosis is an objective, scientific process.

Sociologists, on the other hand, argue that diagnosis is a subjective process. The subjective nature of diagnosis expresses itself in three ways. First, patients with the same symptoms may receive different diagnoses

depending on various social factors. Women who seek medical care for chronic pain, for example, are more likely to receive psychiatric diagnoses than are men who report the same symptoms. Similarly, African Americans (whether male or female) are more likely than whites are to have their chest pain diagnosed as indigestion rather than as heart disease (Hoffman and Tarzian, 2001; Nelson, Smedley, and Stith, 2002). Second, patients with the same underlying illness may experience different symptoms, resulting in different diagnoses. For example, the polio virus typically causes paralysis in adults but only flu-like symptoms in very young children, who often go undiagnosed. Third, different cultures identify a different range of symptoms and categorize those symptoms into different illnesses. For example, U.S. doctors assign the label of attention deficit disorder (ADD) to children who in Europe would be considered lazy troublemakers. And French doctors often attribute headaches to liver problems, whereas U.S. doctors seek psychiatric or neurological explanations (Payer, 1996). In practice, the American medical model of illness assumes that illnesses manifest themselves in other cultures in the same way as in American culture and, by extension, that American doctors can readily transfer their knowledge of illness to the treatment and prevention of illness elsewhere.

Finally, the medical model of illness assumes that each illness has not only unique symptoms but also a unique **etiology,** or cause (Mishler, 1981). Modern medicine assumes, for example, that **tuberculosis,** polio, **HIV disease,** and so on, are each caused by a unique microorganism. Similarly, doctors continue to search for limited and unique causes of heart disease and cancer, such as high-cholesterol diets and exposure to asbestos. Yet even though illness-causing microorganisms exist everywhere and environmental health dangers are common, relatively few people become ill as a result. By the same token, although cholesterol levels and heart disease are strongly correlated among middle-aged men, many men eat high-cholesterol diets without developing heart disease, and others eat low-cholesterol diets but die of heart disease anyway. The doctrine of unique etiology discourages medical researchers from asking why individuals respond in such different ways to the same health risks and encourages researchers to search for **magic bullets**—a term first used by Paul Ehrlich, discoverer of the first effective treatment for syphilis, in referring to drugs that almost miraculously prevent or cure illness by attacking one specific etiological factor. Box 5.1 describes the work of Doctors Without Borders, an organization that offers an inspiring example of doctors and other health care workers who take a truly broad view of the causes and treatment of illness.

Popular Explanations for Illness

Although medicine as an institution certainly affects how the general public thinks about illness, it does not fully control popular beliefs about illness. Consequently, we also need to look at those popular beliefs. As we will see,

Box 5.1 ***Making a Difference: Doctors Without Borders***

Doctors Without Borders/Médecins Sans Frontières (MSF) is an independent humanitarian organization, founded in 1971, that assists people around the globe whose health has been damaged by disasters, war, or political violence. After an enormous tsunami killed more than 200,000 Indonesians in December 2004, for example, MSF sent doctors, nurses, and other health care workers to treat those who were injured by debris carried by the tsunami, infected by diarrheal diseases spread when sewage systems washed away, or overwhelmed psychologically when loved ones died. Once these "first aid" needs were met, MSF members began working on the broader infrastructure needed to protect the health of the tsunami survivors: organizing vaccination campaigns against tetanus and measles (which had started spreading following the tsunami), food distribution programs (so that malnutrition in the wake of the tsunami would not lead to further mortality), sanitation programs (to prevent disease transmission through unsafe water supplies), and home- and boat-building programs (so people had shelter and a means of earning a living once again).

As this example suggests, MSF's model of illness and how to treat it goes far beyond treating specific symptoms of specific diseases. MSF not only attempts to treat the underlying causes of disease but also includes in its mission the responsibility to publicly bear witness to the problems it sees. Because of its impeccable nonpartisan reputation—taking no sides in any conflict other than on behalf of the people it assists—the doctors and other workers of MSF speak with great moral authority. On its website (www.doctorswithoutborders.org) and in frequent news releases, articles, opinion columns, testimony given at the United Nations General Assembly, and the like, MSF speaks out about illness as well as the social causes of illness. MSF has spoken publicly about how attitudes toward women underlie the use of rape as a military tactic, how international economic dynamics contribute to the short and brutal lives of street-children in developing nations, how pharmaceutical company policies have made treatment for AIDS and other diseases unaffordable in the developing world, how governments use violence to subdue their own populations, and so on. The doctors and other workers of MSF exemplify a broad-based, sociological understanding of illness and health care.

because people consider illness undesirable and because it can strike anyone at any time, they most often react with fear and confusion. To relieve their anxiety and make the world seem less capricious and frightening, they typically seek explanations for why illness occurs and why it strikes some rather than others. Most often, those explanations define illness as a deserved punishment and blame individuals for their own illnesses (Brandt and Rozin, 1997; Weitz, 1991). Such explanations provide psychological reassurance by reinforcing people's belief in a "just world," in which punishment falls only on the guilty (Meyerowitz, Williams, and Gessner, 1987).

According to George Foster (1976), all traditional, prescientific theories of illness causation around the world divide into only two, somewhat overlapping, categories: personalistic and naturalistic. **Personalistic theories,**

the more common type (Murdock, 1980), hold that illness occurs when a god, witch, spirit, or other supernatural power lashes out at an individual, either deservedly or maliciously. **Naturalistic theories** assert that illness occurs when heat, cold, wind, damp, or other natural forces upset the body's equilibrium. Both personalistic and naturalistic theories blame ill persons for causing their illness, whether by displeasing supernatural beings or by exposing themselves to harmful natural elements. And both define ill persons as less morally worthy than others, whether as sinners or as fools.

Personalistic theories have played an especially important role in the Western world, which in the past often equated illness with divine punishment for sin (Murdock, 1980: 42–52). For example, both the Jewish and Christian Bibles describe leprosy as punishment for an individual's sin. Biblical explanations for leprosy, coupled perhaps with some awareness that leprosy was contagious, led Western societies for centuries to isolate affected individuals. Throughout the Middle Ages and until the Reformation, Christian society required anyone diagnosed with leprosy to participate in a special mass for the dead, known as the lepers' mass. Following the mass, a priest would shovel dirt on the individual's feet to symbolize his or her civil and religious death. From then on, the individual was legally prohibited from entering public gathering places, washing in springs or streams, drinking from another's cup, wearing anything other than the special "leper's dress," touching anything before buying it, talking to anyone without first moving downwind, and so on (Richards, 1977: 123–124). This social banishment continued even after death: Like those who committed suicide or other mortal sins, persons with leprosy could not be buried in church graveyards.

