PARTNERING FOR RECOVERY IN MENTAL HEALTH

A Practical Guide to Person-Centered Planning

JANIS TONDORA • REBECCA MILLER
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WILEY Blackwell

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A PRACTICAL GUIDE TO PERSON-CENTERED PLANNING

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To our children,

Caleb and Rylee

Cecilia

Emily and Isabel

and

Abbey, Alana, and Lexi

in the hope that all mental health services will be encouraging, person-centered, and collaborative if and when they, or their children, decide to use them.

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Acknowledgments

This book is the result of over a decade of on-the-ground development, implementation, and evaluation of a person-centered approach to recovery planning for adults with serious mental illnesses. Consequently, there are far too many individuals who have been instrumental in this process for us to acknowledge each and every one of the service users, clinical practitioners, peer staff, family members, administrators, system leaders, and advocates by name. Nonetheless, we thank you all for your invaluable contributions to this work. We think that you know who you are.

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In the following chapters, we make the point that it is not "person-centered" to insist that a person make his own decisions when his cultural and personal preference is for a more collective decision-making process involving family members, elders, or other respected parties. We also point out that it is not in keeping with the principles of "person first language" to insist that a person describe herself as a "woman with an addiction" when she prefers to use the term "addict" (even though that may be offensive to others). These are but two examples of the ways in which we have seen well-meaning practitioners turn

person-centered principles on their head in the earnest attempt to be faithful to what they interpret person-centeredness to be. We offer this manual in the hope that readers will feel as free to "fiddle" with aspects of this approach as they may need to be faithful to it, and that above all, being person-centered means respecting the uniqueness and honoring the dignity of each individual you have the privilege to serve.

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Module 1: What is mental health recovery and how does it relate to person-centered care planning?

Goal

This module introduces the key concepts in mental health recovery and recovery-oriented practice. It reviews the history and development of "person-centered" care planning and places it within the broader context of recovery-oriented efforts that are transforming the mental health system as a whole.

Learning Objectives

After completing this module, you will be better able to:

- define mental health recovery;
- describe the difference between traditional practices and recovery-oriented approaches;
- define person-centered care planning;
- understand how person-centered planning differs from past practice.

Learning Assessment

A learning assessment is included at the end of the module. If you are already familiar with mental health recovery and its implications for care planning, you can go to the end of this module to take the assessment section to test your understanding.

Recovery is about living a fulfilling and rewarding life in the context of mental health challenges. While some people recover in the sense that they no longer experience psychiatric symptoms, recovery is not necessarily about becoming symptom- or problem-free. A large part of recovery for many people is moving beyond being labeled as a "mental patient,"

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"client," or even "consumer" to find new meaning, purpose, and possibility in life. For many people, recovery means [1]:

- No longer defining oneself by the experience of mental illness.
- Being a full participant in the community with valued roles such as worker, parent, student, neighbor, friend, artist, tenant, lover, and citizen.
- Running one's own life and making one's own decisions.
- Having a rich network of personal and social support outside of the mental health system.
- Celebrating the newfound strength and skills gained from living with, and recovering from, mental illness.
- Having hope and optimism for the future.

> Recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential.
>
> —*SAMHSA National Consensus Statement on Mental Health Recovery* [2]

All around the world people have been demonstrating the possibility, and reality, of mental health recovery. Their stories of lived experience are supported by a mounting evidence base that suggests that recovery is more the norm than the exception in serious mental illness. Beginning with the World Health Organization's (WHO) International Pilot Study of Schizophrenia launched in 1967, there have been a series of long-term, longitudinal studies conducted that have produced a consistent picture of broad heterogeneity in outcome for persons with serious mental illnesses. For example, with respect to schizophrenia, the WHO study documented partial to full recovery in between 45% and 65% of each sample, even when recovery was defined in a clinical fashion as a remission in symptoms, while an even larger percentage of people were able to live independently despite continued symptoms [3].

Similarly, the Vermont Longitudinal Study conducted by Courtney Harding and colleagues found recovery or significant improvement in 62%–68% of the people studied—a finding that was all the more important given that the research was carried out on individuals discharged from a state hospital who were considered to have the most severe and persistent of conditions [4]. Since then, eight more long-term studies (e.g., 22–37 years) have been completed around the world, yielding comparable—and at times, better—results [5].

