Chapter 1

People in the Shadows: The Many Faces of Mental Illness

Well, we have to take our share of the illnesses of our time, and it seems after all only right that—having lived for years in relatively good health—we should sooner or later receive our part. As for me, you must know that I shouldn't precisely have chosen madness if there had been any choice, but once such a thing has taken hold of you, you can't very well get out of it.[1]

—Vincent van Gogh, from an 1889 letter written while he was involuntarily confined in a psychiatric hospital

In the shadows of mental illness there are many faces. One is that of Thomas McGuire (not his real name), a 45-year-old human resource specialist who for 15 years had been employed by a large manufacturing firm. A college graduate, he had served with the Air Force in Vietnam, had been married for 22 years, and had a teenage son and daughter. He lived in a large city in the eastern United States and used a prestigious university teaching hospital for emergency medical care.

On March 19, 1985, Mr. McGuire went to the emergency room complaining of chest pain and shortness of breath. An electrocardiogram confirmed he was having a heart attack. He was admitted to the hospital and treated for his heart problem. During the admission process, doctors carefully explored precipitating risk factors such as hypertension, cholesterol level, smoking, and work stress. Upon discharge, Mr. McGuire was enrolled in a follow-up program to decrease his cholesterol level and thereby reduce the chances of his having another heart attack.

Ten years later, on November 14, 1995, Mr. McGuire went to the same emergency room. He had called 911 and described suicidal symptoms. According to the notes of the physicians who saw him, Mr. McGuire had lost almost 50 pounds in the previous six months; was sleeping very little; had spent thousands of dollars foolishly, including mailing a postcard with $70 in stamps on it; had written numerous letters to his congressman offering to reorganize the government and "ship icebergs to Africa and reforest the Sahara"; and claimed to be a prophet who was "ushering in the millennium." Mr. McGuire's wife told the emergency room doctors that he had been hospitalized for one previous manic episode 20 years before, and had a history of periodic episodes of hypomania (minor attacks of mania) for which he had not been treated. The resident psychiatrist diagnosed Mr. McGuire as having acute manic-depressive illness (bipolar disorder) and recommended his admission to the hospital. Mr. McGuire refused voluntary admission, so his wife and son offered to testify to support an involuntary admission. The senior psychiatrist, however, refused to admit Mr. McGuire involuntarily, writing in his hospital chart: "There are no issues of danger to self [or] others. . . . Though patient is mentally impaired he does not at present present enough evidence to warrant detention." Mr. McGuire was released from the emergency room without being given any medication. A few hours later he hung himself with a rope he found in the basement of his home. His wife found him, and paramedics brought him to the emergency room from which he had just been released. He was pronounced dead there.

The contrast between the treatment Mr. McGuire was given for his heart attack and the treatment he received for his manic-depressive illness vividly illustrates what is wrong with our psychiatric health care system. Both conditions are well-established medical emergencies, one involving dysfunction of the heart, the other of the brain. Both conditions demand immediate hospitalization and the rapid administration of medication. Once stabilized, both conditions should be followed up with a plan for decreasing risk factors that might trigger recurrence and for providing education about early warning signs.

The reasons Mr. McGuire received excellent care for his heart attack but disgraceful treatment for his manic-depressive illness can be surmised from the notes of his psychiatrists and from what is known about psychiatric services in the state where he lived. It is a state that has closed over 80 percent of its public psychiatric beds in an effort to shift costs from the state government to the federal government (as will be discussed in Chapter 7). Increasing numbers of psychiatric emergencies have been

referred to that university hospital and to other general hospitals in the community, many of which are already overcrowded and unprepared to treat such severely ill patients. It is a state in which civil rights lawyers and other advocates have waged a highly publicized fight to limit the grounds for involuntary psychiatric hospitalization to danger-to-self-or-others, and to have this interpreted as narrowly as possible in the courts (as will be discussed in Chapter 8). It is also a state with a long history of promoting "mental health" issues. And some members of the staff at the university hospital at which Mr. McGuire sought treatment still adhere to a psychoanalytic, rather than a medical understanding of mental illness. It is possible that the senior psychiatrist who released Mr. McGuire without treating him did not consider manic-depressive illness to be a medical emergency but rather to be a product of intrapersonal and interpersonal conflict that should be treated with long-term psychotherapy.

