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VOLUME

Recovery from Severe Mental Illnesses:
Research Evidence and Implications for Practice

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Foreword

Until the 1980s, and officially until the appearance of *DSM-III-R,* (American Psychiatric Association, 1987), the understanding in our field was that a severe mental illness, particularly schizophrenia, almost universally followed a deteriorative course. With this understanding mental health researchers, not surprisingly, have tended to focus on psychopathology and symptoms, rather than on processes and interventions that promote role functioning and coping with mental illnesses. This lack of understanding of recovery no doubt inhibited the study of the positive outcomes of schizophrenia and other severe mental illnesses by focusing on maintenance and stabilization, rather than on growth-promoting interventions. More recently, however, research has begun to focus on recovering instrumental roles and quality of life in the community.

In the last several decades, several sources of data have converged to demonstrate that people with severe mental illnesses are achieving higher levels of role functioning, subjective well-being, and adjustment than had previously been considered, and that severe mental illnesses are not universally deteriorative. One source of information has been the writing of people with severe mental illnesses. Another source of knowledge is the synthesis and dissemination of long-term outcome studies, which suggested that a significant percentage of people with severe mental illnesses were dramatically improving over time. Currently, according to Harding, there are 10 national and international longitudinal studies of 22 to 37 years duration investigating the recovery and community integration of people with schizophrenia and other severe mental illnesses. A final source of data is the research evidence suggesting that substantial improvements for individuals with severe mental illnesses can be effected through mental health interventions. All of these different types of evidence are covered in this groundbreaking text.

A review of systems-level literature and mental health policy is also included in this text. Even though there is as of yet no explicit consensus about the meaning of the term *recovery,* our current understanding of recovery is now guiding policies and practice in many state mental health systems as well as in entire countries like New Zealand.

Despite increasing and widespread use in mental health systems' practice, planning, and funding, the concept of recovery until recently has been poorly understood, poorly operationalized, and frequently used in policy/political statements rather than as an empirically-based, operationally defined term. More recently, however, as shown by the readings in this text, there has been a convergence of thinking about the meaning of the term recovery and its definition. Taken together, these sources of information sug-

gest that the recovery process is a long-term, multidimensional process with both objective and subjective dimensions that should be viewed along a continuum (rather than dichotomous as recovered vs. not recovered). Also, recovery outcomes involve interdependent domains of functioning (including social, vocational, emotional, cognitive, and spiritual). Additionally, the literature indicates that recovery involves psychosocial adjustment to the disability itself; achievement of subjective well-being; some degree of remission of the signs and symptoms of the illness; and improvement in instrumental role functioning and community integration.

One definition of recovery outcomes (as opposed to recovery processes) focuses on the psychological dimensions of recovery by suggesting that it involves the development of new meaning and purpose in life as a person grows beyond the effects of mental illness. Other authors have developed criterion-based definitions that emphasize instrumental role functioning across domains such as work, social functioning, and living independence as well as reduced symptomatology. There remains disagreement about the extent to which being symptom free is a requisite for recovery or whether the need for treatment, medications, or hospitalizations should factor into the definition. For example, in one of the Vermont follow-up study reports by Harding and Zahniser (1995), the authors used the following definition of recovery from schizophrenia: "no signs or symptoms of mental illness, no current medications, work, relating well to family and friends, integrated into the community...." A further complication of the use of the term recovery is that some researchers and authors refer to recovery as an outcome while others refer to recovery as a process.

In essence, the term recovery is increasingly being used to denote a severely mentally ill person's potential for growth, healing, and community integration. The literature focused on in this text encompasses this broader understanding of recovery. This conception was largely absent from the last century's diagnostic schemes, maintenance-type interventions, and mental health research. Furthermore, for most of the previous century, throughout North America and Europe, people with severe mental illnesses were not expected to recover, and were also dehumanized and devalued by both society and sometimes inadvertently by treatment professionals. The view that people with mental illnesses lacked potential for growth and change, and responded only to interventions designed to prevent deterioration has gradually dissipated. This change in practice and attitudes essentially views people with psychiatric disabilities as "people first." This text represents the first attempt at presenting the research that has led to this paradigm shift.

The advent of the awareness of recovery has started to change the field of mental health significantly; we are now just beginning that transforma-

tion process (President's New Freedom Commission on Mental Health, 2003). This second of two volumes is a beginning effort to overview the key literature that empirically supports this new understanding of recovery. Also addressed are the key roles that the person, peers, family members, practitioners, and researchers can play in recovery policy and practice.

