

The Fundamentals of Mental Health and Mental Illness

A vast body of research on mental health and, to an even greater extent, on mental illness constitutes the foundation of this Surgeon General's report. To understand and better appreciate the content of the chapters that follow, readers outside the mental health field may desire some background information. Thus, this chapter furnishes a "primer" on topics that the report addresses.

The chapter begins with an overview of research under way today that is focused on the neuroscience of mental health. Modern integrative neuroscience offers a means of linking research on broad "systems level" aspects of brain function with the remarkably detailed tools and findings of molecular biology. The report begins with a discussion of the brain because it is central to what makes us human and provides an understanding of mental health and mental illness. All of human behavior is mediated by the brain. Consider, for example, a memory that most people have from childhood—that of learning to ride a bicycle with the help of a parent or friend. The fear of falling, the anxiety of lack of control, the reassurances of a loved one, and the final liberating experience of mastery and a newly extended universe create an unforgettable combination. For some, the memories are not good ones: falling and being chased by dogs have left marks of anxiety and fear that may last a lifetime. Science is revealing how the skill learning, emotional overtones, and memories of such experiences are put together physically in the brain. The brain and mind are two sides of the same coin. Mind is not possible without the remarkable physical complexity that is built into the brain, but, in addition, the physical complexity of the brain is useless without the sculpting that environment, experience, and thought itself provides. Thus the brain is now known to be physically shaped by contributions from our genes and our experience, working together. This strengthens the view that mental disorders are both caused and can be treated by biological and experiential processes, working together. This understanding has emerged from the breathtaking progress in modern neuroscience that has begun to integrate knowledge from biological and behavioral sciences.

An overview of mental illness follows the section on modern integrative brain science. The section highlights topics including symptoms, diagnosis, epidemiology (i.e., research having to do with the distribution and determinants of mental disorders in population groups, including various racial and ethnic minority groups), and cost, all of which are discussed in greater and more pointed detail in the chapters that follow. Etiology is the study of the origins and causes of disease, and that section reviews research that is seeking to define, with ever greater precision, the causes of mental disorders. As will be seen, etiology research examines fundamental biological, behavioral, and sociocultural processes, as well as a necessarily broad array of life events. The section on development of temperament reveals how mental health science has attempted over much of the past century to understand how biological, psychological, and sociocultural factors meld in health as well as in illness. The chapter then reviews research approaches to the prevention and treatment of mental disorders and provides an overview of mental health services and their delivery. Final sections cover the growing influence on the mental health field of the need for attention to cultural diversity, the importance of the

consumer movement, and new optimism about recovery from mental illness—that is, the possibility of recovering one's life.

The Neuroscience of Mental Health¹

Complexity of the Brain I: Structural

As befits the organ of the mind, the human brain is the most complex structure ever investigated by our science. The brain contains approximately 100 billion nerve cells, or neurons, and many more supporting cells, or glia. In and of themselves, the number of cells in this 3-pound organ reveal little of its complexity. Yet most organs in the body are composed of only a handful of cell types; the brain, in contrast, has literally thousands of different kinds of neurons, each distinct in terms of its chemistry, shape, and connections (Figure 2-1 depicts the structural variety of neurons). To illustrate, one careful, recent investigation of a kind of interneuron that is a small local circuit neuron in the retina, called the amacrine cell, found no less than 23 identifiable types.

But this is only the beginning of the brain's complexity.

The workings of the brain depend on the ability of nerve cells to communicate with each other. Communication occurs at small, specialized structures called synapses. The synapse typically has two parts. One is a specialized presynaptic structure on a terminal portion of the sending neuron that contains packets of signaling chemicals, or neurotransmitters. The second is a postsynaptic structure on the dendrites of the receiving neuron that has receptors for the neurotransmitter molecules.

The typical neuron has a cell body, which contains the genetic material, and much of the cell's energy-producing machinery. Emanating from the cell body are dendrites, branches that are the most important receptive surface of the cell for communication. The dendrites of neurons can assume a great many shapes and sizes, all relevant to the way in which incoming messages are processed. The output of neurons is carried along what is usually a single branch called the axon. It is down this part of the neuron that signals are transmitted out to the next neuron. At its end, the axon may branch into many terminals. (Figure 2-2.)

The usual form of communication involves electrical signals that travel within neurons, giving rise to chemical signals that diffuse, or cross, synapses, which in turn give rise to new electrical signals in the postsynaptic neuron. Each neuron, on average, makes more than 1,000 synaptic connections with other neurons. One type of cell—a Purkinje cell—may make between 100,000 and 200,000 connections with other neurons. In aggregate, there may be between 100 trillion and a quadrillion synapses in the brain. These synapses are far from random. Within each region of the brain, there is an exquisite architecture consisting of layers and other anatomic substructures in which synaptic connections are formed. Ultimately, the pattern of synaptic connections gives rise to what are called circuits in the brain. At the integrative level, large- and small-scale circuits are the substrates of behavior and of mental life. One of the most awe-inspiring mysteries of brain science is how neuronal activity within circuits gives rise to behavior and, even, consciousness.

The complexity of the brain is such that a single neuron may be part of more than one circuit. The organization of circuits in the brain reveals that the brain is a massively parallel, distributed information processor. For example, the circuits involved in vision receive information from the retina. After initial processing, these circuits analyze information into different streams, so that there is one stream of information describing what the visual object is, and another stream is concerned with where the object is in space. The information stream having to do with the identity of the object is actually broken down into several more refined parallel streams. One, for example, analyzes shape while another analyzes color. Ultimately, the visual world is resynthesized with information about the tactile world, and the auditory world, with information from memory, and with emotional coloration. The massively parallel design is a great pattern recognizer and very tolerant of failure in individual elements. This is why a brain of neurons is still a better and longer-lasting information processor than a computer.

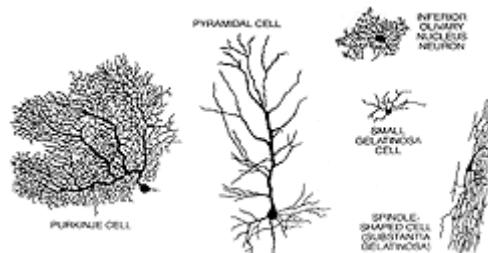
The specific connectivity of circuits is, to some degree, stereotyped, or set in expected patterns within the brain, leading to the notion that certain places in the brain are specialized for certain functions (Figure 2-3). Thus, the cerebral cortex, the mantle of neurons with its enormous surface area increased by outpouchings, called gyri, and indentations, called sulci, can be functionally subdivided. The back portion of the cerebral cortex (i.e., the occipital lobe), for example, is involved in the initial stages of visual processing. Just behind the central sulcus is the part of the cerebral cortex involved in the processing of tactile information (i.e., parietal lobe). Just in front of the central sulcus is a part of the cerebral cortex involved in motor behavior (frontal lobe). In the front of the brain is a region called the prefrontal cortex, which is involved with some of the highest integrated functions of the human being, including the ability to plan and to integrate cognitive and emotional streams of information.

Beneath the cortex are enormous numbers of axons sheathed in the insulating substance, myelin. This subcortical "white matter," so named because of its appearance on freshly cut brain sections, surrounds deep aggregations of neurons, or "gray matter," which, like the cortex, appears gray because of the presence of neuronal cell bodies. It is within this gray matter that the brain processes information. The white matter is akin to wiring that conveys information from one region to another. Gray matter regions include the basal ganglia, the part of the brain that is involved in the initiation of motion and thus profoundly affected in Parkinson's disease, but that is also involved in the integration of motivational states and, thus, a substrate of addictive disorders. Other important gray matter structures in the brain include the amygdala and the hippocampus. The amygdala is involved in the assignment of emotional meaning to events and objects, and it appears to play a special role in aversive, or negative, emotions such as fear. The hippocampus includes, among its many functions, responsibility for initially encoding and consolidating explicit or episodic memories of persons, places, and things.

In summary, the organization of the brain at the cellular level involves many thousands of distinct kinds of neurons. At a higher integrative level, these neurons form circuits for information processing determined by their patterns of synaptic connections. The organization of these parallel distributed circuits results in the specialization of different geographic regions of the brain for different functions. It is important to state at this point, however, that, especially in younger individuals, damage to a particular brain region may yield adaptations that permit circuits spared

the damage and, therefore, other regions of the brain, to pick up some of the functions that would otherwise have been lost.

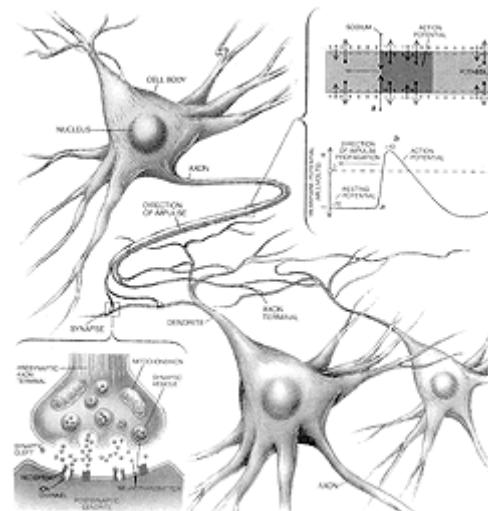
Figure 2-1. Structural variety of neurons



[Click to enlarge](#)

Source: Fischbach, 1992, p. 53. (Permission granted: Patricia J. Wynne.)

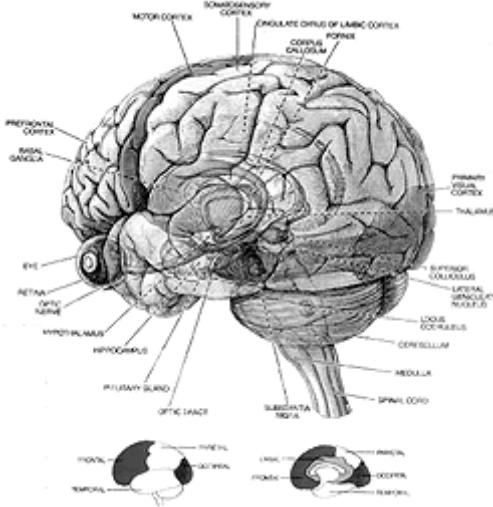
Figure 2-2. How neurons communicate



[Click to enlarge](#)

Source: Fischbach, 1992, p. 52. (Permission granted: Tomo Narashima.)

Figure 2-3. The brain: Organ of the mind



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Source: Fischbach, 1992, p. 51. (Permission granted: Carol Donner.)

Complexity of the Brain II: Neurochemical

Superimposed on this breathtaking structural complexity is the chemical complexity of the brain. As described above, electrical signals within neurons are converted at synapses into chemical signals which then elicit electrical signals on the other side of the synapse. These chemical signals are molecules called neurotransmitters. There are two major kinds of molecules that serve the function of neurotransmitters: small molecules, some quite well known, with names such as dopamine, serotonin, or norepinephrine, and larger molecules, which are essentially protein chains, called peptides. These include the endogenous opiates, Substance P, and corticotropin releasing factor (CRF), among others. All told, there appear to be more than 100 different neurotransmitters in the brain (Table 2-1 contains a selected list).

A neurotransmitter can elicit a biological effect in the postsynaptic neuron by binding to a protein called a neurotransmitter receptor. Its job is to pass the information contained in the neurotransmitter message from the synapse to the inside of the receiving cell. It appears that almost every known neurotransmitter has more than one different kind of receptor that can confer rather different signals on the receiving neuron. Dopamine has 5 known neurotransmitter receptors; serotonin has at least 14.

Table 2-1. Selected neurotransmitters important in psychopharmacology

Excitatory amino acid
Glutamate

Inhibitory amino acids
Gamma aminobutyric acid
Glycine

Monoamines and related neurotransmitters

Norepinephrine
Dopamine
Serotonin
Histamine
Acetylcholine (quaternary amine)

Purine
Adenosine

Neuropeptides

Opioids

Enkephalins
Beta-endorphin
Dynorphin

Tachykinin

Substance P

Hypothalamic-releasing factors

Corticotropin-releasing hormone

Although there are many kinds of receptors with many different signaling functions, we can divide most neurotransmitter receptors into two general classes. One class of neurotransmitter receptor is called a ligand-gated channel, where "ligand" simply means a molecule (i.e., a neurotransmitter) that binds to a receptor. When neurotransmitters interact with this kind of receptor, a pore within the receptor molecule itself is opened and positive or negative charges enter the cell. The entry of positive charge may activate additional ion channels that allow more positive charge to enter. At a certain threshold, this causes a cell to fire an action potential—an electrical event that leads ultimately to the release of neurotransmitter. By definition, therefore, receptors that admit positive charge are excitatory neurotransmitter receptors. The classic excitatory neurotransmitter receptors in the brain utilize the excitatory amino acids glutamate and, to a lesser degree, aspartate as neurotransmitters. Conversely, inhibitory neurotransmitters act by permitting negative charges into the cell, taking the cell farther away from firing. The classic inhibitory neurotransmitters in the brain are the amino acids gamma amino butyric acid, or GABA, and, to a lesser degree, glycine.

Most of the other neurotransmitters in the brain, such as dopamine, serotonin, and norepinephrine, and all of the many neuropeptides constitute the second major class. These are neither precisely excitatory nor inhibitory but rather act to produce complex biochemical changes in the receiving cell. Their receptors do not contain intrinsic ion pores but rather interact with signaling proteins, called "G proteins" found inside the cell membrane. These receptors thus are called G protein-linked receptors. The details are less important than understanding the general scheme. Stimulation of G protein-linked receptors alters the way in which receiving neurons can process subsequent signals from glutamate or GABA. To use a metaphor of a musical instrument, if glutamate, the excitatory neurotransmitter, is puffing wind into a flute

or clarinet, it is the modulatory neurotransmitters such as dopamine or serotonin that might be seen as playing the keys and, thus, altering the melody via G protein-linked receptors.

The architecture of these systems drives home this point. The precise brain circuits that carry specific information about the world and that are involved in precise point-to-point communication within the brain use excitatory or inhibitory neurotransmission. Examples of such circuits, which are massively parallel, can be found in the visual and auditory cortex. Overlying this pattern of precise, rapid (timing in the range of milliseconds) neurotransmission are the modulatory systems in the brain that use norepinephrine, serotonin, and dopamine. In each case, the neurotransmitter in question is made by a very small number of nerve cells clustered in a limited number of areas in the brain. Of the hundred billion neurons in the brain, only about 500,000, for example, make dopamine—that is, for every 200,000 cells in the brain, only one makes dopamine. Even fewer make norepinephrine. The cell bodies of the dopamine neurons are clustered in a few brain regions, most importantly, regions deep in the brain, in the *midbrain*, called the *substantia nigra*, and the *ventral tegmental area*. Norepinephrine neurons are made in the nucleus *locus coeruleus* even farther down in the brain stem in a structure called the *pons*. Serotonin is made by a somewhat larger number of nuclei but, still, not by many cells. Nuclei called the *raphe nuclei* spread along the brain stem. While each of these neurotransmitters is made by a small number of neurons with clustered cell bodies, each sends its axons branching throughout the brain, so that in each case a very small number of neurons, which largely appear to fire in unison when excited, influence almost the entire brain. This is not the picture of systems that are communicating precise bits of information about the world but rather are intrinsic modulatory systems that act via other G protein-linked receptors to alter the overall responsiveness of the brain. These neurotransmitters are responsible for brain states such as degree of arousal, ability to pay attention, and for putting emotional color or significance on top of cold cognitive information provided by precise glutaminergic circuits. It is no wonder that these modulatory neurotransmitters and their receptors are critical targets of medications used to treat mental disorders—for example, the antidepressant and antipsychotic drugs—and also are the targets of drugs of abuse.

Complexity of the Brain III: Plasticity

The preceding paragraphs have illustrated the chemical and anatomic structure of the brain and, in so doing, provided some picture of its complexity as well as some picture of its function. The crowning complexity of the brain, however, is that it is not static. The brain is always changing. People learn so much and have so many distinct types of memory: conscious, episodic memory of the sort that is encoded initially in the hippocampus; memory of motor programs or procedures that are encoded in the striatum; emotional memories that can initiate physiologic and behaviorally adaptive repertoires encoded, for example, in the amygdala; and many other kinds. Every time a person learns something new, whether it is conscious or unconscious, that experience alters the structure of the brain. Thus, neurotransmission in itself not only contains current information but alters subsequent neurotransmission if it occurs with the right intensity and the right pattern. Experience that is salient enough to cause memory creates new synaptic connections, prunes away old ones, and strengthens or weakens existing ones. Similarly, experiences as diverse as stress, substance abuse, or disease can kill neurons, and current data suggest that new neurons continue to develop even in adult brains, where they help to

incorporate new memories. The end result is that information is now routed over an altered circuit. Many of these changes are long-lived, even permanent. It is in this way that a person can look back 10 or 20 or 50 years and remember family, a home or school room, or friends. The general theme is that to really understand the kind of memory—indeed, any brain function—one must think at least at two levels: one, the level of molecular and cellular alterations that are responsible for remodeling synapses, and, two, the level of information content and behavior which circuits and synapses serve.

To summarize this section, scientists are truly beginning to learn about the structure and function of the brain. Its awe-inspiring complexity is fully consistent with the fact that it supports all behavior and mental life. Implied in the foregoing, is the fact that brains are built not only by genes—and again, it is the lion's share of the 80,000 or so human genes that are involved in building a structure so complex as the brain. Genes are not by themselves the whole story. Brains are built and changed through life through the interaction of genes with environment, including experience. It is true that a set of genes might create repetitive multiples of one type of unit, yet the brain appears far more complex than that. It stands to reason that if 50,000 or 60,000 genes are involved in building a brain that may have 100 trillion or a quadrillion synapses, additional information is needed, and that information comes from the environment. It is this fundamental realization that is beginning to permit an understanding of how treatment of mental disorders works—whether in the form of a somatic intervention such as a medication, or a psychological “talk” therapy—by actually changing the brain.

Imaging the Brain

There are many exciting developments in brain science. Of great relevance to the study of mental function and mental illness is the ability to image the activity of the living human brain with technologies developed in recent decades, such as positron emission tomography scanning or functional magnetic resonance imaging. Such approaches can exploit surrogates of neuronal firing such as blood flow and blood oxygenation to provide maps of activity. As science learns more about brain circuitry and learns more from cognitive and affective neuroscience about how to activate and examine the function of particular brain circuits, differences between health and illness in the function of particular circuits certainly will become evident. We will be able to see the action of psychotropic drugs and, perhaps most exciting, we will be able to see the impact of that special kind of learning called psychotherapy, which works after all because it works on the brain.

Different brain chemicals, brain receptors, and brain structures will come up in the discussion of particular illnesses throughout this document. This section is meant to provide a panoramic, not a detailed, introduction and also to provide certain overarching lessons. When something is referred to as biological or brain-based, that is not shorthand for saying it is genetic and, thus, predetermined; similarly, references to “psychological” or even “social” phenomena do not exclude biological processes. The brain is the great integrator, bringing together genes and environment. The study of the brain requires reducing problems initially to bite-sized bits that will allow investigators to learn something, but ultimately, the agenda of neuroscience is not reductionist; the goal is to understand behavior, not to put blinders on and try to explain it away. As the foregoing discussion illustrates, the brain also is complex. Thus, having a disease that affects one or even many critical

circuits does not overthrow, except in extreme cases, such as advanced Alzheimer's disease, all aspects of a person. Typically, people retain their personality and, in most cases, their ability to take responsibility for themselves.

In retrospect, early biological models of the mind seem impoverished and deterministic—for example, models that held that “levels” of a neurotransmitter such as serotonin in the brain were the principal influence on whether one was depressed or aggressive. Neuroscience is far beyond that now, working to integrate information coming “bottom-up” from genes and molecules and cells, with information flowing “top-down” from interactions with the environment and experience to the internal workings of the mind and its neuronal circuits. Ultimately, however, the goal is not only human self-understanding. In knowing eventually precisely what goes wrong in what circuits and what synapses and with what chemical signals, the hope is to develop treatments with greater effectiveness and with fewer side effects. Indeed, as the following chapters indicate, the hope is for cures and ultimately for prevention. There is every reason to hope that as our science progresses, we will achieve those goals.

¹ Special thanks to Steven E. Hyman, M.D., Director, National Institute of Mental Health, and Gerald D. Fischbach, M.D., Director, National Institute of Neurological Diseases and Stroke, for their contributions to this section.

Overview of Mental Illness

Mental illness is a term rooted in history that refers collectively to all of the diagnosable mental disorders. Mental disorders are characterized by abnormalities in cognition, emotion or mood, or the highest integrative aspects of behavior, such as social interactions or planning of future activities. These mental functions are all mediated by the brain. It is, in fact, a core tenet of modern science that behavior and our subjective mental lives reflect the overall workings of the brain. Thus, symptoms related to behavior or our mental lives clearly reflect variations or abnormalities in brain function. On the more difficult side of the ledger are the terms disorder, disease, or illness. There can be no doubt that an individual with schizophrenia is seriously ill, but for other mental disorders such as depression or attention-deficit/hyperactivity disorder, the signs and symptoms exist on a continuum and there is no bright line separating health from illness, distress from disease. Moreover, the manifestations of mental disorders vary with age, gender, race, and culture. The thresholds of mental illness or disorder have, indeed, been set by convention, but the fact is that this gray zone is no different from any other area of medicine. Ten years ago a serum cholesterol of 200 was considered normal. Today, this same number alarms some physicians and may lead to treatment. Perhaps every adult in the United States has some atherosclerosis, but at what point does this move along a continuum from normal into the realm of illness? Ultimately, the dividing line has to do with severity of symptoms, duration, and functional impairment.

Despite the existence of a gray zone between health and illness, science can study the mechanisms by which illness occurs. Indeed, understanding mood regulation and its abnormalities, for example, proceeds independently from any set of diagnostic clinical criteria. Family studies, molecular genetics strategies, epidemiology, and the tools of clinical investigation tailored to specific populations are being used to investigate the mechanisms of mental illness. Specific manifestations of mental illness will be covered in succeeding pages.

This overview of mental illness focuses on those features of the disease process that are most common and characteristic of these disorders. The chapters that follow will present specific details about major categories of mental disorders that occur across the life span. The purpose here is to provide a framework upon which subsequent discussions of specific disorders can rest. The section leads with a descriptive overview of the cardinal manifestations, signs, and symptoms of mental disorders. It then describes how mental disorders are diagnosed and classified and provides an overview of the epidemiology and societal burden of mental disorders.

Manifestations of Mental Illness

Persons suffering from any of the severe mental disorders present with a variety of symptoms that may include inappropriate anxiety, disturbances of thought and perception, dysregulation of mood, and cognitive dysfunction. Many of these symptoms may be relatively specific to a particular diagnosis or cultural influence. For example, disturbances of thought and perception (psychosis) are most commonly associated with schizophrenia. Similarly, severe disturbances in expression of affect and regulation of mood are most commonly seen in depression and bipolar disorder. However, it is not uncommon to see psychotic symptoms in patients diagnosed with mood disorders or to see mood-related symptoms in patients diagnosed with schizophrenia. Symptoms associated with mood, anxiety, thought process, or cognition may occur in any patient at some point during his or her illness.

Anxiety

Anxiety is one of the most readily accessible and easily understood of the major symptoms of mental disorders. Each of us encounters anxiety in many forms throughout the course of our routine activities. It may often take the concrete form of intense fear experienced in response to an immediately threatening experience such as narrowly avoiding a traffic accident. Experiences like this are typically accompanied by strong emotional responses of fear and dread as well as physical signs of anxiety such as rapid heart beat and perspiration. Some of the more common signs and symptoms of anxiety are listed in Table 2-2. Anxiety is aroused most intensely by immediate threats to one's safety, but it also occurs commonly in response to dangers that are relatively remote or abstract. Intense anxiety may also result from situations that one can only vaguely imagine or anticipate.

Anxiety has evolved as a vitally important physiological response to dangerous situations that prepares one to evade or confront a threat in the environment. The appropriate regulation of anxiety is critical to the survival of virtually every higher organism in every environment. However, the mechanisms that regulate anxiety may break down in a wide variety of circumstances, leading to excessive or inappropriate expression of anxiety. Specific examples include phobias, panic attacks, and generalized anxiety. In phobias, high-level anxiety is aroused by specific

situations or objects that may range from concrete entities such as snakes, to complex circumstances such as social interactions or public speaking. Panic attacks are brief and very intense episodes of anxiety that often occur without a precipitating event or stimulus. Generalized anxiety represents a more diffuse and nonspecific kind of anxiety that is most often experienced as excessive worrying, restlessness, and tension occurring with a chronic and sustained pattern. In each case, an anxiety disorder may be said to exist if the anxiety experienced is disproportionate to the circumstance, is difficult for the individual to control, or interferes with normal functioning.

In addition to these common manifestations of anxiety, obsessive-compulsive disorder and post-traumatic stress disorder are generally believed to be related to the anxiety disorders. The specific clinical features of these disorders will be described more fully in the following chapters; however, their relationship to anxiety warrants mention in the present context. In the case of obsessive-compulsive disorder, individuals experience a high level of anxiety that drives their obsessional thinking or compulsive behaviors. When such an individual fails to carry out a repetitive behavior such as hand washing or checking, there is an experience of severe anxiety. Thus while the outward manifestations of obsessive-compulsive disorder may seem to be related to other anxiety disorders, there appears to be a strong component of abnormal regulation of anxiety underlying this disorder. Post-traumatic stress disorder is produced by an intense and overwhelmingly fearful event that is often life-threatening in nature. The characteristic symptoms that result from such a traumatic event include the persistent reexperience of the event in dreams and memories, persistent avoidance of stimuli associated with the event, and increased arousal.