Mr. McGuire's negligent treatment is not an aberration. Similar examples occur throughout the United States virtually every day. Mr. McGuire did not seek help in a rural area with no trained psychiatrists, nor in a city such as Miami, Houston, or Los Angeles, which are known to have very poor public psychiatric services, nor in a public psychiatric hospital such as Hawaii State Hospital, which has been designated as the worst public psychiatric hospital in the United States.[2] Mr. McGuire sought treatment in a prestigious university hospital in a city reputed to be a regional medical Mecca.

The mental illness crisis, then, consists of hundreds of thousands of men and women like Mr. McGuire who represent a large percentage of the estimated 2.2 million Americans with untreated severe mental illnesses. On any given day, approximately 150,000 of them are homeless, living on the streets or in public shelters. Another 159,000 are incarcerated in jails and prisons, mostly for crimes committed because they were not being treated. Some of them become violent and may terrorize their families, towns, or urban neighborhoods. A very large number have died prematurely as a result of accidents and suicide. Tragically, most of these instances of homelessness, incarcerations, episodes of violence, and premature deaths are unnecessary. We know what to do, but for economic, legal, and ideological reasons we fail to do it.

Who Are the Severely Mentally Ill and What Is Wrong with Them?

"Mental illness" is a nonspecific term that covers a broad array of brain disorders, human behaviors, and personality types. The term commonly

designates one end of an amorphous mental health–mental illness spectrum. This book is concerned only with *severe mental illnesses*, defined in 1993 by the National Advisory Mental Health Council, an arm of the National Institute of Mental Health, as including "disorders with psychotic symptoms such as schizophrenia, schizoaffective disorder, manic-depressive disorder, autism, as well as severe forms of other disorders such as major depression, panic disorder, and obsessive-compulsive disorder."[3] The Council determined that over a one-year period, 2.8 percent of the adult population in the United States is affected by such severe mental illness. Additional studies estimated that 3.2 percent of children and adolescents ages 9 through 17 have a severe mental illness in any given six-month period. Based on the total 1995 U.S. population of 262 million, this means that during that year approximately 5.6 million people ages 9 or older had a severe mental illness. According to the National Advisory Mental Health Council, the cost of their care was $27 billion for direct treatment costs and $74 billion if indirect costs such as maintenance and lost productivity are included. These numbers do not include people with a primary diagnosis of alcohol or drug addiction, although many severely mentally ill people also abuse alcohol or drugs.

Research over the past decade has clarified what is wrong with those diagnosed with severe mental illnesses. They have neurobiological disorders of their brains that affect their thinking and moods and that can be measured by changes in both brain structure and function. Figure 1.1 illustrates these changes as shown on MRI (magnetic resonance imaging) scans of two pairs of identical twins. In one pair, one twin has schizophrenia and his identical cotwin is well, and in the other pair, one twin

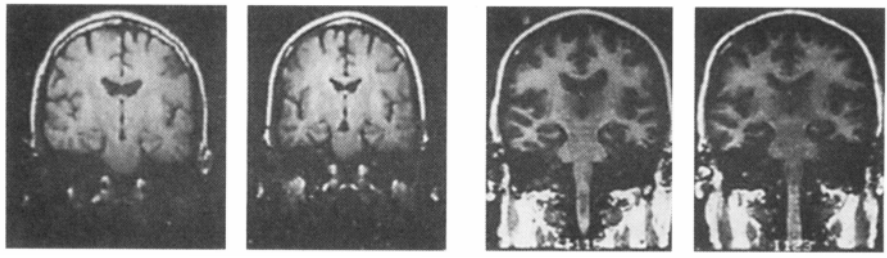

FIGURE 1.1 MRI scans of two pairs of identical twins showing enlarged cerebral ventricles in affected twins.

has manic-depressive illness and her cotwin is well. In both cases, the affected twin has larger cerebral ventricles, the fluid-carrying spaces in the brain, suggesting that the affected twins have had some loss of brain tissue associated with their illnesses. Not everyone with schizophrenia and manic-depressive illness has enlarged cerebral ventricles, but many do.

Research on schizophrenia, schizoaffective disorder, manic-depressive disorder, autism, and severe forms of major depression, panic disorder, and obsessive-compulsive disorder has also revealed a variety of functional disease-related changes in the brains of affected individuals. These include changes in the neurochemistry, metabolism, electrical activity, neurological function, and neuropsychological function of the brain. Some of these changes may be caused by the medication being taken for the illness, but the majority are not medication-related and can be found in those who have never taken medication.

