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*Part I*

*Understanding the Nature  
of Severe and Persistent  
Mental Illness*



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## Chapter 1

# *The Experience of Mental Illness: An Introduction to Psychiatric Rehabilitation*

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*Chapter 1 begins with the story of Paul, a young man diagnosed with a severe mental illness, schizophrenia. After reading about Paul you will cover basic definitions of severe mental illness, disability, and stigma. Most importantly, this chapter will introduce you to the field of psychiatric rehabilitation, an evolving set of methods, strategies, and concepts for the community treatment of persons with severe mental illness. The final section of the chapter discusses how psychiatric rehabilitation knowledge is developed, the identification of evidence-based practices, and the sources of that knowledge for professionals and students.*

*This chapter will answer the following questions:*

- 1. What are some of the symptoms and problems that might afflict a young person stricken with a severe mental illness?*
- 2. What are severe mental illnesses and how are they defined?*

3. *What is psychiatric rehabilitation?*
4. *How and when did the practice of psychiatric rehabilitation begin?*
5. *What is the state of psychiatric rehabilitation today?*

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## **Introduction**

Psychiatric rehabilitation, sometimes referred to as psychosocial rehabilitation, is a comprehensive strategy for meeting the needs of persons with severe and persistent mental illness. A true understanding of psychiatric rehabilitation (PsyR) begins with awareness and sensitivity to the personal experience of severe and debilitating mental illnesses.

Unlike many diseases with predictable symptoms and outcomes, the experience and consequences of mental illness vary considerably from person to person. This is true even for individuals diagnosed with exactly the same condition. Take for example two persons both diagnosed with schizophrenia, undifferentiated type. One may be experiencing auditory hallucinations (hearing voices), while the other person is plagued by paranoid ideas but experiences no auditory hallucinations. The history or course of mental illness may also differ from person to person. One person may have frequent relapses, while another will have additional acute episodes only occasionally. In addition, each person may adjust and respond to his or her illness differently. One person may be severely disabled throughout the course of his or her life, while another may cope well and overcome the disability.

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## **The Story of Paul**

Like any person's story, Paul's is unique. At the same time, in many respects, Paul's story resembles millions of similar situations that unfold every year throughout our country and around the world. Each of us has ideas and attitudes about mental illness that we get from personal experience, from the media, or from speaking with others. Some of these ideas are accurate. Others are half-truths and myths. Some are just plain wrong. As you read about Paul's experience consider the attitudes and ideas you have about mental illness. Also, consider the following questions:

1. Why did Paul become ill when he did? Were there any events or situations that might have led to Paul's illness?
2. What kinds of things did Paul experience as he became ill? Did the disease itself cause all of these things?
3. Could Paul's illness have been predicted or even avoided?
4. How did Paul's family handle the situation? Should they have done something differently?
5. Are there any clues as to how Paul will respond to treatment?

Paul began to realize something was wrong when he couldn't follow the lectures in his college classes. Almost anything could become a distraction. A crack in the blackboard

or the inflection of a particular word would seem as important to him as what the professor was saying. Even in his favorite class, macroeconomics, with a professor he really liked, he couldn't keep his attention on the material. Nineteen years old, a college freshman, living away from home for the first time in his life, Paul found that school was becoming a nightmare. An A-/B+ student in high school, now halfway through his first college semester, Paul was losing his ability to concentrate. He strained to listen and take good notes but his thoughts were confused. He could not seem to maintain his focus. Instead, he would hear a particular word, his thoughts would go off on a tangent, and he would lose the focus of the lecture. After class, he would struggle to summarize the main points, but nothing seemed to stand out. Everything was of equal importance. At first, Paul felt mainly frustration, but as his inability to focus continued, his anxiety increased and he began to feel frightened.

In high school Paul hung around with a group of college-bound, but not particularly motivated students. Blessed with a moderately high IQ, Paul could usually get above-average grades by paying attention in class and cramming for his finals. His one love was business. He could spend hours reading books about successful businessmen like Michael Dell and Bill Gates or books describing how successful companies like Microsoft and Ben and Jerry's were created, developed, and managed. He dreamed of one day developing and becoming the CEO of his own company. For Paul, the business environment seemed to offer opportunities for creativity and self-expression. While not interested in the personal contact necessary for a sales career, Paul was attracted to the problem solving and planning required of a successful executive. Paul's neighbor, Nancy, was his love interest during high school. Like Paul, Nancy was on the quiet side and they got along well together. Paul and Nancy would ride bikes, go to the movies, play computer games, and study together. They were best friends and talked about getting serious. Paul viewed it as a tragedy when she moved out of state with her family the summer after their sophomore year. At first, they wrote to each other weekly, but the connection grew weak and after about 6 months they hardly corresponded at all.

Paul played right field on the junior varsity baseball team during his sophomore year in high school. The coach saw him as a mediocre player and Paul only played when the team was ahead. He didn't go out for baseball again as a junior. Instead, he joined the computer club and began spending most of his time surfing the Internet and following stocks. Likable but shy, Paul spent a lot of his free time with his computer during his junior and senior years.

Paul's friend Kevin was also a member of the computer club and spent many hours hacking, surfing the Internet, and adjusting his imaginary stock portfolio to compete with Paul's. As they became friendlier, Paul felt safe confiding in Kevin. They often talked about their hopes and dreams for the future and their pet likes and dislikes. Although they weren't considered popular, Paul and Kevin were liked by most of their high school peers. Kevin was really serious about computers. He planned to be a math and computer science major in college, and his motivation to get the grades he needed to pursue his goal rubbed off on Paul.

Childhood had been a happy time for Paul. The oldest child in his family, he always got plenty of attention and love from his parents and a lot of encouragement. He thought

of his family as an on-going source of friendship, love, fun, and support. His father worked as a personnel manager for a large manufacturing company. He liked his job, loved his family, and usually had a kind word for everyone. Paul's mom worked as a medical technician at the local laboratory. She was proud of this job because it required technical skill. She also liked it because she could schedule her own hours to make time when her family needed her. It was no secret that her family came first. Paul's sister Alice was a junior in high school and his younger brother Ted was in the eighth grade.

Going away to college had seemed like a great adventure to Paul. During orientation he met his future roommate Ira, who came from out of state. A psychology major, Ira shared Paul's interest in computers and surfing the Internet. An instant friendship emerged. At first, as classes started Ira had the same positive effect on Paul's study habits as his friend Kevin. Ira, like his mother whom he looked up to, wanted to pursue a Ph.D. in psychology. Being very organized, he made sure that he and Paul set aside a block of time each evening to be used only for studying. Ira and Paul joked about becoming nerds, but Paul was secretly glad for the discipline.

Several weeks after he noticed he was having trouble focusing on lectures, Paul found himself feeling both suspicious and angry with Ira. Whenever Ira said something to him, Paul would become suspicious of what he meant or what he might be up to. He felt that Ira was only being friendly with him in order to take control of their relationship. He began to refuse to speak with Ira so that he would not feel like he was being manipulated. But, keeping distant only made him feel rejected and angry and he blamed that on Ira as well. He found that no matter how much he wanted to mend their relationship, he was not really able to be friendly with Ira. When he tried to communicate, he felt manipulated and controlled. When he withdrew, he felt angry and rejected.

At the same time he noticed that he was having trouble relating to his professors. He felt they were manipulating him as well. Studying every night had given Paul a real edge in his classes and early on his professors thought of him as one of the brighter students. Now, after an excellent start, his apparent total reversal came as a real shock to his professors. Several of them asked to speak with Paul after class, asking if everything was all right. Paul denied any problems while wondering why they were singling him out, since he still had a good average. Paul decided that he was being held to a stricter standard than the other students and that the school was closely observing him. After several of these inquiries, Paul found it harder and harder to get to class. His inability to concentrate made it seem pointless anyway. Instead, he spent his time alone in his dorm room playing computer games. Finally, with failing grades in every class, Paul left for home before finals.

