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1 FROM ADHERENCE TO SELF-DETERMINATION

Choosing to Participate in “My” Service Plan

PATRICK W. CORRIGAN AND VIRGINIA SPICKNALL

An evolving foundation to treatment has paralleled development and implementation of shared decision making (SDM) in the service delivery system for people with serious mental illness (SMI). It represents a journey from somewhat dated notions of patient adherence (obeying treatment prescriptions) to contemporary principles of personal determination of goals and ways to accomplish these goals. This chapter recounts the evolution from adherence to self-determination that forms the basis of SDM. We begin by briefly addressing what is meant by SMI and the evidence-based practices that help people meet their goals. We then review the body of research that shows people with SMI often choose not to participate in evidence-based practices. We detour here for a necessary discussion of how to measure lack of participation in evidence-based practices. This leads to our summary of the evolving nature of why people do not participate—for example, resistance and noncompliance. Self-determination has emerged in its place; hence, we review basic psychological theory that explains the benefits and processes of self-determination. Several strategies have gained traction for promoting self-determination in mental health service. We review these strategies and highlight the prominent role SDM has in this regard.

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Shared Decision Making and Serious Mental Illness, P. W. Corrigan (Editor)

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We define *engagement* as the ultimate purpose of strategies that promotes self-determination vis-à-vis treatment services. Engagement rests on two perspectives. First, engagement reflects a view of the person: It represents the sum of considerations and actions individuals experience in actually using evidence-based practices to meet life goals. Engagement rejects the negative valence that is sometimes suggested by not adhering: that by choosing not to do some treatment—for example, not taking one's medication, not working with the job coach, or not participating in family therapy—the person is somehow doing something wrong. This absence of adherence does not represent some kind of moral or personality flaw. Principles of engagement replace any kind of judgment about personal treatment decisions with acceptance; the provider supports personal choice.

Engagement also provides perspective about the provider team and setting, namely, whether the setting offers services that support individual goals. Hence, people may choose not to engage in a specific evidence-based approach because of the way in which it is provided. Concerns about cultural competence and humility are one factor for this disconnect. This is not necessarily meant as an indictment of specific providers or settings as much as a realization that differences between goals and settings may diminish an individual's choice to engage.

Consider the case of Janet.¹ Janet is a 33-year-old woman with schizoaffective disorder who lives in a downtown condo with her partner and is a paralegal at a large law firm. She has been taking the same antipsychotic medication and seeking services from the same provider for the past 5 years. Her symptoms include occasional distressing delusions (e.g., "Everyone knows what I am thinking") and hallucinations (e.g., hearing threatening voices). They seem to be handled well by her mix of medication, counseling, and support. Despite this, Janet is bothered at times by some of the antipsychotic medication's side effects. She occasionally experiences nausea and drowsiness that have led to her staying home from work. Her side effects are interfering with job performance. She wants to consider a change but recalls unintended results of past medicine changes that have led her physician to be conservative about such actions. What should she do?

¹Case examples in this book are hypothetical.

WHAT ARE SERIOUS MENTAL ILLNESSES?

The text revision of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2022) defines many syndromes as serious, including those in the schizophrenia spectrum, anxiety and affective disorders, eating disorders, posttraumatic stress disorder, and personality disorders. Janet's diagnosis of schizoaffective disorder clearly falls in this group. Clinical research has suggested, however, that it is not diagnosis per se that defines seriousness but, rather, the prolonged distress, dysfunctions, and disabilities engendered by experience with the disorder (Linden, 2017; Zimmerman et al., 2018). For example, people with seemingly less severe social anxiety disorders may experience a worse course than those with the prototypic serious illness—schizophrenia—because the fright and nervousness defining their anxiety prevents them from seeking even the least demanding of jobs, thereby rendering them unable to live on their own. Many people diagnosed with schizoaffective disorder, like Janet Williamson, can live with recurring auditory hallucinations without distress; they pursue careers and enjoy full family lives.