By the early nineteenth century, prescientific ideas about illness had begun to erode as the idea grew, especially among the elite, that scientific principles controlled the natural order. According to the new scientific thinking, illness occurred when biological forces combined with personal susceptibility. Doctors (still lacking a concept of germs) argued that illness occurred when persons whose constitutions were naturally weak or had been weakened by unhealthy behaviors came in contact with dangerous **miasma,** or air "corrupted" by foul odors and fumes. According to this theory, therefore, individuals became ill because of unhealthy rather than immoral behavior.

As the history of cholera shows, however, these new ideas still allowed the healthy to blame the ill for their illnesses. Cholera first appeared in the Western world in about 1830, killing its victims suddenly and horrifyingly, through overwhelming dehydration brought on by uncontrollable diarrhea and vomiting. Cholera is caused by waterborne bacteria, generally transmitted when human wastes contaminate food or drinking water. Because of the link to sanitation, cholera most often strikes poor persons who lack clean water and are weakened by insufficient food, clothing, or shelter.

To explain why cholera had struck, and why it struck the poor especially hard, early nineteenth-century doctors asserted that cholera could attack only individuals who had weakened their bodies through improper living

(Risse, 1988; Rosenberg, 1987). According to this theory, the poor caused their own illnesses, first by lacking the initiative required to escape poverty and then by choosing to eat an unhealthy diet, live in dirty conditions, or drink too much alcohol. Thus, for example, the New York City Medical Council could conclude in 1832 that "the disease in the city is confined to the imprudent, the intemperate, and to those who injure themselves by taking improper medicines" (Risse, 1988: 45). Conversely, doctors (and their wealthy patrons) assumed that wealthy persons would become ill only through gluttony, greed, or "innocently" inhaling some particularly noxious air.

Using this theory, doctors, foreshadowing what would happen with HIV disease, divided patients into the "guilty" (the overwhelming majority), the "innocent," and the "suspect," and hospitals provided or refused care accordingly (Risse, 1988; Rosenberg, 1987). This theory of illness allowed the upper classes to adopt the new, scientific explanations for illness while retaining older, moralistic assumptions about ill people and avoiding any sense of responsibility for aiding the poor or the ill. In sum, instead of believing that immorality directly *caused* illness, people now believed that immorality left one *susceptible* to illness.

Despite the tremendous growth in medical knowledge about illness during the last century, popular explanations for illness have remained remarkably stable. Theories connecting illness to sin continue to appear, as do theories that conceptualize illness as a direct consequence of poorly chosen and hence irresponsible (although not necessarily sinful) behavior (Brandt and Rozin, 1997; Zola, 1972). For example, although most Americans know that viruses cause influenza and the common cold, most continue to hold essentially naturalistic theories regarding these illnesses—warning their children to eat warm foods, wear hats and gloves, and cover up against the rain to avoid infection.

Similarly, the mass media, public health authorities, and the general public now often blame illness on individual lifestyles (Brandt and Rozin, 1997; Tesh, 1988). Magazines regularly print articles such as "Beat Your Risk Factors" (Libov, 1999) and "Ten Easy Ways to Boost Your Immunity" (Strote, 2002), exhorting individuals to protect or restore their health through diet, exercise, stress reduction, and the like. Simultaneously, the U.S. government—even while continuing to subsidize the tobacco and beef industries—spends millions on education campaigns encouraging the public to stop smoking and to eat healthier diets.

Another popular ideology ties illness not to individual actions but to individual personalities (Sontag, 1978). For example, a newspaper account of comedian Gilda Radner's death from ovarian cancer quoted her "therapist" explaining how

> Gilda always had this wonderful will to live. Yet she also exhibited the same preconditioning virtually all [cancer patients] have. Fear. Hopelessness. Negativity. What . . . Gilda came to appreciate [in her therapy], is that a positive outlook can

> improve the quality of life—up to and including the immune system. (Kahn, 1989)

Similarly, the media continue to warn that individuals with aggressive and competitive type A personalities are at risk for heart problems (Siegman and Dembroski, 1989), despite considerable scientific evidence refuting this link (Aronowitz, 1998).

In its most extreme form, this sort of theorizing has led some to claim that illness occurs not because individuals ignore their bodies or have illness-producing personalities but because they *choose* to become ill. The most influential statement of this theory appears in the best-selling book *Love, Medicine and Miracles* by surgeon Bernie Siegel (1990). Siegel postulates that people become ill because they "need" their illness—to escape a stressful work situation, receive sympathy from their spouses, punish themselves for misdeeds, and so on—and because they do not love themselves enough to take care of their emotional needs. Consequently, Siegel advises ill persons that they will find lasting cures only when they truly desire a healthy, long life.

Theories such as Siegel's draw on research suggesting that stress, personality, and lifestyle can increase personal susceptibility to illness. Such factors may indeed affect the distribution of illness in society. Yet by focusing on these factors as the primary source of illness, these theories encourage the healthy to devalue and reject those who are ill and promote depression and lowered self-esteem among those who blame themselves for their illnesses.

In addition, by emphasizing how individuals cause their own illnesses, these theories encourage policymakers to ignore how social and environmental factors can foster illness (Crawford, 1979; Tesh, 1988; Waitzkin, 1981; Zola, 1972). For example, magazines that emphasize how individuals make themselves ill rarely discuss how factors largely beyond individual control (such as poverty, malnutrition, pollution, or unsafe conditions in our houses, cars, or workplaces) can produce ill health. Nor do these magazines discuss how social factors (including the advertisements for alcohol and cigarettes in some of these same magazines) can pressure individuals to adopt unhealthy lifestyles—how unemployed teenagers with poor job prospects sometimes smoke cigarettes to demonstrate their adulthood, how young mothers who lack assistance with child care probably also lack time for the recommended three sessions per week of aerobic exercise, or how workers sometimes suffer injuries because of unsafe equipment rather than because of personal carelessness. As Barbara Katz Rothman notes,

> Think of the anti-smoking, anti-drinking "behave yourself" campaigns aimed increasingly at pregnant women. What are the causes [as identified in these campaigns] of prematurity, fetal defects, damaged newborns—flawed products? Bad mothers, of course—inept workers. One New York City subway ad series shows two newborn footprints, one from a full-term and one from a premature infant. The ads read, "Guess which baby's mother smoked while pregnant?" Another asks,

> "Guess which baby's mother drank while pregnant?" And yet another: "Guess which baby's mother didn't get prenatal care?" I look in vain for the ad that says "Guess which baby's mother tried to get by on welfare?"; "Guess which baby's mother had to live on the streets?"; or "Guess which baby's mother was beaten by her husband?" (1989: 21)

In sum, whether or not they are accurate, theories of illness that focus on individual responsibility reinforce existing social arrangements and help us justify our tendency to reject, mistreat, or simply ignore those who suffer illness.