The evidence for the prevalence of recovery and the potential for recovery-oriented care to help people live full lives has recently been gathered in two landmark texts published by the Boston University Center for Psychiatric Rehabilitation [6]. These books present a summary of over 30 years of experience that challenges the long-held view that serious mental illnesses typically follow a deteriorating course, and explore the range of interventions that have been employed to promote recovery for persons with these conditions.[1] Readers seeking a briefer overview of the

> *Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges… The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution.*
>
> —*Deegan* [7]

[1] For more information, see: www.bu.edu/cpr/products/books/titles/rsmi-2.html.

empirical evidence for recovery in serious mental illness are referred to an essay on this topic by Ed Knight, Vice President of Recovery, Rehabilitation, and Mutual Support for Value Options.[2]

Where Did the Idea of Mental Health Recovery Come From?

The idea that people can—and do—actually recover from serious mental illnesses grew in large part from the personal experiences and stories of people who experienced recovery in their own lives. Their voices and perspectives were diverse and were from people who were receiving mental health services ("users" of services); individuals who believed they had survived despite the treatment they received ("psychiatric survivors"); and people who had once been patients receiving services, but who felt they had moved beyond that status in their lives and were now "ex-patients." These voices provide the most powerful, and persuasive, testament to recovery, and readers who are interested in reading such stories can find them in websites such as www.SAMHSA.gov/Recoverytopractice (from the United States), www.recoverydevon.co.uk (from England) and www.scottishrecovery.net (from Scotland), to name a few.

> *Recovery is a process by which an individual with a disability recovers self-esteem, dreams, self worth, pride, choice, dignity, and meaning.*
>
> —*Townsend & Glassner* [9]

These voices and perspectives merged to form a movement that has not only survived, but has also grown and emerged as a powerful force for change in mental health policy and services around the world. Drawing on personal experiences, social justice values, civil and human rights, and a passion for changing the mental health system, users/survivors have been the driving force behind the recovery movement that promises to significantly impact both public policy and treatment practices around the globe [8].

Is Mental Health Recovery the Same as Recovery from Addiction?

A variety of self-help and 12-step programs in the addictions arena has influenced the recovery movement and the value it places on mutual support and shared experience. However, there are some unique differences between the actual experience of recovery in mental illness as compared to recovery from addiction. For example, there are core differences related to issues of power. A common requirement in 12-step programs is to admit powerlessness and turn one's self and life over to a "Higher Power." While respecting the importance spirituality plays in many people's lives, mental health recovery emphasizes empowerment and

[2] This document is available at: http://csipmh.rfmh.org/Knight_recovery.htm.

self-determination as well; helping individuals to find their own voice and to take personal responsibility for their own lives. This is based on the belief that people need to reclaim, not turn over, their power as one of the first steps of recovery.

This distinction between mental health and addiction recovery impacts both the process of self-identification and the use of preferred language and terms. For example, traditional 12-step programs encourage individuals to introduce themselves as: "My name is X and I am an alcoholic." This is consistent with the 12-step focus on acknowledging one's powerlessness over a substance, and self-identification in this manner is respected as a part of the individual's unique recovery process. In contrast, in the mental health recovery community, there is an emphasis on helping individuals to move beyond the diagnostic labels that have been applied to them by others. Therefore, individuals are encouraged to use "person-first" language and thereby NOT to identify themselves, or allow themselves to be identified by others, in any way that makes a psychiatric diagnosis their most salient or defining characteristic: for example, "My name is X and I am schizophrenic." In both the addiction and mental health contexts, it is important to note that individual preferences around language and self-identification vary widely, and additional guidance on this topic is offered in Module 2.

Despite these differences in the process of recovery in mental illness and addiction, there are numerous areas of overlap and commonality [10]. The important thing to remember is that no matter what an individual's particular label or diagnosis, people with mental illnesses and addictions are first and foremost people, and people who know best what kind of life they will find worth living in the wake of a behavioral health condition. This is the hallmark of the recovery movement in both mental health and addiction.

Getting Beyond Us versus Them

When we say that "people with mental illnesses and addictions are first and foremost people," we mean that "they" are fundamentally the same as "us" (i.e., those persons who do not have a mental illness or addiction). Though we may be stating the obvious when we say that people with mental illnesses are still people, the reality and experiences in the past have suggested otherwise. Consider Table 1.1. On the left are the things we typically consider to be important in leading a satisfying life, while on the right are the things that have traditionally been identified in care plans as important for persons with serious mental illnesses. 1) What differences do you see in the lists below? 2) What are the similarities? and 3) Are there differences in tone and language between the two lists?