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Preface

The first research to document the fact that not all people with schizophrenia manifest the progressive deteriorating course proposed by Kraepelin to distinguish this condition from other psychiatric conditions with less virulent courses was published by Strauss and Carpenter in 1972. That was 33 years ago. Even given the 25-year span it typically takes for scientific breakthroughs to make their way into routine clinical practice (IOM, 2002), it is surprising, and troubling, how much of the mental health field remains ignorant of these findings, thereby perpetuating, albeit unwittingly, the Kraepelinian legacy of hopelessness, helplessness, and despair. Even as these volumes are going to press, the American Psychiatric Association is considering adoption of a new diagnostic category for the next version of the *DSM*, which they have labeled "schizophrenia in remission." Even this step, which is limited to relief of symptoms and still is not without its own controversy, falls well short of recognizing the broad heterogeneity consistently found in the outcome of schizophrenia in many studies conducted in multiple countries over the last 35 years. While others may speculate about the reasons why it has taken psychiatry so long to acknowledge and incorporate this body of knowledge, or what function perpetuating Kraepelin's legacy may serve for the field, we offer these volumes as corrective measures to counteract the prevailing ignorance.

In our opinion, our timing could not be better. The last 5 years in the history of mental health policy in the United States in particular have led to broad adoption of the term *recovery* in relation to serious mental illnesses. Beginning with the landmark 1999 *Mental Health: A Report of the Surgeon General* (DHHS, 1999), and culminating (thus far) in the 2003 Final Report of the President's New Freedom Commission on Mental Health, entitled *Achieving the Promise: Transforming Mental Health Care in America* (DHHS, 2003), a notion of recovery that had resided largely on the margins of psychiatry has been unceremoniously dumped into the mainstream of clinical practice. This is not to say that "recovery" did not already have its advocates within the field. The Community Support Movement as a whole, and the discipline of Psychiatric Rehabilitation more specifically, embraced early notions of recovery as well as the eloquent spokespersons of recovery who were themselves ex-patients, survivors, or consumers. What began to change with the Surgeon General's Report was that this notion which had been held dear by an energetic and idealistic minority was now being proposed as the overarching aim and principle for the field as a whole. As the vision statement of the New Freedom Commission Report explicitly and adamantly

announces: "We envision a future when everyone with a mental illness will recover" (DHHS, 2003).

Reactions to this forceful statement have been mixed. Mental health advocates and psychiatric rehabilitation practitioners have rejoiced, of course, but with the nagging suspicion that all of their hard work is about to be co-opted by the very field they have been fighting against for the last 30 years. Many providers, family members, and people with psychiatric disabilities welcome the introduction of a positive and hope-filled message, feeling that it is long overdue. Among those professionals who are more skeptical, some dismiss what they view as recovery "rhetoric" as simply the latest fad in a field that has been slow to embrace the importance of evidence. Others view the introduction of recovery as a short-sighted political gesture that is at least ill-advised, if not altogether irresponsible, claiming that notions such as self-care, self-determination, and client choice are code words used by an uncaring populace to disguise the real agenda of cutting services, and thereby costs. The various forms of skepticism that have surfaced share a common perception that there is no evidence justifying use of the term recovery in relation to serious mental illnesses, dismissing arguments to the contrary as, in the words of one reviewer, "unsubstantiated rubbish."

It is to these skeptics, as well as to the hundreds of thousands of people with psychiatric disabilities, their loved ones, and the compassionate professionals who devote their careers to caring for and supporting them, that these volumes are addressed. We have identified and collected representative publications from the last 30 years of research and clinical and rehabilitative practice that present the evidence supporting use of the term recovery in relation to serious mental illnesses. This literature addresses both the natural history of the illness as well as the effectiveness of various interventions addressing different domains of functioning, such as vocational, emotional, social, physical, cognitive, and spiritual. Overall, it offers a highly variegated picture of a complex, dynamic, and ever evolving condition that, on the one hand, may become lethal when left untreated, but which, on the other hand, also can be contained, managed, and/or overcome over time by the majority of people who experience it. In addition, despite the long-standing belief that psychiatry is a "soft" science in which pretty much anything can masquerade as treatment (from psychoanalysis to lobotomy), the evidence suggests that psychiatric interventions are at least as effective, and in many cases more effective, than their established medical counterparts (DHHS, 1999). Indeed, to the degree that we can emerge out from under the long shadow cast by stigma, discrimination, and societal insensitivity to the needs and dignity of people with serious mental illnesses, we all have much to be hopeful about.

We close this preface with one cautionary note, however. In spite of its broad adoption by policy makers, politicians, and professionals across the

globe, the term "recovery" has many different meanings when used in relation to serious mental illnesses. We explore several of these meanings in our first chapter. Throughout the entirety of these volumes, it will be important for the reader to keep in mind that there are dramatically different uses of the same term by different investigators for different purposes. When evaluating or applying the findings of any of the publications reprinted here, it would be wise for the reader to ask him or herself: What definition or sense of the term recovery is being used here, in relation to what population of persons, from which perspective, and to what ends? We offer only two of the possible uses of the term to illustrate this point.