His parents were worried and confused by Paul's behavior. Telephone conversations with Paul had alerted them that something was wrong but left them puzzled. Paul talked about isolation, people manipulating and controlling him, and being "observed" by the school. Their first thought was that Paul was using drugs. They knew Paul had experimented with marijuana in high school but that had not seemed to be a problem at the time. When they asked Paul about drugs he adamantly denied it and showed none of the telltale signs. When he got home it was obvious to his parents that something else

was wrong. Both parents were very upset and after a long discussion, they decided to ask Paul to see Dr. Williams, the family doctor. Paul had always liked Doc Williams and he was clearly fond of Paul. Ashamed of his poor performance at school and confused by his own thoughts and feelings, he agreed to see him the following week.

Home in a safe place and feeling less suspicious, Paul was able to tell Dr. Williams everything that had been happening to him. As he conveyed his story, he felt that much of what he told the doctor made no sense. Why had he mistrusted his new friend? Why wasn't he able to concentrate in class? Why had he started cutting classes? All the behaviors, thoughts and feelings he reported seemed strange as if they had happened to someone else. Dr. Williams listened to Paul's story and reassured him that it was not uncommon for students going away to college for the first time to have an anxiety reaction. He suggested that Paul see a colleague of his with special training to work with these types of problems, a psychiatrist named Dr. Kline.

During the week he had to wait before his appointment with Dr. Kline, Paul started to become withdrawn and suspicious of his family. During evening meals he heard a voice telling him that he wasn't his mother's child. His parents tried to hide their own anxiety by accepting Paul's odd behavior. When he saw Dr. Kline he was so suspicious that he had trouble relating his story. Dr. Kline suggested that in addition to some medication, Paul might consider signing himself into a hospital for a period of observation and treatment. He assured Paul that this was the best course of action and that he would be able to leave if he ever changed his mind. Feeling very distrustful, Paul refused the hospital as well as the medication Dr. Kline prescribed. Paul stayed home throughout that winter and into the spring. He became progressively more withdrawn and uncommunicative. Most of the time, he stayed in his room listening to music. During June, Paul told his mom that Dr. Kline was giving him orders by broadcasting thoughts to him telepathically. As these symptoms increased, Paul became agitated and threatening. Finally, at Dr. Williams's suggestion, his parents took him to the local private psychiatric hospital where he stayed for 2 weeks.

After 2 weeks in the hospital, Paul felt like he wasn't ready to be discharged. He was still hearing voices, feeling withdrawn, and on a high dose of injectable medication, but the nurses assured him that living at home and going to the community mental health center would be much better for him. Paul visited the mental health center before he was discharged. His intake staff worker gave him a tour of a special program for people with problems like his. People there seemed friendly and the program looked interesting but he still wasn't sure. His parents were both hopeful and concerned about Paul's return. At the suggestion of the hospital social worker, they told Paul that if he were going to live at home he would have to agree to attend the program at the community mental health center.

His first week at the program was difficult. He still wasn't sure what was wrong with him. His doctors at the hospital had been vague about his condition. When he thought about being mentally ill he became really scared, tried to think about something else or decided he was just suffering from stress. While he and a staff person at the program were filling out his initial treatment plan, the staff person told him that he should expect to be at the program for a long period of time, his diagnosis was schizophrenia.

Paul wasn't exactly sure what that meant. But, at the same time it was what he had dreaded all along. He felt fear growing in the pit of his stomach. His old life was over; he felt that the worker was telling him that he was insane.

## Discussion of Paul's Story

Paul's story raises a number of important issues about mental illness that you will learn more about as you read this book. Many of these issues are controversial. Throughout this text you will see that, depending on training and orientation, theorists, researchers, and mental health professionals often have very different answers to these questions.

One important issue involves questions of *etiology*, or the cause(s) of such illnesses. What caused Paul's illness? Could someone have predicted that Paul would become ill by observing his development, and could the illness have been prevented? Partly because there is still a great deal we do not know about the etiology of the severe mental illnesses, this is an area of great controversy and heated debate. Some professionals believe that aspects of Paul's personal history, environment, and family life may help us to understand the cause of his illness. Others feel that these issues have little or no bearing on the disease because its cause is essentially biological rather than environmental. Most importantly, the different etiological beliefs held by professionals, family members, and people like Paul lead to choices of specific treatment strategies.

Another important issue that is raised is the question of *prognosis* or the probable course or outcome of the disease. Will he recover with medication and treatment? Or, will he become progressively more confused, alienated, and withdrawn over time? Can the prognosis of such a disease even be established? Although there is increasing agreement among professionals on the prognosis of these diseases given correct medication and services, there is still great variability between people with the same illness.

The final and most important issue remains: What is the best way to help Paul and other people like him? As you will see, there are many aspects to the care of mental illness. Specific beliefs about the etiology of these diseases lead to specific treatment strategies. *Treatment* is usually considered to be any action designed to cure a disease or reduce its symptoms. *Rehabilitation*, on the other hand, is usually defined as any action intended to reduce the negative effects of the disease on the person's everyday life.

To help explain this difference, let's consider a woman who has had a stroke and has lost her ability to walk. A doctor might prescribe anticoagulants, blood pressure medication, change in diet, and regular exercise to help reduce the probability of future strokes. These prescriptions would be considered treatment. The doctor might also prescribe physical therapy to help return the patient to the highest level of physical mobility after the deficits caused by the stroke. This therapy aimed at returning the patient to normal or near-normal functioning would be considered rehabilitation. Finally, a rehabilitation professional making a home visit might recommend that a ramp be built to the front door, that doorknobs be changed to levers, and that the bathroom be fitted with hand bars. These modifications to the patient's environment would also be considered part of the rehabilitation process.

The differences between treatment and rehabilitation seem clear for the woman who had a stroke. But for the person with mental illness, like Paul, the difference between



treatment and rehabilitation is not always clear. Indeed, some professionals believe that it is a mistake to make a distinction between the *treatment* of mental illness and a process of *rehabilitation*. In fact, researchers have found evidence that the rehabilitation process itself has a direct and positive effect on the disease (Bond et al., 2001; Lysaker et al., 2001). Most PsyR professionals believe that treatment and rehabilitation are complementary processes.

The importance of the differences and similarities between treatment and rehabilitation will become evident as you move through this text. This issue is vital when considering questions such as “Who provides treatment? Who provides rehabilitation? What is the role of the psychiatric rehabilitation practitioner? What kinds of services should be provided?”

This textbook will provide you with answers to many of these questions. Real people, like Paul, and his loved ones are dependent on the answers. You will also learn about new, challenging, and complicated issues that address the best ways to help persons with severe mental illness.

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## **The Severe Mental Illnesses**

Serious and persistent mental illnesses, like the one that struck Paul, affect many people in our society and around the world. In the United States approximately 2.1% to 2.6% of the population have a mental illness that is severe enough to reduce their ability to perform living and working tasks effectively (International Association of Psychosocial Rehabilitation Services [IAPRS], 2001). This translates to 5,250,000 to 6,500,000 people in the United States. The President’s New Freedom Commission on Mental Health puts the estimate somewhat higher, saying 5% to 7% of adults in the United States have a serious mental illness, which would be 15 to 20 million people (President’s New Freedom Commission for Mental Health, 2003).