Dysfunctions that arise from SMI affect the four fundamental spheres of human psychology: (a) affect, (b) perception and cognition, (c) motivation and behavior, and (d) interpersonal functioning (Corrigan et al., 2008, 2024). Affect includes distress, depression, and euphoria. *Distress* is marked by rumination and autonomic reactions, whereas *depression* manifests as intense sadness, anhedonia, and vegetative signs; these are considered the uncomfortable emotions. *Euphoria* is the obverse of these two: an overwhelming sense of intense pleasure and well-being that can lead to significant risks when in the manic phase. Problems in perception and cognition are significant among psychotic disorders and include hallucinations, delusions, and formal thought disorders. People with anxiety disorders and depression may also be harmed by obsessive thoughts that lead to worry or guilt. Many people with SMI have problems with motivation and behavior. These problems may be observed as extremes: lethargic and amotivated when depressed compared with expansive engagement in risky behavior when manic. People with mania and some psychoses might also demonstrate disinhibited behaviors, including sexual or eating behaviors that are extreme for them. Interpersonal functioning is also affected for many people with SMIs. Some may not have mastered basic communication, assertiveness, or problem-solving skills necessary to meet social goals (Cotter et al., 2018; Girard et al., 2017; Speed et al., 2018).

Within these challenges to the basic psychological functions are suicide and violence, which are among the most serious consequences of mental illnesses. The 2016–2020 National Hospital Ambulatory Medical Care Survey estimated the lifetime prevalence of suicidal ideation in the United States to be 15.6% (Alexander et al., 2023). Based on the 2022 National Survey of Drug Use and Mental Health, 0.6% of the adults aged 18 or older made at least one suicide attempt, whereas the most recent Youth Risk Behaviors Survey from 2021 found that 10.0% of youths in Grades 9 through 12 reported that they had made at least one suicide attempt in the past 12 months (Substance Abuse and Mental Health Services Administration [SAMHSA], 2023b). These ratios are significantly higher when the person has an SMI: of those who died by suicide captured in the 2022 report, 90% had a diagnosable mental health condition. Globally, an estimated 703,000 people die by suicide each year (World Health Organization [WHO], 2021). Violence among people with SMI can also be concerning: Epidemiological research has suggested it might be as high as 3.6 times that of the comparable population (Thornicroft, 2020; Van Dorn et al., 2012). Suicide and violence are unlike other symptoms and dysfunctions because of their potential to cause irrevocable harm to self or others.

Distress and dysfunctions lead to disabilities, manifestations of the illness that prevent the person from achieving goals typical of their age and culture (Cree et al., 2020; Linden, 2017; Wade & Halligan, 2017). Three goals are especially relevant to a good quality of life in the Western worldview:

1. **Independent living:** Most adults want to start a household that represents their lifestyle. This includes decisions about place of residence, housing type, roommates/intimacy/commitment, decor, visitors, and neighborhood. It also includes basics related to food, clothing, and other manifestations of style.
2. **Education and employment:** Goals of independent living are more likely to be accomplished when the person has a satisfying job. Meeting higher educational standards is often needed for this kind of job. Employment also includes notions of vocation and affiliation. People want to work at places that meet their sense of achievement and that provide a satisfying interpersonal network.
3. **Health:** People seek good mental and physical health. Beyond health, they wish to pursue wellness, a physical and psychological robustness related to well-being and life satisfaction. Health and wellness are often affected by one's spiritual life.

WHAT ARE EVIDENCE-BASED SERVICES?

Clinical sciences and professional groups have developed and tested evidence-based practice guidelines to help people with serious psychiatric disorders manage distress and disabilities to accomplish life goals (American Psychiatric Association, n.d., 2015, 2020, 2023; American Psychological Association, n.d., 2017, 2021, 2022). Table 1.1 summarizes a number of evidence-based practices currently recognized by SAMHSA (2023a).

In 1997, SAMHSA launched the National Registry of Evidence-based Programs and Practices (NREPP) to track evidence-based services for people with SMI. The original site housed a ranking of expert-endorsed mental health and substance use-related programs and practices. NREPP was replaced

TABLE 1.1. SAMHSA-Recognized Evidence-Based Practices for the Treatment of Mental Illness and Substance Use Disorders

Evidence-based practice	Definition	Systematic review
Supported employment	An approach wherein the goal is to identify competitive employment in the community and to ensure an environment that provides for people's needs through follow-along supports	• Bond et al. (2023) • Richter & Hoffmann (2019)
ACT	A multidisciplinary, team-based service delivery model that provides time-unlimited, community-based services for individuals with SMI who experience or are at particular risk for concurrent substance use, frequent hospitalization, homelessness, involvement with the criminal legal system, and psychiatric crises; the primary goal of ACT is to help individuals achieve recovery through community treatment, rehabilitation, and support	• Arahamthabailu et al. (2023) • Cuddeback et al. (2020) • Mantzouranis et al. (2019)
Psychotropic medication	Medication that affects how the brain works and causes changes in mood, awareness, thoughts, feelings, or behavior	• Cuijpers et al. (2020) • Huang et al. (2022) • Isohanni et al. (2021)