People receiving mental health services want essentially the same things out of life that practitioners do—a home, family, faith, a sense of purpose, health, and other such things. As a result, "recovery" for mental health service users should involve pretty much the same things that mental health service practitioners see as being a part of their own well-being and quality of life. Yet systems are structured in such a way that practitioners are seldom prompted to think of it in this manner. This is particularly true in the context of service planning where "compliance" (with treatment, administering of medications, program rules, etc.) is by far the most commonly identified desired outcome in the "what we expect for them" list reflected in written treatment plans. Recovery-oriented and person-centered care is, at its core, about getting past this "us/them" dynamic to truly partner with people in recovery in their efforts to attain their personally defined and valued goals.

Table 1.1 "Us and Them"

What We Expect for "Us"	What We Expect for "Them"
✓ A life worth living	✓ Attends program, groups, clubhouses
✓ A home to call my own	✓ Residential stability
✓ Faith, spiritual connections	✓ Better judgment
✓ A real job, financial independence	✓ Decreased symptoms/stability
✓ Being a good spouse … parent	✓ Increased insight … accepts illness
✓ Friends	✓ Decreased hospitalization
✓ Joy, fun	✓ Compliance
✓ Nature	✓ Abstinence
✓ Music	✓ Increased functioning
✓ Love … intimacy … sex	✓ Cognitive functioning
✓ Learning, growing	✓ Realistic expectations

Recovery as an Emerging Global Paradigm

A number of prominent reports reflect the emergence of recovery and recovery-oriented care as the driving force behind mental health systems across the globe. For example, a 2012 issue of the *International Review of Psychiatry* contained papers outlining the current stage of recovery research and practice from Austria, Australia, Canada, England, Hong Kong, Israel, New Zealand, Scotland, and the United States [11], while a 2011 review of policy developments identified 30 government documents mandating recovery-oriented care from English-speaking countries around the globe [12]. The following are a few examples from these English-speaking nations:

Achieving the Promise: Transforming Mental Health Care in America, US Department of Health and Human Services [13]. This report called for recovery to be the "common, recognized outcome of mental health services" and recommended "fundamentally reforming how mental health care is delivered in America" to be reoriented to the goal of recovery. This report strongly criticized the nation's current mental health system as one that, too often, "simply manages symptoms and accepts long-term disability."

Improving the Quality of Health Care for Mental and Substance Use Conditions, Institute of Medicine [14]. This report speaks specifically of the decision-making abilities of individuals who have a mental illness as well as those who do not. One harmful stereotype that is referenced in the report is "incompetent decision making." One key recommendation notes that "to promote patient-centered care, all parties involved in health care for mental or substance use conditions should support the decision-making abilities and preferences for treatment and recovery of persons with mental and substance use problems and illnesses."

No Health without Mental Health, UK Department of Health [15]. This national policy framework for England identifies six priorities for the mental health system, including "more people will have good mental health," "more people with mental health

problems will recover," and "fewer people will experience stigma and discrimination." One national initiative being carried out as part of this policy is the Implementing Recovery–Organisational Change (ImROC) program, which is working with 33 of the 55 mental health trusts (provider organizations) in England to support their transformation to a recovery orientation [16]. This initiative includes the recommendation that the mental health workforce comprise 50% people with lived experience of mental illness [17] and introduce Recovery Colleges to provide support to people with mental illnesses through an educational approach [18].

Changing Directions, Changing Lives, Mental Health Commission of Canada [19]. An emerging vehicle of change in several countries has been the establishment of influential Mental Health Commissions. The Canadian commission was established in 2007, and in developing its national mental health strategy, it has taken testimony from thousands of people living with mental health conditions. An important stepping stone was the 2009 discussion document *Toward Recovery and Well-Being* [20], which defined mental health as "*a state of well-being in which the individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his own community*." In this report, a mental health framework is developed as a blueprint for change, with the strategic direction to "*foster recovery and well-being for people of all ages living with mental health problems and illnesses, and to uphold their rights*." The emphasis on well-being in the context of mental illness is consistent with empirical research [21] and the links between well-being research and recovery are becoming clearer [22].