For society as a whole, schizophrenia, which strikes an estimated 1% of the population, is by far the most devastating and the most feared mental illness. In addition, several other mental illnesses also cause untold suffering and disability. The *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition, text revision (DSM-IV-TR), of the American Psychiatric Association (2000) recognizes recurring depressive disorders, bi-polar and unipolar disorders (commonly known as manic depressive disorders), schizoaffective disorder, and organic brain syndromes among others as serious mental illnesses that can become long term, cause psychosis, and lead to psychiatric disability.

Today, there is increasing awareness that people who experience severe mental illness often suffer from other serious maladies as well. These “dually diagnosed” individuals may be coping with substance abuse problems, developmental disabilities, severe learning disabilities, and chronic physical illnesses at the same time they are struggling with their mental illness. As you might imagine, the problems raised when someone is suffering from more than one disorder at the same time can be very difficult. Which disorder should be treated first? Does the treatment of one disorder negatively affect the treatment of another disorder? Which disorder is causing the symptoms that are present? Special programs for people who are dually diagnosed are increasing

around the country. These programs are staffed by professionals who are cross-trained to address multiple problems. The issue of dual diagnosis is covered in depth in Chapter 8.

## **The Symptoms of Mental Illness**

Mental illnesses may present a wide variety of symptoms. The symptoms of the severe mental illnesses can be classified into two categories: positive symptoms and negative symptoms. Positive symptoms refer to what is added to the individual because of the disease. *Psychoses*, the faulty interpretation of reality due to incorrect sensory perceptions (*hallucinations*) or thoughts (*delusions*), are good examples of positive symptoms. Negative symptoms refer to things that the individual has lost because of the disease. Social withdrawal and an inability to experience pleasure, *anhedonia*, are typical examples of the kinds of negative symptoms someone with severe mental illness might experience. The great majority of persons experiencing these conditions are diagnosed with schizophrenia or a bi-polar disorder (manic depression). Chapters 2 and 3 will cover the cause, symptoms, and treatment of mental illness in more depth.

## **The Causes of the Severe Mental Illnesses**

The pathological processes that cause these conditions are still poorly understood (Anthony & Liberman, 1986; Walker et al., 2004). Nevertheless, there is growing consensus that these conditions have a strong biological component (Dincin, 1990; Torrey, 2001). With the development of increasingly sophisticated soft tissue and metabolic imaging techniques such as CAT, PET, and MRI scans, researchers have been able to demonstrate actual changes in brain tissue and brain functioning corresponding with psychotic episodes (Taylor, 1987; Torrey, 2001; see also Andreasen, *The Broken Brain*, 1984). At the same time, researchers have looked at the contribution of genetics by comparing the life spans of individuals whose parents have schizophrenia with those whose parents do not have schizophrenia (Marcus et al., 1987) and studying identical and fraternal twins when one of the twins has the disorder (e.g., Torrey, 1994). These studies provide strong evidence that genetics play an important role when someone is stricken with a severe mental illness. Despite these advances, the causes of severe mental illness are not known. Chapters 2 and 3 will cover the symptoms, diagnosis, probable causes, probable courses, and outcomes of these illnesses in more detail.

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## **Psychiatric Disability**

Without effective rehabilitation, a severe mental illness can disable a person for life. Most often striking during the late teens and early twenties, life disruptions like the one Paul experienced are very common with these illnesses. When school, work, and family are disrupted, the individual cannot acquire the skills needed to cope with the demands of

**BOX 1.1**  
**Biographical Sketches—**  
**Early Theorists**

***Emil Kraepelin (1856–1926)***

An eminent German psychiatrist, Kraepelin is credited with establishing the first classification system for the severe mental illnesses. He was also the first clinician to recognize the difference between dementia praecox (schizophrenia) and manic-depressive illness. Receiving his M.D. degree from the University of Wurzburg in 1878, Kraepelin continued his neurological studies and studied with the “father” of the new field of psychology, Wilhelm Wundt. This work led to his publishing of *Compendium der Psychiatrie (Concise Summary of Psychiatry)* in 1883. Kraepelin divided mental illness into exogenous conditions, which were caused by external factors and were therefore treatable, and endogenous conditions, which he believed were caused by biological or hereditary factors and which he considered incurable. Using this classification strategy, Kraepelin saw manic-depressive illness as exogenous and therefore treatable and dementia praecox as endogenous and essentially incurable. Kraepelin believed dementia praecox stemmed from organic pathological changes in the brain. He is also credited with classifying three important subtypes of dementia praecox: catatonia, halted motor activity;

hebephrenia, regression to a vegetative state; and paranoia, delusions of persecution or grandeur.

***Eugene Bleuler (1857–1939)***

One of the most influential psychiatrists of his time, Bleuler is credited with introducing the term *schizophrenia* by combining two Greek words meaning “split” and “mind.” Rather than the split personality of popular fiction, Bleuler believed that the “split” was usually between the person’s cognitive (thinking) and affective (emotional) processes. A Swiss psychiatrist, Bleuler studied medicine at the University of Bern, was appointed professor of psychiatry at the University of Zurich and became director of the Burgholzli Asylum in Zurich. It was at Burgholzli, where he worked from 1898 to 1927, that he conducted his studies of schizophrenia. In 1911 he published his groundbreaking paper “Dementia Praecox oder Gruppe der Schizophrenien” (“Dementia Praecox: Or the Group of Schizophrenias”). Contrary to the professional wisdom of his day, Bleuler believed that the schizophrenias were actually several different diseases, that they were not necessarily incurable, and that the course of the disease was not always negative. During Bleuler’s later career he was assisted by Freud’s disciple Carl Gustav Jung. Under the influence of Freud’s theories, Bleuler became convinced that schizophrenia could have psychological rather than biological causes and that it could be treated using psychoanalytic techniques.

modern life. Without these skills, which many take for granted, the individual cannot function successfully.

These conditions tend to be long lasting as well as severe and are referred to as “severe and persistent mental illness.” Thus, they often disrupt and stunt normal intellectual, social, and vocational development or lead to conditions where acquired skills are lost due to disuse. This lack of ability, whether because skills were never acquired or were acquired and subsequently lost, is the hallmark of psychiatric *disability*. Although psychiatric symptoms can often be controlled by medication and therapies, disability secondary to the disease often persists. The analogy of a physical trauma may help to clarify this issue. A person who loses the use of his legs because of an automobile accident becomes disabled, because he has lost skills like walking and running. The damage from the accident persists or is permanent, while the physical danger has passed.

**CONTROVERSIAL ISSUE****Schizophrenia or “Neurotransmitter/ Stress Syndrome”**

Since Bleuler coined the term *schizophrenia* and distinguished it from dementia praecox, the term has been widely used in psychiatry. The DSM-IV-TR and its earlier editions have consistently used the term *schizophrenia*, modifying it with disease categories such as paranoid, catatonic, or undifferentiated. Today, literally millions of persons in the United States and around the world carry a diagnostic label of schizophrenia.

The term *schizophrenia* is widely used by the media and entertainment industries, where it is portrayed as the very essence of a severe mental illness. The paranoid schizophrenic label used by the media conjures up images of wild-eyed assassins who kill and maim for no apparent reason.

The term *schizophrenia* is also used to denote apparent contradictions in people, organizations, or policies. The Iran-Contra scandal was often labeled the product of a “schizophrenic” policy of selling arms to our enemies in order to raise money to support our allies. This misuse of the term also reinforces the common misconception that schizophrenia is a form of multiple personality disorder, which it is not.