(continues)

TABLE 1.1. SAMHSA-Recognized Evidence-Based Practices for the Treatment of Mental Illness and Substance Use Disorders (*Continued*)

Evidence-based practice	Definition	Systematic review
Psychotherapy (e.g., CBT, DBT, REBT, acceptance and commitment therapy, motivational interviewing, group therapy, family therapy)	Counseling and therapy usually focused on developing healthy skills to cope and can help one better understand the cause of their thoughts and behaviors, so they can change unhealthy patterns	• Cuijpers (2017, 2019) • Matweychuk et al. (2019) • Pace et al. (2017)
Support groups	Peer support, encompassing a range of activities and interactions among people who share similar experiences of being diagnosed with mental health conditions, substance use disorders, or both; this mutuality—often called <i>peeriness</i> —between a peer support worker and person in or seeking recovery promotes connection and inspires hope	• Brunelli et al. (2016) • Shorey & Chua (2023)
Harm reduction	Engaging directly with people who use drugs to prevent overdose and infectious disease transmission; improve physical, mental, and social well-being; and offer low-barrier options for accessing health care services, including substance use and mental health disorder treatment	• Levensgood et al. (2021) • O’Leary et al. (2024)

Note. SAMHSA = Substance Abuse and Mental Health Services Administration; ACT = assertive community treatment; SMI = serious mental illness; CBT = cognitive behavior therapy; DBT = dialectical behavior therapy; REBT = rational emotive behavior therapy.

by the Evidence-Based Practices Resource Center (EBPRC) in 2018 (Green-Hennessy, 2018). The aim of the EBPRC is to house evidence-based treatment improvement protocols, tool kits, resource guides, and clinical practice guide-lines. The site allows users to search by topic area, substance or condition, resource type, population type (e.g., youths, adult), target audience (e.g., resource for clinicians, prevention professionals, patients, policymakers), and authoring organization.

Choosing Not to Engage in Evidence-Based Services

Of the several reasons that might explain failure of people to engage, two are considered in this section. One is the side effects of medication or psychosocial interventions, and the second is the lack of availability.

Side Effects

Side effects might dissuade a person from pursuing specific practices. Side effects are especially well examined in medications; traditional antipsychotic medication has been shown to affect every organ system deleteriously with particularly troubling effects related to movement and restlessness (Ali et al., 2021). Atypical antipsychotic medications meant to diminish these side effects have their own troubling profile, causing, among other things, significant weight gain, which can lead to diabetes and cardiovascular disease (B. B. Barton et al., 2020). Although generally with fewer side effects, antidepressants like tricyclics and selective serotonin reuptake inhibitors may affect cognitive functioning, sleep, and libido (Wang et al., 2018). Mood stabilizers for bipolar disorder can also cause a range of unintended metabolic effects (Himmerich & Hamilton, 2022).

Although side effects are most commonly examined in terms of psychopharmacology, evidence-based practices with a psychosocial focus may yield similar unintended consequences (Crawford et al., 2016; Lönnqvist, 1985). These might include focusing on goals that are not the person's priority, demanding too much time or other resources, forestalling other interests (e.g., skills training instead of supported education), or excluding important others in the intervention process (e.g., not pursuing family interventions; Corrigan et al., 2024).

The impact of side effects is broadly evidenced across most health conditions. A Centers for Disease Control and Prevention *Morbidity and Mortality Weekly Report* published in 2017 demonstrated that physicians write 3.8 billion prescriptions every year, yet only one in five new ones ever gets filled (Neiman et al., 2017). Further, only 50% of those filled are taken correctly. A meta-analysis comprising 46 studies on adherence to psychotropic medication found similar results: Forty-nine percent of major psychiatric disorder patients chose not to engage in medication (Semahegn et al., 2020). Rates of adherence for those with schizophrenia, major depressive disorders, and bipolar disorders were 56%, 50%, and 44% respectively.