It has now been established that severe mental illnesses, as defined by the National Advisory Mental Health Council, are neurobiological disorders of the brain. These illnesses are thus in the same category as other brain disorders such as Parkinson's disease, Alzheimer's disease, and multiple sclerosis. Like severe mental illnesses, each of these disorders is associated with measurable abnormalities in brain structure and function. And, as with severe mental illnesses, it is not yet known what factors—genes, developmental effects, viruses, toxins, or metabolic defects—contribute to the biological chain of events causing these disorders.

Can They Be Treated and Are They Being Treated?

A persistent myth about severe mental illness is that it cannot be treated. In fact, according to the 1993 report of the National Advisory Mental Health Council, "The efficacy of many treatments for severe mental disorders is comparable to that in other branches of medicine, including surgery."[4] For schizophrenia and schizoaffective disorder (a mixture of schizophrenia and manic-depressive disorder) research has shown that standard antipsychotic medication will "reduce psychotic symptoms in 60 percent of patients and in 70–85 percent of those experiencing symptoms for the first time."[5] Newer antipsychotics such as clozapine are effective in an additional one-third of people who do not respond to the standard antipsychotics. For manic-depressive illness, approximately 75 percent of sufferers respond to lithium, carbemazepine, or a combination

of ancillary medications. For severe depression, at least 80 percent respond to tricyclic (Elavil, Norpramin), selective serotonin reuptake inhibitor (SSRI) (Prozac, Zoloft, and others) or monoamine oxidase inhibitor, (MAOI) (e.g., Nardil, Parnate) antidepressants; some of the nonresponders can be successfully treated using electroconvulsive therapy (ECT). For severe panic disorder, between 70 and 90 percent of sufferers respond to an antidepressant or a benzodiazepine class of medication. And for severe obsessive-compulsive disorder, approximately 60 percent react at least moderately well to one or more antidepressants. Of all the severe mental illnesses, only autism has no effective medication at this time.

It should be emphasized that medications are not the only treatment for those with severe mental illnesses. Many also require rehabilitation and supportive counseling. Excellent model programs have been developed to provide these, including the Program in Assertive Community Treatment (PACT), which originated in Madison, Wisconsin; clubhouse programs patterned after New York City's Fountain House; and employment programs such as Fairweather Lodges, transitional employment programs, and job skills training. I will discuss these in Chapter 7, but for now the important point to remember is that we have effective treatments for the majority of people with severe mental illnesses. The medications do not cure the illnesses, but rather control the symptoms just as insulin does in diabetes. *The mental illness crisis, then, has not occurred because we do not have effective treatments. Rather, it exists because we do not use these treatments for a substantial number of those afflicted.* As we will see, the reasons for this failure say more about our national politics and ideology than about our scientific progress.

Of the 5.6 million individuals who had a severe mental illness in 1995, how many were receiving treatment? According to the National Advisory Mental Health Council, approximately 60 percent of severely mentally ill adults receive treatment in any given year.[6] For schizophrenia, the treatment rate appears to be even lower; for example, a 1981 study of people with schizophrenia living in Baltimore reported that only 50 percent were receiving treatment.[7] If we use an estimated overall treatment rate of 60 percent, then 40 percent are not receiving treatment. Based on the total of 5.6 million, that means that approximately 2.2 million severely mentally ill people are not being treated. These are the men, women, and children at the heart and core of the mental illness crisis.

Who are these people? Mr. McGuire was one of them. Among the thousands of others in the shadows are the following individuals whom I have known:

- A woman with schizophrenia who lived with her parents, and later with her unmarried brother, for 45 years until her recent death. She had originally become ill at age 16 and was hospitalized for six months, but that took place before antipsychotic medications were available. Over the years, her family periodically encouraged her to see a psychiatrist, but she refused. Her family provided for all her needs, and she lived an isolated, hermitlike existence, spending most of the time in her own room.
- A man now in his late 30s, who has suffered from periodic episodes of severe depression for almost 20 years. He also abuses alcohol and occasionally drugs, and it is these problems that he and his family focus on. His depression has never been treated.
- A woman in her 40s with manic-depressive illness who dropped out of school in the eighth grade because of severe "emotional difficulties." She lives in a rural area, and the nearest mental health center is a two-hour drive away. Her family is not well educated and does not understand why she "thinks funny" and sometimes stays in her room for weeks at a time. In one episode, when she became manic, her elderly parents locked her in the attic for several days so she would not run away.
- A 56-year-old man with paranoid schizophrenia, a graduate of an Ivy League university, who has spent the past 20 years wandering the country, often sleeping in public shelters or in the woods. He believes the FBI implanted microchips in his brain and that these broadcast voices in his head. His family has tried on several occasions to get him involuntarily committed to a hospital for treatment, but in court the man is calm, articulate, and able to convince the judge that he has the right to live his alternate lifestyle.
- A 28-year-old man with schizoaffective disorder (a mixture of schizophrenia and manic-depressive disorder) who lives beneath a bridge in a large eastern city. He spent five years in a South Carolina prison for manslaughter, and he periodically threatens people on the street who refuse his demands for money, most of which he uses to buy marijuana and alcohol. Since he left prison, he has received no treatment.

People like these can be found in every city, town, and rural area in the United States.

In addition to the 2.2 million people who receive no treatment, there is another group who are often forgotten: those who, like Mr. McGuire,

have died as a direct or indirect result of not being treated. Suicide is the most common cause of their death. The lifetime suicide rate among those with schizophrenia is 10 to 13 percent and among those with manic-depressive illness 15 to 17 percent, as opposed to about 1 percent among the general population. In addition to suicide, many people with severe mental illnesses die prematurely because of accidents and untreated physical illnesses. We don't know how many of them would be alive today if they had received adequate treatment, but almost certainly hundreds of thousands have paid with their lives for an illness that need not have been fatal.

Deinstitutionalization: A Psychiatric *"Titanic"*

Deinstitutionalization is the name given to the policy of moving severely mentally ill people out of large state institutions and then closing part or all of those institutions; it has been a major contributing factor to the mental illness crisis. (The term also describes a similar process for mentally retarded people, but the focus of this book is exclusively on severe mental illnesses.)

Deinstitutionalization began in 1955 with the widespread introduction of chlorpromazine, commonly known as Thorazine, the first effective antipsychotic medication, and received a major impetus 10 years later with the enactment of federal Medicaid and Medicare. Deinstitutionalization has two parts: the moving of the severely mentally ill out of the state institutions, and the closing of part or all of those institutions. The former affects people who are already mentally ill. The latter affects those who become ill after the policy has gone into effect and for the indefinite future because hospital beds have been permanently eliminated.

The magnitude of deinstitutionalization of the severely mentally ill qualifies it as one of the largest social experiments in American history. In 1955, there were 558,239 severely mentally ill patients in the nation's public psychiatric hospitals. In 1994, this number had been reduced by 486,620 patients, to 71,619, as seen in Figure 1.2. It is important to note, however, that the census of 558,239 patients in public psychiatric hospitals in 1955 was in relationship to the nation's total population at the time, which was 164 million.

By 1994, the nation's population had increased to 260 million. If there had been the same proportion of patients per population in public mental hospitals in 1994 as there had been in 1955, the patients would have totaled 885,010. The true magnitude of deinstitutionalization, then, is the difference between 885,010 and 71,619. In effect, approximately

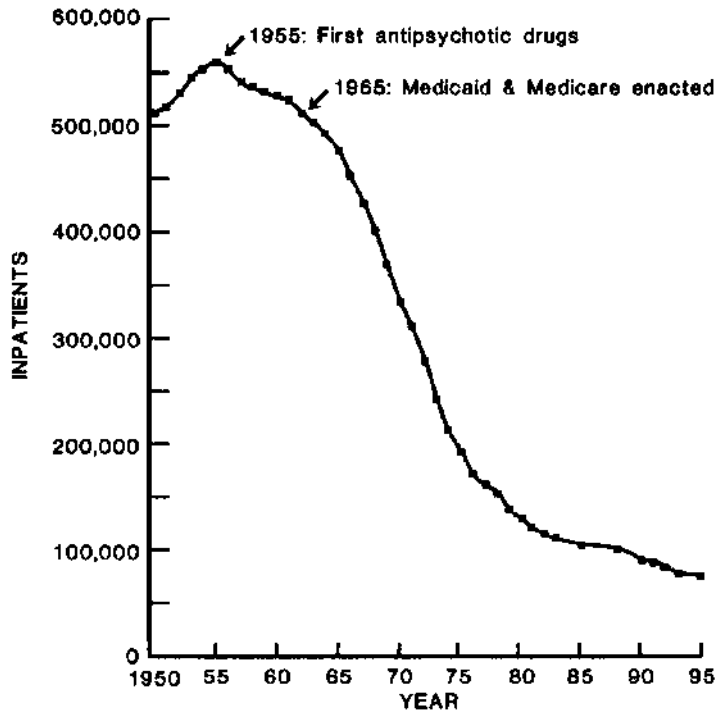

FIGURE 1.2 Number of inpatients in public mental hospitals 1950 through 1995.