The clear abuse of the term and increased understanding of these illnesses has prompted debate about the continued use of “schizophrenia” as a diagnostic label. Jerry Dincin, who served for

many years as the executive director of Thresholds, a large psychiatric rehabilitation agency in Chicago, argued that the diagnostic label schizophrenia should be changed to “neurotransmitter/stress syndrome” (Dincin, 1990). This new diagnostic label captures both the biological basis (neurotransmitter) and the environmental vulnerability (stress) aspects of the severe mental illnesses. But more importantly, “neurotransmitter/stress syndrome,” or a similar term, does not necessarily carry the stigma and negative connotation of a label like schizophrenia. Dincin uses an analogy from the developmental disabilities field to make his point. The terms “morons,” “idiots,” and “imbeciles” of 30 years ago (when they were used as diagnostic labels by professionals) have been replaced by terms with much less negative impact (Dincin, 1990). The probable relationship of neurotransmitters to severe mental illness will be discussed in more depth in Chapter 2.

The actual costs of changing such a label might be large. Besides the obvious changes in charts, records, and diagnostic manuals, a great deal of retraining would need to take place within the mental health delivery system and the systems that pay for treatment.

One might also consider the media’s response to such a change. Popular culture would still need a label for “madness” since individuals with these labels supply the motivating force for many real and fictional stories of crime and violence. Could “neurotransmitter/stress syndrome” become the stigmatized label of the future?

Some PsyR theorists and researchers such as William Anthony and Robert Liberman cite evidence that the degree of psychiatric disability is related to the individual’s premorbid skill level. The term *premorbid* refers to the period before the individual became ill. In this case, to what the individual’s skill level was before the illness. In addition, Anthony and Liberman infer that higher skill levels can reduce the intensity of psychiatric illness. We will cover the contributions of these skill theorists in a later chapter.

*Disability* is an important medical and social concept. The Americans with Disabilities Act of 1990, which is discussed in Chapter 7, defines disability as a substantial limitation in a major life activity (Lawn & Meyerson, from Liberman, 1992). Another important medical body, the World Health Organization, defines *disability* as an inability to partici-

pate or perform at a socially desirable level in such activities as self-care, social relationships, work, and situationally appropriate behavior.

Most importantly for Americans, the Social Security Administration has outlined four key areas of psychiatric disability: (1) activities of daily living (ADLs) (e.g., grooming, hygiene, maintaining a household, managing finances); (2) social functioning (with family, friends, community, and in the workplace); (3) concentration, pace, and task persistence (ability to function for 6 to 8 hours without supervision); and (4) the ability to tolerate competitive work (Lawn & Meyerson, from Liberman, 1992). Duration of disability is also an important factor. To meet the Social Security Administration's definition the disability has to be continuously present for at least 12 months.

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## **The Stigma of Severe Mental Illness**

When someone has a severe mental illness, the diagnosis itself can cause serious problems. As Hall, Andrews, and Goldstein (1985) point out "Schizophrenia is . . . a sentence as well as a diagnosis." The person labeled *schizophrenic* carries a powerful stigma to which other people may react with fear and rejection. Because the symptoms of these diseases can affect how a person thinks, feels, behaves, and communicates, the effects of the diseases are often apparent to other people. Unlike common symptoms such as coughing, sneezing, or running a fever, psychiatric symptoms are often not attributed to a disease. Sometimes, since they are so little understood, psychiatric symptoms are attributed to supernatural, spiritual, or demonic causes.

Mental illness is so frightening that healthy persons often refer to people with mental illness using the name of their mental illness. Someone with schizophrenia may be labeled a "schizophrenic" by some of the people with whom they have regular contact. Someone with paranoid schizophrenia may be called a "paranoid." By contrast, the individual suffering from diabetes is less frequently referred to as a "*diabetic*" by friends and acquaintances and usually only when it is pertinent such as when meals are being planned. E. Fuller Torrey, M.D., a psychiatrist who treats, researches, and writes on schizophrenia believes that persons experiencing schizophrenia are treated like the lepers of the 20th century (Torrey, 2001). The term *stigma* originally referred to the ancient practice of physically marking (scarring) villains so that others would know that they were criminals and be on their guard. Many persons today react in the same way when they meet a person they think is mentally ill.

Peoples' reaction to stigma refers to what Coleman (1986) called "the dilemma of difference." Most people accept that individuals are different in many ways. When some differences are deemed unacceptable, people with undesirable characteristics or differences may be stigmatized. What a given society chooses to stigmatize is somewhat arbitrary. In the past, some societies considered persons who today might be diagnosed with schizophrenia, as higher beings who were specially gifted and able to commune with God. Saint Francis of Assisi was known to speak with the animals, which was considered proof of his saintly nature. Today, our first reaction might be to consider such behavior as evidence of a psychotic process.

Much of the stigma surrounding mental illness has its roots in ignorance and fear. This is not surprising since until very recently there was little scientific evidence to support any theory explaining serious mental illness. Some scholars even questioned the very existence of mental illness. In his writing, Thomas Szasz suggested that mental illness is simply a learned behavior that, for some people, is a realistic reaction to modern society. Today, as we are beginning to get a clearer understanding of mental illness, we can begin to combat the stigma left by centuries of ignorance and fear.

The ignorance that has surrounded mental illness since the beginning of history is being lifted by modern psychiatry with the advent of imaging techniques such as CAT, PET, and MRI scans, genetic research, the development of new drugs, and other breakthroughs. While we fear cancer and have compassion for those who are stricken, medical science has increased our understanding of the disease and reduced the stigma cancer patients once experienced. Recent progress in the treatment of AIDS is helping to reduce the stigma associated with that condition. In the same way, future citizens educated about mental illness may fear the disease but not the person.

In addition to knowledge about the disease, contact with individuals who successfully cope with it can eradicate the stigma it carries. Actual contact with persons who have these serious mental illnesses has been shown to decrease stigma (Corrigan et al., 2003).

The community treatment of mental illness also has the potential to reduce stigma. Treating persons experiencing severe and persistent mental illness in the community means that at one time or another everyone may come in contact with them.

This exposure to persons with mental illness is a powerful tool for reducing the stigma that surrounds the disease. As most psychiatric rehabilitation staff will tell you, persons with mental illness are no different from you and me, except for their disease. Keeping these persons in institutions adds to the stigma surrounding the disease. Accepting them into the community helps to eliminate stigma because living and working in the community on a daily basis highlights their basic humanity not their disability.

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## **Psychiatric Rehabilitation**

### **What Does the Term “Psychiatric Rehabilitation” Mean?**

In the helping professions, the term *rehabilitate* means to restore to an optimal state of constructive activity. Of course, what is “optimal” is relative to the individual. An individual’s “optimal” level of constructive activity depends on several factors. How well a person functions depends on how severe the illness is at the time, the severity of the disability, the abilities he or she still possesses, the outside supports that are available, and what some theorists call the “stage of recovery.” *Stage of recovery* refers to the individual’s level of progress in his or her ability to cope with the disease and disability and his or her self-image as a functioning person. The concept of recovery will be dealt with in some depth in Chapter 4. Psychiatric rehabilitation refers to efforts to restore persons with psychiatric disabilities to optimal states of constructive activity. The degree of disability a person experiences is often variable. Some persons with severe and persistent mental

illness may be disabled in many aspects of their lives. Other persons may be disabled in only one area, while otherwise being generally free of disability.

Numerous definitions of PsyR exist, reflecting a range of philosophical and technical differences among practitioners (Anthony, 1979; Anthony & Liberman, 1986; Carson, B. E., & Chambers, C. in Rutman 1994; Hughes, 1994; Rutman, 1994). Ruth Hughes (1994), former executive director of IAPSRs, provided an excellent definition that most PsyR practitioners can agree with:

The goal of psychiatric rehabilitation is to enable individuals to compensate for, or eliminate the functional deficits, interpersonal barriers and environmental barriers created by the disability, and to restore ability for independent living, socialization and effective life management. (p. 11)

In 1992 the *Psychosocial Rehabilitation Journal* asked its readers to submit definitions of PsyR. The following definition of PsyR, which received an honorable mention in the contest, captures both the humanity and the hope inherent in the rehabilitation process:

“Psychosocial rehabilitation means that a person who before was afraid to go into a store to order an ice cream soda can now be an ice cream store manager” Martha Green (in Rutman, 1994).