We also see adherence issues outside of medication use. For example, people routinely avoid scheduling appointments for mental health-related issues despite obtaining referrals from providers (Andrade et al., 2014; Hacker et al., 2014; Walker et al., 2015). Even once appointments are established,

attrition rates are relatively high. For example, a meta-analysis comprising 20,995 participants receiving cognitive behavior therapy found treatment dropout rates to be 35% on average across 115 studies (E. Fernandez et al., 2015). A similar rate of 30.4% was found in a more recent meta-analysis done by Lappan et al. (2020) when analyzing 151 studies looking at dropout rates of in-person psychosocial substance use disorder treatments. WHO's World Mental Health Survey Initiative yielded average dropout rates of 30% from high-income countries and 45% from low- and middle-income countries for outpatient mental health care programs (D. Fernández et al., 2021). This study also determined that dropout occurs most frequently within the first two visits. Although it seems initiation and retention of mental health services pose challenges, studies also have shown that it is common for those who engage in psychiatric treatment to not complete between-session work recommended by their mental health providers, such as psychoeducational, self-assessment, and modality-specific tasks (Decker et al., 2016; Kazantzis et al., 2016; Leeuwerik et al., 2019; Tang & Kreindler, 2017). Similar issues with engagement can be found when working with people on vocational, independent living, nutrition, and exercise goals (Fahey et al., 2018; Ipsen & Goe, 2016; Lemstra et al., 2016; Mandal & Ose, 2020).

Availability

A separate category of factors that undermine engagement, which is indicative of the provider system, is that services are not available. Many urban settings, for example, lack sufficient resources to provide services throughout their metropolitan area, especially during a significant economic recession (Antunes et al., 2017; Okkels et al., 2018; Ruiz-Pérez et al., 2017). Rural settings have a separate set of hurdles that undermine availability and dissemination of services (Okkels et al., 2018). Compounding these barriers is an absence of services that represent the exigencies of cultural groups like African Americans, Asian Americans, Latinos, and Native Americans (Kirmayer & Minas, 2008; Norcross & Wampold, 2019)—for example, family involvement in treatment decisions.

Some services are available but are not faithful to evidence-based protocol. Evidence-based psychosocial practices include clear principles and strategies necessary to accomplish the goals of such practice. Unfortunately, measures of service fidelity often show providers lack training to do the evidence-based practice or stray from the manual once implemented in a real-world setting (Fonagy & Luyten, 2019; Prowse et al., 2015). The unavailability of high-quality services influences personal attitudes about services, often causing people to become more pessimistic about possible benefits. Although

unavailable services are a compelling concern, it is still clear that choosing not to participate is an individual and powerful cause of nonadherence.

Defining the Problem More Objectively

Attendance is one seemingly easy-to-assess way in which service participation has been construed—for example, does the person show up at weekly scheduled sessions? Although face-to-face meetings may be important, what the person does in the interim is probably more essential to progress. This might be called *homework*, goal-related efforts the person has attempted outside of the treatment setting. Attendance and homework can be surprisingly complex constructs despite the seeming ease in which they are represented as quantity and pattern over time. Quantity, for example, may be simply assessed as hours a week for individual psychotherapy. Most evidence-based practices, however, are not based on such narrow constrictions. For example, participation in evidence-based practices like assertive community treatment (ACT) needs broader indices because the service may be provided in short 20-minute spurts for months or even years. Moreover, many long-term evidence-based practices are not described by linear, continuous patterns. Service consumers may come and go from ACT as their current goals dictate.

Service decisions and behaviors are often centered in interactions that are described as qualities of the person–provider relationship that facilitate experience with the evidence-based practice. Much of this research has focused on qualities of the service provider, but the interest here is a bit different, centering on characteristics of the interaction. Do people, for example, find the exchange satisfying and relevant to their needs (Barkham et al., 2021)? *Trust*—defined as an emotional connection in which the person feels hopeful that the service provider is directing efforts to jointly address the issues of concern (Krupnik, 2023)—is one important way in which satisfying relationships have been studied. Service interactions are often construed as simple, one-to-one exchanges. In reality, many evidence-based practices are provided by teams of providers comprising individuals who vary in discipline and status (e.g., the psychiatrist focusing on medication vs. the paraprofessional providing daily ACT).