Table 2-2. Common signs of acute anxiety

| |
|---|
| • Feelings of fear or dread |
| • Trembling, restlessness, and muscle tension |
| • Rapid heart rate |
| • Lightheadedness or dizziness |
| • Perspiration |
| • Cold hands/feet |
| • Shortness of breath |

Psychosis

Disturbances of perception and thought process fall into a broad category of symptoms referred to as psychosis. The threshold for determining whether thought is impaired varies somewhat with the cultural context. Like anxiety, psychotic symptoms may occur in a wide variety of mental disorders. They are most characteristically associated with schizophrenia, but psychotic symptoms can also occur in severe mood disorders.

One of the most common groups of symptoms that result from disordered processing and interpretation of sensory information are the hallucinations. Hallucinations are said to occur when an individual experiences a sensory impression that has no basis in reality. This impression could involve any of the sensory modalities. Thus hallucinations may be auditory, olfactory, gustatory, kinesthetic, tactile, or visual. For example, auditory hallucinations frequently involve the impression that one is hearing a voice. In each case, the sensory impression is falsely experienced as real.

A more complex group of symptoms resulting from disordered interpretation of information consists of delusions. A delusion is a false belief that an individual holds despite evidence to the contrary. A common example is paranoia, in which a person has delusional beliefs that others are trying to harm him or her. Attempts to persuade the person that these beliefs are unfounded typically fail and may even result in the further entrenchment of the beliefs.

Hallucinations and delusions are among the most commonly observed psychotic symptoms. A list of other symptoms seen in psychotic illnesses such as schizophrenia appears in Table 2-3. Symptoms of schizophrenia are divided into two broad classes: *positive* symptoms and *negative* symptoms. Positive symptoms generally involve the experience of something in consciousness that should not normally be present. For example, hallucinations and delusions represent perceptions or beliefs that should not normally be experienced. In addition to hallucinations and delusions, patients with psychotic disorders such as schizophrenia frequently have marked disturbances in the logical process of their thoughts. Specifically, psychotic thought processes are characteristically loose, disorganized, illogical, or bizarre. These disturbances in thought process frequently produce observable patterns of behavior that are also disorganized and bizarre. The severe disturbances of thought content and process that comprise the positive symptoms often are the most recognizable and striking features of psychotic disorders such as schizophrenia or manic depressive illness.

Table 2-3. Common manifestations of schizophrenia

| Positive Symptoms | |
|--|--|
| • Hallucinations | |
| • Delusions | |
| • Disorganized thoughts and behaviors | |
| • Loose or illogical thoughts | |
| • Agitation | |
| Negative Symptoms | |
| • Flat or blunted affect | |
| • Concrete thoughts | |
| • Anhedonia (inability to experience pleasure) | |
| • Poor motivation, spontaneity, and initiative | |

However, in addition to positive symptoms, patients with schizophrenia and other psychoses have been noted to exhibit major deficits in motivation and spontaneity that are referred to as negative symptoms. While positive symptoms represent the presence of something not normally experienced, negative symptoms reflect the absence of thoughts and behaviors that would otherwise be expected. Concreteness of thought represents impairment in the ability to think abstractly. Blunting of affect refers to a general reduction in the ability to express emotion. Motivational failure and inability to initiate activities represent a major source of long-term disability in schizophrenia. Anhedonia reflects a deficit in the ability to experience pleasure and to react appropriately to pleasurable situations. Positive symptoms such as hallucinations are responsible for much of the acute distress associated with schizophrenia, but negative symptoms appear to be responsible for much of the chronic and long-term disability associated with the disorder.

The psychotic symptoms represent manifestations of disturbances in the flow, processing, and interpretation of information in the central nervous system. They seem to share an underlying commonality of mechanism, insofar as they tend to respond as a group to specific pharmacological interventions. However, much remains to be learned about the brain mechanisms that lead to psychosis.

Disturbances of Mood

Most of us have an immediate and intuitive understanding of the notion of mood. We readily comprehend what it means to feel sad or happy. These concepts are nonetheless very difficult to formulate in a scientifically precise and quantifiable way; the challenge is greater given the cultural differences that are associated with the expression of mood. In turn, disorders that impact on the regulation of mood are relatively difficult to define and to approach in a quantitative manner. Nevertheless, dysregulation of mood and the expression of mood, or affect, represent a major category among mental disorders.

Disturbances of mood characteristically manifest themselves as a sustained feeling of sadness or sustained elevation of mood. As with anxiety and psychosis, disturbances of mood may occur in a variety of patterns associated with different mental disorders. The disorder most closely associated with persistent sadness is major depression, while that associated with sustained elevation or fluctuation of mood is bipolar disorder. The most common signs of these mood disorders are listed in Table 2-4. Along with the prevailing feelings of sadness or elation, disorders of mood are associated with a host of related symptoms that include disturbances in appetite, sleep patterns, energy level, concentration, and memory.

Table 2-4. Common signs of mood disorders

| Symptoms Commonly Associated With Depression |
|---|
| • Persistent sadness or despair |
| • Insomnia (sometimes hypersomnia) |
| • Decreased appetite |
| • Psychomotor retardation |

| | |
|--|--|
| • Anhedonia (inability to experience pleasure) | |
| • Irritability | |
| • Apathy, poor motivation, social withdrawal | |
| • Hopelessness | |
| • Poor self-esteem, feelings of helplessness | |
| • Suicidal ideation | |
| Symptoms Commonly Associated With Mania | |
| • Persistently elevated or euphoric mood | |
| • Grandiosity (inappropriately high self-esteem) | |
| • Psychomotor agitation | |
| • Decreased sleep | |
| • Racing thoughts and distractibility | |
| • Poor judgment and impaired impulse control | |
| • Rapid or pressured speech | |

It is not known why diverse functions such as sleep and appetite should be altered in disorders of mood. However, depression and mania are typically associated with characteristic changes in these basic functions. Mood appears to represent a complex group of behaviors and responses that undergo precise and tightly controlled regulation. Higher organisms that must adapt to changing environments depend on optimal control of basic functions such as sleep, appetite, sex, and physical activity. This regulation must adapt to diurnal and seasonal changes in the environment. In addition, more complex behaviors such as exploration, aggression, and social interaction must also undergo a similar, perhaps closely linked, regulation. In humans, these complex behaviors and their regulation are believed to be associated with the expression of mood. A depressed mood appears to reflect a kind of global damping of these functions, while a manic state may result from an excessive activation of these same functions. The mechanisms underlying the diverse changes associated with the mood disorders are largely unknown, but their appearance as clusters in specific disorders along with their collective response to specific therapeutics suggests a common mechanistic basis.

Disturbances of Cognition

Cognitive function refers to the general ability to organize, process, and recall information. Cognitive tasks may be subdivided into a large number of more specific functions depending on the nature of the information remembered and the circumstances of its recall. In addition, there are many functions commonly associated with cognition such as the ability to execute complex sequences of tasks. Disturbances of cognitive function may occur in a variety of disorders. Progressive deterioration of cognitive function is referred to as dementia. Dementia may be caused by a number of specific conditions including Alzheimer's disease (to be

discussed in subsequent chapters). Impairment of cognitive function may also occur in other mental disorders such as depression. It is not uncommon to find profound disturbances of cognition in patients suffering from severe mood disturbances. More recently, cognitive deficits have been reported in schizophrenia and now have become a major new topic of research. Lastly, cognitive impairment frequently occurs in a host of chemical, metabolic, and infectious diseases that exert an impact on the brain.

The manifestations of cognitive impairment can vary across an extremely wide range, depending on severity. Short-term memory is one of the earliest functions to be affected and, as severity increases, retrieval of more remote memories becomes more difficult. Attention, concentration, and higher intellectual functions can be impaired as the underlying disease process progresses. Language difficulties range from mild word-finding problems to complete inability to comprehend or use language. Functional impairments associated with cognitive deficits can markedly interfere with the ability to perform activities of daily living such as dressing and bathing.

Other Symptoms

Anxiety, psychosis, mood disturbances, and cognitive impairments are among the most common and disabling manifestations of mental disorders. It is important, however, to appreciate that mental disorders leave no aspect of human experience untouched. It is beyond the scope of the present chapter to detail the full spectrum of presentations of mental disorders. Other common manifestations include, for example, somatic or other physical symptoms and impairment of impulse control. Many of these issues will be touched upon in subsequent chapters with reference to specific disorders.

Diagnosis of Mental Illness

The foregoing discussion has suggested that the manifestations of mental disorders fall into a number of distinct categories such as anxiety, psychosis, mood disturbance, and cognitive deficits. These categories are broad, heterogeneous, and somewhat overlapping. Moreover, any particular patient may manifest symptoms from more than one of these categories. This is not unexpected, given the highly complex interactions that take place among the neurobiological and behavioral substrates that produce these symptoms. Despite these confounding difficulties, a systematic approach to the classification and diagnosis of mental illness has been developed. Diagnosis is essential in all areas of health for shaping treatment and supportive care, establishing a prognosis, and preventing related disability. Diagnosis also serves as shorthand to enhance communication, research, surveillance, and reimbursement.

The diagnosis of mental disorders is often believed to be more difficult than diagnosis of somatic, or general medical, disorders, since there is no definitive lesion, laboratory test, or abnormality in brain tissue that can identify the illness. The diagnosis of mental disorders must rest with the patients' reports of the intensity and duration of symptoms, signs from their mental status examination, and clinician observation of their behavior including functional impairment. These clues are grouped together by the clinician into recognizable patterns known as syndromes. When the syndrome meets all the criteria for a diagnosis, it constitutes a mental

disorder. Most mental health conditions are referred to as disorders, rather than as diseases, because diagnosis rests on clinical criteria. The term "disease" generally is reserved for conditions with known pathology (detectable physical change). The term "disorder," on the other hand, is reserved for clusters of symptoms and signs associated with distress and disability (i.e., impairment of functioning), yet whose pathology and etiology are unknown.

The standard manual used for diagnosis of mental disorders in the United States is the *Diagnostic and Statistical Manual of Mental Disorders*. Most recently revised in 1994, this manual now is in its fourth edition (American Psychiatric Association, 1994, hereinafter cited in this report as DSM-IV). The first edition was published in 1952 by the American Psychiatric Association; subsequent revisions, which were made on the basis of field trials, analysis of data sets, and systematic reviews of the research literature, have sought to gain greater objectivity, diagnostic precision, and reliability. DSM-IV organizes mental disorders into 16 major diagnostic classes listed in Table 2-5. For each disorder within a diagnostic class, DSM-IV enumerates specific criteria for making the diagnosis. DSM-IV also lists diagnostic "subtypes" for some disorders. A subtype is a subgroup within a diagnosis that confers greater specificity. DSM-IV is descriptive in its listing of symptoms and does not take a position about underlying causation.

Table 2-5. Major Diagnostic Classes of Mental Disorders (DSM-IV)

| |
|---|
| Disorders usually first diagnosed in infancy, childhood, or adolescence |
| Delerium, dementia, and amnestic and other cognitive disorders |
| Mental disorders due to a general medical condition |
| Substance-related disorders |
| Schizophrenia and other psychotic disorders |
| Mood disorders |
| Anxiety disorders |
| Somatoform disorders |
| Factitious disorders |
| Dissociative disorders |
| Sexual and gender identity disorders |
| Eating disorders |
| Sleep disorders |
| Impulse-control disorders |
| Adjustment disorders |
| Personality disorders |

DSM-IV and its predecessors² represent a unique approach to diagnosis by a professional field. No other sphere of health care has created such an extensive compendium of all of its disorders with explicit diagnostic criteria. The World Health Organization's *International Classification of Diseases* (10th edition, 1992) is a valuable compendium of all diseases. Its mental health categories are expanded upon in DSM-IV. The *International Classification of Diseases* (ICD) is the official classification for mortality and morbidity statistics for all signatories to the U.N. Charter establishing the World Health Organization. ICD-9CM (9th edition, Clinical Modification, 1991) is still the official classification for the Health Care Financing Administration.

Knowledge about diagnosis continues to evolve. Evolution in the diagnosis of mental disorders generally reflects greater understanding of disorders as well as the influence of social norms. Years ago, for instance, addiction to tobacco was not viewed as a disorder, but today it falls under the category of "Substance-Related Disorders." Although DSM-IV strives to cover all populations, it is not without limitations. The difficulties encountered in diagnosing mental disorders in children, older persons, and racial and ethnic minority groups are discussed later in this chapter and throughout this report. Diagnosis rests on clinician judgment about whether clients' symptom patterns and impairments of functioning meet diagnostic criteria. Cultural differences in emotional expression and social behavior can be misinterpreted as "impaired" if clinicians are not sensitive to the cultural context and meaning of exhibited symptoms, a topic discussed later in this chapter in Overview of Cultural Diversity and Mental Health Services.

² DSM-I (American Psychiatric Association, 1952), DSM-II (American Psychiatric Association, 1968), DSM-III (American Psychiatric Association, 1979), and DSM-III-R (American Psychiatric Association, 1987).

³ Although addictive disorders are included as mental disorders in the DSM classification system, the ECA and NCS distinguish between addictive disorders and (all other) mental disorders. Epidemiologic data in this report follow that convention.

⁴ The term "serious emotional disturbance" is used in a variety of Federal statutes in reference to children under the age of 18 with a diagnosable mental health problem that severely disrupts their ability to function socially, academically, and emotionally. The term does not signify any particular diagnosis; rather, it is a legal term that triggers a host of mandated services to meet the needs of these children.

Epidemiology of Mental Illness

Few families in the United States are untouched by mental illness. Determining just how many people have mental illness is one of the many purposes of the field of epidemiology. Epidemiology is the study of patterns of disease in the population. Among the key terms of this discipline, encountered throughout this report, are *incidence*, which refers to new cases of a condition which occur during a specified period of time, and *prevalence*, which refers to cases (i.e., new and existing) of a

condition observed at a point in time or during a period of time. According to current epidemiological estimates, at least one in five people has a diagnosable mental disorder during the course of a year (i.e., 1-year prevalence).

Epidemiological estimates have shifted over time because of changes in the definitions and diagnosis of mental health and mental illness. In the early 1950s, the rates of mental illness estimated by epidemiologists were far higher than those of today. One study, for example, found 81.5 percent of the population of Manhattan, New York, to have had signs and symptoms of mental distress (Srole, 1962). This led the authors of the study to conclude that mental illness was widespread. However, other studies began to find *lower* rates when they used more restrictive definitions that reflected more contemporary views about mental illness. Instead of classifying anyone with signs and symptoms as being mentally ill, this more recent line of epidemiological research only identified people as mentally ill if they had a *cluster* of signs and symptoms that, when taken together, impaired people's ability to function (Pasamanick, 1959; Weissman et al., 1978). By 1978, the President's Commission on Mental Health (1978) concluded conservatively that the annual prevalence of specific mental disorders in the United States was about 15 percent. This figure comports with recent estimates of the extent of mental illness in the population. Even as this figure has become more sharply delineated, the older and larger estimates underscore the magnitude of mental distress in the population, which this report refers to as "mental health problems."

Adults

The current prevalence estimate is that about 20 percent of the U.S. population are affected by mental disorders during a given year. This estimate comes from two epidemiologic surveys: the Epidemiologic Catchment Area (ECA) study of the early 1980s and the National Comorbidity Survey (NCS) of the early 1990s. Those surveys defined mental illness according to the prevailing editions of the *Diagnostic and Statistical Manual of Mental Disorders* (i.e., DSM-III and DSM-IIIR). The surveys estimate that during a 1-year period, 22 to 23 percent of the U.S. adult population—or 44 million people—have diagnosable mental disorders, according to reliable, established criteria. In general, 19 percent of the adult U.S. population have a mental disorder alone (in 1 year); 3 percent have both mental and addictive disorders; and 6 percent have addictive disorders alone.³ Consequently, about 28 to 30 percent of the population have either a mental *or* addictive disorder (Regier et al., 1993b; Kessler et al., 1994). Table 2-6 summarizes the results synthesized from these two large national surveys.

Individuals with co-occurring disorders (about 3 percent of the population in 1 year) are more likely to experience a chronic course and to utilize services than are those with either type of disorder alone. Clinicians, program developers, and policy makers need to be aware of these high rates of comorbidity—about 15 percent of those with a mental disorder in 1 year (Regier et al., 1993a; Kessler et al., 1996).

Based on data on functional impairment, it is estimated that 9 percent of all U.S. adults have the mental disorders listed in Table 2-6 *and* experience some significant functional impairment (National Advisory Mental Health Council [NAMHC], 1993). Most (7 percent of adults) have disorders that persist for at least 1 year (Regier et al., 1993b; Regier et al., in press). A subpopulation of 5.4 percent of adults is considered to have a "serious" mental illness (SMI) (Kessler et al., 1996). Serious

mental illness is a term defined by Federal regulations that generally applies to mental disorders that interfere with some area of social functioning. About half of those with SMI (or 2.6 percent of all adults) were identified as being even more seriously affected, that is, by having "severe and persistent" mental illness (SPMI) (NAMHC, 1993; Kessler et al., 1996). This category includes schizophrenia, bipolar disorder, other severe forms of depression, panic disorder, and obsessive-compulsive disorder. These disorders and the problems faced by these special populations with SMI and SPMI are described further in subsequent chapters. Among those most severely disabled are the approximately 0.5 percent of the population who receive disability benefits for mental health-related reasons from the Social Security Administration (NAMHC, 1993).

Children and Adolescents

The annual prevalence of mental disorders in children and adolescents is not as well documented as that for adults. About 20 percent of children are estimated to have mental disorders with at least mild functional impairment (see Table 2-7). Federal regulations also define a sub-population of children and adolescents with more severe functional limitations, known as "serious emotional disturbance" (SED).⁴ Children and adolescents with SED number approximately 5 to 9 percent of children ages 9 to 17 (Friedman et al., 1996b).

Table 2-6. Best estimate 1-year prevalence rates based on ECA and NCS, ages 18—54

| | ECA Prevalence (%) | NCS Prevalence (%) | Best Estimate ** (%) |
|----------------------|--------------------------|--------------------------|----------------------------|
| Any Anxiety Disorder | 13.1 | 18.7 | 16.4 |
| Simple Phobia | 8.3 | 8.6 | 8.3 |
| Social Phobia | 2.0 | 7.4 | 2.0 |
| Agoraphobia | 4.9 | 3.7 | 4.9 |
| GAD | (1.5)* | 3.4 | 3.4 |
| Panic Disorder | 1.6 | 2.2 | 1.6 |
| OCD | 2.4 | (0.9)* | 2.4 |
| PTSD | (1.9)* | 3.6 | 3.6 |
| | | | |
| Any Mood Disorder | 7.1 | 11.1 | 7.1 |
| MD Episode | 6.5 | 10.1 | 6.5 |
| Unipolar MD | 5.3 | 8.9 | 5.3 |
| Dysthymia | 1.6 | 2.5 | 1.6 |
| Bipolar I | 1.1 | 1.3 | 1.1 |
| Bipolar II | 0.6 | 0.2 | 0.6 |
| | | | |
| Schizophrenia | 1.3 | — | 1.3 |
| Nonaffective | — | 0.2 | 0.2 |

| | | | |
|-----------------------------|-------------|-------------|-------------|
| Psychosis | | | |
| Somatization | 0.2 | — | 0.2 |
| ASP | 2.1 | — | 2.1 |
| Anorexia Nervosa | 0.1 | — | 0.1 |
| Severe Cognitive Impairment | 1.2 | — | 1.2 |
| | | | |
| Any Disorder | 19.5 | 23.4 | 21.0 |

*Numbers in parentheses indicate the prevalence of the disorder without any comorbidity. These rates were calculated using the NCS data for GAD and PTSD, and the ECA data for OCD. The rates were not used in calculating the any anxiety disorder and any disorder totals for the ECA and NCS columns. The unduplicated GAD and PTSD rates were added to the best estimate total for any anxiety disorder (3.3%) and any disorder (1.5%).

**In developing best-estimate 1-year prevalence rates from the two studies, a conservative procedure was followed that had previously been used in an independent scientific analysis comparing these two data sets (Andrews, 1995). For any mood disorder and any anxiety disorder, the lower estimate of the two surveys was selected, which for these data was the ECA. The best estimate rates for the individual mood and anxiety disorders were then chosen from the ECA only, in order to maintain the relationships between the individual disorders. For other disorders that were not covered in both surveys, the available estimate was used.

Key to abbreviations: ECA, Epidemiologic Catchment Area; NCS, National Comorbidity Study; GAD, generalized anxiety disorder; OCD, obsessive-compulsive disorder; PTSD, post-traumatic stress disorder; MD, major depression; ASP, antisocial personality disorder.

Source: D. Regier, W. Narrow, & D. Rae, personal communication, 1999

Table 2-7. Children and adolescents ages 9 to 17 with mental or addictive disorders,* combined MECA sample

| | Prevalence (%) |
|-------------------------|----------------|
| Anxiety disorders | 13.0 |
| Mood disorders | 6.2 |
| Disruptive disorders | 10.3 |
| Substance use disorders | 2.0 |
| Any disorder | 20.9 |

* Disorders include diagnosis-specific impairment and Child Global Assessment Scale <or=70 (mild global impairment).

Source: Shaffer et al., 1996

Not all mental disorders identified in childhood and adolescence persist into adulthood, even though the prevalence of mental disorders in children and adolescents is about the same as that for adults (i.e., about 20 percent of each age population). While some disorders do continue into adulthood, a substantial fraction of children and adolescents recover or "grow out of" a disorder, whereas, a substantial fraction of adults develops mental disorders in adulthood. In short, the nature and distribution of mental disorders in young people are somewhat different from those of adults.

Older Adults

The annual prevalence of mental disorders among older adults (ages 55 years and older) is also not as well documented as that for younger adults. Estimates generated from the ECA survey indicate that 19.8 percent of the older adult population have a diagnosable mental disorder during a 1-year period (Table 2-8). Almost 4 percent of older adults have SMI, and just under 1 percent has SPMI (Kessler et al., 1996); these figures do not include individuals with severe cognitive impairments such as Alzheimer's disease.

Future Directions for Epidemiology

The epidemiology of mental disorders is somewhat handicapped by the difficulty of identifying a "case" of a mental disorder. "Case" is an epidemiological term for someone who meets the criteria for a disease or disorder. It is not always easy to establish a threshold for a mental disorder, particularly in light of how common symptoms of mental distress are and the lack of objective, physical symptoms. It is sometimes difficult to determine when a set of symptoms rises to the level of a mental disorder, a problem that affects other areas of health (e.g., criteria for certain pain syndromes). In many cases, symptoms are not of sufficient intensity or duration to meet the criteria for a disorder and the threshold may vary from culture to culture.

Table 2-8. Best estimate prevalence rates based on Epidemiological Catchment Area, age 55+

| | Prevalence (%) |
|-------------------------------|----------------|
| Any Anxiety Disorder | 11.4 |
| Simple Phobia | 7.3 |
| Social Phobia | 1.0 |
| Agoraphobia | 4.1 |
| Panic Disorder | 0.5 |
| Obsessive-Compulsive Disorder | 1.5 |
| | |
| Any Mood Disorder | 4.4 |
| Major Depressive Episode | 3.8 |

| | |
|---------------------------------|------|
| Unipolar Major Depression | 3.7 |
| Dysthymia | 1.6 |
| Bipolar I | 0.2 |
| Bipolar II | 0.1 |
| | |
| Schizophrenia | 0.6 |
| Somatization | 0.3 |
| Antisocial Personality Disorder | 0.0 |
| Anorexia Nervosa | 0.0 |
| Severe Cognitive Impairment | 6.6 |
| | |
| Any Disorder | 19.8 |

Source: D. Regier, W. Narrow, & D. Rae, personal communication, 1999

Diagnosis of mental disorders is made on the basis of a multidimensional assessment that takes into account observable signs and symptoms of illness, the course and duration of illness, response to treatment, and degree of functional impairment. One problem has been that there is no clearly measurable *threshold* for functional impairments. Efforts are currently under way in the epidemiology of mental disorders to create a threshold, or agreed-upon minimum level of functional limitation, that should be required to establish a "case" (i.e., a clinically significant condition). Epidemiology reflecting the state of psychiatric nosology during the past two decades has focused primarily on symptom clusters and has not uniformly applied—or, at times, even measured—the level of dysfunction. Ongoing reanalyses of existing epidemiological data are expected to yield better understanding of the rates of mental disorder and dysfunction in the population.

Another limitation of contemporary mental health knowledge is the lack of standard measures of "need for treatment," particularly those which are culturally appropriate. Such measures are at the heart of the public health approach to mental health. Current epidemiological estimates therefore cannot definitively identify those who are in need of treatment. Other estimates presented in Chapter 6 indicate that some individuals with mental disorders are in treatment and others are not; some are seen in primary care settings and others in specialty care. In the absence of valid measures of need, rates of disorder estimated in epidemiological surveys serve as an imperfect proxy for the need for care and treatment (Regier et al., in press).