A Recovery Approach within the Irish Mental Health Services—A Framework for Development, Mental Health Commission of Ireland [23]. The Mental Health Commission in Ireland has created a framework for developing services across the island of Ireland, which involves a focus on the strengths and opportunities rather than the limitations and symptoms of illness. The contribution of mental health systems is understood to involve "*enabling and empowering the person to access their inner strengths and resources to build a meaningful, valued, and satisfying life*." One transformation component that is highlighted is that of dynamic leadership because "*if the predominant ethos is one of benign paternalism and illness orientation, or one that ignores the input of service users at management and service development level, then a culture that ignores the principles of recovery is likely to be fostered throughout the organization. Equally, without a stated commitment to the principle of individualism and choice, people may simply re-title current practice as recovery-oriented*." This focus on the role of organizational commitment is consistent with best practices internationally [11].

Blueprint II: Improving Mental Health and Well-Being for All New Zealanders, Mental Health Commission of New Zealand [24]. In 1998, New Zealand developed the first national blueprint for transformation toward recovery. In 2012, it issued a new 10-year national strategy based on the learning from Blueprint I, and addressed specifically the impact of the global economic downturn. It adopted the "Triple Aim" model as a framework for sustainable service development: 1) improving quality, safety, and experience of care; 2) improving health and equity for all populations; and 3) ensuring the best value in public health system resources. In identifying eight priority areas for service development, a shift from Blueprint 1 was evident, involving a greater focus on well-being and a more explicit reference to issues of risk and safety.

Framework for Recovery-Oriented Practice, Department of Health, Victoria [25]. Although a state-based policy rather than a national policy, this framework draws on the best available evidence internationally to identify the key domains of recovery-oriented practice:

promoting a culture of hope; encouraging autonomy and self-determination; fostering collaborative partnerships and meaningful engagement; focusing on strengths; striving for holistic and personalized care; involving family, carers, supporting people, and significant others; maximizing community participation and citizenship; showing responsiveness to diversity; and committing to ongoing reflection and learning. For each domain, the key capabilities and examples of both good practice and good leadership are provided. This is a brief and easily accessible document that informs the development of a recovery orientation as mandated in the fourth National Mental Health Plan (2009–2014) in Australia.

Cross-Cutting Principles, US Substance Abuse and Mental Health Services Administration (SAMHSA) [26]. This report establishes a set of cross-cutting principles to guide the program, policy, and resource allocation based on the belief that people of all ages, with or at risk for mental health or substance use disorders, should have the opportunity for a fulfilling life that includes an education, a job, a home, and meaningful relationships with family and friends. To further this agenda, SAMHSA put forth a *Consensus Statement* that outlines 10 fundamental components of mental health recovery as guideposts for recovery-oriented service providers, policymakers, and advocates. The consensus definition was developed through deliberations at a conference in December 2004 of over 110 expert panelists representing mental health consumers, families, providers, advocates, researchers, managed care organizations, state and local public officials, and others. These fundamental components are summarized in Table 1.2.

A Common Misconception: Is Recovery = Cure?

The widespread misinterpretation that "recovery equals cure" has generated concerns among service users, practitioners, family members, and policymakers alike who fear that recovery-oriented care will "leave certain people behind." However, the notion of mental health recovery, as defined by SAMHSA and presented in these modules, does not advocate complete symptom remission. Rather, it is personally defined and accessible to all. It involves a redefinition of one's illness as only one aspect of a multidimensional sense of self who is capable of identifying, choosing, and pursuing meaningful goals despite the effects of the illness or possible side effects of treatment or stigma.

> "*The goal of the recovery process is not to become 'normal.' The goal is to embrace our human vocation of becoming more deeply, more fully human.*
> *The goal is not normalization.*
> *The goal is to become the unique, awesome, never to be repeated human being that we are called to be.*"
>
> —*Deegan* [27]

In this sense, the notion of recovery borrows from the disability rights movement that argues that the elimination of the disability is not the ultimate goal. The goal is to live life to its fullest even in the face of continued limitations, for example, a person with paraplegia does not have to regain his or her mobility to have a satisfying life in the community, nor does an individual with schizophrenia have to stop hearing voices to work, worship, or volunteer. Recovery restores a positive sense of identity despite one's disability and its limitations, and it is a lifelong process that involves an indefinite number of incremental steps in various life domains.