Medicine as Social Control

Creating Illness: Medicalization

The process through which a condition or behavior becomes defined as a medical problem requiring a medical solution is known as **medicalization** (Conrad and Schneider, 1992; Conrad, 2005). For example, as social conditions have changed, activities formerly considered sin or crime, such as masturbation, homosexual activity, or heavy drinking, have become defined as illnesses. The same has happened to various natural conditions and processes, such as uncircumcised penises, limited sexual desire, aging, pregnancy, and menopause (e.g., E. Armstrong, 2000; Barker, 1998; Figert, 1996; Rosenfeld and Faircloth, 2005). The term *medicalization* also refers to the process through which the definition of an illness is *broadened.* For example, when the World Health Organization (WHO) in 1999 lowered the blood sugar level required for diagnosis with diabetes, the number of persons eligible for this diagnosis increased in some populations by as much as 30 percent (Shaw, de Courten, Boyko, and Zimmet, 1999).

For medicalization to occur, one or more organized social groups must have both a vested interest in it and sufficient power to convince others (including doctors, the public, and insurance companies) to accept their new definition of the situation. Not surprisingly, doctors often play a major role in medicalization, for medicalization can increase their power, the scope of their practices, and their incomes. For example, during the first half of the twentieth century, improvements in the standard of living coupled with the adoption of numerous public health measures substantially reduced the number of seriously ill children. As a result, the market for pediatricians declined, and their focus shifted from treating serious illnesses to treating minor childhood illnesses and offering well-baby care. Pediatrics thus became less well-paid, interesting, and prestigious. To increase their market while obtaining more satisfying and prestigious work, some pediatricians have expanded their practices to include children whose behavior concerns their parents or teachers and who are now defined as having medical conditions such as attention deficit disorder or antisocial personality

disorder (Halpern, 1990). Doctors have played similar roles in medicalizing premenstrual syndrome (Figert, 1996), drinking during pregnancy (E. Armstrong, 1998), impotence (Loe, 2004; Tiefer, 1994), and numerous other conditions.

In other instances, however, doctors have proved indifferent or even opposed to medicalization. For example, although some doctors believe that woman battering is a medical problem and that doctors should accept responsibility for identifying it and intervening when it occurs, others believe that women provoke their own battering, that doctors can do little to help, or that woman battering is best dealt with by the police rather than by doctors (Kurz, 1987). As a result, many doctors oppose medicalizing woman battering and prefer to treat women's injuries without delving into their causes.

In circumstances such as these, pressure for medicalization can instead come from consumers and consumer groups (Conrad, 2005). Alcoholics Anonymous, for example, has fought to medicalize alcoholism partly to reduce the stigma of that condition. Other consumer groups similarly have argued for medicalization in the hope that medical control will be more humanitarian than legal control, in such areas as compulsive gambling, erratic and violent behavior, and homosexuality. In addition, individuals sometimes press for medicalization as a way of gaining validation for their experiences and stimulating research on treatments and cures (Barker, 2005; Ziporyn, 1992). For example, much of the pressure to define premenstrual syndrome, chronic fatigue syndrome, and fibromyalgia as illnesses has come from persons who believe they suffer from these syndromes.

The third major force behind medicalization is the pharmaceutical industry (Conrad, 2005). This industry has a vested economic interest in medicalization whenever it can provide a drug as treatment. The medicalization of shortness exemplifies this process (Conrad, 2005; S. M. Rothman and D. J. Rothman, 2003; Werth, 1991). In 1985, the pharmaceutical company Genentech patented a genetically engineered and mass-produced form of human growth hormone (HGH). At that time, the available data suggested that HGH could increase final height in children whose pituitary glands did not naturally produce enough HGH, but not in children without pituitary defects. Moreover, it was known that HGH could promote a drastic loss of body fat and increase in muscle, with unknown consequences in growing children. Nevertheless, Genentech and, subsequently, Eli Lilly Pharmaceuticals (which patented a slightly different synthetic hormone) embarked on a major campaign to sell HGH. Together, they underwrote two-thirds of the budget of the Human Growth Foundation, a nonprofit advocacy group that works to increase public awareness of the problems experienced by short children. With the pharmaceutical companies' help, the foundation began broadcasting news of HGH across the nation at health fairs, shopping malls, and the like. The pharmaceutical companies also began spending millions of dollars annually to underwrite medical research supporting HGH, to advertise the drug to doctors, and to sponsor in-school screening programs that first

identified the shortest 3 percent of students and then informed the students' parents that their children needed medical treatment.

By 1999, about 30,000 children—20 percent of whom have no disease other than shortness—were being treated with HGH in the United States (B. Greenberg, 1999). As of 2004, treatment costs about $20,000 a year, and most children are treated for three to six years (Conrad and Potter, 2004). According to the only long-term study (partially funded by Genentech) of the drug's effectiveness on children with normal pituitary glands, these children can expect to add about two inches to their adult height (Hintz et al., 1999). Because of HGH's limited effectiveness and potential for long-term health problems (such as tumors and diabetes) and because identifying short children as "diseased" and treating them with daily injections over several years can lead to social stigma and lowered self-esteem, the American Academy of Pediatrics recommends against its use in short but otherwise healthy children, even though the Food and Drug Administration (FDA) has approved its use in this population. Meanwhile, doctors increasingly are prescribing estrogen—also a potentially dangerous drug—to *stunt* the growth of girls who are expected to exceed six feet in height. In addition, increasing numbers of doctors are prescribing HGH to older men as an "antiaging" drug, even though research strongly suggests that the drug offers significant risks but no benefits to this population (Conrad and Potter, 2004). Genotropin, the best-selling HGH drug, earned $475 million in 2003 (S. M. Rothman and D. J. Rothman, 2003).

The final major force in battles over medicalization is managed care organizations (MCOs). MCOs (which are discussed in detail in Chapter 8) are health insurance providers that restrain costs (and, ideally, improve quality of care) by monitoring closely which health services are given by which health care providers to which patients. Unlike pharmaceutical companies, MCOs either support or oppose medicalization, depending on which will best protect their interests (Conrad, 2005). For example, in the past MCOs typically rejected requests for gastric bypass surgeries to help obese patients lose weight, implicitly arguing that obesity was a personal and not a medical issue. More recently, MCOs have started approving these surgeries in the belief that they will reduce the long-term complications of obesity and thus reduce overall costs for MCOs.

Case Study: Working Together to Medicalize Hyperkinesis

Neither doctors, nor consumer groups, nor pharmaceutical companies have enough influence to medicalize a condition on their own. Successful medicalization depends on the interwoven interests and activities of these three groups and sometimes others. The history of hyperkinesis illustrates this process.

