

INTRODUCTION

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I learned in graduate school that schizophrenia was the kiss of death. In the 1980s, most professionals accepted Emil Kraepelin's (1987) description of the illness as a progressive downhill course where people ultimately end up in state hospital wards, unable to care for themselves. Grim prognoses for individuals with schizophrenia and other mental illnesses cast a wide pall; treatment was largely custodial, focusing on symptom management. Poor outcomes were thought to reflect the person's inability to understand illness and interventions; hence, adherence to treatment became a first principle. My job was to help patients by hook or by crook take their medications and protect them from unreasonable goals that would lead to relapse. "Unreasonable" goals typically included those that led to work or independent living.

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Person-Centered Care for Mental Illness: The Evolution of Adherence and Self-Determination,
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I learned from people who had these illnesses that most of what we believed to be true was wrong. Kraepelin's assertions made more than 100 years ago were replaced by long-term follow-up research that showed that most people with even the most serious of mental illnesses recover. Beyond the research, however, were lessons learned from people who had been challenged by significant illness and restrictive treatments but still achieved goals they set for themselves. Their recovery meant they could pursue goals they found meaningful. Not surprisingly, their goals did not always involve strict adherence to their practitioners' prescriptions; rather, they were formed from the person's insights about his or her life. Goals were accomplished by tearing down barriers and building on accomplishments. Interventions that allow people to meet their goals might include evidence-based strategies that have emerged from services research, innovations that have not yet been blessed by services research, and even things of idiosyncratic significance to the person that could not be formally labeled. Central to this was promoting self-determination so that people could achieve personally meaningful goals.

Over the past decade or more, I came to know of and partnered with three scholars doing innovative work in this arena: Larry Davidson from Yale, Beth Angell from Rutgers, and Mark Salzer now from Temple. We thought we might catalyze a program of research that describes the experiences of self-determination. Our work is often practical in nature, so we also sought to understand strategies that promote self-determination. In 2008, we submitted a proposal to the National Institute of Mental Health to support a Developing Center on Interventions and Services Research. We added Steve Marcus from the University of Pennsylvania as a primary investigator responsible for our statistics and methods core and were funded for the following year. Ours was a virtual center with investigators spread out in more than a dozen institutions east of the Mississippi. Central to our process was community-based participatory research, where Center on Adherence and Self-Determination (CASD) investigators partnered with people with mental illness and other stakeholders. In collaboration, we framed research questions, generated methods meant to test these questions, collected data, analyzed data in terms of the questions, and made sense of our findings. Biweekly teleconferences of CASD members were interspersed with twice annual, face-to-face meetings that included more than 20 other investigators over the course of the study. We published well over 150 peer-reviewed papers and captured additional funds from more than 10 successful grant proposals. Our focus was to understand what self-determination meant for the person and what providers might do to promote it. This book is a monument to these efforts.

HOW THIS BOOK IS ORGANIZED

In Chapter 1, Patrick W. Corrigan, Kristin Kosyluk, and Petra Kottsieper briefly review the impact of serious mental illness, the state of evidence-based treatments, and the problem of people opting to not pursue some treatments. We contrast adherence approaches to treatment with self-determined treatment decisions and take a careful look at the costs and benefits of varied perspectives, setting the theoretical tone for much of the rest of the book.

Experienced practitioners know that not all decision making is rational or sequential. In Chapter 2, Patrick W. Corrigan, Karina J. Powell, and Patrick J. Michaels describe decision making as it typically occurs, within contexts that are both immediate and emotion laden.

Stigma is often a barrier to goal attainment for people with mental illness. In Chapter 3, Patrick W. Corrigan and Andrea B. Bink discuss how stigma impedes self-determination. They include recommendations for diminishing stigma in order to promote independent decision making.