The diversity of service agents needs to be considered when assessing consumer interaction relevant to self-determination and service decisions. Peer-provided evidence-based practices have emerged as an especially important way to enhance interactions (Corrigan, 2021; Shin & Choi, 2020; White et al., 2020). Of their many benefits, peer-provided services highlight

another important characteristic of interactions: their level of formality or lack thereof. More classic psychotherapies have trained practitioners for formal, sometimes aloof relationships. Providers of ACT and supported employment tend to demonstrate more informal and immediate interactions. Peer-provider exchanges are less often dictated by preconceived theory but, instead, are directed by the seemingly spontaneous demands of the moment.

Still, research begs the question: What is the metric that shows whether specific decisions and behaviors are helpful, beneficial, or otherwise positive? This is an important question for methodological as well as theoretical reasons. Researchers need to move the dependent variable in research on health decisions and behaviors from categorical indices (yes or no; did the patient decide to take the medication?) to a more statistically powerful and continuous one. Because the focus here is on self-determined medication, a Likert scale of relevance might be various conceptualizations of satisfaction with health decisions and behaviors. Satisfaction might be more fully understood in terms of a hierarchy for evaluating treatments: symptom remission, disability adjustment, goal attainment, and quality of life (Lieberman, 2008; Miglietta et al., 2018). Psychiatry had traditionally restricted assessment of medication to symptom remission: Did the person administering antidepressant medication show remitted sadness and anhedonia? With many chronic symptoms comes disability—for example, the person who is unable to work because of severe and chronic depression. Hence, did treatment lead to less dysfunction and better ability to work, live independently, and enjoy intimate relationships? Functioning gains further meaning when framed in terms of personal goals—for example, did the person return to work? At the end of the day, all these constructs are important in terms of quality of life: Do people have a sense of well-being as a result of their health decisions and behaviors? Only the person seeking care can determine the importance of these spheres in assessing their health decisions.

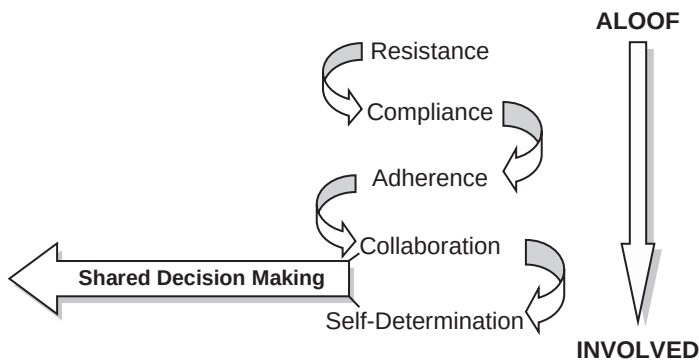
We do not mean to be cavalier—to seemingly dismiss the benefits of traditional medicine and its body of research or ignore harmful outcomes of some medication decisions. Sometimes replacing adherence with treatment satisfaction seems to minimize the complexity of the phenomenon. As such, decisional satisfaction and behavioral satisfaction, and their juxtaposition to treatment decisions, describe a complex area of theory and method development, a topic we have tackled elsewhere (Corrigan et al., 2024). There are, for example, disease processes that confound the decisions and behavior, such as the thought disorders of some psychiatric illnesses; see Chapter 2, this volume. In absence of conditions like these, however, it seems like

only the person can judge the trade-off of increased symptoms, unintended consequences, and overall well-being. Satisfaction is the juxtaposition of the costs and benefits of health decisions, the heart of the rational patient model discussed later in this book.

WHY PEOPLE CHOOSE NOT TO PARTICIPATE

Psychiatry providers have posited various reasons why people choose not to participate in treatment, leading to a winding road of essentially disempowering views about decision making (see Figure 1.1). This road is framed as a progression from relatively patriarchal and aloof notions that people failing treatment are resisting to perspectives centered around partnership and collaboration to the current evolution of self-determination that best reflects and shepherds a person’s recovery. Self-development as both principle and practice fits between collaboration and self-determination. People who did not participate in services were believed to be resisting care and risking symptom remission and relapse. Some intrapsychic processes were hypothesized to block the person from fully engaging in treatment (Messer, 2002); they were mostly ego-protective factors that developed from early interactions with significant others. Many psychoanalytic theorists have expressed the belief that examination of resistance is a central core of the therapeutic process (Adler & Bachant, 1998; H. S. Gill, 1988). Although these ideas may seem out of date, there are still practitioners who view working through treatment resistance as important to care (Siegel et al., 2017; Stivers &

FIGURE 1.1. The Winding Road That Represents Personal Decision Making



Timmermans, 2020), including services for people with psychosis (Sweeney et al., 2015). It was the risk of relapse that metaphorically set off an alarm for aggressive intervention.