As originally defined, hyperkinesis lacked any definitive biological markers and instead referred to children above age 5 who were overactive, impulsive, and easily distracted but who had no brain damage (Diller, 1998). Since the

late 1930s, doctors have known that amphetamines (including methamphetamine or "speed") can reduce distraction in children and adults, regardless of their mental health or illness. In addition, even though biologically amphetamines are stimulants, they cause an intense focus that can make users appear less active. These characteristics made amphetamines a natural choice for treating hyperkinesis. However, because amphetamines are highly addictive and have dangerous side effects, physicians avoided prescribing them.

In the absence of a viable treatment, physicians rarely made the diagnosis of hyperkinesis. This situation changed in the 1960s, when the amphetamine Ritalin (methylphenidate) appeared on the market (Conrad and Schneider, 1992). Ritalin has fewer short-term side effects than other amphetamines have and, in the short term, improves the ability to concentrate, reduces the tendency to act impulsively, and increases willingness to accept discipline. Yet Ritalin is far from a panacea. Chemically, it acts much like cocaine (Vastag, 2001). Its immediate side effects can include addiction, loss of appetite, sleep deprivation, headache, and stomachache. Its long-term side effects are unknown, and its long-term benefits seem minor at best: The little available research suggests that it does not improve users' chances of graduating high school, holding a job, refraining from illicit drugs, or avoiding trouble with the law (Diller, 1998).

Following the development of Ritalin, pharmaceutical companies embarked on a huge campaign to "sell" hyperkinesis to doctors. According to Peter Conrad and Joseph Schneider:

> After the middle 1960s it is nearly impossible to read a medical journal or the free "throw-away" magazines [mailed by pharmaceutical companies to doctors] without seeing some elaborate advertising for either Ritalin or Dexedrine [another amphetamine]. These advertisements explain the utility of treating hyperkinesis . . . and urge the physician to diagnose and treat hyperkinetic children. The advertisements may run from one to six pages. They often advise physicians that "the hyperkinetic syndrome" exists as "a distinct medical entity" and that the "syndrome is readily diagnosed through patient histories and psychometric testing" and "has been classified by an expert panel" of the Department of Health, Education and Welfare as MBD [minimal brain dysfunction]. These same pharmaceutical firms also supply sophisticated packets of "diagnostic and treatment" information on hyperkinesis to physicians, pay for professional conferences on the subject, and support research in the identification and treatment of hyperkinesis. (1992: 159–160)

Pediatricians proved a ready audience for this marketing campaign, which promised a way to boost their flagging income and prestige. This market further increased in the late 1980s, when the diagnosis of hyperkinesis was replaced by "attention deficit disorder" (ADD). Unlike hyperkinesis, the definition of ADD sets no age limits and includes girls who daydream as well as boys who express their boredom or dissatisfaction through physical activity.

Like pediatricians, many teachers readily adopted the concept of ADD, if for different reasons (Diller, 1998). Faced with cuts in staffing and larger classes at the same time that school boards began placing an increased emphasis on testing and competition at earlier and earlier ages, teachers can hardly be blamed for looking with favor on drugs that make their students more manageable. In addition, diagnosing a student with ADD shifts blame for poor student performance from teacher to student. Not surprisingly, the suggestion to place a child on Ritalin now often comes initially from a teacher (Diller, 1998).

Pharmaceutical companies also promoted Ritalin directly to the public, spending $610 million on direct-to-consumer advertisements in 1996, up from $44 million in 1990 (Diller, 1998: 139). Like teachers, parents often are relieved to find an explanation other than poor parenting for their child's behavioral or educational problems. In addition, like those who argue that alcoholism or compulsive gambling is a disease, these parents hope to remove blame from their children, reduce the chances of legal sanctions against their children, and stimulate research on treatment. Finally, parents also seek diagnoses of ADD to help them obtain educational assistance for their children under federal antidiscrimination statutes (Diller, 1998). These statutes set aside funds for individualized educational services for students who suffer disabilities (including ADD), while making it extremely difficult for schools to discipline children for any problem behaviors that could be considered part of their disability. Thus, many parents find that having their child diagnosed with ADD increases the child's educational opportunities while reducing the chances that the child will be suspended or expelled. For this reason, children are much more likely to be diagnosed with ADD if they are wealthy and white than if they are poor or nonwhite. Similarly, adults with ADD can legally request accommodations in the workplace, such as quiet space or extra time to finish tasks, as long as their disability does not substantially interfere with their job performance. To get these accommodations, increasing numbers of adults now seek an ADD diagnosis for themselves (Diller, 1998).

Taken together, these factors produced an astounding increase in the number of persons diagnosed with ADD, from about 150,000 U.S. children in 1970 to almost 5 million in 1998 (Diller, 1998: 2, 27). Almost 14 percent of boys who visit an American doctor's office now leave with a prescription for Ritalin or a related drug, and use of Ritalin is growing rapidly in preschools (National Center for Health Statistics, 2004: 63).

The Consequences of Medicalization

In some circumstances, medicalization can be a boon, leading to social awareness of a problem, sympathy toward its sufferers, and development of beneficial therapies. Persons with epilepsy, for example, lead far happier and more productive lives now that drugs usually can control their seizures and few people view epilepsy as a sign of demonic possession. But defining a condition as an illness does not necessarily improve the social status of

those who have that condition. Those who use alcohol excessively, for example, continue to experience social rejection even when alcoholism is labeled a disease. Moreover, medicalization also can lead to new problems, known by sociologists as **unintended negative consequences** (Conrad and Schneider, 1992; Zola, 1972).

First, once a situation becomes medicalized, doctors become the only experts considered appropriate for diagnosing the problem and for defining appropriate responses to it. As a result, the power of doctors increases while the power of other social authorities (including judges, the police, religious leaders, legislators, and teachers) diminishes. For example, now that troublesome behavior by children is increasingly diagnosed as ADD, parents, teachers, and the children themselves have lost credibility when they disagree with this diagnosis. Similarly, doctors are now given considerable authority to answer questions such as who should receive abortions or organ transplants, how society should respond to drug use, and whether severely disabled infants should receive experimental surgeries, while the authority of the church and family members to answer these questions has diminished.

As this suggests, medicalization significantly expands the range of life experiences under medical control. For example, the existence of "fetal alcohol syndrome"—a constellation of birth defects including mental retardation believed caused by alcohol use during pregnancy—was widely accepted by American doctors based on extremely limited data, collected in a handful of studies that used neither random samples nor statistical controls (E. Armstrong, 1998). Moreover, these studies suggested that the problem was rare, even among severe alcoholics. Nonetheless, doctors have campaigned to forbid restaurants and bars from serving alcohol to pregnant women; to require liquor manufacturers, restaurants, and bars to post warning labels and signs warning of the dangers of drinking during pregnancy; and for legal codes that declare drinking during pregnancy a form of child abuse.