Subsequent sections of this report reveal the population basis of our understanding of mental health. Where appropriate, the report discusses mental health and illness across the entire population. At other times, the focus is on care in specialized mental health settings, primary health care, schools, the criminal justice system, and even the streets. A mainstream public health and population-based perspective demands such a broad view of mental health and mental illness.

Costs of Mental Illness

The costs of mental illness are exceedingly high. Although the question of cost is discussed more fully in Chapter 6, a few of the central findings are presented here. The direct costs of mental health services in the United States in 1996 totaled \$69.0 billion. This figure represents 7.3 percent of total health spending. An additional \$17.7 billion was spent on Alzheimer's disease and \$12.6 billion on substance abuse treatment. Direct costs correspond to spending for treatment and rehabilitation nationwide.

When economists calculate the costs of an illness, they also strive to identify indirect costs. Indirect costs can be defined in different ways, but here they refer to lost productivity at the workplace, school, and home due to premature death or disability. The indirect costs of mental illness were estimated in 1990 at \$78.6 billion (Rice & Miller, 1996). More than 80 percent of these costs stemmed from disability rather than death because mortality from mental disorders is relatively low.

³ Although addictive disorders are included as mental disorders in the DSM classification system, the ECA and NCS distinguish between addictive disorders and (all other) mental disorders. Epidemiologic data in this report follow that convention.

⁴ The term "serious emotional disturbance" is used in a variety of Federal statutes in reference to children under the age of 18 with a diagnosable mental health problem that severely disrupts their ability to function socially, academically, and emotionally. The term does not signify any particular diagnosis; rather, it is a legal term that triggers a host of mandated services to meet the needs of these children.

Overview of Etiology

The precise causes (etiology) of most mental disorders are not known. But the key word in this statement is *precise*. The *precise* causes of most mental disorders—or, indeed, of mental health—may not be known, but the broad forces that shape them *are* known: these are biological, psychological, and social/cultural factors.

What is most important to reiterate is that the causes of health and disease are generally viewed as a product of the *interplay* or *interaction* between biological, psychological, and sociocultural factors. This is true for all health and illness, including mental health and mental illness. For instance, diabetes and schizophrenia alike are viewed as the result of interactions between biological, psychological, and sociocultural influences. With these disorders, a biological predisposition is necessary but not sufficient to explain their occurrence (Barondes, 1993). For other disorders, a psychological or sociocultural cause may be necessary, but again not sufficient.

As described in the section on modern neuroscience, the brain and behavior are inextricably linked by the plasticity of the nervous system. The brain is the organ of mental function; psychological phenomena have their origin in that complex organ. Psychological and sociocultural phenomena are represented in the brain through memories and learning, which involve structural changes in the neurons and

neuronal circuits. Yet neuroscience does not intend to reduce all phenomena to neurotransmission or to reinterpret them in a new language of synapses, receptors, and circuits. Psychological and sociocultural events and phenomena continue to have meaning for mental health and mental illness.

Much of the research that is presented in the remainder of this report draws on theories and investigations that predate the more modern view of integrative neuroscience. It is still meaningful, however, to speak of the interaction of biological and psychological and sociocultural factors in health and illness. That is where the overview of etiology begins—with the biopsychosocial model of disease, followed by an explanation of important terms used in the study of etiology. Then, against the backdrop of the introductory section on brain and behavior, the following sections address biological and psychosocial influences on mental health and mental illness, a separation that reflects the distinctive research perspectives of past decades. The overview of etiology draws to a close with a discussion of the convergence of biological and psychosocial approaches in the study of mental health and mental illness.

Biopsychosocial Model of Disease

The modern view that many factors interact to produce disease may be attributed to the seminal work of George L. Engel, who in 1977 put forward the *Biopsychosocial Model of Disease* (Engel, 1977). Engel's model is a framework, rather than a set of detailed hypotheses, for understanding health and disease. To many scientists, the model lacks sufficient specificity to make predictions about the given cause or causes of any one disorder. Scientists want to find out what *specifically* is the contribution of different factors (e.g., genes, parenting, culture, stressful events) and *how* they operate. But the purpose of the biopsychosocial model is to take a broad view, to assert that simply looking at biological factors alone—which had been the prevailing view of disease at the time Engel was writing—is not sufficient to explain health and illness.

According to Engel's model, biopsychosocial factors are involved in the causes, manifestation, course, and outcome of health and disease, including mental disorders. The model certainly fits with common experience. Few people with a condition such as heart disease or diabetes, for instance, would dispute the role of stress in aggravating their condition. Research bears this out and reveals many other relationships between stress and disease (Cohen & Herbert, 1996; Baum & Posluszny, 1999).

One single factor in isolation—biological, psychological, or social—may weigh heavily or hardly at all, depending on the behavioral trait or mental disorder. That is, the relative importance or role of any one factor in causation often varies. For example, a personality trait like extroversion is linked strongly to genetic factors, according to identical twin studies (Plomin et al., 1994). Similarly, schizophrenia is linked strongly to genetic factors, also according to twin studies (see Chapter 4). But this does not mean that genetic factors completely preordain or fix the nature of the disorder and that psychological and social factors are unimportant. These social factors modify expression and outcome of disorders. Likewise, some mental disorders, such as post-traumatic stress disorder (PTSD), are clearly caused by exposure to an extremely stressful event, such as rape, combat, natural disaster, or concentration camp (Yehuda, 1999). Yet not everyone develops PTSD after such exposure. On average,

about 9 percent do (Breslau et al., 1998), but estimates are higher for particular types of trauma. For women who are victims of crime, one study found the prevalence of PTSD in a representative sample of women to be 26 percent (Resnick et al., 1993). The likelihood of developing PTSD is related to pretrauma vulnerability (in the form of genetic, biological, and personality factors), magnitude of the stressful event, preparedness for the event, and the quality of care after the event (Shalev, 1996).

The relative roles of biological, psychological, or social factors also may vary across individuals and across stages of the life span. In some people, for example, depression arises primarily as a result of exposure to stressful life events, whereas in others the foremost cause of depression is genetic predisposition.

Understanding Correlation, Causation, and Consequences

Any discussion of the etiology of mental health and mental illness needs to distinguish three key terms: correlation, causation, and consequences. These terms are often confused. All too frequently a biological change in the brain (a lesion) is purported to be the "cause" of a mental disorder, based on finding an association between the lesion and a mental disorder. The fact is that any simple association—or correlation—cannot and does not, by itself, mean causation. The lesion could be a correlate, a cause of, or an effect of the mental disorder.

When researchers begin to tease apart etiology, they usually start by noticing correlations. A correlation is an association or linkage of two (or more) events. A correlation simply means that the events are linked in some way. Finding a correlation between stressful life events and depression would prompt more research on causation. Does stress cause depression? Does depression cause stress? Or are they both caused by an unidentified factor? These would be the questions guiding research. But, with correlational research, several steps are needed before causation can be established.

If a correlational study shows that a stressful event is associated with an increased probability for depression and that the stress usually precedes depression's onset, then stress is called a "risk factor" for depression.⁵ Risk factors are biological, psychological, or sociocultural variables that increase the probability for developing a disorder and antedate its onset (Garmezy, 1983; Werner & Smith, 1992; Institute of Medicine [IOM], 1994a). For each mental disorder, there are likely to be multiple risk factors, which are woven together in a complex chain of causation (IOM, 1994a). Some risk factors may carry more weight than others, and the interaction of risk factors may be additive or synergistic.

Establishing causation of mental health and mental illness is extremely difficult, as explained in Chapter 1. Studies in the form of randomized, controlled experiments provide the strongest evidence of causation. The problem is that experimental research in humans may be logistically, ethically, or financially impossible. Correlational research in humans has thus provided much of what is known about the etiology of mental disorders. Yet correlational research is not as strong as experimental research in permitting inferences about causality. The establishment of a cause and effect relationship requires multiple studies and requires judgment about the weight of *all* the evidence. Multiple correlational studies can be used to support causality, when, for example, evaluating the effectiveness of clinical treatments

(Chambless et al., 1996). But, when studying etiology, correlational studies are, if possible, best combined with evidence of biological plausibility (IOM, 1994b).⁶ This means that correlational findings should fit with biological, chemical, and physical findings about mechanisms of action relating to cause and effect.

Biological plausibility is often established in animal models of disease. That is why researchers seek animal models in which to study causation. In mental health research, there are some animal models—such as for anxiety and hyperactivity—but a major problem is the difficulty of finding animal models that simulate what is often uniquely human functioning. The search for animal models, however, is imperative.

Consequences are defined as the later outcomes of a disorder. For example, the most serious consequence of depression in older people is increased mortality from either suicide or medical illness (Frasure-Smith et al., 1993, 1995; Conwell, 1996; Penninx et al., 1998). The basis for this relationship is not fully known. The relationship between depression and suicide in adolescents is presented in Chapter 3.

Putting this all together, the biopsychosocial model holds that biological, psychological, or social factors may be causes, correlates, and/or consequences in relation to mental health and mental illness. A stressful life event, such as receiving the news of a diagnosis of cancer, offers a graphic example of a psychological event that causes immediate biological changes and later has psychological, biological, and social consequences. When a patient receives news of the cancer diagnosis, the brain's sensory cortex simultaneously registers the information (a correlate) and sets in motion biological changes that cause the heart to pound faster. The patient may experience an almost immediate fear of death that may later escalate to anxiety or depression. This certainly has been established for breast cancer patients (Farragher, 1998). Anxiety and depression are, in this case, *consequences* of the cancer diagnosis,⁷ although the exact mechanisms are not understood. Being anxious or depressed may prompt further changes in behavior, such as social withdrawal. So there may be social consequences to the diagnosis as well. This example is designed to lay out some of the complexity of the biopsychosocial model applied to mental health and mental illness.

Biological Influences on Mental Health and Mental Illness

There are far-reaching biological and physical influences on mental health and mental illness. The major categories are genes, infections, physical trauma, nutrition, hormones, and toxins (e.g., lead). Examples have been noted throughout Chapter 1 and earlier in this chapter. This section focuses on the first two categories—genes and infections—for these are among the most exciting and intensive areas of research relating to biological influences on mental health and mental illness.

The Genetics of Behavior and Mental Illness

That genes influence behavior, normal and abnormal, has long been established (Plomin et al., 1997). Genes influence behavior across the animal spectrum, from the lowly fruitfly all the way to humans. Sorting out which genes are involved and determining how they influence behavior present the greatest challenge. Research suggests that many mental disorders arise in part from defects not in single genes, but in *multiple* genes. However, none of the genes has yet been pinpointed for common mental disorders (National Institute of Mental Health [NIMH], 1998).

The human genome contains approximately 80,000 genes that occupy approximately 5 percent of the DNA sequences of the human genome. By the spring of 2000, the human genome project will have provided an initial rough draft version of the entire sequence of the human genome, and in the ensuing years, gaps in the sequence will be closed, errors will be corrected, and the precise boundaries of genes will be identified.

In parallel, clinical medicine is studying the aggregation of human disease in families. This effort includes the study of mental illness, most notably schizophrenia, bipolar disorder (manic depressive illness), early onset depression, autism, attention-deficit/hyperactivity disorder, anorexia nervosa, panic disorder, and a number of other mental disorders (NIMH, 1998). From studying how these disorders run in families, and from initial molecular analyses of the genomes of these families, we have learned that heredity—that is, genes—plays a role in the transmission of vulnerability of all the aforementioned disorders from generation to generation.

But we have also learned that the transmission of risk is not simple. Certain human diseases such as Huntington's disease and cystic fibrosis result from the transmission of a mutation—that is, a deleteriously altered gene sequence—at one location in the human genome. In these diseases, a single mutation has everything to say about whether one will get the illness. The transmission of a trait due to a single gene in the human genome is called Mendelian transmission, after the Austrian monk, Gregor Mendel, who was the first to develop principles of modern genetics and who studied traits due to single genes. When a single gene determines the presence or absence of a disease or other trait, genes are rather easy to discover on the basis of modern methods. Indeed, for almost all Mendelian disorders across medicine that affect more than a few people, the genes already have been identified.

In contrast to Mendelian disorders, to our knowledge, all mental illnesses and all normal variants of behavior are genetically complex. What this means is that no single gene or even a combination of genes dictates whether someone will have an illness or a particular behavioral trait. Rather, mental illness appears to result from the interaction of multiple genes that confer risk, and this risk is converted into illness by the interaction of genes with environmental factors. The implications for science are, first, that no gene is equivalent to fate for mental illness. This gives us hope that modifiable environmental risk factors can eventually be identified and become targets for prevention efforts. In addition, we recognize that genes, while significant in their aggregate contribution to risk, may each contribute only a small increment, and, therefore, will be difficult to discover. As a result, however, of the Human Genome Project, we will know the sequence of each human gene and the common variants for each gene throughout the human race. With this information, combined with modern technologies, we will in the coming years identify genes that confer risk of specific mental illnesses.

This information will be of the highest importance for several reasons. First, genes are the blueprints of cells. The products of genes, proteins, work together in pathways or in building cellular structures, so that finding variants within genes will suggest pathways that can be targets of opportunity for the development of new therapeutic interventions. Genes will also be important clues to what goes wrong in the brain when a disease occurs. For example, once we know that a certain gene is involved in risk of a particular mental illness such as schizophrenia or autism, we can ask at what time during the development of the brain that particular gene is active

and in which cells and circuits the gene is expressed. This will give us clues to critical times for intervention in a disease process and information about what it is that goes wrong. Finally, genes will provide tools for those scientists who are searching for environmental risk factors. Information from genetics will tell us at what age environmental cofactors in risk must be active, and genes will help us identify homogeneous populations for studies of treatment and of prevention.

Heritability refers to how much genetics contributes to the variation of a disease or trait in a population at a given point in time (Plomin et al., 1997). Once a disorder is established as running in families, the next step is to determine its heritability (see below), then its mode of transmission, and, lastly, its location through genetic mapping (Lombroso et al., 1994).

One powerful method for estimating heritability is through twin studies.⁸ Twin studies often compare the frequency with which identical versus fraternal twins display a disorder. Since identical twins are from the same fertilized egg, they share the exact genetic inheritance. Fraternal twins are from separate eggs and thereby share only 50 percent of their genetic inheritance. If a disorder is heritable, identical twins should have a higher rate of concordance—the expression of the trait by *both* members of a twin pair—than fraternal twins. Such studies, however, do not furnish information about *which* or *how many* genes are involved. They just can be used to estimate heritability. For example, the heritability of bipolar disorder, according to the most rigorous twin study, is about 59 percent, although other estimates vary (NIMH, 1998). The heritability of schizophrenia is estimated, on the basis of twin studies, at a somewhat higher level (NIMH, 1998).

Even with a high level of heritability, however, it is essential to point out that environmental factors (e.g., psychosocial environment, nutrition, health care access) can play a significant role in the severity and course of a disorder.

Another point is that environmental factors may even protect against the disorder developing in the first place. Even with the relatively high heritability of schizophrenia, the median concordance rate among identical twins is 46 percent⁹ (NIMH, 1998), meaning that in over *half* of the cases, the second twin does not manifest schizophrenia even though he or she has the same genes as the affected twin. This implies that environmental factors exert a significant role in the onset of schizophrenia.

Infectious Influences

It has been known since the early part of the 20th century that infectious agents can penetrate into the brain where they can cause mental disorders. A highly common mental disorder of unknown etiology at the turn of the century, termed "general paresis," turned out to be a late manifestation of syphilis. The sexually transmitted infectious agent—*Treponema pallidum*—first caused symptoms in reproductive organs and then, sometimes years later, migrated to the brain where it led to neurosyphilis. Neurosyphilis was manifest by neurological deterioration (including psychosis), paralysis, and later death. With the wide availability of penicillin after World War II, neurosyphilis was virtually eliminated (Barondes, 1993).

Neurosyphilis may be thought of as a disease of the past (at least in the developed world), but dementia associated with infection by the human immunodeficiency virus

(HIV) is certainly not. HIV-associated dementia continues to encumber HIV-infected individuals worldwide. HIV infection penetrates into the brain, producing a range of progressive cognitive and behavioral impairments. Early symptoms include impaired memory and concentration, psychomotor slowing, and apathy. Later symptoms, usually appearing years after infection, include global impairments marked by mutism, incontinence, and paraplegia (Navia et al., 1986). The prevalence of HIV-associated dementia varies, with estimates ranging from 15 percent to 44 percent of patients with HIV infection (Grant et al., 1987; McArthur et al., 1993). The high end of this estimate includes patients with subtle neuropsychological abnormalities. What is remarkable about HIV-associated dementia is that it appears to be caused not by *direct* infection of neurons, but by infection of immune cells known as macrophages that enter the brain from the blood. The macrophages *indirectly* cause dysfunction and death in nearby neurons by releasing soluble toxins (Epstein & Gendelman, 1993).

Besides HIV-associated dementia and neurosyphilis, other mental disorders are caused by infectious agents. They include herpes simplex encephalitis, measles encephalomyelitis, rabies encephalitis, chronic meningitis, and subacute sclerosing panencephalitis (Kaplan & Sadock, 1998). More recently, research has uncovered an infectious etiology to one form of obsessive-compulsive disorder, as explained below.

PANDAS

In the late 1980s, it was discovered that some children with obsessive-compulsive disorder (OCD) experienced a sudden onset of symptoms soon after a streptococcal pharyngitis (Garvey et al., 1998). The symptoms were classic for OCD—concerns about contamination, spitting compulsions, and extremely excessive hoarding—but the abrupt onset was unusual. Further study of these children led to the identification of a new classification of OCD called PANDAS. This acronym stands for pediatric autoimmune neuropsychiatric disorders associated with streptococcal infection. PANDAS are distinct from classic cases of OCD because of their episodic clinical course marked by sudden symptom exacerbation linked to streptococcal infection, among other unique features. The exacerbation of symptoms is correlated with a rise in levels of antibodies that the child produces to fight the strep infection. Consequently, researchers proposed that PANDAS are caused by antibodies against the strep infection that also manage to attack the basal ganglia region of the child's brain (Garvey et al., 1998). In other words, the strep infection triggers the child's immune system to develop antibodies, which, in turn, may attack the child's brain, leading to obsessive and compulsive behaviors. Under this proposal, the strep infection does not directly induce the condition; rather, it may do so *indirectly* by triggering antibody formation. How the antibodies are so damaging to a discrete region of the child's brain and how this attack ignites OCD-like symptoms are two of the fundamental questions guiding research.

Psychosocial Influences on Mental Health and Mental Illness

This chapter thus far has highlighted some of the psychosocial influences on mental health and mental illness. Stressful life events, affect (mood and level of arousal), personality, and gender are prominent psychological influences. Social influences include parents, socioeconomic status, racial, cultural, and religious background, and interpersonal relationships. These psychosocial influences, taken individually or together, are integrated into many chapters of this report in discussions of

epidemiology, etiology, risk factors, barriers to treatment, and facilitators to recovery.

Since these psychosocial influences are familiar to the general reader, detailed description of each is beyond the scope of this section (with the exception of cultural influences, which are discussed in the Overview of Cultural Diversity and Mental Health Services section). Instead, this section summarizes the sweeping theories of individual behavior and personality that inspired a vast body of psychosocial research: psychodynamic theories, behaviorism, and social learning theories. The therapeutic strategies that arose from these theories, and modifications necessary to make them relevant to the changing demography of the U.S. population, are discussed in a later section, Overview of Treatment.

Psychodynamic Theories

Psychodynamic theories of personality assert that behavior is the product of underlying conflicts over which people often have scant awareness. Sigmund Freud (1856–1939) was the towering proponent of psychoanalytic theory, the first of the 20th-century psychodynamic theories. Many of Freud's followers pioneered their own psychodynamic theories, but this section covers only psychoanalytic theory. A brief discussion of Freud's work contributes to a historical perspective of mental health theory and treatment approaches.

Freud's theory of psychoanalysis holds two major assumptions: (1) that much of mental life is unconscious (i.e., outside awareness), and (2) that past experiences, especially in early childhood, shape how a person feels and behaves throughout life (Brenner, 1978).

Freud's structural model of personality divides the personality into three parts—the id, the ego, and the superego. The id is the unconscious part that is the cauldron of raw drives, such as for sex or aggression. The ego, which has conscious and unconscious elements, is the rational and reasonable part of personality. Its role is to maintain contact with the outside world in order to help keep the individual in touch with society. As such, the ego mediates between the conflicting tendencies of the id and the superego. The latter is a person's conscience that develops early in life and is learned from parents, teachers, and others. Like the ego, the superego has conscious and unconscious elements (Brenner, 1978).

When all three parts of the personality are in dynamic equilibrium, the individual is thought to be mentally healthy. However, according to psychoanalytic theory, if the ego is unable to mediate between the id and the superego, an imbalance would occur in the form of psychological distress and symptoms of mental disorders.

Psychoanalytic theory views symptoms as important only in terms of expression of underlying conflicts between the parts of personality. The theory holds that the conflicts must be understood by the individual with the aid of the psychoanalyst who would help the person unearth the secrets of the unconscious. This was the basis for psychoanalysis as a form of treatment, as explained later in this chapter.

Behaviorism and Social Learning Theory

Behaviorism (also called learning theory) posits that personality is the sum of an individual's observable responses to the outside world (Feldman, 1997). As charted

by J. B. Watson and B. F. Skinner in the early part of the 20th century, behaviorism stands at loggerheads with psychodynamic theories, which strive to understand underlying conflicts. Behaviorism rejects the existence of underlying conflicts and an unconscious. Rather, it focuses on observable, overt behaviors that are learned from the environment (Kazdin, 1996, 1997). Its application to treatment of mental problems, which is discussed later, is known as behavior modification.

Learning is seen as behavior change molded by experience. Learning is accomplished largely through either classical or operant conditioning. Classical conditioning is grounded in the research of Ivan Pavlov, a Russian physiologist. It explains why some people react to formerly *neutral* stimuli in their environment, stimuli that previously would not have elicited a reaction. Pavlov's dogs, for example, learned to salivate merely at the sound of the bell, without any food in sight. Originally, the sound of the bell would not have elicited salvation. But by repeatedly pairing the sight of the food (which elicits salvation on its own) with the sound of the bell, Pavlov taught the dogs to salivate just to the sound of the bell by itself.

Operant conditioning, a process described and coined by B. F. Skinner, is a form of learning in which a voluntary response is strengthened or attenuated, depending on its association with positive or negative consequences (Feldman, 1997). The strengthening of responses occurs by positive reinforcement, such as food, pleasurable activities, and attention from others. The attenuation or discontinuation of responses occurs by negative reinforcement in the form of removal of a pleasurable stimulus. Thus, human behavior is shaped in a trial and error way through positive and negative reinforcement, without any reference to inner conflicts or perceptions. What goes on inside the individual is irrelevant, for humans are equated with "black boxes." Mental disorders represented maladaptive behaviors that were learned. They could be unlearned through behavior modification (behavior therapy) (Kazdin, 1996, 1997).

The movement beyond behaviorism was spearheaded by Albert Bandura (1969, 1977), the originator of social learning theory (also known as social cognitive theory). Social learning theory has its roots in behaviorism, but it departs in a significant way. While acknowledging classical and operant conditioning, social learning theory places far greater emphasis on a different type of learning, particularly observational learning. Observational learning occurs through selectively observing the behavior of another person, a model. When the behavior of the model is rewarded, children are more likely to imitate the behavior. For example, a child who observes another child receiving candy for a particular behavior is more likely to carry out similar behaviors. Social learning theory asserts that people's cognitions—their views, perceptions, and expectations toward their environment—affect what they learn. Rather than being passively conditioned by the environment, as behaviorism proposed, humans take a more active role in deciding what to learn as a result of cognitive processing. Social learning theory gave rise to cognitive-behavioral therapy, a mode of treatment described later in this chapter and throughout this report.

The Integrative Science of Mental Illness and Health

Progress in understanding depression and schizophrenia offers exciting examples of how findings from different disciplines of the mental health field have many common threads (Andreasen, 1997). Despite the differences in terminology and methodology,

the results from different disciplines have converged to paint a vivid picture of the nature of the fundamental defects and the regions of the brain that underlie these defects. Even in the case of depression and schizophrenia, there is much to be uncovered about etiology, yet the mental health field is seen as poised "to use the power of multiple disciplines." The disciplines are urged to link together the study of the mind and the brain in the search for understanding mental health and mental illness (Andreasen, 1997).

This linkage already has been cemented between cognitive psychology, behavioral neurology, computer science, and neuroscience. These disciplines have knit together the field of "cognitive neuroscience" (Kosslyn & Shin, 1992). This new and joint discipline has carved out its own professional society, journals (Waldrop, 1993), and textbooks (Gazzaniga et al., 1998). There is movement toward integration of other disciplines within the field. To promote linkages between psychiatry and the neurosciences, neuroscientist Eric R. Kandel has furnished a novel approach. His essay, "A New Intellectual Framework for Psychiatry," supplies a set of biological principles to forge a rapprochement—conceptual as well as practical—between the two disciplines (Kandel, 1998). Integrated approaches are seen as vital to tackle the monumental complexity of mental function.

⁵ Chapter 4 contains a fuller discussion of the relationship between stress and depression. In common parlance, stress refers either to the stressful event or to the individual's response to the event. However, mental health professionals distinguish the two by referring to the external events as the "stressor" (or stressful life event) and to the individual's response as the "stress response."