Some theorists have tried to transcend seemingly accusatory notions behind resistance and have transitioned into ideas of compliance. Compliance was meant more as an objective indicator—a categorical assessment: yes or no—regarding whether the person has taken medications or otherwise participated in treatment as prescribed (Vuckovich, 2010). Treatment failure—for example, not taking one's medication—can lead to some kind of irreversible tragedy like suicide. Concerns about compliance led researchers into a useful search for unbiased and sensitive measures of whether people were participating in treatment as written by their physicians (Velligan et al., 2010). For some, compliance meant people doing their treatment regardless of its effect on self-determination. Hence, strategies meant to serve compliance have included inpatient and outpatient commitment, more benign coercion (e.g., exercise of a guardian's authority), diminished personal control (e.g., depot injections of antipsychotic medication), or benevolent trickery (e.g., not sharing the full range of side effects; Burns, 2009; Redlich et al., 2006; Szasz, 2007).

Adherence followed compliance: Practitioners defined active participation in treatment decisions, rather than actual actions, as the goal. This was partly meant to reflect an ethical perspective—that by virtue of their humanity, service recipients are due agency over their lives (Rudnick, 2008a, 2008b). Partly, this was also recognition of basic behavioral science. People will retreat from social exchanges of any kind in which a specific behavior is forced on them in a sort of “don't tell me what to think” phenomenon (Jonas et al., 2009; C. H. Miller & Quick, 2010; Quick & Stephenson, 2008). Adherence is a call to service providers for the active participation of people with mental illnesses in their care. Service providers might still dominate in developing treatment goals but seek to involve individuals with SMIs when possible.

Collaboration recognizes the expertise in the person and care provider—that, for example, the psychiatrist is expert in symptoms and biological processes whereas the person is expert in their own illness, the life in which the illness plays out, and previous treatments that have helped or have caused unintended side effects. The idea of collaboration was an insightful perspective for its time, elevating the patient to equal status with the provider and, through this peer relationship as it were, generating the most effective plan. This reflects the basics of SDM, namely that the provider partners with the person to develop and implement effective treatment plans. Self-determination enhances the person's role in this partnership. The

ultimate worth of goals and interventions rests in the person's perspective. Hence, ultimately, person and provider may not be partners. Regardless of provider insight and wisdom, people decide among SDM-derived options what works best for them.

SELF-DETERMINATION IN A RECOVERY-ORIENTED CARE SYSTEM

Principles that matured in person-centered service systems add additional conceptual perspective for self-determination and decision making. These include ideas related to recovery and hope, empowerment, and personal responsibility.

Recovery and Hope

Recovery

refers to the process in which people are able to live, work, learn, and participate fully in their communities. For some individuals, recovery is the ability to live a fulfilling and productive life despite a disability. For others, recovery implies the reduction or complete remission of symptoms. (Hogan, 2003, p. 5; see also Davidson et al., 2021, and Slade & Longden, 2015)

Classic notions of mental illness, best represented by Kraepelin's (1919) *dementia praecox*, described schizophrenia, for example, as marked by a progressive downhill course and suggested that treatment should be focused on realistic expectations of never being able to live independently, work, marry, or have children. Long-term follow-up studies, however, have not supported this pessimism. Many people with mental illness are able to live a high-quality life outside the mental health system (Calabrese & Corrigan, 2005; Leonhardt et al., 2017). This has led to psychiatric services that now foster hope in terms of attaining the person's goals. Recovery reintroduces ideas of the future and aspiration to describing SMI. In hope is the idea of goals and attainment, which emerged as a mental health priority largely from person-led movements with the motto "Nothing About Us Without Us" (Chamberlin, 1978).