Second, once a condition is medicalized, medical treatment may become the only logical response to it. For example, if woman battering is considered a medical condition, then doctors need to treat women and the men who batter them. However, if woman battering is considered a social problem stemming from male power and female subordination, then it makes more sense to arrest the men, assist the women in developing financial and emotional independence, and work for broader structural changes that will improve all women's status and options.

Third, when doctors define situations in medical terms, they reduce the chances that these situations will be understood in *political* terms. For example, China, Pakistan, and other countries have removed political dissidents from the public eye by committing them to mental hospitals. By so doing, these governments discredited and silenced individuals who might otherwise have offered powerful dissenting voices. In other words, medicalization allowed these governments to **depoliticize** the situation—to define it as a medical rather than a political problem.

Fourth, and as the example of China and Pakistan illustrated, medicalization can justify not only voluntary but also involuntary treatment. Yet treatment does not always help and sometimes can harm. For example, beginning in the 1980s, U.S. courts have forced women to submit to cesarean deliveries, in which babies are surgically removed from their mothers' uteruses rather than delivered naturally through the vagina (Daniels, 1993). In these cases, doctors argued successfully that childbirth is a dangerous medical condition, not a natural process, and that therefore mothers lack the expertise to decide whether cesarean deliveries are in their and their babies' best interests. Yet doctors' judgment is not infallible. In six of the first fifteen cases in which doctors sought court orders to force cesarean deliveries, the mothers in the end delivered healthy babies vaginally (Kolder, Gallagher, and Parsons, 1987); the remaining nine women were forced to have cesareans, so we cannot know whether they might have safely delivered vaginally. Moreover, as of 2005, 29 percent of American women are having cesarean deliveries, even though the WHO recommends a rate of only 10 to 15 percent (Hamilton, Martin, and Sutton, 2004; World Health Organization, 1985: 437), suggesting that U.S. doctors are far too ready to perform this potentially life-threatening surgery. This chapter's ethical debate (Box 5.2) explores the issues involved in forced obstetrical interventions, and the broader issue of "fetal rights."

The Rise of Demedicalization

The dangers of medicalization have fostered a countermovement of **demedicalization** (R. Fox, 1977). A quick look at medical textbooks from the late 1800s reveals many "diseases" that no longer exist. For example, nineteenth-century medical textbooks often included several pages on the health risks of masturbation. One popular textbook from the late nineteenth century asserted that masturbation caused "extreme emaciation, sallow or blotched skin, sunken eyes, . . . general weakness, dullness, weak back, stupidity, laziness, . . . wandering and illy defined pains," as well as infertility, impotence, consumption, epilepsy, heart disease, blindness, paralysis, and insanity (Kellogg, 1880: 365). Today, however, medical textbooks describe masturbation as a normal part of human sexuality.

Like medicalization, demedicalization often begins with lobbying by consumer groups. For example, medical ideology now defines childbirth as an inherently dangerous process, requiring intensive technological, medical assistance. Since the 1940s, however, growing numbers of American women have attempted to redefine childbirth as a generally safe, simple, and natural process and have promoted alternatives ranging from natural childbirth classes, to hospital birthing centers, to home births assisted only by midwives (Sullivan and Weitz, 1988). Similarly, and as described in Chapter 7, gay and lesbian activists have at least partially succeeded in redefining homosexuality from a pathological condition to a normal human variation. More broadly, in recent years, books, magazines, television shows, and popular organizations devoted to teaching people to care for their own health rather than relying on medical care

Box 5.2 ***Ethical Debate: Medical Social Control and Fetal Rights***

In 1985, Pamela Rae Stewart became pregnant. Her doctor, knowing her history of drug use, warned her to stop using amphetamines. Later, when problems developed during her pregnancy, he advised her to stay off her feet, avoid sexual intercourse, and seek medical attention if she began to bleed heavily.

On November 23, 1985, Stewart gave birth to a severely brain-damaged baby. On the day her child was born, according to police reports, Stewart took amphetamines and had intercourse with her husband. She subsequently began bleeding but did not go to the hospital for several hours. Six weeks later, the baby died, and the District Attorney filed criminal charges against Stewart for child neglect.

Since 1990, about 300 pregnant women—most of them drug users—have been arrested or involuntarily hospitalized to force them to follow medical advice (K. Johnson, 2004). Ironically, pregnant drug users are most likely to face criminal sanctions if they are poor or minorities, even though such women are least likely to have access to substance abuse treatment (Chasnoff, Landress, and Barrett, 1990). Less commonly, doctors and the courts have forced women to have cesarean sections in the belief that these operations were in the babies' best interests. A 1987 study identified the first twenty one cases nationally in which doctors sought court orders to force obstetrical interventions, and found that the doctors succeeded in 86 percent of these cases (Kolder et al., 1987). In these successful suits, 81 percent of the women were African American or Hispanic, 44 percent were unmarried, 24 percent were not fluent in English, and all were poor.

These actions reflect a growing tendency among doctors, lawyers, and the general public to view mother and fetus as separate beings, with separable and sometimes conflicting rights, and to see the fetus rather than the mother as obstetricians' primary patient (B. Rothman, 1989; Daniels, 1993). This tendency reflects both technological and political changes. The growth of technologies like ultrasound, electronic fetal monitoring, and fetal surgery, which allow doctors to view and act on the fetus, have made fetuses seem more like independent beings than ever before (Casper, 1998). And the antiabortion movement has convinced many Americans to think of fetuses as children or "almost children," even though less than one-quarter of Americans believe abortion should be illegal in all circumstances (PollingReport.com, 2005).

The state has a legal obligation to protect children from parents who abuse or otherwise endanger them. Similarly, both ethical and legal guidelines require doctors who learn of child abuse to report it to the state. Should doctors and the state have a similar obligation to protect the fetus even if it means superseding parents' wishes?

Those who argue in favor of medical intervention find it illogical to protect children from bodily harm *after* birth but to deny them protection that might ensure their health *before* birth. Children born prematurely, addicted to drugs, or with birth defects because their mothers did not follow medical advice may suffer short, painful lives or may survive with mental or physical disabilities. In addition, these children cost hospitals and taxpayers vast sums every year. Those costs alone, one could argue, give the medical and legal systems the right to intervene when women endanger their fetuses.

(continued)

Box 5.2 ***Ethical Debate (continued)***

Others, however, have raised several objections to placing **fetal rights** above mothers' wishes. First, these individuals question whether doctors necessarily know better than mothers what is in their fetuses' best interest. During the 1950s, for example, doctors routinely X-rayed women's abdomens to check fetal growth; this technique is now known to lead to miscarriages and cancer (B. Rothman, 1989). At any rate, almost all well-structured research studies have found that mothers' drug use during pregnancy causes little if any long-term harm to their children (E. Armstrong, 1998; Koren et al., 1989; Pollitt, 1990; Singer et al., 2002). This information has had relatively little impact on public or medical attitudes, partly because of cultural bias against illicit drugs and partly because of the bias in publishing (including medical journals) toward "breaking news." As a result, well-designed research studies suggesting that illicit drugs do not affect fetuses are regarded as uninteresting and go unpublished more often than do poorly designed studies suggesting that drugs do matter (Koren and Klein, 1991; Koren et al., 1989).