⁶ Other types of information used to establish cause and effect relationships are the strength and consistency of the association, time sequence information, dose-response relationships, and disappearance of the effect when the cause is removed.

⁷ Anxiety and depression may in some cases be caused by hormonal changes related to the tumor itself.

⁸ Establishing that a disorder runs in families could suggest environmental and/or genetic influences because families share genes and environment. Comparing identical versus fraternal twins assumes that their shared environments are about equal, thereby providing insight about genetic influences. Such comparisons are further enhanced by studies of twins (identical vs. fraternal) separated at birth and adopted by different families.

⁹ The median concordance rate for identical twins is only 14 percent (NIMH, 1998).

Overview of Development, Temperament, and Risk Factors

How we come to be the way we are is through the process of development. Generally defined as the lifelong process of growth, maturation, and change,

development is the product of the elaborate interplay of biological, psychological, and social influences. By studying development, researchers hope to uncover the origins of both mental health and mental illness.

This section elaborates and extends concepts introduced above regarding the fundamental workings of the brain at different developmental stages. It then proceeds to explain several seminal theories of development pioneered by Jean Piaget, Erik Erikson, and John Bowlby. Their theories cover cognitive development, personality development, and social development, respectively, although there is some overlap. Their major works, published in the 1950s and 1960s, were pivotal for the psychological and social sciences, galvanizing a huge body of theoretical and empirical research. However, with the advancements of science and the diversity of the population, these models may not apply to all groups without some adaptation for cultural context. The section concludes with a reminder that the brain is the "great synthesizer" of the many biological, psychological, and sociocultural phenomena that make us who we are.

Physical Development

Physical development of the nervous system provides the architecture for mental function (cognition, mood, and intentional behavior). As can be inferred from the discussion of brain complexity in the introductory section, nervous system development is arguably one of the most monumentally complicated developmental achievements. One hundred billion neurons must form elaborate and precise arrays of interconnections. Neurons begin the developmental process as undifferentiated cells, cells so seemingly anonymous that they are almost indistinguishable from other cells in an embryo. On the basis of genetic and epigenetic¹⁰ influences, the cells must first specialize, or differentiate, into neurons, migrate to their final position, and then send their growing axons (the branch of a neuron that transmits impulses) to project over long distances in order to form synapses with distant target cells (Kandel et al., 1995).

Most neurobiologists are astounded at the level of precision that neurons achieve in their interconnections. The process of nervous system development has been studied at increasingly complex levels—molecular, cellular, tissue, and behavioral levels. Yet, while researchers have charted many of the behavioral milestones of development because they are so amenable to observation and analysis, far less is known about molecular, cellular, and tissue interactions that underlie them.

Four overarching findings or organizing principles have been gleaned from decades of neuroscience research. The first finding is that the formation of connections between neurons and their target cells depends on axons growing along anatomical pathways that are studded with signaling molecules, much like landing lights illuminate the runway for a descending plane. The second finding is that an axon's reaching the vicinity of, and locating, its correct target cell depends on diffusible chemical signals being transmitted from the target cell. The third finding is that if an axon does not reach its correct target, it is likely to die. This phenomenon, known as cell death, or apoptosis, is so common that it affects up to half of all developing neurons. The brain overproduces the number of cells it needs, from which it pares down to only the correct connections (Kandel et al., 1995). Finally, neuron *activity* is essential to strengthening the connections that are formed. In other words, stimulation from the environment—which is translated into neuron activity—is vital

for the forging of normal neural development (Shatz, 1993; Kandel, 1995). This is a fundamental principle that is revisited later in this section. This principle helps to explain why, for example, babies who are deprived of a stimulating environment during their first year sometimes suffer irreparable developmental effects.

Behavior at birth consists of a repertoire of simple reflexes, that is, inborn neurological reactions that are involuntary in nature. Two examples are the sucking reflex and the rooting reflex,¹¹ both of which are designed to ensure food intake. Over time, the infant displays an expanded repertoire of fine and gross motor skills (e.g., crawling, walking) that begin to unfold in the first few months and year of life. These include the cherished ability to smile, which helps to solidify a social bond with parents and caregivers. What begins as a child's biological survival need for food—evidenced by such behaviors as rooting and sucking—can turn into a social, interpersonal experience with the caregiver, as in the smile of an infant at the sight of a nurturing parent. These burgeoning motor capabilities are the forerunners of more complex behavioral and mental functions, but the actual relationships between early and later abilities, and their molecular and cellular basis, are understood only in the most rudimentary terms.

Theories of Psychological Development

Theories of human development are grounded in the developmental perspective. The developmental perspective takes into account the biological, social, and psychological environment; their interaction; and their combined effect upon the individual throughout the life span. Developmentalist L. Breger (1974) proposes that the developmental perspective incorporates three key precepts:

- Behavioral maturation proceeds from the simple to the complex;
- Future behaviors, whether temporally near or distant, are a product of their antecedents (prior responses to the developmental environment); and
- The human response to a particular event or experience often depends on the developmental stage at which the experience occurs.

Each of these precepts is thought to apply to neurobiological development, as well as behavioral/psychosocial development. Moreover, each has implications for whether an individual experiences either healthful or unhealthful development that may lead to a mental disorder.

The three precepts are at the heart of each of the three major mainstream theories of developmental psychology that have guided research and increased our understanding of both normal and abnormal human development across the life span. The following paragraphs offer brief sketches of the developmental theories of Jean Piaget, Erik Erikson, and John Bowlby; again, these sketches are provided to afford the reader an historical perspective of research on psychological development.

Piaget: Cognitive Developmental Theory

Jean Piaget formulated one of the most influential theories of cognitive development (Inhelder & Piaget, 1958). Its focus was on cognitive (intellectual) development, that is, the processes by which children come to know and understand the world. Other aspects of human growth, both physical and emotional, are beyond the scope of his

theory. Piaget posited that each step of cognitive development proceeds from the previous step in a fixed pattern, beginning at birth and ending in the teen years.

Piaget had a seminal influence on the discipline of cognitive psychology. Although empirical research has called into question some of the specifics of his theories, the broad outlines remain widely accepted.

Erik Erikson: Psychoanalytic Developmental Theory

The psychoanalytic theory of development is best exemplified in the work of Erik Erikson, a psychoanalyst who expanded upon Freud's original theories of psychosexual development. One of Erikson's pioneering contributions was that development unfolded throughout the life span, a view that has become widely embraced.

Freud postulated that development proceeded through a series of stages in which children seek pleasure or gratification from a particular body part (i.e., the oral, anal, and phallic stage). In contrast, Erikson's theories of child development focus on the interrelationship between a developing child's internal psychosexual development and his or her more external emotional development, emphasizing the interpersonal relationships that arise between the child and parents (Erikson, 1950).

Erikson conceived of the life course, from birth to old age, as a series of eight epigenetic stages that, as other developmental theories, proceed in a stepwise fashion, the next dependent upon how well the previous has been mastered: trust versus mistrust; autonomy versus shame and doubt; initiative versus guilt; industry versus inferiority; identity versus role diffusion; intimacy versus isolation; generativity versus stagnation; ego integrity versus despair.

Erikson portrayed each stage as a crisis or conflict that needed resolution, either at the time or at a subsequent stage. Each successive stage presents its own challenges but, at the same time, offers the opportunity for correction of unresolved challenges of previous stages. At each stage the tension was between the psychosocial and psychosexual—the outward-looking versus inward-looking perspectives. Psychopathology, in the form of a mental disorder, would arise if a stage was ultimately not mastered successfully.

Over the years, Erikson's theory has had great heuristic value to guide theorists and practitioners in organizing their approach to mental health and mental illness. However, his theory does not readily lend itself to empirical scrutiny. His theory also has been criticized as reflecting the concerns of male European culture (where Erikson was born and trained before moving to the United States) rather than those of women and other cultures. The need for cultural sensitivity and competence is discussed later in this chapter.

John Bowlby: Attachment Theory of Development

Fifty years ago, a new conceptualization of the psychoanalytic approach to development came into the lexicon of human development theory. John Bowlby's reinterpretation of Freudian development is grounded in both Darwinian evolutionary theory and animal ethology. The previous work of Konrad Lorenz and others, who explored the relationship between other animals and their caregivers, determined

that the bonds of infant care and the attachment of young to their caregivers are seminal in the drive for survival. Similarly, Bowlby theorized that for humans, attachment to a caregiver had a biological basis in the need for survival (Bowlby, 1951). Moreover, he suggested that this attachment drive exists alongside the drive for nutrition and the sex drive, yet distinct and separate from them. Attachment is seen as the anchor that enables the developing child to explore the world.

With the comfort and security of a stable and routine attachment to the mother—or other primary caregiver—a child is able to organize other elements of development in a coherent way. In contrast, instability in the caregiving relationship—whether physical distance, erratic patterns of parental behavior, or even physical or emotional abuse—may interfere with the sense of trust and security, potentially giving rise to anxiety and psychological problems later in childhood or even decades later in life.

Nature and Nurture: The Ultimate Synthesis

For over a century, an intense debate among developmentalists and other scientists has pitted nature (genetic inheritance) against nurture (environment) as the engine of human development and behavior. Francis Galton, a 19th-century geneticist and cousin of Charles Darwin, declared that “there is no escape from the conclusion that nature prevails enormously over nurture” (cited in Plomin, 1996). As the debate raged, either nature or nurture gained ascendancy. During the 1940s and 1950s, for example, behaviorism held sway over American psychology with its argument that nurture was preeminent.

The pendulum now is coming to rest with the recognition that behavior is the product of both nature and nurture (Plomin, 1996). Each contributes to the development of mental health and mental illness. Nature and nurture are not necessarily independent forces but can interact with one another: nature can influence nurture, and nurture can influence nature (Plomin, 1996).

Studies comparing identical and fraternal twins have shed light on the contributions of nature and nurture. These studies show that for many behavioral traits, as well as mental disorders, there is a noticeable heritable component (see earlier discussion of heritability). Yet even with the most highly heritable traits or conditions, identical twins who share the same genetic endowment display marked differences. Identical twins, for example, are concordant for schizophrenia in 46 percent of pairs (NIMH, 1998), meaning that more than 50 percent of pairs are *not* concordant. Something yet unknown about the environment protects against the development of schizophrenia in genetically identical individuals (Plomin, 1996).

How do nature and nurture interact? This question cannot be directly answered by twin studies. Animal models have proven to be fertile ground for study of the mechanisms—at the molecular and cellular level—by which nature and nurture interact. As reviewed earlier, research in different animal models has established that the environment can alter the *structure* and *function* of the central nervous system (Baily & Kandel, 1993). This holds true not only during early development, but also into adulthood. Nurture influences nature, right down to detectable changes in the brain.

During development of the nervous system, each neuron forms myriad intricate synaptic connections with other neurons, the outcome of the interaction of genes and

the environment described above. In this case, the environment is a very general term—it denotes the local extracellular environment surrounding the growing neuron, as well as what we traditionally think of as the environment (sensory environment, psychosocial environment, diet, etc.). When a neuron forms a synapse with its target cell, the pattern of activity, usually furnished by external environmental stimulation, strengthens or weakens the developing synapse. Only strengthened synaptic connections survive early development to form enduring connections, while weakened synaptic connections are eliminated (Shatz, 1993; Kandel et al., 1995). For example, kittens deprived of visual experience early in life sustain permanent disruption to synapses in parts of their visual cortex (Hubel & Wiesel, 1970).

Later in the course of development, established patterns of connections still can be altered by the environment—through learning. Studies in a variety of animal models have found that certain forms of learning lead to changes in the structure and function of neurons. With long-term memory—the long-term storage of learned information—these changes take the form of an enhanced number of synaptic connections and increased gene expression (Kandel et al., 1995). Increased gene expression appears to be for synthesis of new proteins needed for the structural changes occurring at the synapse (Bailey & Kandel, 1993).

Researchers continue to probe for changes in the brain associated with mental disorders. They have found, for instance, that repeated stress from the environment affects the hippocampus, an area of the brain located deep within the cerebral hemispheres. Research in animals has shown that repeated stress triggers atrophy of dendrites of certain types of neurons in a segment of the hippocampus (Sapolsky, 1996; McEwen, 1998). Similarly, imaging studies in humans suggest that stress-related disorders (e.g., post-traumatic stress disorder) induce possibly irreversible atrophy of the hippocampus (McEwen & Magarinos, 1997). Anxiety disorders also alter neuroendocrine systems (Sullivan et al., 1998). These are some of the tantalizing ways in which nurture influences nature.

The mental health field is far from a complete understanding of the biological, psychological, and sociocultural bases of development, but development clearly involves interplay among these influences. Understanding the process of development requires knowledge, ranging from the most fundamental level—that of gene expression and interactions between molecules and cells—all the way up to the highest levels of cognition, memory, emotion, and language. The challenge requires integration of concepts from many different disciplines. A fuller understanding of development is not only important in its own right, but it is expected to pave the way for our ultimate understanding of mental health and mental illness and how different factors shape their expression at different stages of the life span.

¹⁰ Epigenetic influences are those that arise from outside the genes and lead to emergent, as opposed to predetermined, properties.

¹¹ Newborns turn their head towards things—typically the breast—that touch their cheek.

Overview of Prevention

The field of public health has long recognized the imperative of prevention to contain a major health problem (IOM, 1988). The principles of prevention were first applied to infectious diseases in the form of mass vaccination, water safety, and other forms of public hygiene. As successes amassed, prevention came to be applied to other areas of health, including chronic diseases (IOM, 1994a). A landmark report published by the Institute of Medicine in 1994 extended the concept of prevention to mental disorders (IOM, 1994a). *Reducing Risks for Mental Disorders* evaluated the body of research on the prevention of mental disorders, offered new definitions of prevention, and provided recommendations on Federal policies and programs, among other goals.

Preventing an illness from occurring is inherently better than having to treat the illness after its onset. In many areas of health, increased understanding of etiology and the role of risk and protective factors in the onset of health problems has propelled prevention. In the mental health field, however, progress has been slow because of two fundamental and interrelated problems: for most major mental disorders, there is insufficient understanding about etiology and/or there is an inability to alter the *known* etiology of a particular disorder. While these have stymied the development of prevention interventions, some successful strategies have emerged in the absence of a full understanding of etiology.

Rigorous scientific trials have documented successful prevention programs in such areas as dysthymia and major depressive disorder (Munoz et al., 1987; Clarke et al., 1995), conduct problems (Berrento-Clement et al., 1984), and risky behaviors leading to HIV infection (Kalichman et al., in press) and low birthweight babies (Olds et al., 1986). Much progress also has been made to prevent the occurrence of lead poisoning, which, if unchecked, can lead to serious and persistent cognitive deficits in children (Centers for Disease Control and Prevention, 1991; Pirkle et al., 1994). Lastly, historical milestones in prevention of mental illness led to the successful eradication of neurosyphilis, pellagra, and measles encephalomyelitis (measles invasion of the brain) in the developed world.

Definitions of Prevention

The term "prevention" has different meanings to different people. It also has different meanings to different fields of health. The classic definitions used in public health distinguish between primary prevention, secondary prevention, and tertiary prevention (Commission on Chronic Illness, 1957). Primary prevention is the prevention of a disease before it occurs; secondary prevention is the prevention of recurrences or exacerbations of a disease that already has been diagnosed; and tertiary prevention is the reduction in the amount of disability caused by a disease to achieve the highest level of function.

The Institute of Medicine report on prevention identified problems in applying these definitions to the mental health field (IOM, 1994a). The problems stemmed mostly from the difficulty of diagnosing mental disorders and from shifts in the definitions of mental disorders over time (see Diagnosis of Mental Illness). Consequently, the Institute of Medicine redefined prevention for the mental health field in terms of three core activities: prevention, treatment, and maintenance (IOM, 1994a). Prevention, according to the IOM report, is similar to the classic concept of primary prevention from public health; it refers to interventions to ward off the initial onset of a mental disorder. Treatment refers to the identification of individuals with mental

disorders and the standard treatment for those disorders, which includes interventions to reduce the likelihood of future co-occurring disorders. And maintenance refers to interventions that are oriented to reduce relapse and recurrence and to provide rehabilitation. (Maintenance incorporates what the public health field traditionally defines as some forms of secondary and all forms of tertiary prevention.)

The Institute of Medicine's new definitions of prevention have been very important in conceptualizing the nature of prevention activities for mental disorders; however, the terms have not yet been universally adopted by mental health researchers. As a result, this report strives to use the terms employed by the researchers themselves. To avoid confusion, the report furnishes the relevant definition along with study descriptions.

When the term "prevention" is used in this report *without a qualifying term*, it refers to the prevention of the initial onset of a mental disorder or emotional or behavioral problem, including prevention of comorbidity. First onset corresponds to the initial point in time when an individual's mental health problems meet the full criteria for a diagnosis of a mental disorder.

Risk Factors and Protective Factors

The concepts of risk and protective factors, risk reduction, and enhancement of protective factors (also sometimes referred to as fostering resilience) are central to most empirically based prevention programs. Risk factors are those characteristics, variables, or hazards that, if present for a given individual, make it more likely that this individual, rather than someone selected at random from the general population, will develop a disorder (Garmezy, 1983; Werner & Smith, 1992; IOM, 1994a). To qualify as a risk factor the variable must antedate the onset of the disorder. Yet risk factors are not static. They can change in relation to a developmental phase or a new stressor in one's life, and they can reside within the individual, family, community, or institutions. Some risks such as gender and family history are fixed; that is, they are not malleable to change. Other risk factors such as lack of social support, inability to read, and exposure to bullying can be altered by strategic and potent interventions (Coie & Krehbiel, 1984; Silverman, 1988; Olweus, 1991; Kellam & Rebok, 1992). Current research is focusing on the interplay between biological risk factors and psychosocial risk factors and how they can be modified. As explained earlier, even with a highly heritable condition such as schizophrenia, concordance studies show that in over half of identical twins, the second twin does not have schizophrenia. This suggests the possibility of modifying the environment to eventually prevent the biological risk factor (i.e., the unidentified genes that contribute to schizophrenia) from being expressed.

Prevention not only focuses on the risks associated with a particular illness or problem but also on protective factors. Protective factors improve a person's response to some environmental hazard resulting in an adaptive outcome (Rutter, 1979). Such factors, which can reside with the individual or within the family or community, do not necessarily foster normal development in the absence of risk factors, but they may make an appreciable difference on the influence exerted by risk factors (IOM, 1994a). There is much to be learned in the mental health field about the role of protective factors across the life span and within families as well as individuals. The potential for altering these factors in intervention studies is

enormous. The construct of "resilience" is related to the concept of protective factors, but it focuses more on the ability of a single individual to withstand chronic stress or recover from traumatic life events. There are many different perceptions of what constitutes resilience or "competence," another related term. Despite the increasing popularity of these ideas, "virtually no intervention studies have been conducted that test the outcomes of resilience variables" (Grover, 1998).

Preventive researchers use risk status to identify populations for intervention, and then they target risk factors that are thought to be causal and malleable and target protective factors that are to be enhanced. If the interventions are successful, the amount of risk decreases, protective factors increase, and the likelihood of onset of the potential problem also decreases. The risks for onset of a disorder are likely to be somewhat different from the risks involved in relapse of a previously diagnosed condition. This is an important distinction because at-risk terminology is used throughout the mental health intervention spectrum. The optimal treatment protocol for an individual with a serious mental condition aims to reduce the length of time the disorder exists, halt a progression of severity, and halt the recurrence of the original disorder, or if not possible, to increase the length of time between episodes (IOM, 1994a). To do this requires an assessment of the individual's specific risks for recurrence.

Many mental health problems, especially in childhood, share some of the same risk factors for initial onset, so targeting those factors can result in positive outcomes in multiple areas. Risk factors that are common to many disorders include individual factors such as neurophysiological deficits, difficult temperament, chronic physical illness, and below-average intelligence; family factors such as severe marital discord, social disadvantage, overcrowding or large family size, paternal criminality, maternal mental disorder, and admission into foster care; and community factors such as living in an area with a high rate of disorganization and inadequate schools (IOM, 1994a). Also, some individual risk factors can lead to a state of vulnerability in which other risk factors may have more effect. For example, low birthweight is a general risk factor for multiple physical and mental outcomes; however, when it is combined with a high-risk social environment, it more consistently has poorer outcomes (McGauhey et al., 1991). The accumulation of risk factors usually increases the likelihood of onset of disorder, but the presence of protective factors can attenuate this to varying degrees.

The concept of accumulation of risks in pathways that accentuate other risks has led prevention researchers to the concept of "breaking the chain at its weakest links" (Robins, 1970; IOM, 1994a). In other words, some of the risks, even though they contribute significantly to onset, may be less malleable than others to intervention. The preventive strategy is to change the risks that are most easily and quickly amenable to intervention. For example, it may be easier to prevent a child from being disruptive and isolated from peers by altering his or her classroom environment and increasing academic achievement than it is to change the home environment where there is severe marital discord and substance abuse.

Because mental health is so intrinsically related to all other aspects of health, it is imperative when providing preventive interventions to consider the interactions of risk and protective factors, etiological links across domains, and multiple outcomes. For example, chronic illness, unemployment, substance abuse, and being the victim of violence can be risk factors or mediating variables for the onset of mental health

problems (Kaplan et al., 1987). Yet some of the same factors also can be related to the consequences of mental health problems (e.g., depression may lead to substance abuse, which in turn may lead to lung or liver cancer).

Overview of Treatment

Introduction to Range of Treatments

Mental disorders are treatable, contrary to what many think.¹² An armamentarium of efficacious treatments is available to ameliorate symptoms. In fact, for most mental disorders, there is generally not just one but a *range* of treatments of proven efficacy. Most treatments fall under two general categories, psychosocial and pharmacological.¹³ Moreover, the combination of the two—known as multimodal therapy—can sometimes be even more effective than each individually (see Chapter 3).

The evidence for treatment being more effective than placebo is overwhelming, as documented in the main chapters of this report (Chapters 3 through 5). The degree of effectiveness tends to vary, depending on the disorder and the target population (e.g., older adults with depression). What is optimal for one disorder and/or age group may not be optimal for another. Further, treatments generally need to be tailored to the client and to client preferences.

The inescapable point is that studies demonstrate conclusively that treatment is more effective than placebo. Placebo (an inactive form of treatment) in both pharmacological and psychotherapy studies has a powerful effect in its own right, as this section later explains. Placebo is more effective than no treatment. Therefore, to capitalize on the placebo response, people are encouraged to seek treatment, even if the treatment is not as optimal as that described in this report.

If treatment is so effective, then why are so few people receiving it? Studies reveal that less than one-third of adults with a diagnosable mental disorder, and even a smaller proportion of children, receive any mental health services in a given year. This section of the chapter strives to explain why by examining the types of barriers that prevent people from seeking help. But the chapter first covers some general points about psychological and pharmacological therapies. It also discusses why therapies that work so well in research settings do not work as well in practice.

Psychotherapy

Psychotherapy is a learning process in which mental health professionals seek to help individuals who have mental disorders and mental health problems. It is a process that is accomplished largely by the exchange of verbal communication, hence it often is referred to as "talk therapy." Many of the theories undergirding each orientation to psychotherapy were summarized earlier in this chapter.

Participants in psychotherapy can vary in age from the very young to the very old, and problems can vary from mental health problems to disabling and catastrophic

mental disorders. Although people often are seen individually, psychotherapy also can be done with couples, families, and groups. In each case, participants present their problems and then work with the psychotherapist to develop a more effective means of understanding and handling their problems. This report focuses on individual psychotherapy and also mentions couples therapy and various forms of family interventions, particularly psycho-educational approaches. Although not discussed in the report, group psychotherapy is effective for selected individuals with some mood disorders, anxiety disorders, schizophrenia, personality disorders, and for mental health problems seen in somatic illness (Yalom, 1995; Kanas, in press).

Estimates of the number of orientations to psychotherapy vary from a very small number to well over 400. The larger estimate generally refers to all the variations of the three major orientations, that is, psychodynamic, behavioral, and humanistic. Each orientation falls under the more general conceptual category of either action or reflection.

Psychodynamic orientations are the oldest. They place a premium on self-understanding, with the implicit (or sometimes explicit) assumption that increased self-understanding will produce salutary changes in the participant. Behavioral orientations are geared toward action, with a clear attempt to mobilize the resources of the patient in the direction of change, whether or not there is any understanding of the etiology of the problem. Humanistic orientations aim toward increased self-understanding, often in the direction of personal growth, but use treatment techniques that often are much more active than are likely to be employed by the psychodynamic clinician.

While the following paragraphs focus on psychodynamic, behavioral, and humanistic orientations, they also discuss interpersonal therapy and cognitive-behavioral therapy as outgrowths of psychodynamic and behavioral therapy, respectively. Psychodynamic, interpersonal, and cognitive-behavioral therapy are most commonly the focus of treatment research reported throughout this report.

Psychodynamic Therapy

The first major approach to psychotherapy was developed by Sigmund Freud and is called psychoanalysis (Horowitz, 1988). Since its origin more than a century ago, psychoanalysis has undergone many changes. Today, Freudian (or classical) psychoanalysis is still practiced, but other variations have been developed—ego psychology, object relations theory, interpersonal psychology, and self-psychology, each of which can be grouped under the general term “psychodynamic” (Horowitz, 1988). The psychodynamic therapies, even though they differ somewhat in theory and approach, all have some concepts in common. With each, the role of the past in shaping the present is emphasized, so it is important, in understanding behavior, to understand its origins and how people come to act and feel as they do. A second critical concept common to all psychodynamic approaches is the belief in the unconscious, so that there is much that influences our behavior of which we are not aware. This makes the process of understanding more difficult, as we often act for reasons that we cannot state, and these reasons often are linked to previous experiences. Thus, an important part of psychodynamic psychotherapy is to make the unconscious conscious or to help the patient understand the origin of actions that are troubling so that they can be corrected.