The research alluded to above, which began with the seminal work of Strauss, Carpenter, and others in the 1970s (e.g., Strauss & Carpenter, 1972), utilized a conventional medical sense of the term recovery, restricted to the narrow perspective of clinical investigation. In this case, recovery meant the absence of any symptoms, signs, or other sequaelae of the illness. Many people were found to recover from serious mental illnesses in this sense in a way similar to how people recover from other medical conditions such as the flu, an infection, or (in the case of a longer-term course of illness) asthma. Some within the field, including some advocates, insist that this is the only viable or accurate use of the term recovery and suggest that any other use serves solely to obfuscate the issue.

Increasingly common, however, is a use of the term recovery which resembles more a disability paradigm than a purely medical one. In this sense of the term, recovery refers to a person's right and ability to live a safe, dignified, and meaningful life in the community of his or her choice despite continuing disability associated with the illness. Borrowed initially from the addiction self-help community, this sense of recovery refers instead to learning how to live fully in the presence of a disabling condition. As a result, this sense of recovery makes no sense for people who recover fully from their illness in the biomedical sense of the term used above. In other words, this sense of recovery is most relevant for those people whose illness does not simply "go away." Why, then, use the term recovery to refer to this process of learning how to manage and minimize the destructive impact of one's illness on one's life? Doesn't this just confuse things unnecessarily? From our perspective, it is important to include this sense of recovery in the following text because this is the term, and the sense of recovery, that has been chosen and promoted by people living with mental illnesses. For many of them, the term recovery represents first and foremost a crucial civil rights issue that they face as a consequence of several thousand years of discrimination. In the words of Patricia Deegan, one of the most eloquent spokespersons for this sense of the term: "The concept of recovery is rooted in the simple yet pro-

found realization that people who have been diagnosed with a mental illness are human beings" (1992, p. 12).

We understand the ambiguity and confusion that is introduced into a field when one term is used by so many different people to mean such very different things. We agree that this is not an ideal situation, nor does it represent an optimal strategy for promoting the health and well-being of people with psychiatric disabilities. It is, nonetheless, the situation in which we find ourselves. We offer one other recommendation in this regard in addition to encouraging the reader to be as clear as possible about which sense of recovery is being used when and by whom. This recommendation is that we all agree to accept the basic civil rights claims made by people with psychiatric disabilities as our point of departure. This means that we accept the premise that people with psychiatric disabilities are, and remain, people just like everyone else—i.e., just like people who do not have psychiatric disabilities—until we discover otherwise, and then only in the specific ways for which we have accumulated persuasive evidence. Why is this important?

The longitudinal research described above not only discovered a broad heterogeneity in outcome for schizophrenia across people, but also found heterogeneity in functioning across various domains, such as vocational, emotional, social, physical, cognitive, and spiritual, within any given individual over time. Some people may experience florid positive symptoms of hallucinations and delusions while having no cognitive deficits, while others may suffer from profound negative symptoms and cognitive impairments while having few observable positive symptoms. And these profiles can change, even within the same individual, over time. Psychosis does not take over the entirety of the person, as Kraepelin had suggested, but exerts various degrees of impact on various domains of functioning. It leaves some domains of functioning intact, so that people retain areas of health and competence that co-exist alongside of symptoms and dysfunction. As a result, the person is very much still there and should be accorded all of the rights and responsibilities that accrue to this status unless and until he or she offers persuasive evidence to the contrary.

Until we fully accept this premise, we will continue in our research and our practice to stumble across findings that reflect the fact that people with mental illnesses are in fact just like people in general. Several of the contributions to these volumes, including some of our own, conclude with such insights. While still useful to the field, for example, the findings of our early supported socialization studies have been considered somewhat anti-climactic in their suggestion that friendship is important for people with psychiatric disabilities (i.e., just like it is for everyone else). Until we can get beyond proving such obvious, if nonetheless overlooked, points, we will make little

progress in determining what it is that is unique in the challenges presented by mental illness and what it is that is specific to the illness that people need to learn to manage and recover from. In reviewing the existing research base for where we are as a field currently, we hope not only to silence the skeptics amongst us, but, even more importantly, to provide the foundation for this next generation of even more promising research.

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Introduction to Chapter 4

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In 1961, a small book entitled *The Vermont Story* appeared and reported on an innovative biopsychosocial rehabilitation program at the only state hospital in Vermont (Chittick et al., 1961). This program targeted the most impaired and chronic group of patients. It was the classic custodial era, when the clinical director, George W. Brooks, MD, received one of the first Smith-Kline and French fellowships to study the effects of thorazine in the early 1950s. All the so-called "hopeless patients," languishing in the back wards, were provided with a therapeutic dosage range of this new medication. Suddenly, 178 people became significantly better and were able to be discharged. This response galvanized the staff to want to help the remaining 269 people who had had only a modest response to the new medication. There were no books written on how to treat the "chronic" patient, so Dr. Brooks returned to the back wards and asked the patients: "What do you need to get out of here?" Thus began a collaborative effort between patients and clinical staff that between the years of 1955 and 1965 developed into a pioneer rehabilitation and community mental health program. (For a more detailed description of this effort and the long-term outcome of these people, see Volume 1, Chapter 2).