The rest of the book focuses on practical topics. Chapters 4 through 11 illustrate how providers can shift away from a perspective that asks, “What should the patient be doing?” thus orienting themselves toward questions such as “How do we provide services that people feel will help them achieve their life goals?” In Chapter 4, Larry Davidson, Janis Tondora, Rebecca Miller, and Maria J. O’Connell summarize the principles and practices of person-centered care, the approach that undergirds many strategies that promote self-determination. Person-centered care frames the treatment system in terms of goals and desires of the person in need. The Institute of Medicine supported a version of person-centered care in its 2001 report, *Crossing the Quality Chasm: A New Health System for the 21st Century*. Person-centered care is the foundation of medical practice laid out in the Patient Protection and Affordable Care Act of 2010. Davidson et al. apply the medical principles of the law to mental health care.

In Chapter 5, Maria J. O’Connell summarizes one of the emerging instruments for ensuring self-determination: psychiatric advance directives. These directives are legal documents in which people spell out their treatment preferences and expectations before they find themselves in a distressing situation in which reviewing these decisions is more difficult.

The principles and practices of shared decision making are reviewed by Beth Angell, Elizabeth Matthews, Victoria Stanhope, and Michael Rowe in Chapter 6. Shared decision making is a set of strategies that help people fully understand challenges and treatments while immersed in a person-centered counselling exchange. One version of shared decision making is motivational interviewing, where providers help others to understand avenues for

change based on weighing the pros and cons of various options. In Chapter 7, Jonathon E. Larson reviews this approach in terms of work goals and supported employment.

Sometimes people cannot make decisions about life options because of cognitive limitations. In Chapter 8, Patrick J. Michaels, Karina J. Powell, and Patrick W. Corrigan review cognitive strategies that might assist a person in decision-making. Some of these strategies come from cognitive therapy and help the person make sense of specific beliefs; others are taken from cognitive rehabilitation and facilitate information processes such as attention and memory.

Self-determination is not always a function of person and provider exchanges; community situations affect decisions and goals, too. Amy C. Watson, in Chapter 9, discusses self-determination within the context of legally mandated care. She explains the functions of coercion and procedural justice in engaging people with mental illness involved in the criminal justice system.

Peer support is one resource for navigating communities that hamstring self-determination. In Chapter 10, Mark S. Salzer and Petra Kottsieper summarize the character of peer support programs and research that backs up its effectiveness. They report on a recent research project conducted by their group that showed how peer programs foster service engagement in the broader system.

The community's impact on health, at the broadest level, reflects the influence of culture. Self-determination mostly reflects individualist values that reflect Western perspectives. In Chapter 11, Eun-Jeong Lee, Chow Lam, and Nicole Ditchman consider the intersection of self-determination and perspectives in Asian cultures. Their chapter includes critical considerations of how decision making may vary by culture.

In the final chapter of the volume (Chapter 12), Patrick W. Corrigan encourages readers to adopt a critical stance toward self-determination. We will continue to realize the vision of patient self-determination only when we carefully consider its implications in clinical settings.

WHO MIGHT BENEFIT FROM THIS BOOK?

This book provides useful lessons for many audiences. Perhaps most important are students of mental health services who will learn from the beginning of their career the risks of adherence as a treatment perspective and the mandate for self-determination. One program currently pursued by our research center examines mentorship between student nurses and people with lived experience as a way to teach self-determination. The “mentoring”

relationship we've designed turns the status quo on its head. Rather than nurses learning to be "one-up" and bestowing care to the "patient," people with lived experience are seen as authorities from whom nurses might learn.

Some practitioners might find that this book cements the value of promoting self-determination, offering practical approaches that can be used in clinical settings. For others, it offers guidance for the adoption of progressive approaches to helping people reach their goals.

Finally, chapters in this book provide a ready summary of the body of literature on care seeking and self-determination. They also provide direction for research avenues in the field.

Self-determination is a core principle of recovery. Recovery is the vision of our time. Readers of this book should embrace the goal of recovery in order to exponentially boost the opportunities and accomplishments of people challenged by mental illness.

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