## The Emergence of Psychiatric Rehabilitation

Practitioners of PsyR are united in believing that persons with severe and persistent mental illness can achieve greater independence and a better quality of life with the help of psychiatric rehabilitation services. This assumption, that persons with psychiatric disabilities can participate in a successful rehabilitation process, is in marked contrast to the beliefs of many mental health professionals only a few generations ago and some today. Until the late 1970's and early 1980's, the conventional wisdom about severe mental illness was that it took an insidious downward course with little or no hope of recovery. Prior to 1987, the DSM-III (*Diagnostic and Statistical Manual of Mental Disorders*, third edition) published by the American Psychiatric Association (1980) stated that the most common course of schizophrenia consisted of acute episodes followed by “increasing residual impairments” (p. 185). In contrast to this pessimistic view, recent research has demonstrated that, even for those with severe psychiatric disability often labeled as “backward” patients, the long-term *prognosis* is positive (DeSisto, Harding, McCormack, Ashikaga, and Brooks, 1995; Harding, Brooks, Ashikaga, Strauss, and Breier, 1987; Torrey, 2001).

Another positive development is the work researchers, practitioners, and consumers of PsyR services are doing to develop the concept of *recovery* from psychiatric disability. Even though some of the disabilities and residual symptoms may be life-long, the field of PsyR is rapidly learning and defining what it means to “recover” from major mental illness (Anthony, 1993, 2000; Deegan, 1988). The concept of recovery will be discussed in greater detail in Chapter 4.

## Deinstitutionalization

The emergence of PsyR as a unique enterprise can be directly traced to the *deinstitutionalization* movement that began in the 1960s and early 1970s. Between 1960 and today,



approximately 90% of the persons in long-term state psychiatric institutions were discharged into the community. Based on current population estimates, to date some 900,000 persons experiencing severe and persistent mental illness have either been discharged from psychiatric hospitals or not institutionalized (Torrey, 2001). When the policy of deinstitutionalization began, literally thousands of patients who had been institutionalized for much of their adult lives were discharged into the community for treatment. Given their traditional mental health training, many, if not most, of the community mental health staff workers were unprepared for this challenge (Stern & Minkoff, 1979; Farkas, O'Brien, and Nemecek, 1988). In many areas of the United States, persons who were deinstitutionalized were deemed to be "inappropriate" for the existing community services in place at that time. This despite the fact that the major impetus for the nationwide federal funding of community mental health centers begun in 1963 was specifically designed to care for this population. Workers trained to provide individual psychotherapy for persons with supposed psychodynamic problems tended to classify these people as not being good "treatment cases." Marianne Farkas, of the Center for Psychiatric Rehabilitation, Boston University, found that this newly deinstitutionalized population had low "patient" status because they were not highly verbal and did not demonstrate high rates of treatment success (Farkas et al., 1988). As a result, many persons with chronic mental illness were relegated to programs staffed by less educated persons with non-traditional academic degrees and by paraprofessionals (persons without academic credentials).

Torrey (2001) asserts that only about 5% of the 789 federally funded community mental health centers (CMHCs) accepted the challenge of providing appropriate services to the deinstitutionalized population. The majority of the centers focused their efforts on providing counseling, psychotherapy, consultation, and education in the broader area of mental illness. Mostly because CMHC staff members were ill equipped to deal with them, persons with severe mental illness became increasingly isolated and remained underserved in the community.

The academic preparation of mental health professionals was very slow to adjust to the needs of the deinstitutionalization movement. This poor academic response was caused by a lack of recognition of the plight of this population as well as a lack of awareness of the treatment strategies necessary to aide them. A review of introductory undergraduate psychology textbooks carried out as late as 1992 revealed that lobotomy (brain surgery to relieve symptoms) was written about more than psychiatric rehabilitation (Halter, Bond, & De Graaf-Kaser, 1992). None of the 28 introductory textbooks mentioned common PsyR approaches such as the Clubhouse Model (e.g., Fountain House, Horizon House, etc.), the National Institute of Mental Health's Community Support System, or social skills training. In addition, hospital treatment was given much more coverage than community treatment at a time when hospital stays were being reduced and large psychiatric hospitals being closed.

In addition to the textbooks, in many cases the clinical focus of undergraduate curricula has remained focused on the more traditional psychodynamic, cognitive, and behavioral treatment models. Graduate education curricula have often sidestepped the issue of treating persons with major mental illness by stating that this population is not appropriate for the treatment strategies they are training their students to use (e.g., psychotherapy).



Despite growing scientific evidence that the major mental illnesses have a strong biological component if not cause, some graduate programs to prepare clinicians have maintained their focus on psychodynamic approaches emphasizing individual therapy aimed at uncovering past trauma. There has been evidence for some time that this type of intense, interpersonal treatment can be harmful for persons with severe mental illness (e.g., Linn, Caffey, Klett, Hogarty, & Lamb, 1979). The neglect of the proper care of persons with these illnesses is especially troubling given the emphasis many of the helping professions place on championing the needy and down-trodden. Persons diagnosed with severe mental illness constitute one of the most rejected, stigmatized, disadvantaged, and needy groups in our nation.

Today, a growing number of academic programs are devoted to psychiatric rehabilitation education at all academic levels. Special issues of the journals *Psychiatric Rehabilitation Skills* (Gill, 2001), *Rehabilitation Education* (Dell Orto, 2001), and the *American Journal of Psychiatric Rehabilitation* (Pratt, 2005) have been devoted to progress in psychiatric rehabilitation education and credentialing. In addition, a nation-wide consortium of psychiatric rehabilitation educators meets twice annually to discuss PsyR education issues.

Besides the mental illnesses themselves, community workers of the 1960s and 1970s had to face an additional problem when providing services to this newly deinstitutionalized population. Not surprisingly, spending years in an institutional setting such as a large psychiatric hospital caused many of the patients to become *institutionalized*. This institutionalization syndrome caused functional deficits, atypical or inappropriate behavior, and extreme dependency in long-term patients (Lehrman, 1961; Ridgway & Zipple, 1990; Schmieding, 1968). This syndrome often mixed with their mental illnesses, thus increasing the levels of psychiatric disability. Awareness of the debilitating effects of long-term institutionalization brought about increased emphasis on the community mental health principle of *least restrictive treatment environment*. This principle holds that every individual should be provided treatment in the least restrictive environment possible. For example, consider a patient who might equally benefit from hospitalization or a community treatment program. The patient should be treated in the community program because it is a less restrictive treatment environment and less likely to promote “institutional” behavior. The individual in the community program is also more likely to retain skills and have the opportunity to be part of the community.

The 1990 Americans with Disabilities Act (ADA) strongly supports the notion of deinstitutionalization. One part of the act, the “integration regulation,” requires a “public entity [to] administer . . . programs . . . in the most integrated setting appropriate to the needs of qualified individuals with disabilities” (28 CFR § 35.130(d)). A Supreme Court decision, *Olmstead v. L. C.* (1999), upheld this interpretation of the ADA and is currently being used to help deinstitutionalize individuals with disabilities around the nation.

## Psychiatric Rehabilitation Terminology and Language

Each profession has its own peculiar jargon of words, names, and sayings. Psychiatric rehabilitation is no different. The language we use can reflect our attitudes and prejudices.

