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VOLUME

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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*, 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 20 to 30 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 suggest 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 the Vermont follow-up study reported by Harding and Zahniser, 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 transformation process (President’s New Freedom Commission on Mental Health, 2003).

This book is a beginning effort at overviewing 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.

WILLIAM A. ANTHONY, PHD

President's New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America, final report* (No. Pub. No. SMA-03-3832.). Rockville, MD: U.S. Department of Health and Human Services.

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 Report on Mental Health 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, 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 sequelae 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 1

Larry Davidson

In this first chapter, we begin with a recent paper that attempts to summarize the various meanings of the term *recovery* both inside and outside of mental health, in the hope that this will provide a useful framework for the remainder of the two volumes. We then examine the ten long-term follow-up studies of serious mental illnesses that lay the groundwork for the possibility of recovery, and demonstrate consistently that 50 to 60% of each sample were able to experience significant improvements in the illnesses and in their lives. These studies contain many important findings, including a broad heterogeneity in outcome; early course fluctuations followed by later decreases in severity; the failure of traditional indicators to predict course or outcome over the longer term; the existence of multiple pathways to recovery, including the restoration of social and occupational functioning; and the fact that many people do not continue to take psychiatric medications for the entirety of their lives as we have come to expect (and as we continue to teach to patients and their families). John Strauss reflects upon his many years of research involving face-to-face interviews with people with psychiatric disability. He restates his key finding of the possibilities for recovery and describes his frustration with the lack of acceptance by mental health professions of this now well documented fact.

The next several contributions to this chapter represent the perspectives and experiences of people who have recovered, to various degrees, from serious mental illnesses, providing by virtue of their own lives a different kind of “evidence” of the possibility of recovery. As a result of their own struggles and accomplishments, Patricia Deegan, Shery Mead, and Mary Ellen Copeland have become extremely effective, as well as eloquent, spokespersons within the Recovery Movement. Their contributions suggest a number of factors and processes that promote, facilitate, and/or sustain recovery, highlighting also the central role that the person plays in learning about, managing, compensating for, and minimizing the destructive impact of his or her illness. As Harding’s summary of long-term follow-up studies offers a review of what we know about the more narrow, biomedical sense of recovery (i.e., referring to the absence of symptoms, signs, and corrections of the deficits associated with the illness), these two contributions offer a review of that sense of recovery promoted most vigorously by the Consumer/Survivor/User Movement.

Following these consumer accounts, Spaniol and colleagues present qualitative findings pertaining to processes of recovery culled from narrative accounts of people with serious mental illnesses who have experienced sig-

nificant improvements in their condition. They suggest, in particular, that people go through phases of recovery, beginning with being overwhelmed by and struggling with the disability prior to learning how to live with and then finally live beyond the limitations of the disability. Reflecting one of the major unanticipated adverse consequences of deinstitutionalization, Drake and colleagues then review the impact of substance use disorders on the lives of people with serious mental illnesses. Since people with serious mental illnesses have been able to live the majority of their adult lives outside of institutional settings, substance use and abuse has become the single most detrimental factor negatively impacting on outcome. In addition to reviewing these data, this paper also describes the failures of fragmented systems to address co-occurring disorders and offers hope for the development and dissemination of more effective practices based on an integrated model of treatment and rehabilitation. Harding's article identifies some major myths about serious mental illnesses that serve as attitudinal and belief barriers to the treatment and recovery process. We then end this chapter, as we do each of the following chapters, with a first-person account that describes in rich, narrative detail the ways in which these various factors interweave within the life context of any given individual and/or family affected by serious mental illnesses.

By the end of this chapter, we hope that our readers will grasp the possibility of at least two different senses of recovery in serious mental illnesses, be able to identify a variety of factors that facilitate or impede recovery, and begin to have a better understanding of what processes of recovery look like and involve for people living with these conditions.