In addition, opponents argue, arresting or forcibly hospitalizing pregnant drug users may encourage other such women to avoid health care altogether, further endangering their fetuses. Moreover, forcibly withdrawing pregnant women from the drugs their bodies have become accustomed to can endanger the fetus more than does steady drug use (Pollitt, 1990).

Opponents of forced intervention further argue that doctors cannot make better decisions than mothers do, because they cannot understand fully the circumstances in which mothers make those decisions. For example, many women continue to use drugs during pregnancy only because they cannot obtain access to treatment programs, which usually have long waiting periods and often will not accept pregnant women. In addition, to enter a treatment program, women almost always have to leave their existing children with relatives or in foster care; for example, Arizona currently has an estimated 5,000 drug-addicted parents but only one treatment facility, with a total of ten beds, that allows parents to keep their children with them (Bland, 1999). Yet leaving children with relatives or in foster care may place children at greater risk than having a drug-using mother, given that women often begin drug use because of problems in their family and that foster care sometimes results in physical, sexual, or mental abuse.

Opponents of forced intervention also argue that the benefits of intervention do not

have proliferated. For example, in the early 1970s, the Boston Women's Health Book Collective published a 35-cent mimeographed booklet on women's health. From this, they have built a virtual publishing empire that has sold to consumers worldwide millions of books (including the best-selling *Our Bodies, Ourselves*) on the topics of childhood, adolescence, aging, and women's health.

Social Control and the Human Genome Project

The potential for medicine to act as a form of social control may soon grow through the work of the internationally funded Human Genome Project. The project's goal is to map the locations of all human genes and to determine the role each gene plays in health and illness.

justify the costs to women's civil liberties. Once we decide that women must put their fetuses' welfare above their own, where do we draw the line? Given that tobacco poses a far greater threat to fetuses than does any illicit drug, do we prosecute or hospitalize women who continue to smoke during pregnancy? What about women who continue to eat junk food rather than eating healthy meals? Or women who work two jobs and get insufficient rest? Already, some employers have used the language of fetal rights to bar women (but not men) from work involving toxic chemicals (Nelkin and Tancredi, 1989).

Finally, the effect of fetal rights on women's rights leads to questions regarding the true purposes of the fetal rights movement. Although we require parents to guard their children's health and welfare, we do not require them to donate kidneys, bone marrow, or even blood for their children's sake. Why, then, should we require women—and only women—to protect their fetuses? After all, fathers' use of tobacco, alcohol, and other drugs may damage sperm and therefore fetuses, but no court yet has charged a man for fetal abuse. Similarly, working in toxic environments damages sperm as well as ova and fetuses, yet no employers have tried to "protect" men from holding such jobs. And during Pamela Stewart's pregnancy, her husband not only used amphetamines and had sexual intercourse with her but also beat her periodically. Yet no district attorney arrested him for wife abuse or fetal abuse. These facts have led some to conclude that the true, if perhaps unconscious, motive behind the rhetoric of fetal rights is not to protect fetuses or children but to restrict women's lives—especially the lives of those women who are most different from and hence considered most suspect by those who make laws and policy.

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?

Genes affect health in two ways: by causing "true" genetic diseases and by increasing individuals' predisposition to develop disease. True genetic diseases, such as hemophilia, are caused directly by specific genes. Such diseases are relatively uncommon and typically become apparent at birth or early in life. Some can be treated, but none can be cured. As researchers learn which genes cause these diseases and develop tests to determine the presence of those genes, they can offer individuals the opportunity to learn whether they, their children, or (for pregnant women) their fetuses carry the gene. Individuals who learn they have a genetic defect may choose to avoid becoming pregnant; to abort any fetuses that also carry the defect; or to continue a pregnancy to term, knowing that the fetus carries the defect and

hoping that this foreknowledge will better prepare them for the birth of an ill or disabled child. Finally, individuals who know they have a genetic defect but who want to have a child that is biologically theirs can have fetuses created through in vitro fertilization (in which eggs removed from the woman's body are mixed with the man's sperm in the laboratory). They can then have their doctors test the resulting fetuses for genetic defects and implant any nondefective fetuses in the woman's uterus. This strategy is rare because the physical costs to the woman and the financial and psychological costs to the couple are extremely high, and the odds of success are low.

In other cases, genes do not directly cause disease but can increase the likelihood of disease developing. For example, no single gene causes Alzheimer's disease, breast cancer, heart disease, or diabetes. These diseases occur more often in some families than others, however, which suggests that the diseases may occur only in those who have some genetic predisposition. In these cases, if doctors can learn which genes correlate with the disease and develop ways of identifying which individuals have those genes, doctors might find it easier to convince at-risk individuals to take potentially health-preserving actions. For example, women who learn that they have the *BRCA-1* gene, which correlates with an increased risk of breast cancer, might choose to adopt a low-fat diet or to have their breasts removed before any cancer appears.

The Human Genome Project brings with it tremendous potential for both good and harm. Those who learn they are at increased risk can adopt healthier behaviors, and those who learn that they are *not* at risk can gain peace of mind. Testing could even benefit those who learn that they will develop a genetic disorder, for some will prefer certainty to the anxieties of uncertainty.

Yet the potential harm this knowledge can cause is also great. First, although some might cope well with the knowledge that they or their children will develop an unpreventable genetic disease later in life, others will be overwhelmed by this knowledge. It is hard, for example, to imagine how it can help individuals to learn at age 21 that by their forties they will develop Huntington's disease, a devastating neurological disorder that invariably causes progressive insanity, total disability, and death.

Second, as the knowledge and technologies developed by the Human Genome Project increase and become part of everyday medicine, the use of genetic testing will undoubtedly spread rapidly; already individuals can order genetic tests for themselves on the Internet. Genetic *counseling,* on the other hand, will probably spread more slowly because it is considerably more expensive to provide. In the future more people, especially those who are poor or live far from medical centers, thus are likely to receive complicated, confusing, and potentially devastating information from genetic tests without receiving the counseling necessary to help them understand and cope with this information.

Third, individuals identified through genetic testing as having an illness or being at high risk for illness may experience discrimination and stigma as a result. Individuals have been refused jobs, health insurance, or life insurance

because they are carriers of a genetic disease, have a genetic defect although they are still asymptomatic, or are suspected of having or carrying a genetic disease (Billings et al., 1992; Natowicz, Alper, and Alper, 1992). The **Americans with Disabilities Act (ADA)** (described in Chapter 6) outlaws employment discrimination based on illness, disability, or genetic characteristics, but it is legally unclear whether the ADA applies to discrimination in other areas of life (Gostin, Feldblum, and Webber, 1999). Most states have outlawed genetic discrimination in health insurance and in the workplace, and federal legislators are debating similar national legislation, but such laws can help only those who know about them, have evidence of discrimination, and can afford legal assistance (National Genome Research Institute, 2005).