The words we use to describe others may also designate whether we consider them to be like us or different from us. When we label people, we relegate them to a particular category. Some categories can be innocuous: “She’s an Oilers’ fan”; some negative: “He’s an ex-con”; and some may frighten: “He has AIDS.” Because labels help determine how we feel about someone, they tend to determine how we will react to that person in the future. This issue is particularly important for persons with mental illness.

Since the deinstitutionalization movement and the advent of community treatment, the labels given people who experience severe and persistent mental illness have taken on some very specific meanings. When these persons are hospitalized they are known as “patients” since they are in a medical environment. This term usually connotes dependency. After discharge, if they attend a Clubhouse-type day program they are often known as “members.” The “member” label conveys the philosophy of egalitarianism, sharing, and inclusion espoused by Clubhouse programs. Conversely, if they attend a more traditional community mental health center they are probably known as “clients.” This labels them as recipients of the center’s services. Persons living in residential facilities, whether operated for profit or by a publicly funded community mental health facility, are usually known as “residents.”

Some persons unhappy with existing labels began calling themselves “consumers” (meaning consumers of mental health services). Other persons have labeled themselves “survivors.” For some, the “survivor” label represents the fact that they have been able to exist with a terrifying illness. For others, the label denotes their displeasure with the services they have been provided. As increasing numbers of persons with mental illness become employed in psychiatric rehabilitation, some of these persons have labeled themselves “prosumers,” indicating their joint professional-consumer status. As you can see, how persons with mental illness label themselves or how a professional labels them can carry a great deal of meaning about their status and the kinds of services they are receiving and expect to receive.

One 1996 survey of 300 persons receiving mental health services found that “client” was the term most preferred (48%), followed by “patient” (20%) and “consumer” (8%). The remainder of those surveyed (24%) responded “other” or “don’t care” (Mueser, Glynn, Corrigan, & Baber, 1996). No doubt, a similar survey conducted today would find different results. A new term for individuals with severe mental illness, “persons in recovery,” has been suggested as being most appropriate (United States Psychiatric Rehabilitation Association Language Guidelines). Consumer groups and PsyR professionals concerned with combating the negative effects of stigma have emphasized the need for people-first language. For example, rather than calling someone a schizophrenic, which is calling them by their disease, using people-first language, the individual would be called a person who has schizophrenia. This may seem a subtle difference but it is very important for the person being so labeled.

The statement in Box 1.2 was put out by the Center for Community Change through Housing and Support, formerly located at the University of Vermont.

### **BOX 1.2** **Choosing Words with Dignity**

The words we choose to use to portray people with mental illness reflect our attitudes and beliefs about the value, dignity and worth of people with disabilities. Our words influence the public perception and acceptance of people with disabilities. People with disabilities are people first and foremost, who also happen to have a disability, or a different set of abilities.

Progressive mental health systems use, at all times, descriptive words that emphasize the person's worth and abilities, not the disabling condition. They understand that people may have a disorder or disability but the people are not the disability. They also recognize that people are diminished when they are described by diagnosis (e.g., "schizophrenic," "paranoid," "borderline"), by slang (e.g., "psychos," "schizos"), and by phrases that negatively categorize them (e.g., "the mentally ill," "the chronically mentally ill," "young chronics," "retarded," "dually diagnosed"). Medical terms such as "patient" are not used in these systems to refer to people who are not in medical settings, because

they are inconsistent with rehabilitation and community support philosophy.

IAPSRs (2003) proposed use of the term "people in recovery," in an attempt to reflect the fact that many, if not all persons with severe and persistent mental illnesses are engaged in an active process of recovery. This term reflects the "person first" thinking, but actually begs the question of whether all people with mental illness are recovering or not. Assuming everyone is in recovery, in a way, trivializes the process of recovery. It's almost like saying all living people are "breathing."

It should be the written and public policy of all systems and agencies working with people with disabilities not to use labels like "the seriously mentally ill" or use terms like "he is a bi-polar disorder." It should be the policy of all programs to consult with consumers and ex-patients in their states to identify a phrase or phrases that are respectful of individual dignity and reflect the preferences of the majority of individuals. Some phrases with general growing acceptance are "people with psychiatric disabilities," "persons with severe and persistent mental illness," "ex-patients," or "consumers." All current and future documents should reflect this policy.

## **Developing Psychiatric Rehabilitation Knowledge**

Early practitioners of psychiatric rehabilitation learned their trade by experience through a trial-and-error process. The typical community-based mental health center was originally designed for persons with less severe conditions. When the national policy of deinstitutionalization began, community workers and services were confronted with a large group of individuals being released from psychiatric institutions who did not respond well to existing treatment modalities, medications, and services. It soon became apparent that neither the existing community services nor the types of services previously offered in the psychiatric hospitals were helping this new group adapt to the community environment. In response, many of the community mental health staff assigned to work with this population began devising new strategies and services to meet their needs. These pioneer staff struggled to develop treatment philosophies consistent with the goals of community treatment. They often had to design programs for this new population where none had existed. Without recourse to references or handbooks, using emerging concepts such as

least restrictive treatment environment, client involvement, and normalization as guidelines, innovative programs and services were created. These new services were evaluated by their success or failure. Of course, many of these solutions failed or were later discarded as better solutions were developed.

Some successful models already existed in places like Fountain House in New York City and Horizon House in Philadelphia. These successful programs, which we will deal with in greater depth in Chapter 6, served as models for the services that were being developed in communities around the country.

Since very little, if any, formal education about psychiatric rehabilitation existed at the time, programs tended to hire bright, young, motivated individuals and teach them psychiatric rehabilitation on the job as it was practiced at that setting. Much of what was known was handed down from supervisor to supervisee, and the staff from individual programs tended to share the same ideas and philosophy. Knowledge was also picked up at the yearly conferences of emerging PsyR professional associations, or from journal articles on PsyR that appeared infrequently in publications dedicated to other disciplines.

The process of developing new programs and services based on emerging philosophical concepts made psychiatric rehabilitation an exciting and very creative profession in the 1970s and 1980s. Without models or reference points, program staff members were free to create programs in many forms, and they did. Psychiatric rehabilitation services today cover a wide range of styles, types, and philosophies. This wealth of program types and designs has provided excellent opportunities for testing and refining PsyR theories and practices. Like other emerging fields, PsyR periodically experiences a “shaking out” of some of these ideas as new knowledge is acquired and agreement is reached on which ideas are the most effective (producing positive results) and efficient (producing results economically). More effective strategies are retained while others are discarded. The recent identification of some psychiatric rehabilitation strategies as evidence-based practices (EBPs), which will be covered extensively in this text, is ushering in just such a “shaking out.”

### **Psychiatric Rehabilitation: A Science or an Art?**

Brainstorming sessions, sometimes with staff and consumers combined, to develop creative strategies for achieving PsyR goals and objectives are a far cry from the systematic precision required for scientific research. Creating new programs and strategies can be an art and some of the creations are ingenious; for example, using consumers as job coaches to help other consumers learn and keep regular jobs in the community. Or, helping consumers learn about their illnesses by participating in discussion groups where they read and discuss research literature from PsyR journals, such as the *Psychiatric Rehabilitation Journal* and the *American Journal of Psychiatric Rehabilitation*.

The developments of strategies like these are often serendipitous. New strategies and techniques are also developed by improving on the ideas of others. A previous executive director of a very large rehabilitation agency known for developing innovative programming once stated that he really is not that intelligent, he mainly “steals” or adopts other

people's ideas and then improves on them. Of course, we can judge the intelligence of this strategy by observing the effectiveness of the programs he developed.