For some psychodynamic approaches, such as the classical Freudian approach, the focus is on the individual and the experiences the person had in the early years that give shape to current behavior, even beyond the awareness of the patient. For other, more contemporary approaches, such as *interpersonal therapy*, the focus is on the relationship between the person and others. First developed as a time-limited treatment for midlife depression, interpersonal therapy focuses on grief, role disputes, role transitions, and interpersonal deficits (Klerman et al., 1984). The goal of interpersonal therapy is to improve current interpersonal skills. The therapist takes an active role in teaching patients to evaluate their interactions with others and to become aware of self-isolation and interpersonal difficulties. The therapist also offers advice and helps the patient to make decisions.

Behavior Therapy

A second major approach to psychotherapy is known as behavior modification or behavior therapy (Kazdin, 1996, 1997). It focuses on current behavior rather than on early patterns of the patient. In its earlier form, behavior therapy dealt exclusively with what people did rather than what they thought or felt. The general principles of learning were applied to the learning of maladaptive as well as adaptive behaviors. Thus, if a person could be conditioned to act in a functional way, there was no reason why the same principles of conditioning could not be employed to help the person unlearn dysfunctional behavior and learn to replace it with more functional behavior. The role of the environment was very important for behavior therapists, because it provided the positive and negative reinforcements that sustained or eliminated various behaviors. Therefore, ways of shaping that environment to make it more responsive to the needs of the individual were important in behavior therapy.

More recently, there has been a significant addition to the interests and activities of behavior therapists. Although behavior continued to be important in relation to reinforcements, cognitions—what the person *thought* about, perceived, or interpreted what was transpiring—were also seen as important. This combined emphasis led to a therapeutic variant known as *cognitive-behavioral therapy*, an approach that incorporates cognition with behavior in understanding and altering the problems that patients present (Kazdin, 1996).

Cognitive-behavioral therapy draws on behaviorism as well as cognitive psychology, a field devoted to the scientific study of mental processes, such as perceiving, remembering, reasoning, decision making, and problem solving. The use of cognition in cognitive-behavioral therapy varies from attending to the role of the environment in providing a model for behavior, to the close study of irrational beliefs, to the importance of individual thought processes in constructing a vision of the surrounding world. In each case, it is critical to study what the individual in therapy thinks and does and less important to understand the past events that led to that pattern of thinking and doing. Cognitive-behavioral therapy strives to alter faulty cognitions and replace them with thoughts and self-statements that promote adaptive behavior (Beck et al., 1979). For instance, cognitive-behavioral therapy tries to replace self-defeatist expectations ("I can't do anything right") with positive expectations ("I can do this right"). Cognitive-behavioral therapy has gained such ascendancy as a means of integrating cognitive and behavioral views of human functioning that the field is more frequently referred to as cognitive-behavioral therapy rather than behavior therapy (Kazdin, 1996).

Humanistic Therapy

The third wave of psychotherapy is referred to variously as humanistic (Rogers, 1961), existential (Yalom, 1980), experiential, or Gestalt therapy. It owes its origins as a treatment to the client-centered therapy that was originated by Carl Rogers, and the theory can be traced to philosophical roots beginning with the 19th century philosopher, Soren Kierkegaard. The central focus of humanistic therapy is the immediate experience of the client. The emphasis is on the present and the potential for future development rather than on the past, and on immediate feelings rather than on thoughts or behaviors. It is rooted in the everyday subjective experience of the person seeking assistance and is much less concerned with mental illness than it is with human growth.

One critical aspect of humanistic treatment is the relationship that is forged between the therapist, who in some ways serves as a guide in an exploration of self-discovery, and the client, who is seeking greater knowledge of the self and an expansion of inherent human potential. The focus on the self and the search for self-awareness is akin to psychodynamic psychotherapy, while the emphasis on the present is more similar to behavior therapy.

Although it is possible to describe distinctive orientations to psychotherapy, as has been done above, most psychotherapists describe themselves as eclectic in their practice, rather than as adherents to any single approach to treatment. As a result, there is a growing development referred to as "psychotherapy integration" (Wolfe & Goldfried, 1988). It strives to capture what is best about each of the individual approaches. Psychotherapy integration includes various attempts to look beyond the confines of any single orientation but rather to see what can be learned from other perspectives. It is characterized by an openness to various ways of integrating diverse theories and techniques. Psychotherapy also should be modified to be culturally sensitive to the needs of racial and ethnic minorities (Acosta et al., 1982; Sue et al., 1994; Lopez, in press).

The scientific evidence on efficacy presented in this report, however, is focused primarily on specific, standardized forms of psychotherapy.

Pharmacological Therapies

The past decade has seen an outpouring of new drugs introduced for the treatment of mental disorders (Nemeroff, 1998). New medications for the treatment of depression and schizophrenia are among the achievements stoked by research advances in both neuroscience and molecular biology. Through the process known as rational drug design, researchers have become increasingly sophisticated at designing drugs by manipulating their chemical structures. Their goal is to create more effective therapeutic agents, with fewer side effects, exquisitely targeted to correct the biochemical alterations that accompany mental disorders.

The process was not always so rational. Many of the older pharmacotherapies (drug treatments) that had been introduced by 1960 had been discovered largely by accident. Researchers studying drugs for completely different purposes serendipitously found them to be useful for treating mental disorders (Barondes, 1993). Thanks to their willingness to follow up on unexpected leads, drugs such as chlorpromazine (for psychosis), lithium (for bipolar disorder), and imipramine (for

depression) became available. The advent of chlorpromazine in 1952 and other neuroleptic drugs was so revolutionary that it was one of the major historical forces behind the deinstitutionalization movement that is discussed later in this chapter.

The past generation of pharmacotherapies, once shown to be safe and effective, was introduced to the market generally before their mechanism of action was understood. Years of research after their introduction revealed how many of them work therapeutically. Knowledge about their actions has had two cardinal consequences: it helped probe the etiology of mental disorders, and it ushered in the next generation of pharmacotherapies that are more selective in their mechanism of action.

Mechanisms of Action

The mechanism of action refers to how a pharmacotherapy interacts with its target in the body to produce therapeutic effects. Pharmacotherapies that act in similar ways are grouped together into broad categories (e.g., stimulants, antidepressants). Within each category are several chemical classes. The individual pharmacotherapies within a chemical class share similar chemical structures. Table 2-9 presents several common categories and classes, along with their indication, that is, their clinical use.

Many pharmacotherapies for mental disorders have as their initial action the alteration—either increase or decrease—in the amount of a neurotransmitter. Neurotransmitter levels can be altered by pharmacotherapies in myriad ways: pharmacotherapies can mimic the action of the neurotransmitter in cell-to-cell signaling; they can block the action of the neurotransmitter; or they can alter its synthesis, breakdown (degradation), release, or reuptake, among other possibilities (Cooper et al., 1996).

Neurotransmitters generally are concentrated in separate brain regions and circuits. Within the cells that form a circuit, each neurotransmitter has its own biochemical pathway for synthesis, degradation, and reuptake, as well as its own specialized molecules known as receptors. At the time of neurotransmission, when a traveling signal reaches the tip (terminal) of the presynaptic cell, the neurotransmitter is released from the cell into the synaptic cleft. It migrates across the synaptic cleft in less than a millisecond and then binds to receptors situated on the membrane of the postsynaptic cell. The neurotransmitter's binding to the receptor alters the shape of the receptor in such a way that the neurotransmitter can either excite the postsynaptic cell, and thereby transmit the signal to this next cell, or inhibit the receptor, and thereby block signal transmission. The neurotransmitter's action is terminated either by enzymes that degrade it right there, in the synaptic cleft, or by transporter proteins that return unused neurotransmitter back to the presynaptic neuron for reuse, a "recycling" process known as reuptake. The widely prescribed class of antidepressants referred to as the selective serotonin reuptake inhibitors primarily block the action of the transporter protein for serotonin, thus leaving more serotonin to remain at the synapse (Schloss & Williams, 1998). Depression is thought to be reflected in decreased serotonin transmission, so one rationale for this class of antidepressants is to boost the level of serotonin (see Chapter 4).

Table 2-9. Selected types of pharmacotherapies

| Category and Class | Example(s) of Clinical Use |
|---|--|
| Antipsychotics (neuroleptics) Typical antipsychotics* Atypical antipsychotics** | Schizophrenia, psychosis |
| Antidepressants Selective serotonin reuptake inhibitors Tricyclic and heterocyclic antidepressants*** Monoamine oxidase inhibitors | Depression, anxiety |
| Stimulants | Attention-deficit/hyperactivity disorder |
| Antimanic Lithium Anticonvulsants Thyroid supplementation | Mania |
| Antianxiety (anxiolytics) Benzodiazepines Antidepressants B-Adrenergic-blocking drugs | Anxiety |
| Cholinesterase inhibitors | Alzheimer's disease |

* Also known as first-generation antipsychotics, they include these chemical classes: phenothiazines (e.g., chlorpromazine), butyrophenones (e.g., haloperidol), and thioxanthenes (Dixon et al., 1995).

** Also known as second-generation antipsychotics, they include these chemical classes: dibenzoxazepine (e.g., clozapine), thienobenzodiazepine (e.g., olanzapine), and benzisoxazole (e.g., risperidone).

*** Include imipramine and amitriptyline.

Source: Perry et al., 1997

Although the effects of reuptake inhibitors on neurotransmitter concentrations in the synapse occur with the first dose, therapeutic benefit typically lags behind by days or weeks. This observation has spurred considerable recent research on chronic and "downstream" actions of psychotropics, particularly antidepressants. For example, in animal models the repeated administration of nearly all antidepressants is associated with a reduction in the number of postsynaptic 12/7/99 receptors, so-called down-regulation that parallels the time course of clinical effect in patients (Schatzberg & Nemeroff, 1998). Some of the secondary effects of reuptake inhibitors may be

mediated by the activation of intraneuronal "second messenger" proteins which result from the stimulation of postsynaptic receptors (Schatzberg & Nemeroff, 1998).

Receptors for each transmitter come in numerous varieties. Not only are there several types of receptor for each neurotransmitter, but there may be many subtypes. For serotonin, for example, there are seven types of receptors, designated 5-HT₁ –5-HT₇, and seven receptor subtypes, totaling 14 separate receptors (Schatzberg & Nemeroff, 1998). The pace at which receptors are identified has become so dizzying that these figures are likely to be obsolete by the time this paragraph is read.

A pharmacotherapy typically interacts with a receptor in either one of two ways—as an agonist or as an antagonist.¹⁴ When a pharmacotherapy acts as an agonist, it mimics the action of the natural neurotransmitter. When a pharmacotherapy acts as an antagonist, it inhibits, or blocks, the neuro-transmitter's action, often by binding to the receptor and preventing the natural transmitter from binding there. An antagonist disrupts the action of the neurotransmitter.

The diversity of receptors presents vast opportunities for drug development. Through rational drug design, pharmacotherapies have become increasingly selective in their actions. Generally speaking, the more selective the pharmacotherapy's action, the more targeted it is to one receptor rather than another, the narrower its spectrum of action, and the fewer the side effects. Conversely, the broader the pharmacotherapy's action, the less targeted to a receptor type or subtype, the broader the effects, and the broader the side effects (Minneman, 1994). However, the interaction among neurotransmitter systems in the brain renders some of the apparent distinctions among medications more apparent than real. Thus, despite differential initial actions on neurotransmitters, both serotonin and norepinephrine reuptake blockers have similar biochemical effects after chronic dosing (Potter et al., 1985).

Complementary and Alternative Treatment

Recent interest in the health benefits of a plethora of natural products has engendered claims related to putative effects on mental health. These have ranged from reports of enhanced memory in people taking the herb, ginseng, to the use of the St. John's wort flowers as an antidepressant (see Chapter 4).

There are major challenges to evaluating the role of complementary and alternative treatments in maintaining mental health or treating mental disorders. In many cases, preparations are not standardized and consist of a variable mixture of substances, any of which may be the active ingredient(s). Purity, bioavailability, amount and timing of doses, and other factors that are standardized for traditional pharmaceutical agents prior to testing cannot be taken for granted with natural products. Current regulations in the United States classify most complementary and alternative treatments as "food supplements," which are not subject to premarketing approval of the Food and Drug Administration.

At present, no conclusions about the role, if any, of complementary and alternative treatments in mental health or illness can be accepted with certainty, as very few claims or studies meet acceptable scientific standards. With funding from government and private industry, controlled clinical trials are under way, including

the use of St. John's wort (*Hypericum perforatum*) as a treatment for depression, and omega-3 fatty acids (fish oils) as a mood stabilizer in bipolar depression. In addition, it is important for clinicians and investigators to account for any herbs or natural products being taken by their patients or research subjects that might interact with traditional treatments.

Issues in Treatment

The foregoing section has furnished an overview of the types and nature of mental health treatment. The resounding message, which is echoed throughout this report, is that a range of efficacious treatments is available. The following material deals with four issues surrounding treatment—the placebo response, benefits and risks, the gap between how well treatments work in clinical trials versus in the real world, and the constellation of barriers that hinder people from seeking mental health treatment.

Placebo Response

Recognized since antiquity, the placebo effect refers to the powerful role of patients' attitudes and perceptions that help them improve and recover from health problems. Hippocrates established the therapeutic principle of physicians laying their hands in a reassuring manner to draw on the inner resources of the patient to fight disease. Technically speaking, the placebo effect refers to treatment responses in the placebo group, responses that cannot be explained on the basis of active treatment (Friedman et al., 1996a). A placebo is an inactive treatment, either in the form of an inert pill for studying a new drug treatment or an inactive procedure for studying a psychological therapy. The effects of active treatment are often compared with a control group that receives a pharmacological or psychological placebo.

It is not unusual for a placebo effect to be found in up to 50 percent of patients in any study of a medical treatment (Schatzberg & Nemeroff, 1998). For example, about 30 percent of patients typically respond to a placebo in a clinical trial of a new antidepressant (see Chapter 4). The rate is even higher for an antianxiety agent (an anxiolytic) (Schweizer & Rickels, 1997). The placebo effect is of such import that a placebo group or other control group¹⁵ is mandated by the Food and Drug Administration in clinical trials of a new pharmacotherapy to establish its efficacy prior to marketing (Friedman et al., 1996a). If the pharmacotherapy is not statistically superior to the control, efficacy cannot be established. It is somewhat more difficult to fashion an analog of an inert pill in the testing of new and experimental psychological therapies. Psychological studies can employ a "psychological" placebo in the form of a treatment known to be ineffectual. Or they can employ a comparison group, which receives an alternative psychological therapy. Some treatment studies employ both a "psychological" placebo, as well as a comparison group.¹⁶

The basis of the placebo response is not fully known, but there are thought to be many possible reasons. These reasons, which relate to attributes of the disorder or the disease, the patient, and the treatment setting, include spontaneous remission, personality variables (e.g., social acquiescence), patient expectations, attitudes of and compassion by clinicians, and receiving treatment in a specialized setting (Schweizer & Rickels, 1997). In studies of postoperative pain, the placebo response

is mediated by patients' production of endogenous pain-killing substances known as endorphins (Levine et al., 1978).

Benefits and Risks

Throughout this report, currently accepted treatments for mental disorders will be described. Except where otherwise indicated, the efficacy of these interventions has been documented in multiple controlled, clinical trials published in the peer-reviewed literature. In some cases, these have been supplemented by expert consensus reports or practice guidelines.

Most studies of efficacy of specific treatments for mental disorders have been highly structured clinical trials, performed on individuals with a single disorder, in good physical health. While necessary and important, these trials do not always generalize easily to the wider population, which includes many individuals whose mental disorder is accompanied by another mental or somatic disorder and/or alcohol or substance abuse, and who may be taking other medications. Moreover, children, adolescents, and the elderly are excluded from many clinical trials,¹⁷ as are those in certain settings, such as nursing homes. Newer, more generalizable studies are being undertaken to address these shortcomings of the scientific literature (Lebowitz & Rudorfer, 1998).

Pending the results of these newer studies, it is important for clinical decisionmakers to review the current best evidence for the *efficacy* of treatments. People with mental disorders and their health providers should consider all possible options and carefully weigh the pros and cons of each, as well as the possibility of no treatment at all, before deciding upon a course of action. Such an informed consent process entails the calculation of a benefit-to-risk ratio¹⁸ for each available treatment option. Most medications or somatic treatments have side effects, for example, but a likelihood of significant clinical benefit often overrides side effects in support of a treatment recommendation.

Gap Between Efficacy and Effectiveness

Mental health professionals have long observed that treatments work better in the clinical research trial setting as opposed to typical clinical practice settings. The diminished level of treatment effectiveness in real-world settings is so perceptible that it even has a name, the "efficacy-effectiveness gap." Efficacy is the term for what works in the clinical trial setting, and effectiveness is the term for what works in typical clinical practice settings. The efficacy-effectiveness gap applies to both pharmacological therapies and to psychotherapies (Muñoz et al., 1994; Seligman, 1995). The gap is not unique to mental health, for it is found with somatic disorders too.

The magnitude of the gap can be surprisingly high. With schizophrenia medications, one review article found that, in clinical trials, the use of traditional antipsychotic medications for schizophrenia was associated with an average annual relapse rate of about 23 percent, whereas the same medications used in clinical practice carried a relapse rate of about 50 percent (Dixon et al., 1995). The magnitude of the gap found in this study may not apply to other medications and other disorders, much less to psychological therapies. Studies of real-world effectiveness are scarce. Yet some degree of gap is widely recognized. The question is, why?

Efficacy studies test whether treatment works under ideal circumstances. They typically exclude patients with other mental or somatic disorders. In the past, they typically have examined relatively homogeneous populations, usually white males. Furthermore, efficacy studies are carried out by highly trained specialists following strict protocols that require frequent patient monitoring. Finally, participation in efficacy studies is often free of charge to patients.

It is not surprising that the reasons commonly cited to explain the discrepancy between efficacy and effectiveness focus on the practicalities and constraints imposed by the real world. In real-world settings, patients often are more heterogeneous and ethnically diverse, are beset by comorbidity (more than one mental or somatic disorder),¹⁸ are often less compliant, and are seen more often in general medical rather than specialty settings; providers are less inclined to adequately monitor and standardize treatment; and cost pressures exist on both patients and providers, depending on the nature of the financing of care (Dixon et al., 1995; Wells & Sturm, 1996). This constellation of real-world constraints appears to explain the gap.

Barriers to Seeking Help

Most people with mental disorders do not seek treatment, according to figures presented in the next section of this chapter and in Chapter 6. This general statement applies to adults and older adults and to parents and guardians who make treatment decisions for children with mental disorders. There is a multiplicity of reasons why people fail to seek treatment for mental disorders but few detailed studies. The barriers to treatment fall under several umbrella categories: demographic factors, patient attitudes toward a service system that often neglects the special needs of racial and ethnic minorities, financial, and organizational.

Several demographic factors predispose people against seeking treatment. African Americans, Hispanics (Sussman et al., 1987; Gallo et al., 1995), and poor women (Miranda & Green, 1999) are less inclined than non-Hispanic whites—particularly females—to seek treatment. Common patient attitudes that deter people from seeking treatment are not having the time, fear of being hospitalized, thinking that they could handle it alone, thinking that no one could help, and stigma (being too embarrassed to discuss the problem) (Sussman et al., 1987). Above all, the cost of treatment is the most prevalent deterrent to seeking care, according to a large study of community residents (Sussman et al., 1987). Cost is a major determinant of seeking treatment even among people with health insurance because of inferior coverage of mental health as compared with health care in general. Finally, the organizational barriers include fragmentation of services and lack of availability of services (Horwitz, 1987). Members of racial and ethnic minority groups often perceive that services offered by the existing system do not or will not meet their needs, for example, by taking into account their cultural or linguistic practices. These particular barriers are discussed in greater depth with respect to minority groups (later in this chapter) and with respect to different ages (Chapters 3 to 5).

Demographic, attitudinal, financial, and organizational barriers operate at various points and to various degrees. Seeking treatment is conceived of as a complex process that begins with an individual or parent recognizing that thinking, mood, or behaviors are unusual and severe enough to require treatment; interpreting symptoms as a “medical” or mental health problem; deciding whether or not to seek

help and from whom; receiving care; and, lastly, evaluating whether continuation of treatment is warranted (Sussman et al., 1987)

¹² About 40 percent of those surveyed thought that they "didn't think anyone could help" as a reason for not seeking mental health treatment (Sussman et al., 1987).

¹³ Other treatments are electroconvulsive therapy (Chapters 4 and 5) and some types of surgery.

¹⁴ There are certainly exceptions to this general rule. Some pharmacotherapies work as partial agonists and partial antagonists simultaneously.

¹⁵ When it is unethical to deprive patients of treatment, such as the case with AIDS, conventional treatment is given as the control.

¹⁶ The criteria developed by a division of the American Psychological Association for establishing treatment efficacy call for the experimental treatment to be statistically superior to "pill or psychological placebo or to another treatment" (Chambless et al., 1998).

¹⁷ In March 1998, the NIH issued a policy guideline stating that NIH-funded investigators will be expected to include children in clinical trials, which normally would involve adults only, when there is sound scientific rationale and in the absence of a strong justification to the contrary.

¹⁸ Having a second disorder increases the possibility of drug interactions, which may translate into reduced dosing. Comorbidity is discussed throughout this report.

Overview of Mental Health Services

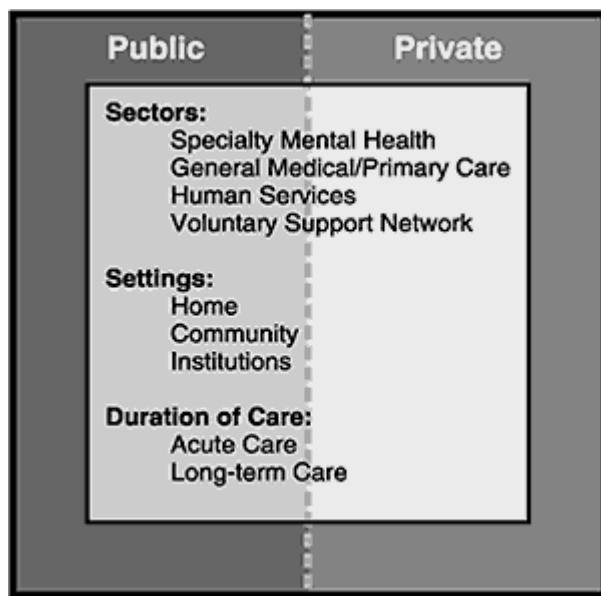
Over the past three centuries, the complex patchwork of mental health services in the United States has become so fragmented that it is referred to as the *de facto mental health system* (Regier et al., 1993b). Its shape has been determined by many heterogeneous factors rather than by a single guiding set of organizing principles. The *de facto* system has been characterized as having distinct sectors, financing, duration of care, and settings (see Figure 2-4).

The four sectors of the system are the specialty mental health sector, the general medical/primary care sector, the human services sector, and the voluntary support network sector. Specialty mental health services include services provided by specialized mental health professionals (e.g., psychologists, psychiatric nurses, psychiatrists, and psychiatric social workers) and the specialized offices, facilities, and agencies in which they work. Specialty services were designed expressly for the provision of mental health services. The general medical/primary care sector consists of health care professionals (e.g., family physicians, nurse practitioners, internists,

pediatricians, etc.) and the settings (i.e., offices, clinics, and hospitals) in which they work. These settings were designed for the full range of health care services, including, but not specialized for, the delivery of mental health services. The human services sector consists of social welfare, criminal justice, educational, religious, and charitable services. The voluntary support network refers to self-help groups and organizations. These are groups devoted to education, communication, and support, all of which extend beyond formal treatment.

Financing of the de facto system refers to the payer of services. The system is often described as being divided into a public (i.e., government) and a private sector. The term "public sector" refers both to services directly operated by government agencies (e.g., state and county mental hospitals) and to services financed with government resources (e.g., Medicaid, a Federal-state program for financing health care services for people who are poor and disabled, and Medicare, a Federal health insurance program primarily for older Americans and people who retired early due to disability). Publicly financed services may be provided by private organizations. The term "private sector" refers both to services directly operated by private agencies and to services financed with private resources (e.g., employer-provided insurance).

Figure 2-4. The mental health service system



The duration of care is divided between services for the treatment of acute conditions and those devoted to the long-term care of chronic (i.e., severe and persistent) conditions, such as schizophrenia, bipolar disorder, and Alzheimer's disease. The former, provided in psychiatric hospitals, psychiatric units in general hospitals, and in beds "scattered" in general hospital wards, includes brief treatment-oriented services. Long-term care includes residential care as well as some treatment services. Residential care is often referred to as "custodial," when supervised living predominates over active treatment.