Table 1.2 Ten Core Components of Mental Health Recovery

Self-Direction: Individuals lead, control, exercise choice over, and determine their own path of recovery by optimizing autonomy, independence, and control of resources to achieve a self-determined life. Individualized and Person-Centered: There are multiple pathways to recovery based on an individual's unique strengths and resiliencies as well as his or her needs, preferences, experiences (including past trauma), and cultural background in all of its diverse representations. Empowerment: Individuals have the authority to choose from a range of options and to participate in all decisions—including the allocation of resources—that will affect their lives, and are educated and supported in so doing. Holistic: Recovery encompasses an individual's whole life, including mind, body, spirit, and community. Nonlinear: Recovery is not a step-by-step process but one based on continual growth, occasional setbacks, and learning from experience.	Strengths-Based: Recovery focuses on valuing and building on the multiple capacities, resiliencies, talents, coping abilities, and inherent worth of individuals. Peer Support: Mutual support—including the sharing of experiential knowledge and skills and social learning—can play an invaluable role in recovery. Respect: Community, systems, and societal acceptance and appreciation of individuals with mental illnesses—including protecting their rights and eliminating discrimination and stigma—are crucial in achieving recovery. Responsibility: Individuals with mental illnesses have a personal responsibility for their own self-care and journey of recovery. Hope: Recovery provides the essential and motivating message of a better future—that individuals can and do overcome the barriers and obstacles that confront them.

(Adapted from U.S. Department of Health and Human Services, 2006).

How Does the Concept of Recovery Transform Care?

The concept of recovery is increasingly recognized as stimulating a new way to think about serious mental health problems, treatment, and outcomes, and it is gradually being accepted and incorporated by traditional mental health programs. Many practitioners are looking for new ways to relate to, and work with, people who receive services in the hope that they can transform their programs to be more recovery focused in meaningful and significant ways [7]. Often, the first step in this process is acknowledging the core differences between traditional models of care and recovery-oriented approaches.

Until fairly recently, most mental health services have been organized around a deficit-based model that perceives mental illness as a disease that must be "cured" [28] through the remission or elimination of symptoms. Because they are trained to focus on

treating deficits and symptoms—the things that are wrong with people—practitioners and service delivery organizations have had a tendency to overlook the things that are right with people, such as strengths and competencies [29]. A recovery orientation shifts the focus to "the glass as half full." It is a perspective that allows us to see that no matter how disabled, "all people have existing strengths and capabilities as well as the capacity to become more competent" [30].

With all this attention on strengths, how then, does a recovery-oriented system view the very real, and sometimes serious, difficulties experienced by people living with mental illnesses? Furthermore, with its emphasis on self-determination, what does the recovery model say about the role of practitioners and clinical care?

"Both/And" rather than "Either/Or"

The notion of recovery-oriented care presented throughout this manual does not imply that exclusive power is turned over to the service user with disregard for the knowledge and value of practitioners. Rather, recovery-oriented care, and the representative practice of person-centered care planning, is based on a foundation of partnership in which there is mutual respect between the practitioner and the individual service user. While the emphasis is on maximizing the person's autonomy, the recovery paradigm also respects the expertise of the caregiver and recognizes the important role of the practitioner in the person-centered partnership.

> *Hope is a frame of mind that colors every perception. By expanding the realm of the possible, hope lays the groundwork for healing to begin.*
>
> —*Jacobson & Greenley* [31]

It is equally important to acknowledge that there have been major advances made within the context of traditional clinical and rehabilitative care. Now more than ever, the mental health field has the ability to offer individuals a wider range of evidence-based practices, diagnostically based treatment modalities, and diverse medication options, and these advances have had a significant impact on the treatment of symptoms for persons with serious mental illnesses. However, no matter how skilled the professional community has become in treating the *illness*, the voice of the recovery community suggests that doing so is not sufficient in and of itself to recover the *person*—or more accurately, for the person *to recover*. The interventions of traditional clinical models will definitely continue to play an important role in transformed mental health systems, and recovery-oriented care is based on an understanding that the field can, and must, do better to reframe the goal of treatment as helping people to move beyond achieving clinical stability to recovering lives worth living. This is the essence both of recovery-oriented care planning and of recovery-oriented practice.

Hope as the Foundation

So, how will the field get there? Self-determination, freedom of choice, control over one's own life, personal responsibility, and meaningful community belonging—this is the recovery vision of a transformed mental health system. Throughout the remainder of these modules, the reader will be introduced to a wide range of strategies and tools that will assist him or her in implementing the potential recovery-oriented practice of "person-centered care