Many of these creative solutions work, as the staff and consumers who utilize them will attest. But what is it about these strategies that works and what should another PsyR program do to ensure that the same strategies will work for them? Many of the solutions that appear to be effective to staff and consumers alike, in fact, are not. A common mistake, for example, is crediting a new strategy with rehabilitation gains when the improvement is actually caused by what is known as a "Hawthorne effect." You may have heard about the experiments at the Hawthorne plant of the Western Electric Company in Cicero, Illinois, during the 1930s. In one experiment, researchers found that no matter how they manipulated the lighting intensity in the work rooms (higher, lower, or no change), production went up. After much consideration, they concluded that instead of responding to the intensity of the lighting, the workers were responding to being studied by the researchers. In the case of PsyR, a Hawthorne effect implies that the consumers' improvements or gains may actually be caused by the attention they are getting because they are using the new strategy, rather than by the strategy itself. This might also be the case with staff members who strive harder when they are enthusiastic about a new program and convey their optimism to the consumers they are working with.

Is PsyR a science, an art, or some combination of both? The three goals of any scientific inquiry are (1) description (What is the process or phenomenon?), (2) explanation (How does it work?), and (3) prediction (What will happen in the future?). These principles can be applied to severe mental illness. In that case we would like to (1) describe the effects of severe mental illness, (2) explain why mental illness has these effects, and (3) predict the course and outcome of these illnesses. The same set of principles can be applied to PsyR interventions. We need to (1) describe a PsyR intervention, (2) explain how the intervention works, and (3) predict what the outcome of the intervention will be. Many dedicated PsyR practitioners believe that approaching the task from this technical-scientific perspective will produce the best results for their clients. In fact, it is just this formulation that is behind the advent of evidence-based practices (Gill & Pratt, 2005).

Research produces knowledge. Scientific PsyR knowledge is developed through rigorous systematic research based on the scientific method of observation, description, control, and replication. For PsyR this means that, in general, if we apply the same treatment to the same population under the same conditions, we expect to get approximately the same results. To foster this type of scientific knowledge, several research centers focusing specifically on PsyR and the community treatment of persons with severe mental illness have received public funding. Notable among these research centers are the Center for Psychiatric Rehabilitation at Boston University; the New Hampshire-Dartmouth Psychiatric Research Center; the Center for Psychiatric Rehabilitation at the Illinois Institute of Technology; the Mendota Mental Health Research Center, Madison, Wisconsin; and Thresholds, Chicago, Illinois. Additionally, the National Institute for Disability and Rehabilitation Research (NIDRR) funds Rehabilitation Research and Training Centers (RRTC) at Boston University, the University of Pennsylvania, and the University of Illinois at Chicago to develop and disseminate new knowledge. Many of these RRTCs deal with

aspects of the rehabilitation of severe mental illness. These research centers strive to increase our knowledge of how to provide effective services for persons with severe mental illnesses. Recent work identifying specific EBPs holds great promise for improving services.

## **Evidence-Based Practices**

From its earliest beginnings, psychiatric rehabilitation has sought, usually by trial and error, to develop effective services for persons with severe mental illness. This process has led to the existence of a large number of essentially idiosyncratic services, some of which are effective and some not. The adoption of an evidence-based practice approach is addressing this problem. The EBP process employs controlled clinical trials to identify effective services and define the critical elements that produce positive outcomes.

### ***The Implementing Evidence-Based Practice Project***

As the PsyR research and knowledge base grew, it became clear that some practices and strategies were superior to others at producing desired outcomes for persons. This situation was clearly demonstrated by the recommendations of the Schizophrenia Patient Outcome Research Team (PORT) project (Lehman & Steinwachs, 1998). The PORT study, which made recommendations for the treatment of schizophrenia, also found that in many cases individuals with schizophrenia were not provided with proper treatment and services. Additionally, there was increasing recognition by researchers and administrators that service providers and programs were slow to adopt new research findings to usual practice, indicating a large lag between research findings and implementing those findings in the field.

To address this issue, in 1998 the Robert Wood Johnson Foundation sponsored a meeting of researchers, clinicians, administrators, consumers, and family members to begin the process of identifying evidence-based practices for PsyR. This group, dubbed the Implementing Evidence-Based Practices Project, was charged with identifying interventions that were backed up by reliable research results. Through an extensive review of the research literature this group was able to identify six potential evidence-based practices.

### ***Identifying an Evidence-Based Practice***

A number of important steps must be carried out to establish an EBP. Most EBPs started from a service innovation. Such innovations (e.g., assertive community treatment [Chapter 7], supported employment [Chapter 9]) typically come about through the trial-and-error efforts of dedicated professionals trying to improve services. After an innovation shows promise, the next step is to carefully and objectively define the service including carefully explaining just how the service is performed, who performs it, for how long, and so forth. The definition of the service becomes the service model that will subsequently be field tested.

The service model of a potential EBP must be studied using multiple *controlled clinical trials*. This type of research, which typically involves random assignment of participants



**BOX 1.3****Robert E. Drake**

Robert E. Drake, M.D., Ph.D., is the Andrew Thomson Professor of Psychiatry and Community and Family Medicine at Dartmouth Medical School. He is also the director of the New Hampshire-Dartmouth Psychiatric Research Center. Dr. Drake has been a long-term contributor to the psychiatric rehabilitation knowledge base through his work developing and evaluating innovative community programs for persons with severe mental disorders. He is one of the recognized leaders in the development of evidence-based practices for PsyR. He is well known for his work in integrated dual disorders treatment (substance use disorder and severe mental illness), supported employment services, and assertive community treatment, among other work. Dr. Drake's many books and more than 300 papers cover diverse aspects of adjustment and quality of life among persons with severe mental disorders and those in their support systems. Educated at Princeton, Duke, and Harvard universities, he has worked for many years as a clinician in community mental health centers. Dr. Drake is a sought-after speaker in the United States and internationally regarding his work on improving services for people with severe mental illness.

to experimental and control groups, has the advantage of allowing researchers to make causal inferences between the variables under study. For example, a researcher may determine that a specific educational strategy helps consumers learn about their illness, or that a specific medication reduces a specific category of symptoms. In addition, controlled clinical trials greatly reduce the possible effects of bias on the results. A good example of bias reduction in research is the use of "blind" evaluators. In an experiment comparing, let us say, consumer quality of life in different housing situations, the "blind" evaluator would not know which experimental condition (e.g., experimental group or control group), in this case which housing type, was represented by the consumers she was evaluating. In this way, the evaluator is protected from unconsciously biasing the evaluations and hence the research results. Evaluators might also be blind to the hypothesis being studied or the exact form of the research design.

The evidence to support an EBP must be in the form of *reliable, objective evidence*. Of course, we have just stressed that controlled clinical trials are designed to produce reliable, objective evidence if it is present. Still, the reliability of data and the objectivity of data can and should be independently assessed. In addition, such research needs to be repeated in different settings, by different researchers, and produce similar corroborating results. This replicability is one of the hallmarks of science.

If the model for the EBP, refined by the research results, proves to effectively produce specific desirable outcomes for persons with severe mental illness its elements are converted into a *fidelity scale*. Think of this fidelity scale as a blueprint for how the service should be provided as well as a rating scale that determines how close a service comes to replicating the model. The fidelity scale of an EBP is used to determine how well other programs are providing the same service. In short, how much fidelity to the EBP model do they demonstrate? Research findings suggest that services with higher fidelity to the EBP model produce better outcomes (e.g., Bond, 2004).

### ***Current Evidence-Based Practices***

To date six EBPs, each of which will be described in some detail in this textbook, have been identified:

1. Medication management
2. Assertive community treatment (ACT)
3. Supported employment (SE)
4. Illness management and recovery education
5. Family education
6. Integrated treatment for dual disorders (Dixon et al., 2001; Drake et al., 2001; Mueser, Torrey, Lynde, Singer, & Drake, 2003; Torrey et al., 2001).