The settings for care and treatment include institutional, community-based, and home-based. The former refers to facilities, particularly public mental hospitals and nursing homes, which usually are seen by patients and families as large, regimented,

and impersonal. They often are removed from the community by distance and frequency of contact with friends and family. In contrast, community-based services are close to where patients or clients live. Services are typically provided by community agencies and organizations. Home-based services include informal supports provided in an individual's residence.

Chapter 6 examines the impact of recent changes in financing and organizing services on access and quality of care. Many of these issues also are addressed in Chapters 3 to 5, where they are discussed in the context of care and treatment at each stage of the life cycle. The following material provides general information on current patterns of use and focuses on the historical origins of mental health services.

Overall Patterns of Use

According to recent national surveys (Regier et al, 1993b; Kessler et al., 1996), a total of about 15 percent of the U.S. adult population use mental health services in any given year. Eleven percent receive their services from either the general medical care sector or the specialty mental health sector, in roughly equal proportions. In addition, about 5 percent receive care from the human services sector, and about 3 percent receive care from the voluntary support network. (The overlap across these latter two sectors accounts for these figures totaling more than 15 percent.)

Slightly more than *half* of the 15 percent of the adult population that use mental health services have a diagnosable mental or addictive disorder (8 percent), while the remaining portion has a mental health problem (7 percent). Bearing in mind that 28 percent of the population have a diagnosable mental or substance abuse disorder, only about one-third with a diagnosable mental disorder receives treatment in 1 year (Figure 2-5). In short, this translates to the *majority* of those with a diagnosable mental disorder *not receiving* treatment.

Similarly, about 21 percent of the child and adolescent population use mental health services annually. Nine percent receive care from the health care sector, almost exclusively from the specialty mental health sector. Seventeen percent of the child and adolescent population receive care from the human services sector, mostly in the school system, yet there is much overlap with the health sector (again accounting for the sum being more than 21 percent). The distribution of those who do and do not currently meet diagnostic criteria for a mental disorder is similar to that for adults (Figure 2-6).

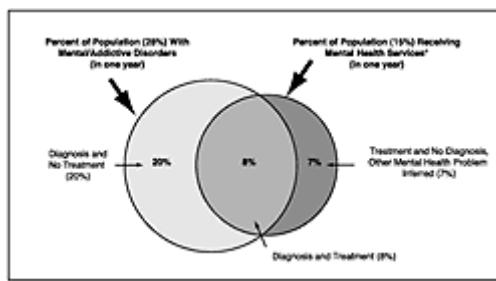
History of Mental Health Services

The history of mental health services in the United States has been chronicled by historian Gerald N. Grob in a series of landmark books from which this account is drawn (Grob, 1983, 1991, 1994). The origins of the mental health services system coincide with the colonial settlement of the United States. Individuals with mental illness were cared for at home until urbanization induced state governments to confront a problem that had been relegated largely to families. The states' response was to build institutions, known first as asylums and later as mental hospitals. When the Pennsylvania Hospital opened in Philadelphia in the mid-18th century, it had provisions for individuals with mental illness housed in its basement. Also in the mid-18th century, colonial Virginia was the first state to build an asylum for mentally ill

citizens, which it constructed in its capital at Williamsburg. If not cared for at home or in asylums, those with mental illness were likely to be found in jails, almshouses, work houses, and other institutions. By the time of the Revolutionary War, the beginnings were in place for each of the four sectors of the de facto mental health system.

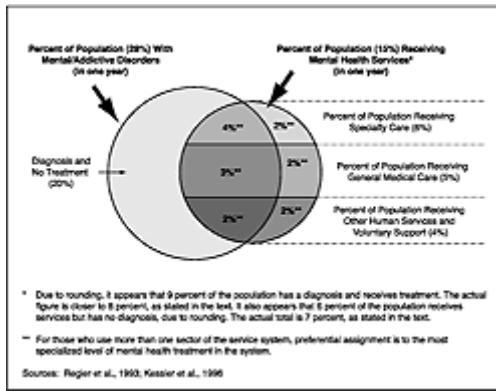
The origins of treatment for mental illness in the general medical/primary care sector can be traced to the Pennsylvania Hospital. The origins of specialty mental health care can be traced to the Williamsburg asylum. Home care, the most common response to mental illness, probably became a part of the voluntary support network, whereas the human services sector was by far the most common organized or institutional response, by placing individuals in almshouses (homes for the poor) and work houses. The first form of treatment—known as “moral treatment”—was not given until the very end of the 18th century, after the Revolutionary War.

Figure 2-5a. Annual prevalence of mental/addictive disorders and services for adults



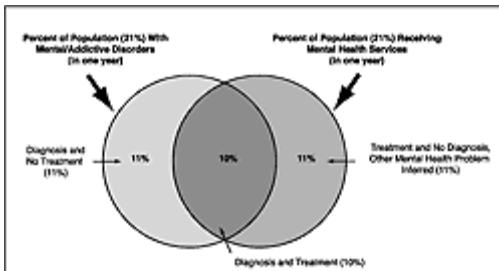
[Click to enlarge](#)

Figure 2-5b. Annual prevalence of mental/addictive disorders and services for adults



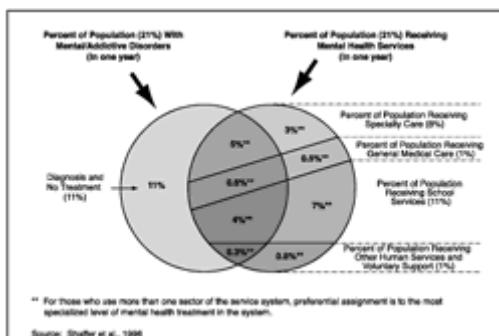
[Click to enlarge](#)

Figure 2-6a. Annual prevalence of mental/addictive disorders for children



[Click to enlarge](#)

Figure 2-6b. Annual prevalence of mental/addictive disorders for children



[Click to enlarge](#)

Figure 2-7. Definitions of recovery from consumer writings

Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again. . . . The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution (Deegan, 1988, p. 15).

One of the elements that makes recovery possible is the regaining of one's belief in oneself (Chamberlin, 1997, p. 9).

Having some hope is crucial to recovery; none of us would strive if we believed it a futile effort. . . I believe that if we confront our illnesses with courage and struggle with our symptoms persistently, we can overcome our handicaps to live independently, learn skills, and contribute to society, the society that has traditionally abandoned us (Leete, 1989, p. 32).

A recovery paradigm is each person's unique experience of their road to recovery. . . . My recovery paradigm included my reconnection which included the following four key ingredients: connection, safety,

hope, and acknowledgment of my spiritual self (Long, 1994, p. 4).

To return renewed with an enriched perspective of the human condition is the major benefit of recovery. To return at peace, with yourself, your experience, your world, and your God, is the major joy of recovery (Granger, 1994, p. 10).

An era of "moral treatment" was introduced from Europe at the turn of the 19th century, representing the first of four reform movements in mental health services in the United States (Morrissey & Goldman, 1984; Goldman & Morrissey, 1985) (Table 2-10).

The first reformers, including Dorothea Dix and Horace Mann, imported the idea that mental illness could be treated by removing the individual to an asylum to receive a mix of somatic and psychosocial treatments in a controlled environment characterized by "moral" sensibilities. The term "moral" had a connotation different from that of today. It meant the return of the individual to reason by the application of psychologically oriented therapy¹⁹ (Grob, 1994). The "moral treatment" period was characterized by the building of private and public asylums. Almost every state had an asylum dedicated to the early treatment of mental illness to restore mental health and to keep patients from becoming chronically ill. Moral treatment accomplished the former objective, but it could not prevent chronicity.

Shortly after the Civil War, the failures of the promise of early treatment were recognized and asylums were built for untreatable, chronic patients. The quality of care deteriorated in public institutions, where overcrowding and underfunding ran rampant. A new reform movement, devoted to "mental hygiene," began late in the 19th century. It combined the newly emerging concepts of public health (which at the time was referred to as "hygiene"), scientific medicine, and social progressivism. Although the states built the public asylums, local government was expected to pay for each episode of care. To avoid the expense, many communities continued to use local almshouses and jails. Asylums could not maintain their budgets, care deteriorated, and newspaper exposés revealed inhuman conditions both in asylums and local welfare institutions. State Care Acts were passed between 1894 and World War I. These acts centralized financial responsibility for the care of individuals with mental illness in every state government. Local government took the opportunity to send everyone with a mental illness, including dependent older citizens, to the state asylums. Dementia was redefined as a mental illness, although only some of the older residents were demented. For the past century the states have carried this responsibility at very low cost, in spite of the magnitude of the task.

The reformers of the "mental hygiene" period, who formed the National Committee on Mental Hygiene (now the National Mental Health Association [NMHA]), called for an expansion of the new science, particularly of neuropathology, in asylums, which were renamed mental hospitals. They also called for "psychopathic hospitals and clinics" to bring the new science to patients in smaller institutions associated with medical schools. They opened several psychiatric units in general hospitals to move mental health care into the mainstream of health care. The mental hygienists believed in the principles of early treatment and expected to prevent chronic mental illness. To support this effort, they advocated for outpatient treatment to identify early cases of mental disorder and to follow discharged inpatients.

Treatments were not effective. Early treatment was no more successful in preventing patients from becoming chronically ill in the early 20th century than it was in the early years of the previous century. At best, the hospitals provided humane custodial care; at worst, they neglected or abused the patients. Length of stay did begin to decline for newly admitted inpatients, but older, long-stay patients filled public asylums. The financial problems and overcrowding deepened during the Depression and during World War II.

Enthusiasm for early interventions, developed by military mental health services during World War II, brought a new sense of optimism about treatment by the middle of the 20th century. Again, early treatment of mental disorders was championed and a new concept was born, "community mental health." The NMHA figured prominently in this reform, along with the Group for the Advancement of Psychiatry. Borrowing some ideas from the mental hygienists and capitalizing on the advent of new drugs for treating psychosis and depression, community mental health reformers argued that they could bring mental health services to the public in their communities. They suggested that long-term institutional care in mental hospitals had been neglectful, ineffective, even harmful. The joint policies of "community care" and "deinstitutionalization" led to dramatic declines in the length of hospital stay and the discharge of many patients from custodial care in hospitals.

Table 2-10. Historical reform movements in mental health treatment in the United States

| Reform movement | Era | Setting | Focus of Reform |
|-------------------------|--------------|--------------------------------|--|
| Moral Treatment | 1800-1850 | Asylum | Humane, restorative treatment |
| Mental Hygiene | 1890-1920 | Mental hospital or clinic | Prevention, scientific orientation |
| Community Mental Health | 1955-1970 | Community mental health center | Deinstitutionalization, social integration |
| Community Support | 1975-present | Community support | Mental illness as a social welfare problem (e.g., housing, employment) |

Sources: Morrissey & Goldman, 1984; Goldman & Morrissey, 1985.

Concomitantly, these policies led to the expansion of outpatient services in the community, particularly in federally funded community mental health centers. Federal legislation beginning in the mid-1960s fueled this expansion through grants to centers and then through the inclusion of some (albeit limited) mental health benefits in Medicare and Medicaid. The latter was particularly important, because it stimulated the transfer of many long-term inpatients from public mental hospitals to nursing homes, encouraged the opening of psychiatric units in general hospitals, and ultimately paid for many rehabilitation services for individuals with severe and persistent mental disorders.

The dual policies of community care and deinstitutionalization, however, were implemented without evidence of effectiveness of treatments and without a social welfare system attuned to the needs of hundreds of thousands of individuals with disabling mental illness. Housing, support services, community treatment approaches, vocational opportunities, and income supports for those unable to work were not universally available in the community. Neither was there a truly welcoming spirit of community support for "returning" mental patients. Many discharged mental patients found themselves in welfare and criminal justice institutions, as had their predecessors in earlier eras; some became homeless or lived in regimented residential (e.g., board and care) settings in the community.

The special needs of individuals with severe and persistent mental illness were not being met (General Accounting Office, 1977; Turner & TenHoor, 1978). Early treatment did not prevent disability, although new approaches to treatment would eventually reduce morbidity and improve quality of life. A fourth reform era (1975–present), called the "community support" movement, grew directly out of the "community mental health movement." This new reform movement called for an end to viewing and responding to chronic mental disorder only as the object of neglect, by favoring acute treatment and prevention. Reformers advocated for developing "community support systems," with an expanded vision of care and treatment as encompassing the social welfare needs of individuals with disabling mental illness. The emphasis favored the view that individuals could once again become citizens of their community, if given support and access to mainstream resources such as housing and vocational opportunities (Goldman, 1998). At first, mental health treatments were de-emphasized in favor of social supports, but newer medications, such as SSRIs and novel antipsychotic drugs, and more effective psychosocial interventions, such as assertive community treatment for schizophrenia (Chapter 4), facilitated the objectives of community support and recovery in the community.

The voluntary support network expanded with an emphasis on "recovery," a concept introduced by service users, or consumers, who began to take an active role in their own care and support and in making policy. From their inception in the late 1970s, family organizations, such as the National Alliance for the Mentally Ill and the Federation of Families, advocated for services for individuals who are most impaired. As discussed later in this chapter, consumers, who also call themselves "survivors," have formed their own networks for support and advocacy and work with other advocacy groups such as the National Mental Health Association and the Bazelon Center for Mental Health Law.

The de facto mental health system is complex because it has metamorphosed over time under the influence of a wide array of factors, including reform movements and their ideologies, financial incentives based on who would pay for what kind of services, and advances in care and treatment technology. Each factor has been important in its own way. The hybrid system that emerged serves many diverse functions. Unfortunately for those individuals with the most complex needs, and who often have the fewest financial resources, the system is fragmented and difficult to use to meet those needs effectively. Efforts at integrating the service system and tailoring it to those with the greatest needs are discussed, by age group, in subsequent chapters of the report. Many problems remain, including the lack of health insurance by 16 percent of the U.S. population, underinsurance for mental disorders even among those who have health insurance, access barriers to members

of many racial and ethnic groups, discrimination, and the stigma about mental illness, which is one of the factors that impedes help-seeking behavior.

¹⁹ According to a student of the originator of moral treatment, Philippe Pinel, "moral treatment is the application of the faculty of intelligence and of the emotions in the treatment of mental alienation" (Grob, 1994).

Overview of Cultural Diversity and Mental Health Services

The U.S. mental health system is not well equipped to meet the needs of racial and ethnic minority populations. Racial and ethnic minority groups are generally considered to be underserved by the mental health services system (Neighbors et al., 1992; Takeuchi & Uehara, 1996; Center for Mental Health Services [CMHS], 1998). A constellation of barriers deters ethnic and racial minority group members from seeking treatment, and if individual members of groups succeed in accessing services, their treatment may be inappropriate to meet their needs.

Awareness of the problem dates back to the 1960s and 1970s, with the rise of the civil rights and community mental health movements (Rogler et al., 1987) and with successive waves of immigration from Central America, the Caribbean, and Asia (Takeuchi & Uehara, 1996). These historical forces spurred greater recognition of the problems that minority groups confront in relation to mental health services.

Research documents that many members of minority groups fear, or feel ill at ease with, the mental health system (Lin et al., 1982; Sussman et al., 1987; Scheffler & Miller, 1991). These groups experience it as the product of white, European culture, shaped by research primarily on white, European populations. They may find only clinicians who represent a white middle-class orientation, with its cultural values and beliefs, as well as its biases, misconceptions, and stereotypes of other cultures.

Research and clinical practice have propelled advocates and mental health professionals to press for "linguistically and culturally competent services" to improve utilization and effectiveness of treatment for different cultures. Culturally competent services incorporate respect for and understanding of, ethnic and racial groups, as well as their histories, traditions, beliefs, and value systems (CMHS, 1998). Without culturally competent services, the failure to serve racial and ethnic minority groups adequately is expected to worsen, given the huge demographic growth in these populations predicted over the next decades (Takeuchi & Uehara, 1996; CMHS, 1998; Snowden, 1999).

This section of the chapter amplifies these major conclusions. It explains the confluence of clinical, cultural, organizational, and financial reasons for minority groups being underserved by the mental health system. The first task, however, is to explain which ethnic and racial groups constitute underserved populations, to describe their changing demographics, and to define the term "culture" and its consequences for the mental health system.

Introduction to Cultural Diversity and Demographics

The Federal government officially designates *four* major racial or ethnic minority groups in the United States: African American (black), Asian/Pacific Islander, Hispanic American (Latino),²⁰ and Native American/American Indian/Alaska Native/Native Hawaiian (referred to subsequently as "American Indians") (CMHS, 1998). There are many other racial or ethnic minorities and considerable diversity within each of the four groupings listed above. The representation of the four officially designated groups in the U.S. population in 1999 is as follows: African Americans constitute the largest group, at 12.8 percent of the U.S. population; followed by Hispanics (11.4 percent), Asian/Pacific Islanders (4.0 percent), and American Indians (0.9 percent) (U.S. Census Bureau, 1999). Hispanic Americans are among the fastest-growing groups. Because their population growth outpaces that of African Americans, they are projected to be the predominant minority group (24.5 percent of the U.S. population) by the year 2050 (CMHS, 1998).

Racial and ethnic populations differ from one another and from the larger society with respect to culture. The term "culture" is used loosely to denote a common heritage and set of beliefs, norms, and values. The cultures with which members of minority racial and ethnic groups identify often are markedly different from industrial societies of the West. The phrase "cultural identity" specifies a reference group—an identifiable social entity with whom a person identifies and to whom he or she looks for standards of behavior (Cooper & Denner, 1998). Of course, within any given group, an individual's cultural identity may also involve language, country of origin, acculturation,²¹ gender, age, class, religious/spiritual beliefs, sexual orientation²², and physical disabilities (Lu et al., 1995). Many people have multiple ethnic or cultural identities.

The historical experiences of ethnic and minority groups in the United States are reflected in differences in economic, social, and political status. The most measurable difference relates to income. Many racial and ethnic minority groups have limited financial resources. In 1994, families from these groups were at least three times as likely as white families to have incomes placing them below the Federally established poverty line. The disparity is even greater when considering extreme poverty—family incomes at a level less than half of the poverty threshold—and is also large when considering children and older persons (O'Hare, 1996). Although some Asian Americans are somewhat better off financially than other minority groups, they still are more than one and a half times more likely than whites to live in poverty. Poverty disproportionately affects minority women and their children (Miranda & Green, 1999). The effects of poverty are compounded by differences in total value of accumulated assets, or total wealth (O'Hare et al., 1991).

Lower socioeconomic status—in terms of income, education, and occupation—has been strongly linked to mental illness. It has been known for decades that people in the lowest socioeconomic strata are about two and a half times more likely than those in the highest strata to have a mental disorder (Holzer et al., 1986; Regier et al., 1993b). The reasons for the association between lower socioeconomic status and mental illness are not well understood. It may be that a combination of greater stress in the lives of the poor and greater vulnerability to a variety of stressors leads to some mental disorders, such as depression. Poor women, for example, experience more frequent, threatening, and uncontrollable life events than do members of the population at large (Belle, 1990). It also may be that the impairments associated

with mental disorders lead to lower socioeconomic status (McLeod & Kessler, 1990; Dohrenwend, 1992; Regier et al., 1993b).

Cultural identity imparts distinct patterns of beliefs and practices that have implications for the willingness to seek, and the ability to respond to, mental health services. These include coping styles and ties to family and community, discussed below.

Coping Styles

Cultural differences can be reflected in differences in preferred styles of coping with day-to-day problems. Consistent with a cultural emphasis on restraint, certain Asian American groups, for example, encourage a tendency not to dwell on morbid or upsetting thoughts, believing that avoidance of troubling internal events is warranted more than recognition and outward expression (Leong & Lau, 1998). They have little willingness to behave in a fashion that might disrupt social harmony (Uba, 1994). Their emphasis on willpower is similar to the tendency documented among African Americans to minimize the significance of stress and, relatedly, to try to prevail in the face of adversity through increased striving (Broman, 1996).

Culturally rooted traditions of religious beliefs and practices carry important consequences for willingness to seek mental health services. In many traditional societies, mental health problems can be viewed as spiritual concerns and as occasions to renew one's commitment to a religious or spiritual system of belief and to engage in prescribed religious or spiritual forms of practice. African Americans (Broman, 1996) and a number of ethnic groups (Lu et al., 1995), when faced with personal difficulties, have been shown to seek guidance from religious figures.²³

Many people of all racial and ethnic backgrounds believe that religion and spirituality favorably impact upon their lives and that well-being, good health, and religious commitment or faith are integrally intertwined (Taylor, 1986; Priest, 1991; Bacote, 1994; Pargament, 1997). Religion and spirituality are deemed important because they can provide comfort, joy, pleasure, and meaning to life as well as be means to deal with death, suffering, pain, injustice, tragedy, and stressful experiences in the life of an individual or family (Pargament, 1997). In the family/community-centered perception of mental illness held by Asians and Hispanics, religious organizations are viewed as an enhancement or substitute when the family is unable to cope or assist with the problem (Acosta et al., 1982; Comas-Diaz, 1989; Cook & Timberlake, 1989; Meadows, 1997).

Culture also imprints mental health by influencing whether and how individuals experience the discomfort associated with mental illness. When conveyed by tradition and sanctioned by cultural norms, characteristic modes of expressing suffering are sometimes called "idioms of distress" (Lu et al., 1995). Idioms of distress often reflect values and themes found in the societies in which they originate.

One of the most common idioms of distress is somatization, the expression of mental distress in terms of physical suffering. Somatization occurs widely and is believed to be especially prevalent among persons from a number of ethnic minority backgrounds (Lu et al., 1995). Epidemiological studies have confirmed that there are relatively high rates of somatization among African Americans (Zhang & Snowden, in

press). Indeed, somatization resembles an African American folk disorder identified in ethnographic research and is linked to seeking treatment (Snowden, 1998).

A number of idioms of distress are well recognized as culture-bound syndromes and have been included in an appendix to DSM-IV. Among culture-bound syndromes found among some Latino psychiatric patients is *ataque de nervios*, a syndrome of "uncontrollable shouting, crying, trembling, and aggression typically triggered by a stressful event involving family. . . ." (Lu et al., 1995, p. 489). A Japanese culture-bound syndrome has appeared in that country's clinical modification of ICD-10 (WHO *International Classification of Diseases*, 10th edition, 1993). *Taijin kyofusho* is an intense fear that one's body or bodily functions give offense to others. Culture-bound syndromes sometimes reflect comprehensive systems of belief, typically emphasizing a need for a balance between opposing forces (e.g., yin/yang, "hot-cold" theory) or the power of supernatural forces (Cheung & Snowden, 1990). Belief in indigenous disorders and adherence to culturally rooted coping practices are more common among older adults and among persons who are less acculturated. It is not well known how applicable DSM-IV diagnostic criteria are to culturally specific symptom expression and culture-bound syndromes.

Family and Community as Resources

Ties to family and community, especially strong in African, Latino, Asian, and Native American communities, are forged by cultural tradition and by the current and historical need to assist arriving immigrants, to provide a sanctuary against discrimination practiced by the larger society, and to provide a sense of belonging and affirming a centrally held cultural or ethnic identity.

Among Mexican-Americans (del Pinal & Singer, 1997) and Asian Americans (Lee, 1998) relatively high rates of marriage and low rates of divorce, along with a greater tendency to live in extended family households, indicate an orientation toward family. Family solidarity has been invoked to explain relatively low rates among minority groups of placing older people in nursing homes (Short et al., 1994).

The relative economic success of Chinese, Japanese, and Korean Americans has been attributed to family and communal bonds of association (Fukuyama, 1995). Community organizations and networks established in the United States include rotating credit associations based on lineage, surname, or region of origin. These organizations and networks facilitate the startup of small businesses.

There is evidence of an African American tradition of voluntary organizations and clubs often having political, economic, and social functions and affiliation with religious organizations (Milburn & Bowman, 1991). African Americans and other racial and ethnic minority groups have drawn upon an extended family tradition in which material and emotional resources are brought to bear from a number of linked households. According to this literature, there is "(a) a high degree of geographical propinquity; (b) a strong sense of family and familial obligation; (c) fluidity of household boundaries, with greater willingness to absorb relatives, both real and fictive, adult and minor, if need arises; (d) frequent interaction with relatives; (e) frequent extended family get-togethers for special occasions and holidays; and (f) a system of mutual aid" (Hatchett & Jackson, 1993, p. 92).

Families play an important role in providing support to individuals with mental health problems. A strong sense of family loyalty means that, despite feelings of stigma and shame, families are an early and important source of assistance in efforts to cope, and that minority families may expect to continue to be involved in the treatment of a mentally ill member (Uba, 1994). Among Mexican American families, researchers have found lower levels of expressed emotion and lower levels of relapse (Karno et al., 1987). Other investigators have demonstrated an association between family warmth and a reduced likelihood of relapse (Lopez et al., in press).

Epidemiology and Utilization of Services

One of the best ways to identify whether a minority group has problems accessing mental health services is to examine their *utilization* of services in relation to their *need* for services. As noted previously, a limitation of contemporary mental health knowledge is the lack of standard measures of "need for treatment" and culturally appropriate assessment tools. Minority group members' needs, as measured indirectly by their prevalence of mental illness in relation to the U.S. population, should be proportional to their utilization, as measured by their representation in the treatment population. These comparisons turn out to be exceedingly complicated by inadequate understanding of the prevalence of mental disorders among minority groups in the United States.²⁴ Nationwide studies conducted many years ago overlooked institutional populations, which are disproportionately represented by minority groups. Treatment utilization information on minority groups in relation to whites is more plentiful, yet, a clear understanding of health seeking behavior in various cultures is lacking.