With the publication of *The Vermont Story* and the awards that followed, the American Psychiatric Association, the American Academy of Neurology, and the U.S. Department of Justice issued a Joint Commission report called *Action for Mental Health* (1961). In it they said: "The fallacies of 'total insanity, hopelessness, and incurability' should be attacked and the prospects of recovery and improvement through modern concepts of treatment and rehabilitation emphasized." From 1961 onward, ten world studies reported more positive outcomes for once very disabled persons, but the dominance of a deficits paradigm that focuses on problems, disability, deficits, and damage (e.g., Seligman & Csikszentmihalyi, 2000) persisted over the last century. This volume presents a small sampling of the investigators, persons with psychiatric disbilities, and family members who continue onward and challenge this persistent pessimism within the professions (see Harding, Zubin, & Strauss, 1987, 1992; see also Thomas Kuhn, 1996).

Chapter 4 examines how treatment, case management,* and advocacy helps people to improve. It starts with a strategy proposed by Harding that

* The editors of this volume and the authors Rapp and Goscha, acknowledge that many people with psychiatric disabilities take issue with the use of the term *case management*, arguing that they are not "cases" who need to be "managed." The intent within is a reference to the services and/or resources that are managed in order to help people reach their goals.

presents several critical biopsychosocial questions to ask when a person appears to be stopped on the road to recovery. This is followed by a discussion from Rapp and Goscha outlining ten principles for the provision of effective case management based on a review of 22 studies. They contrast the research on Assertive Community Treatment (ACT) approaches to those emphasizing strengths-based work and present findings that indicate that ACT tends to target reducing hospitalizations and strength-based work focuses on non-hospital outcomes.

These articles are followed by a focus on integrated treatment for persons suffering from both mental illness and substance abuse by the Dartmouth group of Mueser, Drake, and Noordsy. Their work, along with that of others, has established some of the six accepted evidence-based practices crucial for this population.

An early article by Malamud and McCrory presents a specific approach to get people back to work by setting up transitional employment (TEP) opportunities with employers to help patients become workers and become adapted to the workplace. TEP often has been dismissed as a program from which patients never graduate and are kept from the "real" world of competitive employment. However, this approach still works for many people emerging into the world of work. A new paper has shown that the approach can be effective and provide competitive employment (personal communication about a paper being revised by Andrew Schonebaum, January 6, 2006).

Wayne Fenton, former research director of the well-known Chestnut Lodge, discusses empirical testing of targeted and phase-specific individual psychotherapies including Personal Therapy as proposed by G. Hogarty and asociates from Pittsburgh (2002); "flexible psychotherapy" that provides a wide variety of interventions depending on the current needs of the client (e.g., Need-Adapted Treatment by Alanen, [1997]); and the British version of Cognitive Behavioral Therapy for psychoses. This treatment is described at length in an additional paper included here by Garety, Fowler, and Kuipers with many other authors in agreement such as Max Birchwood (1996). Fenton also suggests that the successful practices use evaluation, continuous re-evaluation, timing, titration, and integration with psychopharmacology. The immediate challenge is to transfer what has been learned in the laboratory to general practice.

In addition to all of these strategies, persons with psychiatric disabilities and their families weigh in on what works and does not work for them in working with professionals. Mestamaker not only writes about the obstacles presented by the clinicians, but also speaks about those erected by families and consumers. Chamberlin has been fighting for consumer rights and social justice since the 1970s. Her paper describes the "fundamental expectations that governs the relationship between individuals and societies." An elo-

quent spokesperson for the rights and needs of family members, Harriet Lefley is also a psychologist and a professor of psychiatry and thus bridges many worlds. Her paper provides an overview of the national efforts for advocacy, a summary of actual organizations with their primary goals and functions and their impact on national health care reform. In his vivid first-hand description of life stresses, drugs, mental illness, and immigration, Patrick Brown writes about taking control in self-management and partnering with professionals in seeking recovery as a process and how he reacquired hopefulness about his future.

In the end, after perusing all of these papers, the reader might be tempted to agree with Falloon and associates (1998) who have decided that "optimal treatment strategies to enhance recovery from schizophrenia" includes "psychoeducation, medication strategies, career-based stress management training, community-based intensive treatment, living skills training, specific drug and cognitive-behavioral strategies for residual symptoms." It seems to take a village to help reclaim lives.

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