Each of these EBPs has been shown to have a positive impact on one or more aspects of these disorders. Specifically, multiple controlled clinical trials of the six EBPs just listed have been shown, among other things, to produce:

- Symptom improvement (especially for positive symptoms)
- Less hospital utilization
- Fewer and less severe relapses
- Higher rates of competitive employment
- Improved quality of life
- Increased community involvement
- Better control of substance abuse problems (Dixon et al., 2001; Drake et al., 2001; Mueser et al., 2003; Torrey et al., 2001).

## **Scientific Literature and Meetings**

Starting from a small group of psychiatrists, psychologists, social workers, and other professionals working and publishing in related areas, PsyR research has come into its own during the last three decades. The first regular issue of *Schizophrenia Bulletin*, a quarterly journal of the National Institute of Mental Health, was published in 1974. This journal was dedicated to facilitating “the dissemination and exchange of information about schizophrenia.” In 1977 the IAPSR and the Boston University Center for Psychiatric Rehabilitation launched the *Psychosocial Rehabilitation Journal*, today called the *Psychiatric Rehabilitation Journal*. This quarterly journal has been the primary source for PsyR research, evaluation, and ideas. *Psychiatric Rehabilitation Skills*, today called the *American Journal of Psychiatric Rehabilitation*, published by the Illinois Institute of



Technology and the University of Medicine and Dentistry of New Jersey, is dedicated to publishing PsyR research from around the world. Several other journals regularly carry PsyR research and evaluation reports, such as *Psychiatric Services*, an American Psychiatric Association journal, and *Community Mental Health Journal*, the journal of the National Council of Community Mental Health Centers. Articles about PsyR also appear in journals from the fields of psychology, psychiatry, social work, vocational rehabilitation, and other disciplines.

International, national, and local PsyR conferences are excellent places for discussing PsyR research, evaluation, and ideas. Initially, these conferences provided the opportunity for PsyR professionals to get together with others doing the same work to share ideas. Today's conferences include consumers and family members and take in a broad spectrum of issues and interests. The United States Psychiatric Rehabilitation Association (USPRA, formerly IAPSRS), which holds a yearly conference at a major city in the United States, has chapter organizations in more than 40 states. These state organizations also sponsor conferences, meetings, and institutes on special topics. The World Association for Psychosocial Rehabilitation (WAPR) sponsors a congress of PsyR professionals approximately every 2 to 3 years at a major world city. WAPR congresses are genuine multi-lingual, multi-cultural events with presentations by PsyR professionals representing countries from the Americas, Europe, Asia, Africa, and Australia.

These worldwide conferences help to emphasize the global nature and impact of severe mental illness. With some slight variations, the incidences of diseases such as schizophrenia are constant both around the world and over time. The plight of persons experiencing severe and persistent mental illness in Third World countries is especially troubling. At the 1989 WAPR congress, Dr. Vijay Nagaswami of the Schizophrenia Research Foundation in Madras, India, stated that "In developing countries . . . the mentally ill continue to languish and can be considered lucky if they receive even medication" (1989, p. 20). The international PsyR movement is actively promoting the sharing of knowledge and ideas to meet this challenge.

## **Standards for Creating Psychiatric Rehabilitation Professionals**

USPRA, formerly known as IAPSRS, the largest organization of psychiatric rehabilitation professionals in the United States, has taken the initiative in establishing PsyR as a profession. This effort includes the establishment of a national test-based professional certification, the Certified Psychiatric Rehabilitation Practitioner, and accredited program standards through the Council on the Accreditation of Rehabilitation Facilities (CARF) and the Council on Accreditation (COA). In addition, IAPSRS had established practice guidelines for the assessment, evaluation, and interventions of psychiatric rehabilitation (IAPSRS, 2001). As of this writing (2006), these guidelines are undergoing revision. Finally, IAPSRS had outlined a Code of Ethics for PsyR professionals (IAPSRS, 1996).

Like other professions such as doctors, lawyers, and public school teachers, official recognition of one's professional status requires being licensed by the state where the professional provides services. To be licensable by states, a profession needs to have very clear guidelines spelling out who practitioners are, what special knowledge they have,

what services they provide, and their professional standards and ethics. In short, defining who is qualified to provide what type of services to the public.

### ***The Certified Psychiatric Rehabilitation Practitioner (CPRP)***

Efforts to define the professional role of the psychiatric rehabilitation practitioner has advanced significantly during the last several years. In 2000–2001, IAPSRS sponsored a role delineation study (IAPSRS, 2001). More than 300 PsyR experts contributed to a multi-step project in which they identified both the knowledge and the skills required to be a minimally competent practitioner. More than 90 tasks, each with several pieces of knowledge and skills, were identified. Later these tasks were ranked in terms of how frequently they are used, how important they are for helping people with mental illness, and how critical they are for avoiding harm to persons with mental illness. The seven broad domains that were identified are ranked here in terms of their overall importance, criticality, and frequency as rated by PsyR experts (IAPSRS, 2001):

1. Interpersonal competencies
2. Interventions
3. Assessment, planning, and outcomes
4. Community resources
5. Professional role
6. Systems competencies
7. Diversity

This role delineation report was used to develop the test questions contained in the Certified Psychiatric Rehabilitation Practitioner (CPRP) examination. This standardized exam, which serves as a demonstration of competence, is combined with an assessment of level of education, amount of experience, and professional references to designate an individual a Certified Psychiatric Rehabilitation Practitioner. A listing of all the individuals who are certified PsyR professionals is published by USpra on the World Wide Web at <http://www.uspra.org/certification>. The certification program, now overseen by the Commission on the Certification of Psychiatric Rehabilitation, is a major development in the definition of PsyR professionals. The written test is now used on an international basis to evaluate PsyR knowledge. The first exam was offered in 2002 in the United States and Canada. Singapore is using the certification program and New Zealand is considering it.

By 2005, 12 U.S. states had passed legislation recognizing the CPRP as identifying individuals qualified to deliver these services in their state. Several states are considering a license based on this credential. The Canadian Province of Nova Scotia and the country of Singapore have also recognized the CPRP credential.

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## **Summary**

Being struck with a major mental illness can be a devastating experience affecting a person's entire life. Particularly because they tend to strike during the late teen/early adult

years, these diseases often cause severe disabilities. Despite the extreme personal and societal costs of these conditions, we are still unclear as to their cause. With the advent of modern diagnostic tools it has become clear that these conditions are biologically based. An additional major source of disability is the stigma attached to these diseases. Increased knowledge and education are helping to reduce stigma, but we still have a long way to go in this respect.

Psychiatric rehabilitation encompasses the community treatment and rehabilitation of persons with severe mental illness. Psychiatric rehabilitation in its present form began in response to the deinstitutionalization movement in the late 1960s. Initially through trial and error and later through systematic clinical research, services are increasingly becoming more refined. Psychiatric rehabilitation is emerging as a unique discipline with its own body of research, journals and publications, and professional organizations and conferences. The major U.S. organization, USpra, is actively working toward the professionalization of PsyR personnel and practices.

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### **Class Exercise**

#### **Knowledge and Attitudes about Severe Mental Illness**

Imagine that you are a case worker in a psychiatric rehabilitation program. A new client, diagnosed with schizophrenia, and recently assigned to your case load asks you the following questions. How would you respond?

1. Why did I become ill? What causes this disease?
2. I feel O.K. right now. Will I get sick again?
3. How long will I have this condition? Will I ever get better?
4. Will I be able to have a “normal” life?

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