The following paragraphs reveal that disparities abound in treatment utilization: some minority groups are underrepresented in the outpatient treatment population while, at the same time, overrepresented in the inpatient population. Possible explanations for the differences in utilization are discussed in a later section.

African Americans

The prevalence of mental disorders is estimated to be higher among African Americans than among whites (Regier et al., 1993a). This difference does not appear to be due to intrinsic differences between the races; rather, it appears to be due to socioeconomic differences. When socioeconomic factors are taken into account, the prevalence difference disappears. That is, the socioeconomic status-adjusted rates of mental disorder among African Americans turn out to be the same as those of whites. In other words, it is the lower socioeconomic status of African Americans that places them at higher risk for mental disorders (Regier et al., 1993a).

African Americans are underrepresented in some outpatient treatment populations, but overrepresented in public inpatient psychiatric care in relation to whites (Snowden & Cheung, 1990; Snowden, in press-b). Their underrepresentation in outpatient treatment varies according to setting, type of provider, and source of payment. The racial gap between African Americans and whites in utilization is smallest, if not nonexistent, in community-based programs and in treatment financed by public sources, especially Medicaid (Snowden, 1998) and among older people (Padgett et al., 1995). The underrepresentation is largest in privately financed care, especially individual outpatient practice, paid for either by fee-for-service arrangements or managed care. As a result, underrepresentation in the

outpatient setting occurs more among working and middle-class African Americans, who are privately insured, than among the poor. This suggests that socioeconomic standing alone cannot explain the problem of underutilization (Snowden, 1998).

African Americans are, as noted above, overrepresented in inpatient psychiatric care (Snowden, in press-b). Their rate of utilization of psychiatric inpatient care is about *double* that of whites (Snowden & Cheung, 1990). This difference is even higher than would be expected on the basis of prevalence estimates. Overrepresentation is found in hospitals of all types except private psychiatric hospitals.²⁵ While difficult to explain definitively, the problem of overrepresentation in psychiatric hospitals appears more rooted in poverty, attitudes about seeking help, and a lack of community support than in clinician bias in diagnosis and overt racism, which also have been implicated (Snowden, in press-b). This line of reasoning posits that poverty, disinclination to seek help, and lack of health and mental health services deemed appropriate, and responsive, as well as community support, are major contributors to delays by African Americans in seeking treatment until symptoms become so severe that they warrant inpatient care.

Finally, African Americans are more likely than whites to use the emergency room for mental health problems (Snowden, in press-a). Their overreliance on emergency care for mental health problems is an extension of their overreliance on emergency care for other health problems. The practice of using the emergency room for routine care is generally attributed to a lack of health care providers in the community willing to offer routine treatment to people without insurance (Snowden, in press-a).

Asian Americans/Pacific Islanders

The prevalence of mental illness among Asian Americans is difficult to determine for methodological reasons (i.e., population sampling). Although some studies suggest higher rates of mental illness, there is wide variance across different groups of Asian Americans (Takeuchi & Uehara, 1996). It is not well known how applicable DSM-IV diagnostic criteria are to culturally specific symptom expression and culture-bound syndromes. With respect to treatment-seeking behavior, Asian Americans are distinguished by extremely low levels at which specialty treatment is sought for mental health problems (Leong & Lau, 1998). Asian Americans have proven less likely than whites, African Americans, and Hispanic Americans to seek care. One national sample revealed that Asian Americans were only a quarter as likely as whites, and half as likely as African Americans and Hispanic Americans, to have sought outpatient treatment (Snowden, in press-a). Asian Americans/Pacific Islanders are less likely than whites to be psychiatric inpatients (Snowden & Cheung, 1990). The reasons for the underutilization of services include the stigma and loss of face over mental health problems, limited English proficiency among some Asian immigrants, different cultural explanations for the problems, and the inability to find culturally competent services. These phenomena are more pronounced for recent immigrants (Sue et al., 1994).

Hispanic Americans

Several epidemiological studies revealed few differences between Hispanic Americans and whites in lifetime rates of mental illness (Robins & Regier, 1991; Vega & Kolody, 1998). A recent study of Mexican Americans in Fresno County, California, found that Mexican Americans born in the United States had rates of mental disorders similar to

those of other U.S. citizens, whereas immigrants born in Mexico had lower rates (Vega et al., 1998a). A large study conducted in Puerto Rico reported similar rates of mental disorders among residents of that island, compared with those of citizens of the mainland United States (Canino et al., 1987).

Although rates of mental illness may be similar to whites in general, the prevalence of particular mental health problems, the manifestation of symptoms, and help-seeking behaviors within Hispanic subgroups need attention and further research. For instance, the prevalence of depressive symptomatology is higher in Hispanic women (46%) than men (almost 20%); yet, the known risk factors do not totally explain the gender difference (Vega et al., 1998a; Zunzunegui et al., 1998). Several studies indicate that Puerto Rican and Mexican American women with depressive symptomatology are underrepresented in mental health services and overrepresented in general medical services (Hough et al., 1987; Sue et al., 1991, 1994; Duran, 1995; Jimenez et al., 1997).

Native Americans

American Indians/Alaska Natives have, like Asian Americans and Pacific Islanders, been studied in few epidemiological surveys of mental health and mental disorders. The indications are that depression is a significant problem in many American Indian/Alaska Native communities (Nelson et al., 1992). One study of a Northwest Indian village found rates of DSM-III-R affective disorder that were notably higher than rates reported from national epidemiological studies (Kinzie et al., 1992). Alcohol abuse and dependence appear also to be especially problematic, occurring at perhaps twice the rate of occurrence found in any other population group. Relatedly, suicide occurs at alarmingly high levels. (Indian Health Service, 1997). Among Native American veterans, post-traumatic stress disorder has been identified as especially prevalent in relation to whites (Manson, 1998). In terms of patterns of utilization, Native Americans are overrepresented in psychiatric inpatient care in relation to whites, with the exception of private psychiatric hospitals (Snowden & Cheung, 1990; Snowden, in press-b).

Barriers to the Receipt of Treatment

The underrepresentation in outpatient treatment of racial and ethnic minority groups appears to be the result of cultural differences as well as financial, organizational, and diagnostic factors. The service system has not been designed to respond to the cultural and linguistic needs presented by many racial and ethnic minorities. What is unresolved are the relative contribution and significance of each factor for distinct minority groups.

Help-Seeking Behavior

Among adults, the evidence is considerable that persons from minority backgrounds are less likely than are whites to seek outpatient treatment in the specialty mental health sector (Sussman et al., 1987; Gallo et al., 1995; Leong & Lau, 1998; Snowden, 1998; Vega et al., 1998a, 1998b; Zhang et al., 1998). This is not the case for emergency department care, from which African Americans are more likely than whites to seek care for mental health problems, as noted above. Language, like economic and accessibility differences, can play an important role in why people from

other cultures do not seek treatment (Hunt, 1984; Comas-Diaz, 1989; Cook & Timberlake, 1989; Taylor, 1989).

Mistrust

The reasons why racial and ethnic minority groups are less apt to seek help appear to be best studied among African Americans. By comparison with whites, African Americans are more likely to give the following reasons for not seeking professional help in the face of depression: lack of time, fear of hospitalization, and fear of treatment (Sussman et al., 1987). Mistrust among African Americans may stem from their experiences of segregation, racism, and discrimination (Primm et al., 1996; Priest, 1991). African Americans have experienced racist slights in their contacts with the mental health system, called "microinsults" by Pierce (1992). Some of these concerns are justified on the basis of research, cited below, revealing clinician bias in overdiagnosis of schizophrenia and underdiagnosis of depression among African Americans.

Lack of trust is likely to operate among other minority groups, according to research about their attitudes toward government-operated institutions rather than toward mental health treatment per se. This is particularly pronounced for immigrant families with relatives who may be undocumented, and hence they are less likely to trust authorities for fear of being reported and having the family member deported. People from El Salvador and Argentina who have experienced imprisonment or watched the government murder family members and engage in other atrocities may have an especially strong mistrust of any governmental authority (Garcia & Rodriguez, 1989). Within the Asian community, previous refugee experiences of groups such as Vietnamese, Indochinese, and Cambodian immigrants parallel those experienced by Salvadoran and Argentine immigrants. They, too, experienced imprisonment, death of family members or friends, physical abuse, and assault, as well as new stresses upon arriving in the United States (Cook & Timberlake, 1989; Mollica, 1989).

American Indians' past experience in this country also imparted lack of trust of government. Those living on Indian reservations are particularly fearful of sharing any information with white clinicians employed by the government. As with African Americans, the historical relationship of forced control, segregation, racism, and discrimination has affected their ability to trust a white majority population (Herring, 1994; Thompson, 1997).

Stigma

The stigma of mental illness is another factor preventing African Americans from seeking treatment, but not at a rate significantly different from that of whites. Both African American and white groups report that embarrassment hinders them from seeking treatment (Sussman et al., 1987). In general, African Americans tend to deny the threat of mental illness and strive to overcome mental health problems through self-reliance and determination (Snowden, 1998). Stigma, denial, and self-reliance are likely explanations why other minority groups do not seek treatment, but their contribution has not been evaluated empirically, owing in part to the difficulty of conducting this type of research. One of the few studies of Asian Americans identified the barriers of stigma, suspiciousness, and a lack of awareness about the availability of services (Uba, 1994). Cultural factors tend to encourage the

use of family, traditional healers, and informal sources of care rather than treatment-seeking behavior, as noted earlier.

Cost

Cost is yet another factor discouraging utilization of mental health services (Chapter 6). Minority persons are less likely than whites to have private health insurance, but this factor alone may have little bearing on access. Public sources of insurance and publicly supported treatment programs fill some of the gap. Even among working class and middle-class African Americans who have private health insurance, there is underrepresentation of African Americans in outpatient treatment (Snowden, 1998). Yet studies focusing only on poor women, most of whom were members of minority groups, have found cost and lack of insurance to be barriers to treatment (Miranda & Green, 1999). The discrepancies in findings suggest that much research remains to be performed on the relative importance of cost, cultural, and organizational barriers, and poverty and income limitations across the spectrum of racial and ethnic and minority groups.

Clinician Bias

Advocates and experts alike have asserted that bias in clinician judgment is one of the reasons for overutilization of inpatient treatment by African Americans. Bias in clinician judgment is thought to be reflected in overdiagnosis or misdiagnosis of mental disorders. Since diagnosis is heavily reliant on behavioral signs and patients' reporting of the symptoms, rather than on laboratory tests, clinician judgment plays an enormous role in the diagnosis of mental disorders. The strongest evidence of clinician bias is apparent for African Americans with schizophrenia and depression. Several studies found that African Americans were more likely than were whites to be diagnosed with schizophrenia, yet less likely to be diagnosed with depression (Snowden & Cheung, 1990; Hu et al., 1991; Lawson et al., 1994).

In addition to problems of overdiagnosis or misdiagnosis, there may well be a problem of underdiagnosis among minority groups, such as Asian Americans, who are seen as "problem-free" (Takeuchi & Uehara, 1996). The presence and extent of this type of clinician bias are not known and need to be investigated.

Improving Treatment for Minority Groups

The previous paragraphs have documented underutilization of treatment, less help-seeking behavior, inappropriate diagnosis, and other problems that have beset racial and ethnic minority groups with respect to mental health treatment. This kind of evidence has fueled the widespread perception of mental health treatment as being uninviting, inappropriate, or not as effective for minority groups as for whites. The Schizophrenia Patient Outcome Research Team demonstrated that African Americans were less likely than others to have received treatment that conformed to recommended practices (Lehman & Steinwachs, 1998). Inferior treatment outcomes are widely assumed but are difficult to prove, especially because of sampling, questionnaire, and other design issues, as well as problems in studying patients who drop out of treatment after one session or who otherwise terminate prematurely. In a classic study, 50 percent of Asian Americans versus 30 percent of whites dropped out of treatment early (Sue & McKinney, 1975). However, the disparity in dropout rates may have abated more recently (O'Sullivan et al., 1989; Snowden et al.,

1989). One of the few studies of clinical outcomes, a pre- versus post-treatment study, found that African Americans fared more poorly than did other minority groups treated as outpatients in the Los Angeles area (Sue et al., 1991). Earlier studies from the 1970s and 1980s had given inconsistent results (Sue et al., 1991).

Ethnopsychopharmacology

There is mounting awareness that ethnic and cultural influences can alter an individual's responses to medications (pharmacotherapies). The relatively new field of ethnopsychopharmacology investigates cultural variations and differences that influence the effectiveness of pharmacotherapies used in the mental health field. These differences are both genetic and psychosocial in nature. They range from genetic variations in drug metabolism to cultural practices that affect diet, medication adherence, placebo effect, and simultaneous use of traditional and alternative healing methods (Lin et al., 1997). Just a few examples are provided to illustrate ethnic and racial differences.

Pharmacotherapies given by mouth usually enter the circulation after absorption from the stomach. From the circulation they are distributed throughout the body (including the brain for psychoactive drugs) and then metabolized, usually in the liver, before they are cleared and eliminated from the body (Brody, 1994). The rate of metabolism affects the amount of the drug in the circulation. A slow rate of metabolism leaves more drug in the circulation. Too much drug in the circulation typically leads to heightened side effects. A fast rate of metabolism, on the other hand, leaves less drug in the circulation. Too little drug in the circulation reduces its effectiveness.

There is wide racial and ethnic variation in drug metabolism. This is due to genetic variations in drug-metabolizing enzymes (which are responsible for breaking down drugs in the liver). These genetic variations alter the activity of several drug-metabolizing enzymes. Each drug-metabolizing enzyme normally breaks down not just one type of pharmacotherapy, but usually several types. Since most of the ethnic variation comes in the form of inactivation or reduction in activity in the enzymes, the result is higher amounts of medication in the blood, triggering untoward side effects.

For example, 33 percent of African Americans and 37 percent of Asians are slow metabolizers of several antipsychotic medications and antidepressants (such as tricyclic antidepressants and selective serotonin reuptake inhibitors) (Lin et al., 1997). This awareness should lead to more cautious prescribing practices, which usually entail starting patients at lower doses in the beginning of treatment. Unfortunately, just the opposite typically had been the case with African American patients and antipsychotic drugs. Clinicians in psychiatric emergency services prescribed more oral doses and more injections of antipsychotic medications to African American patients (Segel et al., 1996). The combination of slow metabolism and overmedication of antipsychotic drugs in African Americans can yield very uncomfortable extrapyramidal ²⁶ side effects (Lin et al., 1997). These are the kinds of experiences that likely contribute to the mistrust of mental health services reported among African Americans (Sussman et al., 1987).

Psychosocial factors also can play an important role in ethnic variation. Compliance with dosing may be hindered by communication difficulties; side effects can be

misinterpreted or carry different connotations; some groups may be more responsive to placebo treatment; and reliance on psychoactive traditional and alternative healing methods (such as medicinal plants and herbs) may result in interactions with prescribed pharmacotherapies. The result could be greater side effects and enhanced or reduced effectiveness of the pharmacotherapy, depending on the agents involved and their concentrations (Lin et al., 1997). Greater awareness of ethnopsychopharmacology is expected to improve treatment effectiveness for racial and ethnic minorities. More research is needed on this topic across racial and ethnic groups.

²⁰ The term "Latino(a)" refers to all persons of Mexican, Puerto Rican, Cuban, or other Central and South American or Spanish origin (CMHS, 1998).

²¹ Acculturation refers to the "social distance" separating members of an ethnic or racial group from the wider society in areas of beliefs and values and primary group relations (work, social clubs, family, friends) (Gordon, 1964). Greater acculturation thus reflects greater adoption of mainstream beliefs and practices and entry into primary group relations.

²² Research is emerging on the importance of tailoring services to the special needs of gay, lesbian, and bisexual mental health service users (Cabaj & Stein, 1996).

²³ Of the 15 percent of the U.S. population that use mental health services in a given year, about 2.8 percent receive care only from members of the clergy (Larson et al., 1988).

²⁴ In spring 2000, survey field work begins on an NIMH-funded study of the prevalence of mental disorders, mental health symptoms, and related functional impairments in African Americans, Caribbean blacks, and non-Hispanic whites. The study will examine the effects of psychosocial factors and race-associated stress on mental health, and how coping resources and strategies influence that impact. The study will provide a database on mental health, mental disorders, and ethnicity and race. James Jackson, Ph.D., University of Michigan, is principal investigator.

²⁵ African Americans are overrepresented among persons undergoing involuntary civil commitment (Snowden, in press-b).

²⁶ Dystonia (brief or prolonged contraction of muscles), akathisia (an urge to move about constantly), or parkinsonism (tremor and rigidity) (Perry et al., 1997).

Overview of Consumer and Family Movements

Since the late 1970s, mental health services continue to be transformed by the growing influence of consumer and family organizations (Lefley, 1996). Through strong advocacy, consumer and family organizations have gained a voice in legislation and policy for mental health service delivery. Organizations representing

consumers and family members, though divergent in their historical origins and philosophy, have developed some important, overlapping goals: overcoming stigma and preventing discrimination, promoting self-help groups, and promoting recovery from mental illness (Frese, 1998).

This section covers the history, goals, and impact of consumer and family organizations, whereas the next section covers the process of recovery from mental illness. With literally hundreds of grassroots consumer organizations across the United States, no single organization speaks for all consumers or all families. In fact, even the term "consumer" is not uniformly accepted. Despite the heterogeneity, these organizations typically offer some combination of advocacy and self-help groups (Lefley, 1996).

Many users of mental health services refer to themselves as "consumers." The lexicon is complicated by objections to the term "consumer." To some, being a consumer erroneously signifies that service users have the power to choose services most suitable to their needs. Those who object contend that consumers have neither choices, leverage, nor power to select services. Instead, some consumers refer to themselves as "survivors" or "ex-patients" to denote that they have survived what they experienced as oppression by the mental health system (Chamberlin & Rogers, 1990). This distinction can best be understood in its historical context.

Origins and Goals of Consumer Groups

The consumer movement arose as a protest in the 1970s by former patients of mental hospitals. Their antecedents trace back to the 19th century, when a handful of individuals recovered enough to write exposés expressing their outrage at the indignities and abuses inside mental hospitals. The most persuasive former patient was Clifford Beers, whose classic book, *A Mind That Found Itself* (1908), galvanized the mental hygiene reform movement (Grob, 1994). Beers was among the founders of the National Committee on Mental Hygiene, an advocacy group that later was renamed the National Mental Health Association. This group focuses on linking citizens and mental health professionals in broad-based prevention of mental illness.

With the advent of deinstitutionalization in the 1950s, increasing numbers of former patients of mental hospitals began to forge informal ties in the community. By the 1960s, the civil rights movement inspired former patients to become better organized into what was then coined the mental patients' liberation movement (Chamberlin, 1995). Groups of patients saw themselves as having been rejected by society and robbed of power and control over their lives. To surmount what they saw as persecution, they began to advocate for self-determination and basic rights (Chamberlin, 1990; Frese & Davis, 1997). The posture of these early groups was decidedly militant against psychiatry, against laws favoring involuntary commitment, and often against interventions such as electroconvulsive therapy and antipsychotic medications (Lefley, 1996; Frese, 1998). Groups called Alliance for the Liberation of Mental Patients, the Insane Liberation Front, and Project Release met in homes and churches, drawing their membership from those with firsthand experiences with the mental health system. Largely unfunded, they sustained their membership by providing peer support, education about services in the community, and advocacy to help members access services and to press for reforms (Furlong-Norman, 1988).

The book *On Our Own* (1978) by former patient Judi Chamberlin was a benchmark in the history of the consumer movement. Consumers and others were able to read in the mainstream press what it was like to have experienced the mental health system. For many consumers, reading this book was the beginning of their involvement in consumer organizations (Van Tosh & del Vecchio, in press). Early consumer groups, although geographically dispersed, voluntary, and independent, were linked through the newsletter *Madness Network News*, which continued publication from 1972 to 1986. During the same era, the Conference on Human Rights and Against Psychiatric Oppression was established and met annually from 1973 through 1985 (Chamberlin, 1990). In 1978, early consumer groups gained what they perceived as their first official acknowledgment from the highest levels of government. The President's Commission on Mental Health stated that ". . . groups composed of individuals with mental or emotional problems are being formed all over the United States" (President's Commission on Mental Health, 1978, pp. 14–15). To date, racial and ethnic minority group members are underrepresented within the consumer movement proportionate to their growing representation in the U.S. population. There is a need for more outreach and involvement of consumers representing the special concerns of racial and ethnic minorities.

The advocacy positions of consumers have dealt with the role of involuntary treatment, self-managed care, the role of consumers in research, the delivery of services, and access to mental health services. By 1985, consumer views became so divergent that two groups emerged: The National Association of Mental Patients²⁷ and the National Mental Health Consumers' Association. The former opposed all forms of involuntary treatment, supported the prohibition of electroconvulsive therapy, and rejected psychotropic medications and hospitalization. The latter organization held more moderate views for improving rather than eschewing the mental health service system (Lefley, 1996; Frese, 1998). Both groups eventually disbanded, but the differences of opinion that they reflected became deeply entrenched.

Self-Help Groups

Self-help refers to groups led by peers to promote mutual support, education, and growth (Lefley, 1996). Self-help is predicated on the belief that individuals who share the same health problem can help themselves and each other to cope with their condition. The self-help approach enjoys a long history, most notably with the formation of Alcoholics Anonymous in 1935 (IOM, 1990). Over time, the self-help approach has been brought to virtually every conceivable health condition.

Since the 1970s, many mental health consumer groups emphasized self-help as well as advocacy (Chamberlin, 1995), although to different degrees. Self-help for recovering mental patients initially emphasized no involvement with mental health professionals. Over time the numbers and types of self-help groups began to flourish and more moderate viewpoints became represented. Self-help groups assume three different postures toward health professionals: the separatist model, the supportive model that allows professionals to aid in auxiliary roles, and partnership models in which professionals act as leaders alongside patients (Chamberlin, 1978; Emerick, 1990). The focus of groups varies, with some groups united on the basis of diagnosis, such as Schizophrenics Anonymous and the National Depressive and Manic-Depressive Association, whereas others are more broad based.

Chamberlin's influential book and another book by former patients, *Reaching Across* (Zinman et al., 1987), explained to consumers how to form self-help groups. These books also extended the concept of self-help more broadly into the provision of consumer-run services as alternatives (as opposed to adjuncts) to mental health treatment (Lefley, 1996).

Programs entirely run by consumers include drop-in centers, case management programs, outreach programs, businesses, employment and housing programs, and crisis services (Long & Van Tosh, 1988; National Resource Center on Homelessness and Mental Illness, 1989; Van Tosh & del Vecchio, in press). Drop-in centers are places for consumers to obtain social support and assistance with problems. Although research is limited, the efficacy of consumer-run services is discussed in Chapter 4.

Consumer positions also are being incorporated into more conventional mental health services—as job coaches and case manager extenders, among others. The rationale for employing consumers in service delivery—in consumer-run or conventional programs—is to benefit those hired and those served. Consumers who are hired obtain employment, enhance self-esteem, gain work experience and skills, and sensitize other service providers to the needs of people with mental disorders. Consumers who are served may be more receptive to care and have role models engaged in their care (Mowbray et al., 1996).

Accomplishments of Consumer Organizations

Consumer organizations have had measurable impact on mental health services, legislation, and research. One of their greatest contributions has been the organization and proliferation of self-help groups and their impact on the lives of thousands of consumers of mental health services. In 1993, a collaborative survey found that 46 state mental health departments funded 567 self-help groups and agencies for persons with mental disabilities and their family members (National Association of State Mental Health Program Directors, 1993). A nationwide directory lists all 50 states and the District of Columbia as having 235 different mental health consumer organizations (South Carolina SHARE, 1995).

On a systems level, the consumer movement has substantially influenced mental health policy to tailor services to consumer needs. This influence is described by consumers and researchers as "empowerment." A concept from the social sciences, empowerment has come to be defined by mental health researchers as "gaining control over one's life in influencing the organizational and societal structures in which one lives" (Segal et al., 1995).

Consumers are now involved in all aspects of the planning, delivery, and evaluation of mental health services, and in the protection of individual rights. One prominent example is the passage of Public Law 102-321, which established mental health planning councils in every state. Planning councils are required to have membership from consumers and families. Having a planning council so constituted is required for the receipt of Federal block grant funds for mental health services. Other Federal legislation required the establishment of protection and advocacy agencies for patients' rights in every state (Chamberlin & Rogers, 1990; Lefley, 1996).

Another significant development has been the establishment of offices of consumer affairs in many state mental health authorities. Offices of consumer affairs are generally staffed by consumers to support consumer empowerment and self-help in their particular states. A recent survey of state mental health authorities identified 27 states as having paid positions for consumers in central offices (Geller et al., 1998). In 1995, the Federal Center for Mental Health Services hired its first consumer affairs specialist.

The consumer movement also has had a substantial influence on increasing the utilization of consumers as employees in the traditional mental health system, as well as in other human service agencies (Specht, 1988; U.S. Department of Education, 1990; Schlageter, 1990; Interagency Council on the Homeless, 1991). Consumers are being hired at all levels in the mental health system, ranging from case manager aides to management positions in national advocacy organizations, as well as state and Federal governmental agencies.