Fourth, genetic tests can tell whether an individual carries the gene for a disease, but not how soon or how severely he or she will be affected. For example, although doctors can tell if a fetus has Down syndrome, they cannot tell if the fetus will become a child who could be self-supporting or a child who could neither walk nor talk. Increasingly, too, tests are identifying genetic anomalies whose effects, if any, are unknown. As a result, couples often must decide whether to abort a genetically abnormal fetus with little idea what their child's life might be like.

Fifth, except for true genetic diseases, genetic tests can only suggest the *probability* that a fetus, child, or adult will develop an illness. For example, prospective parents might learn that their fetus has a 60 percent chance of developing breast cancer as an adult. No one can offer any logical rules for making decisions based on such probabilities. Parents in these circumstances will face far more complex decisions than will parents who know their child would have a genetic disease. Moreover, genetic testing cannot tell the former group of parents any more than the latter regarding when or how severely the illness will affect their children.

Finally, the Human Genome Project raises the potential for genetic controls far beyond anything now available. Relatively few persons oppose programs to prevent the birth of children with Tay-Sachs disease, which causes initially healthy children to deteriorate totally—both mentally and physically—and to die between the ages of 3 and 5. Yet many geneticists hope in the future to expand vastly the number of conditions for which genetic tests are run. Already many fetuses are aborted simply because they are female, as described in Chapter 4 (Banister, 1999; Wertz and Fletcher, 1998). Would the world really be a better place if we could abort fetuses because they would be mentally slow or predisposed toward fatness?

The potential impact of the Human Genome Project is magnified by the treatment it has received in the news media. Like illness, news is a social construction, for news media first decide which stories are newsworthy and then decide how those stories will be told. Research conducted by sociologist Peter Conrad (1997) suggests that the media consistently overplay the impact of genes in presenting news stories. Conrad looked at all coverage of genetics in five major newspapers (including the *Los Angeles Times* and the

Wall Street Journal) and three news magazines (*Time, Newsweek,* and *U.S. News and World Report*) between 1965 and 1995 and found that the media routinely gave prominent coverage to the discovery of a supposed link between a gene and a condition or illness, but either ignored later disconfirmations of the link or relegated them to back pages. For example, all eight news outlets gave prominent and optimistic coverage to a 1990 article published in the *Journal of the American Medical Association* that reported a link between a specific gene and alcoholism. Yet none of the magazines and only a few of the newspapers covered an article, published eight months later in the same journal, refuting the findings of the first article. Moreover, all news stories on the second article were relegated to the back of newspapers, and all suggested that new evidence of genetic links would surely be found soon.

These findings led Conrad to conclude that the news media has adopted a **genetic paradigm,** a way of looking at the world that emphasizes genetic causes. This paradigm

> has considerable appeal. It promises primary causes, located on a basic level of biological reality. Genes are often depicted as an essence, what one is really made of . . . We now can be tempted by the lure of specificity, associating specific genes and particular problems. Identifying specific genes seems so much neater than complex, messy, epidemiological and social analyses. This specificity feeds hopes for genetic "magic bullets" to alleviate human problems. (Conrad, 1997: 142)

Social Control and the Sick Role

Until now, we have looked at how medicine functions as an institution of social control by defining individuals either as sick or as biologically defective. Medicine also can work as an institution of social control by pressuring individuals to *abandon* sickness, a process first recognized by Talcott Parsons (1951).

Parsons was one of the first and most influential sociologists to recognize that illness is deviance. From his perspective, when people are ill, they cannot perform the social tasks normally expected of them. Workers stay home, homemakers tell their children to make their own meals, students ask to be excused from exams. Because of this, either consciously or unconsciously, people can use illness to evade their social responsibilities. To Parsons, therefore, illness threatened social stability.

Parsons also recognized, however, that allowing some illness can *increase* social stability. Imagine a world in which no one could ever "call in sick." Over time, production levels would fall as individuals, denied needed recuperation time, succumbed to physical ailments. Morale, too, would fall while resentment would rise among those forced to perform their social duties day after day without relief. Illness, then, acts as a kind of pressure valve for society—something we recognize when we speak of taking time off work for "mental health days."

From Parsons's perspective, then, the important question was how did society control illness so that it would increase rather than decrease social stability? The author's emphasis on social stability reflected his belief in the broad social perspective known as **functionalism.** Underlying functionalism is an image of society as a smoothly working, integrated whole, much like the biological concept of the human body as a homeostatic environment. In this model, social order is maintained because individuals learn to accept society's norms and because society's needs and individuals' needs match closely, making rebellion unnecessary. Within this model, deviance—including illness—is usually considered **dysfunctional** because it threatens to undermine social stability.

Defining the Sick Role

Parsons's interest in how society manages to allow illness while minimizing its impact led him to develop the concept of the **sick role.** The sick role refers to social expectations regarding how society should view sick people and how sick people should behave. According to Parsons, the sick role as it currently exists in Western society has four parts. First, the sick person is considered to have a legitimate reason for not fulfilling his or her normal social role. For this reason, we allow people to take time off from work when sick rather than firing them for malingering. Second, sickness is considered beyond individual control, something for which the individual is not held responsible. This is why, according to Parsons, we bring chicken soup to people who have colds rather than jailing them for stupidly exposing themselves to germs. Third, the sick person must recognize that sickness is undesirable and work to get well. So, for example, we sympathize with people who obviously hate being ill and strive to get well and question the motives of those who seem to revel in the attention their illness brings. Finally, the sick person should seek and follow medical advice. Typically, we expect sick people to follow their doctors' recommendations regarding drugs and surgery, and we question the wisdom of those who do not.

Parsons's analysis of the sick role moved the study of illness forward by highlighting the social dimensions of illness, including identifying illness as deviance and doctors as agents of social control. It remains important partly because it was the first truly sociological theory of illness. Parsons's research also has proved important because it stimulated later research on interactions between ill people and others. In turn, however, that research has illuminated the analytical weaknesses of the sick role model.