92 percent of the people who would have been living in public psychiatric hospitals in 1955 were not living there in 1994. Even allowing for the approximately 40,000 patients who occupied psychiatric beds in general hospitals or the approximately 10,000 patients who occupied psychiatric beds in community mental health centers (CMHCs) on any given day in 1994, that still means that approximately 763,391 severely mentally ill people (over three-quarters of a million) are living in the community today who would have been hospitalized 40 years ago. That number is more than the population of Baltimore or San Francisco.

Deinstitutionalization varied from state to state. In assessing these differences in census for public mental hospitals, it is not sufficient merely to subtract the 1994 number of patients from the 1955 number, because state populations shifted in the various states during those 40 years. In Iowa, West Virginia, and the District of Columbia, the total populations actually decreased during that period, whereas in California, Florida, and Arizona, the population increased dramatically, and in

Nevada, it increased more than sevenfold, from 0.2 million to 1.5 million. The table in the Appendix takes these population changes into account and provides an effective deinstitutionalization rate for each state based on the number of patients hospitalized in 1994 subtracted from the number of patients that would have been expected to be hospitalized in 1994 based on that state's population. It assumes that the ratio of hospitalized patients to population would have remained constant over the 40 years.

Rhode Island, Massachusetts, New Hampshire, Vermont, West Virginia, Arkansas, Wisconsin, and California all have effective deinstitutionalization rates of over 95 percent. Rhode Island's rate is over 98 percent, meaning that for every 100 state residents in public mental hospitals in 1955, fewer than 2 patients are there today. On the other end of the curve, Nevada, Delaware, and the District of Columbia have effective deinstitutionalization rates below 80 percent.

Most of those who were deinstitutionalized from the nation's public psychiatric hospitals were severely mentally ill. Between 50 and 60 percent of them were diagnosed with schizophrenia. Another 10 to 15 percent were diagnosed with manic-depressive illness and severe depression. An additional 10 to 15 percent were diagnosed with organic brain diseases—epilepsy, strokes, Alzheimer's disease, and brain damage secondary to trauma. The remaining individuals residing in public psychiatric hospitals had conditions such as mental retardation with psychosis, autism and other psychiatric disorders of childhood, and alcoholism and drug addiction with concurrent brain damage. The fact that most deinstitutionalized people suffer from various forms of brain dysfunction was not as well understood when the policy of deinstitutionalization got under way.

Thus deinstitutionalization has helped create the mental illness crisis by discharging people from public psychiatric hospitals without ensuring that they received the medication and rehabilitation services necessary for them to live successfully in the community. Deinstitutionalization further exacerbated the situation because, once the public psychiatric beds had been closed, they were not available for people who later became mentally ill, and this situation continues up to the present. Consequently, approximately 2.2 million severely mentally ill people do not receive any psychiatric treatment.

Deinstitutionalization was based on the principle that severe mental illness should be treated in the least restrictive setting. As further defined by President Jimmy Carter's Commission on Mental Health, this ideology rested on "the objective of maintaining the greatest degree of

freedom, self-determination, autonomy, dignity, and integrity of body, mind, and spirit for the individual while he or she participates in treatment or receives services."[8] This is a laudable goal and for many, perhaps for the majority of those who are deinstitutionalized, it has been at least partially realized.

For a substantial minority, however, deinstitutionalization has been a psychiatric *Titanic*. Their lives are virtually devoid of "dignity" or "integrity of body, mind, and spirit." "Self-determination" often means merely that the person has a choice of soup kitchens. The "least restrictive setting" frequently turns out to be a cardboard box, a jail cell, or a terror-filled existence plagued by both real and imaginary enemies. Even one Thomas McGuire is too many; hundreds of thousands are a disgrace.