Finally, consumers continue to be involved in research in several ways: as *participants* of clinical research; as *respondents* who are asked questions about conditions in their life; as *partners* in some aspect of the planning, designing, and conducting of the research project with professional researchers in control; and as *independent researchers* who conduct, analyze the data, and publish the results of the research project (Campbell et al., 1993). The past decade has witnessed the blossoming of a vibrant consumer research agenda and the growing belief that consumer involvement in research and evaluation holds great promise for system reform, quality improvement, and outcome measurement (Campbell et al., 1993; Campbell, 1997). In an effort to enhance the active role of consumers and others in the research process, the National Institute of Mental Health is developing a systematic means of including public participants in the initial review of grant applications in the areas of clinical treatment and services research. This innovation follows up on a recommendation made by the Institute of Medicine and Committee for the Study of the Future of Public Health (1988).

Family Advocacy

The family movement has experienced spectacular growth and influence since its beginnings in the late 1970s (Lefley, 1996). Although several advocacy and professional organizations speak to the needs of families, the family movement is principally represented by three large organizations. They are the National Alliance for the Mentally Ill (NAMI), the Federation of Families for Children's Mental Health (FFCMH), and the National Mental Health Association (NMHA). NAMI serves families of adults with chronic mental illness, whereas the Federation serves children and youth with emotional, behavioral, or mental disorders. NMHA serves a broad base of family members and other supporters of children and adults with mental disorders and mental health problems. Though the target populations are different, these organizations are similar in their devotion to advocacy, family support, research, and public awareness.

Fragmentation and lack of availability of services were motivating forces behind the establishment of the family movement. Deinstitutionalization, in particular, was a cogent impetus for the formation of NAMI. Deinstitutionalization of the mentally ill left families in the unexpected position of having to assume care for their adult children, a role for which they were ill prepared. Another motivating force behind the

family movement was the past tendency by the mental health establishment to blame parents for the mental illness in children (Frese, 1998). The cause of schizophrenia, for example, had been attributed to the "schizophrenogenic mother," who was cold and aloof, according to a reigning but now discredited view of etiology. Similarly, parents were viewed as partly to blame for children with serious emotional or behavioral disturbances (Melaville & Asayesh 1993; Friesen & Stephens, 1998).

NAMI was created as a grassroots organization in 1979 by a small cadre of families in Madison, Wisconsin. Since then, its membership has skyrocketed to 208,000 in all 50 states (NAMI, 1999). NAMI's principal goal is to advocate for improved services for persons with severe and persistent mental illness—for example, schizophrenia and bipolar disorder. Its sole emphasis on the most severely affected consumers distinguishes it from most other consumer and family organizations. Another NAMI goal is to transform public attitudes and reduce stigma by emphasizing the biological basis of serious mental disorders, as opposed to poor parenting (Frese, 1998; NAMI, 1999). Correspondingly, NAMI advocates for intensification of research in the neurosciences. Through state and local affiliates, NAMI operates a network of family groups for self-help and education purposes.

NAMI's accomplishments are formidable. The organization has become a powerful voice for the expansion of community-based services to fulfill the vision of the community support reform movement. NAMI has successfully pressed for Federal legislation for family membership in state mental health planning boards. It is a prime force behind congressional legislation for parity in the financing of mental health services. It also has made substantial inroads in the training of mental health professionals to sensitize them to the predicament of the chronically mentally ill. It has promoted "psychoeducation," specific information to family members, usually in small-group settings, about schizophrenia and about strategies for dealing with relatives with schizophrenia (Lamb, 1994). Finally, NAMI has successfully lobbied for increased Federal research funding, and it has set up private research foundations (Lefley, 1996).

Similarly, advocacy by parents on behalf of children with serious emotional or behavioral disturbances has had a compelling impact. Advocacy for children was electrified by the publication of Jane Knitzer's 1982 book, *Unclaimed Children*; shortly afterward, the National Mental Health Association (NMHA) issued *Invisible Children* (NMHA, 1983), followed by *A Guide for Advocates to All Systems Failure* (NMHA, 1993). Knitzer chronicled the plight of families in trying to access care from disparate and uncoordinated public agencies, many of which blamed or ignored parents. NMHA, a pioneer in the mental health advocacy field, assumed a pivotal role in strengthening the child mental health movement in the 1980s and early 1990s. Over time, the Federation of Families for Children's Mental Health has become another focal point for families, championing family participation and support in systems of care and access to services. The Federation's chapters across the United States offer self-help, education, and networking (FFCMH, 1999). Through the efforts of these groups and individuals, among the most noteworthy accomplishments of the family movement has been the emergence of family participation in decisionmaking about care for children, one of the decisive historical shifts in service delivery in the past 20 years.

Overview of Recovery

Until recently, some severe mental disorders were generally considered to be marked by lifelong deterioration. Schizophrenia, for instance, was seen by the mental health profession as having a uniformly downhill course (Harding et al., 1992). At the beginning of the 20th century, the leading psychiatrist of the era, Emil Kraepelin, judged the outcome of schizophrenia to be so dismal that he named the disorder "dementia praecox," or premature dementia. Negative conceptions of severe mental illness, perpetuated in textbooks for decades by Kraepelin's original writings, dampened consumers' and families' expectations, leaving them without hope. A turnaround in attitudes came as a result of the consumer movement and self-help activities. They mobilized a shift toward a more positive set of consumer attitudes and self-perceptions. Research provided a scientific basis for and supported a more optimistic view of the possibility of recovering function (Harding et al., 1992). Promoting recovery became a rallying point and common ground for the consumer and family movements (Frese, 1998).

The concept of recovery is having substantial impact on consumers and families, mental health research, and service delivery. Before describing that impact, this section first turns to an introduction and definitions.

Introduction and Definitions

Recovery is a *concept* introduced in the lay writings of consumers beginning in the 1980s. It was inspired by consumers who had themselves recovered to the extent that they were able to write about their experiences of coping with symptoms, getting better, and gaining an identity (Deegan, 1988; Leete, 1989). Recovery also was fueled by longitudinal research uncovering a more positive course for a significant number of patients with severe mental illness (Harding et al., 1992), although findings across several studies were variable (Harrow et al., 1997) (see discussion in Chapter 4).

Recovery is variously called a process, an outlook, a vision, a guiding principle. There is neither a single agreed-upon definition of recovery nor a single way to measure it. But the overarching message is that hope and restoration of a meaningful life are possible, despite serious mental illness (Deegan, 1988; Anthony, 1993; Stocks, 1995; Spaniol et al., 1997). Instead of focusing primarily on symptom relief, as the medical model dictates, recovery casts a much wider spotlight on restoration of self-esteem and identity and on attaining meaningful roles in society.

Written testimonials by former mental patients have appeared for centuries. These writings, according to historian of medicine Roy Porter, "shore up that sense of personhood and identity which they feel is eroded by society and psychiatry" (Porter, 1987). What distinguishes the contemporary wave of writings is their critical mass, organizational backing, and freedom of expression from outside the confines of the institution. Deinstitutionalization, the emergence of community supports and psychosocial rehabilitation, and the growth of the consumer and family advocacy movements all paved the way for recovery to take hold (Anthony, 1993).

The concept of recovery continues to be defined in the writings of consumers (see Figure 2-7). These lay writings offer a range of possible definitions, many of which

seek to discover meaning, purpose, and hope from having mental illness (Lefley, 1996). The definitions do not, however, imply full recovery, in which full functioning is restored and no medications are needed. Instead they suggest a journey or process, not a destination or cure (Deegan, 1997). One of the most prominent professional proponents of recovery, William A. Anthony, crystallized consumer writings on recovery with the following definition:

... a person with mental illness can recover even though the illness is not "cured" . . . [Recovery] is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (Anthony, 1993).

It is important to point out that consumers see a distinction between recovery and psychosocial rehabilitation. The latter, which is discussed more extensively in Chapter 4, refers to professional mental health services that bring together approaches from the rehabilitation and the mental health fields (Cook et al., 1996). These services combine pharmacological treatment, skills training, and psychological and social support to clients and families in order to improve their lives and functional capacities. Recovery, by contrast, does not refer to any specific services. Rather, according to the writings of pioneering consumer Patricia Deegan, recovery refers to the "lived experience" of gaining a new and valued sense of self and of purpose (Deegan, 1988).

Figure 2-7. Definitions of recovery from consumer writings

Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again. . . .The need is to meet the challenge of the disability and to reestablish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution (Deegan, 1988, p. 15).

One of the elements that makes recovery possible is the regaining of one's belief in oneself (Chamberlin, 1997, p. 9).

Having some hope is crucial to recovery; none of us would strive if we believed it a futile effort. . . .I believe that if we confront our illnesses with courage and struggle with our symptoms persistently, we can overcome our handicaps to live independently, learn skills, and contribute to society, the society that has traditionally abandoned us (Leete, 1989, p. 32).

A recovery paradigm is each person's unique experience of their road to recovery. . . .My recovery paradigm included my reconnection which included the following four key ingredients: connection, safety,

hope, and acknowledgment of my spiritual self (Long, 1994, p. 4).

To return renewed with an enriched perspective of the human condition is the major benefit of recovery. To return at peace, with yourself, your experience, your world, and your God, is the major joy of recovery (Granger, 1994, p. 10).

Impact of the Recovery Concept

The impact of the recovery concept is felt most by consumers and families. Consumers and families are energized by the message of hope and self-determination. Having more active roles in treatment, research, social and vocational functioning, and personal growth strikes a responsive cord. Consumers' harboring more optimistic attitudes and expectations may improve the course of their illness, based on related research from the field of psychosocial and vocational rehabilitation (see Chapter 4). Yet direct empirical support for the salutary, long-term effect of positive expectations, on both consumers and families, is still in its infancy (Lefley, 1997).

The recovery concept likewise is having a bearing on mental health research and services. Researchers are beginning to study consumer attitudes and behavior to attempt to identify the elements contributing to recovery. Though still at an early stage, research is being driven by consumer perspectives on recovery. Consumers assert that the recovery process is governed by internal factors (their psychological perceptions and expectations), external factors (social supports), and the ability to self-manage care, all of which interact to give them mastery over their lives. The first systematic efforts to define consumer perceptions of recovery was conducted by consumers. The Well-Being Project, sponsored by the California Department of Mental Health, was a landmark effort in which mental health consumers conducted a multifaceted study to define and explore factors promoting or deterring the well-being of persons diagnosed with serious mental illness (Campbell & Schraiber, 1989). Using quantitative survey research, focus groups, and oral histories, Campbell (1993) arrived at a definition of recovery that incorporates "good health, good food, and a decent place to live, all supported by an adequate income that is earned through meaningful work. We need adequate resources and a satisfying social life to meet our desires for comfort and intimacy. Well-being is enriched by creativity, a satisfying spiritual and sexual life, and a sense of happiness" (p. 28).

Through semistructured interviews with consumers about recovery, a subsequent study identified the most common factors associated with their success in dealing with a mental illness. They included medication, community support/case management, self-will/self-monitoring, vocational activity (including school), and spirituality (Sullivan, 1994). Other researchers, also using semistructured interviews, suggested that the rediscovery and reconstruction of a sense of self were important to recovery (Davidson & Strauss, 1992).

These early forays by researchers set the stage for consumer-driven research efforts to identify some of the aspects of recovery. A group of consumers with consultant researchers developed the Empowerment Scale (Rogers et al., 1997). After testing a 28-item scale on members of six self-help programs in six states, factor analysis

revealed the underlying dimensions of empowerment to be (1) self-efficacy–self-esteem; (2) power-powerlessness ; (3) community activism; (4) righteous anger; and (5) optimism–control over the future. Other instruments, found to have consistency and construct validity, are the Personal Empowerment Scale, the Organizational Empowerment Scale, and the Extra-Organizational Empowerment Scale (Segal et al., 1995).

Mental health services continue to be refined and shaped by the consumer and recovery emphasis. The most tangible changes in services come from assertive community treatment and psychosocial and vocational rehabilitation, which emphasize an array of approaches to maximize functioning and promote recovery. Consumer interest in self-help and recovery has stimulated the proliferation of interventions for what has been called “illness management” or “self-managed care” for relapse prevention of psychotic symptoms. Illness management training programs now teach individuals to identify early warning signs of relapse and to develop strategies for their prevention. All of these transformations in service delivery and research affirming their benefits are discussed at length in Chapter 4.

Champions of recovery assert that its greatest impact will be on mental health providers and the future design of the service system. They envision services being structured to be recovery-oriented to ensure that recovery takes place. They envision mental health professionals believing in and supporting consumers in their quest to recover. In a groundbreaking article, William A. Anthony described recovery as a guiding vision that “pulls the field of services into the future. A vision is not reflective of what we are currently achieving, but of what we hope for and dream of achieving. Visionary thinking does not raise unrealistic expectations. A vision begets not false promises but a passion for what we are doing.”

Conclusions

The past 25 years have been marked by several discrete, defining trends in the mental health field. These have included:

1. The extraordinary pace and productivity of scientific research on the brain and behavior;
2. The introduction of a range of effective treatments for most mental disorders;
3. A dramatic transformation of our society’s approaches to the organization and financing of mental health care; and
4. The emergence of powerful consumer and family movements.

Scientific Research. The brain has emerged as the central focus for studies of mental health and mental illness. New scientific disciplines, technologies, and insights have begun to weave a seamless picture of the way in which the brain mediates the influence of biological, psychological, and social factors on human thought, behavior, and emotion in health and in illness. Molecular and cellular biology and molecular genetics, which are complemented by sophisticated cognitive and behavioral science, are preeminent research disciplines in the contemporary neuroscience of mental health. These disciplines are affording unprecedented opportunities for “bottom-up”

studies of the brain. This term refers to research that is examining the workings of the brain at the most fundamental levels. Studies focus, for example, on the complex neurochemical activity that occurs within individual nerve cells, or neurons, to process information; on the properties and roles of proteins that are expressed, or produced, by a person's genes; and on the interaction of genes with diverse environmental influences. All of these activities now are understood, with increasing clarity, to underlie learning, memory, the experience of emotion, and, when these processes go awry, the occurrence of mental illness or a mental health problem.

Equally important to the mental health field is "top-down" research; here, as the term suggests, the aim is to understand the broader behavioral context of the brain's cellular and molecular activity and to learn how individual neurons work together in well-delineated neural circuits to perform mental functions.

Effective Treatments. As information accumulates about the basic workings of the brain, it is the task of translational research to transfer new knowledge into clinically relevant questions and targets of research opportunity—to discover, for example, what specific properties of a neural circuit might make it receptive to safer, more effective medications. To elaborate on this example, theories derived from knowledge about basic brain mechanisms are being wedded more closely to brain imaging tools such as functional Magnetic Resonance Imaging (MRI) that can observe actual brain activity. Such a collaboration would permit investigators to monitor the specific protein molecules intended as the "targets" of a new medication to treat a mental illness or, indeed, to determine how to optimize the effect on the brain of the learning achieved through psychotherapy.

In its entirety, the new "integrative neuroscience" of mental health offers a way to circumvent the antiquated split between the mind and the body that historically has hampered mental health research. It also makes it possible to examine scientifically many of the important psychological and behavioral theories regarding normal development and mental illness that have been developed in years past. The unswerving goal of mental health research is to develop and refine clinical treatments as well as preventive interventions that are based on an understanding of specific mechanisms that can contribute to or lead to illness but also can protect and enhance mental health.

Mental health clinical research encompasses studies that involve human participants, conducted, for example, to test the efficacy of a new treatment. A noteworthy feature of contemporary clinical research is the new emphasis being placed on studying the effectiveness of interventions in actual practice settings. Information obtained from such studies increasingly provides the foundation for services research concerned with the cost, cost-effectiveness, and "deliverability" of interventions and the design—including economic considerations—of service delivery systems.

Organization and Financing of Mental Health Care. Another of the defining trends has been the transformation of the mental illness treatment and mental health services landscapes, including increased reliance on primary health care and other human service providers. Today, the U.S. mental health system is multifaceted and complex, comprising the public and private sectors, general health and specialty mental health providers, and social services, housing, criminal justice, and educational agencies. These agencies do not always function in a coordinated manner. Its configuration reflects necessary responses to a broad array of factors

including reform movements, financial incentives based on who pays for what kind of services, and advances in care and treatment technology. Although the hybrid system that exists today serves diverse functions well for many people, individuals with the most complex needs and the fewest financial resources often find the system fragmented and difficult to use. A challenge for the Nation in the near-term future is to speed the transfer of new evidence-based treatments and prevention interventions into diverse service delivery settings and systems, while ensuring greater coordination among these settings and systems.

Consumer and Family Movements. The emergence of vital consumer and family movements promises to shape the direction and complexion of mental health programs for many years to come. Although divergent in their historical origins and philosophy, organizations representing consumers and family members have promoted important, often overlapping goals and have invigorated the fields of research as well as treatment and service delivery design. Among the principal goals shared by much of the consumer movement are to overcome stigma and prevent discrimination in policies affecting persons with mental illness; to encourage self-help and a focus on recovery from mental illness; and to draw attention to the special needs associated with a particular disorder or disability, as well as by age or gender or by the racial and cultural identity of those who have mental illness.

Chapter 2 of the report was written to provide background information that would help persons from outside the mental health field better understand topics addressed in subsequent chapters of the report. Although the chapter is meant to serve as a mental health primer, its depth of discussion supports a range of conclusions:

1. The multifaceted complexity of the brain is fully consistent with the fact that it supports all behavior and mental life. Proceeding from an acknowledgment that all psychological experiences are recorded ultimately in the brain and that all psychological phenomena reflect biological processes, the modern neuroscience of mental health offers an enriched understanding of the inseparability of human experience, brain, and mind.
2. Mental functions, which are disturbed in mental disorders, are mediated by the brain. In the process of transforming human experience into physical events, the brain undergoes changes in its cellular structure and function.
3. Few lesions or physiologic abnormalities define the mental disorders, and for the most part their causes remain unknown. Mental disorders, instead, are defined by signs, symptoms, and functional impairments.
4. Diagnoses of mental disorders made using specific criteria are as reliable as those for general medical disorders.
5. About one in five Americans experiences a mental disorder in the course of a year. Approximately 15 percent of all adults who have a mental disorder in one year also experience a co-occurring substance (alcohol or other drug) use disorder, which complicates treatment.
6. A range of treatments of well-documented efficacy exists for most mental disorders. Two broad types of intervention include psychosocial treatments—for example, psychotherapy or counseling and—psychopharmacologic treatments; these often are most effective when combined.
7. In the mental health field, progress in developing preventive interventions has been slow because, for most major mental disorders, there is insufficient understanding about etiology (or causes of illness) and/or there is an inability

- to alter the *known* etiology of a particular disorder. Still, some successful strategies have emerged in the absence of a full understanding of etiology.
- 8. About 10 percent of the U.S. adult population uses mental health services in the health sector in any year, with another 5 percent seeking such services from social service agencies, schools, religious, or self-help groups. Yet critical gaps exist between those who need service and those who receive service.
 - 9. Gaps also exist between optimally effective treatment and what many individuals receive in actual practice settings.
 - 10. Mental illness and less severe mental health problems must be understood in a social and cultural context, and mental health services must be designed and delivered in a manner that is sensitive to the perspectives and needs of racial and ethnic minorities.
 - 11. The consumer movement has increased the involvement of individuals with mental disorders and their families in mutual support services, consumer-run services, and advocacy. They are powerful agents for changes in service programs and policy.
 - 12. The notion of recovery reflects renewed optimism about the outcomes of mental illness, including that achieved through an individual's own self-care efforts, and the opportunities open to persons with mental illness to participate to the full extent of their interests in the community of their choice.

Mental Health and Mental Illness Across the Lifespan

The Surgeon General's report takes a lifespan approach to its consideration of mental health and mental illness. Three chapters that address, respectively, the periods of childhood and adolescence, adulthood, and later adult life beginning somewhere between ages 55 and 65, capture the contributions of research to the breadth, depth, and vibrancy that characterize all facets of the contemporary mental health field.

The disorders featured in depth in Chapters 3, 4, and 5 were selected on the basis of the frequency with which they occur in our society, and the clinical, societal, and economic burden associated with each. To the extent that data permit, the report takes note of how gender and culture, in addition to age, influence the diagnosis, course, and treatment of mental illness. The chapters also note the changing role of consumers and families, with attention to informal support services (i.e., unpaid services), with which many consumers are comfortable and upon which they depend for information. Persons with mental illness and, often, their families welcome a proliferating array of support services—such as self-help programs, family self-help, crisis services, and advocacy—that help them cope with the isolation, family disruption, and possible loss of employment and housing that may accompany mental disorders. Support services can help to dissipate stigma and to guide patients into formal care as well.

Mental health and mental illness are dynamic, ever-changing phenomena. At any given moment, a person's mental status reflects the sum total of that individual's genetic inheritance and life experiences. The brain interacts with and responds—both in its function and in its very structure—to multiple influences continuously, across every stage of life. At different stages, variability in expression of mental health and mental illness can be very subtle or very pronounced. As an example, the symptoms

of separation anxiety are normal in early childhood but are signs of distress in later childhood and beyond. It is all too common for people to appreciate the impact of developmental processes in children, yet not to extend that conceptual understanding to older people. In fact, people continue to develop and change throughout life. Different stages of life are associated with vulnerability to distinct forms of mental and behavioral disorders but also with distinctive capacities for mental health.

Even more than is true for adults, children must be seen in the context of their social environments—that is, family and peer group, as well as that of their larger physical and cultural surroundings. Childhood mental health is expressed in this context, as children proceed along the arc of development. A great deal of contemporary research focuses on developmental processes, with the aim of understanding and predicting the forces that will keep children and adolescents mentally healthy and maintain them on course to become mentally healthy adults. Research also focuses on identifying what factors place some at risk for mental illness and, yet again, what protects some children but not others despite exposure to the *same* risk factors. In addition to studies of normal development and of risk factors, much research focuses on mental disorders in childhood and adolescence and what can be done to prevent or treat these conditions and on the design and operation of service settings best suited to the needs experienced by children.

For about one in five Americans, adulthood—a time for achieving productive vocations and for sustaining close relationships at home and in the community—is interrupted by mental illness. Understanding why and how mental disorders occur in adulthood, often with no apparent portents of illness in earlier years, draws heavily on the full panoply of research conducted under the aegis of the mental health field. In years past, the onset, or occurrence, of mental illness in the adult years, was attributed principally to observable phenomena—for example, the burden of stresses associated with career or family, or the inheritance of a disease viewed to run in a particular family. Such explanations now may appear naive at best.

Contemporary studies of the brain and behavior are racing to fill in the picture by elucidating specific neurobiological and genetic mechanisms that are the platform upon which a person's life experiences can either strengthen mental health or lead to mental illness. It now is recognized that factors that influence brain development prenatally may set the stage for a vulnerability to illness that may lie dormant throughout childhood and adolescence. Similarly, no single gene has been found to be responsible for any specific mental disorder; rather, variations in multiple genes contribute to a disruption in healthy brain function that, under certain environmental conditions, results in a mental illness. Moreover, it is now recognized that socioeconomic factors affect individuals' vulnerability to mental illness and mental health problems. Certain demographic and economic groups are more likely than others to experience mental health problems and some mental disorders. Vulnerability alone may not be sufficient to cause a mental disorder; rather, the causes of most mental disorders lie in some combination of genetic and environmental factors, which may be biological or psychosocial.

The fact that many, if not most, people have experienced mental health problems that mimic or even match some of the symptoms of a diagnosable mental disorder tends, ironically, to prompt many people to underestimate the painful, disabling nature of severe mental illness. In fact, schizophrenia, mood disorders such as major

depression and bipolar illness, and anxiety often are devastating conditions. Yet relatively few mental illnesses have an unremitting course marked by the most acute manifestations of illness; rather, for reasons that are not yet understood, the symptoms associated with mental illness tend to wax and wane. These patterns pose special challenges to the implementation of treatment plans and the design of service systems that are optimally responsive to an individual's needs during every phase of illness. As this report concludes, enormous strides are being made in diagnosis, treatment, and service delivery, placing the productive and creative possibilities of adulthood within the reach of persons who are encumbered by mental disorders.

Late adulthood is when changes in health status may become more noticeable and the ability to compensate for decrements may become limited. As the brain ages, a person's capacity for certain mental tasks tends to diminish, even as changes in other mental activities prove to be positive and rewarding. Well into late life, the ability to solve novel problems can be enhanced through training in cognitive skills and problem-solving strategies.

The promise of research on mental health promotion notwithstanding, a substantial minority of older people are disabled, often severely, by mental disorders including Alzheimer's disease, major depression, substance abuse, anxiety, and other conditions. In the United States today, the highest rate of suicide—an all-too-common consequence of unrecognized or inappropriately treated depression—is found in older males. This fact underscores the urgency of ensuring that health care provider training properly emphasizes skills required to differentiate accurately the causes of cognitive, emotional, and behavioral symptoms that may, in some instances, rise to the level of mental disorders, and in other instances be expressions of unmet general medical needs.

As the life expectancy of Americans continues to extend, the sheer number—although not necessarily the proportion—of persons experiencing mental disorders of late life will expand, confronting our society with unprecedented challenges in organizing, financing, and delivering effective mental health services for this population. An essential part of the needed societal response will include recognizing and devising innovative ways of supporting the increasingly more prominent role that families are assuming in caring for older, mentally impaired and mentally ill family members.

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