Critiquing the Sick Role Model

Many recent sociological writings on illness—including this textbook—have adopted a **conflict perspective** rather than a functionalist perspective. Whereas functionalists envision society as a harmonious whole held together largely by socialization, mutual consent, and mutual interests, those who hold a conflict perspective argue that society is held together

Key Concepts 5.2

Strengths and Weaknesses of the Sick Role Model

Elements of the Sick Role	Model Fits Well:	Model Poorly Fits:
Legitimate reason for not fulfilling obligations	Appendicitis, cancer	Undiagnosed chronic fatigue
Individual not held responsible	Measles, hemophilia	AIDS, lung cancer
Should strive to get well	Tuberculosis, broken leg	Diabetes, epilepsy
Should seek medical help	Strep throat, syphilis	Alzheimer's, cold

largely by power and coercion, as dominant groups impose their will on others. Consequently, whereas functionalists view deviance as a dysfunctional element to be controlled, conflict theorists view deviance as a necessary force for social change and as the conscious or unconscious expression of individuals who refuse to conform to an oppressive society. Conflict theorists therefore have stressed the need to study social control agents as well as, if not more than, the need to study deviants.

The conflict perspective has helped sociologists to identify the strengths and weaknesses in each of the four elements of the sick role model (see Key Concepts 5.2). That model declares that sick persons are not held responsible for their illnesses. Yet, as we saw earlier in this chapter, and as Eliot Freidson (1970a), the most influential critic of Parsons, has noted, society often *does* hold individuals responsible for their illnesses. In addition, ill persons are not necessarily considered to have a legitimate reason for abstaining from their normal social tasks. Certainly no one expects persons with end-stage cancer to continue working, but what about people with arthritis or those labeled malingerers or hypochondriacs because they cannot obtain a diagnosis after months of pain, increasing disability, and visits to doctors (Ziporyn, 1992)? Parsons's model also fails to recognize that the social legitimacy of adopting the sick role depends on the socially perceived seriousness of the illness, which in turn depends not only on biological factors but also on the social setting; a nonunionized factory worker, for example, is less likely than a salaried worker with good health benefits to take time off when sick.

Other aspects of the sick role model are equally problematic. The assumption that individuals will attempt to get well fails to recognize that much illness is **chronic** and by definition not likely to improve. Similarly, the assumption that sick people will seek and follow medical advice ignores the many people who lack access to medical care. In addition, it ignores the many persons, especially those with chronic rather than **acute** conditions, who have found mainstream health care of limited benefit and who therefore

rely mostly on their own experience and knowledge and that of other nonmedical people. Finally, the concept of a sick role ignores how gender, ethnicity, age, and social class affect the response to illness and to ill people. For example, women are both more likely than men are to seek medical care when they feel ill and less likely to have their symptoms taken seriously by doctors (Council on Ethical and Judicial Affairs, 1991; Steingart, 1991).

In sum, the sick role model is based on a series of assumptions about both the nature of society and the nature of illness. In addition, the sick role model confuses the experience of *patienthood* with the experience of *illness* (Conrad, 1987). The sick role model focuses on the interaction between the ill person and the mainstream health care system. Yet interactions with the medical world form only a small part of the experience of living with illness or disability, as the next chapter will show. For these among other reasons, research on the sick role has declined precipitously; whereas *Sociological Abstracts* listed 71 articles on the sick role between 1970 and 1979, it listed only 7 articles between 1990 and 1999, even though overall far more academic articles were published during the 1990s than during the 1970s.

Conclusion

The language of illness and disease permeates our everyday lives. We routinely talk about living in a "sick" society or about the "disease" of violence infecting our world, offhandedly labeling anyone who behaves in a way we don't understand or don't condone as "sick."

This metaphoric use of language reveals the true nature of illness: behaviors, conditions, or situations that powerful groups find disturbing and believe stem from internal biological or psychological roots. In other times or places, the same behaviors, conditions, or situations might have been ignored, condemned as sin, or labeled crime. In other words, illness is both a social construction and a moral status.

In many instances, using the language of medicine and placing control in the hands of doctors offers a more humanistic option than the alternatives. Yet, as this chapter has demonstrated, medical social control also carries a price. The same surgical skills and technology for cesarean sections that have saved the lives of so many women and children now endanger the lives of those who have cesarean sections unnecessarily. At the same time, forcing cesarean sections on women potentially threatens women's legal and social status. Similarly, the development of tools for genetic testing has saved many individuals from the anguish of rearing children doomed to die young and painfully, but has cost others their jobs or health insurance.

In the same way, then, that automobiles have increased our personal mobility in exchange for higher rates of accidental death and disability, adopting the language of illness and increasing medical social control bring both benefits and costs. These benefits and costs will need to be weighed carefully as medicine's technological abilities grow.

Suggested Readings

Barker, Kristin K. 2005. *The Fibromyalgia Story: Medical Authority and Women's Worlds of Pain.* Philadelphia: Temple University Press. In this sensitive and remarkably evenhanded book, Barker analyzes why fibromyalgia emerged as a diagnosis, and why it has proven so controversial.

Conrad, Peter, and Joseph W. Schneider. 1992. *Deviance and Medicalization: From Badness to Sickness.* Philadelphia: Temple University Press. Presents a theoretical framework for understanding medicalization, as well as several case studies of this process.

Rothman, Barbara Katz. 1998. *Genetic Maps and Human Imaginations: The Limits of Science in Understanding Who We Are.* New York: Norton. A fascinating exploration of the sources and consequences of the genetic paradigm.

Getting Involved

ACT UP. 332 Bleecker St., Suite G5, New York, NY 10014. (212) 966–4873. www.actupny.org. Seeks to increase public awareness and government involvement in the fight against AIDS through rallies and demonstrations.

Council for Responsible Genetics. 5 Upland Road, Suite 3, Cambridge, MA 02140. (617) 868–0870. www.gene-watch.org. Works to educate the public about the social implications of genetic technologies and to advocate socially responsible use and development of those technologies.

Review Questions

What does it mean to say that illness is a social construction and a moral status?

How have explanations for illness changed over time, and how have explanations for illness blamed ill people for their illnesses?

What is the medical model of illness, and what are some of the problems with that model?

What is medicalization, why does it occur, and what are some of its consequences?

How might the Human Genome Project act as social control?

What is the sick role model, and what are some of the problems with that model?

Internet Exercises

1. Although medical sociologists, health psychologists, and doctors are all interested in issues related to illness, their specific interests vary greatly. Using your library or the web, obtain access to the major online indexes in these three fields: *Medline, Sociological Abstracts,* and *PsycInfo.* Search each

database for information on *susto* and on medicalization. How does coverage of these issues differ across fields? To what extent does coverage overlap? What does this tell you about these three fields?

2. Using your library or the web, obtain access to *Periodical Abstracts, the Readers Guide to Periodical Literature,* or another index of popular magazine articles. Look for articles on premenstrual syndrome (PMS) published in the last five years. Copy the results of your search onto a diskette, or download it to your hard drive. Based on the titles and abstracts of the articles, sort the articles into those that assume PMS is an objectively defined illness, those that question the nature or existence of PMS, and those whose position is unclear. What does this tell you about the medicalization of PMS?