Personal Empowerment

Out of recovery has come the call for empowerment. Some people believe personal empowerment and self-determination are different sides of the same coin (Sprague & Hayes, 2000). Research studies have unpacked the

complexity of empowerment and found it to include five recurring themes: (a) self-efficacy and self-esteem, (b) powerlessness, (c) optimism/control over future, (d) righteous anger, and (e) group/community action (Rogers et al., 1997, 2010). A hierarchical factor analysis showed these constructs actually represent two higher order concepts that serve as excellent foci for self-determination: self- versus community orientations to personal empowerment (Corrigan et al., 1999). A *self-orientation* reflects the ideas of personal agency and confidence in deciding about and following through on goals and choices: What must the person have in place to successfully determine their directions? A *community orientation* redirects the lens of determination: What must the system do to make sure people have power over their choices? Self-determination is promoted by helping people grasp personal empowerment for themselves and by directing the community not to throw up barriers to the process.

Personal Responsibility

Self-determination is not meant as *carte blanche* for the pursuit of personal goals. Self-determination of people with SMIs needs to be understood in terms of limits experienced by most adults. No one can expect all goals to be achievable without an effect on others or that the person should be able to achieve an aspiration regardless of real-world demands. The public generally expects people will make decisions that reflect not only their interest, but those of other important people, such as friends and family, with, perhaps most prominent here, being one's spouse or children. The idea of responsibility might be viewed as a restraint to self-determination—that people are responsible for partaking in treatment so as not to burden others. We believe the idea of responsibility is empowering; indeed, many advocates for the recovery movement outline the key role of personal accountability (Price-Robertson et al., 2017; Slade, 2009). Personal accountability suggests that people with mental illness are just like others: capable of making righteous choices and therefore deserving of self-determination.

Still, at the end of the day, people with SMIs must identify for themselves their goals of the moment given external pressures. This means they consider who is important in their network and what is the relative value of specific goals as long as these considerations of one's network and goals do not supersede minimum social assumptions as laid out in criminal and civil statutes. It seems reasonable, for example, that a woman moves out on her husband when that spouse has physically abused her. Less support would be found for the father moving out on his young children because he wants to

return to trade school. Self-determination requires a balanced perspective, exercising one's personal agency while responsibly considering the concerns of important others.

WAYS TO PROMOTE SELF-DETERMINATION

We limit this section to examine a proposed dichotomy of engagement highlighted earlier: (a) what can be done to help people understand options, make decisions, and act on these decisions and (b) how the community and clinic might facilitate this process while tearing down barriers to self-determined options. SDM is the best paradigm for the first, whereas community-level considerations that promote unencumbered health decisions reflect the second.

The Power of Shared Decision Making

Although the basics of SDM are described more fully throughout this book, it's important at this stage to know that SDM is a fairly well-developed and evaluated approach to health options that combines three basic principles and strategies: (a) cost–benefit analyses, (b) education, and (c) support (Drake et al., 2010). The primary goal here is to assist people in making decisions by helping them examine costs and benefits of health options and life goals. Namely, people are encouraged to identify and make sense of the advantages and disadvantages of the interventions that lead to achieving specific goals. This cost–benefit analysis is facilitated by information that aids people in better understanding life goals vis-à-vis health challenges, corresponding interventions, and other relevant parameters.

The education process requires the development of meaningful and user-friendly information channels. These might include face-to-face classroom kinds of endeavors or online technologies, such as interactive websites and social media forums (Bevan Jones et al., 2018; Naslund et al., 2016; Seyedfatemi et al., 2021). Health-related decision making is fundamentally social intercourse between person and provider. Skills that enhance the qualities of the exchange positively affect treatment decisions. This consideration has been prominently incorporated in motivational interviewing, suggesting SDM exchanges need to sidestep some kind of actuarial process to include empathy, genuineness, and the promotion of self-efficacy (Elwyn et al., 2016; W. R. Miller & Rose, 2010). Meaningful and genuine exchanges like these can provide a sense of support for individuals involved in treatment. In the

process of SDM, the support offered can be both instrumental and emotional. The balance between these types of support may vary depending on the needs and goals of the person receiving treatment, the service organization, and the type of provider involved.

Research has examined SDM for a variety of illnesses and disabilities, including treatment decisions related to cancer (Herrera et al., 2023; Martínez-González et al., 2018), heart disease (Mitropoulou et al., 2023), prostatic hypertrophy (Ngu et al., 2022), mental illness (Alguera-Lara et al., 2017; Slade, 2017; Thomas et al., 2021; Zisman-Ilani et al., 2021), substance abuse (Friedrichs et al., 2016; Marchand et al., 2019), and gastrointestinal disorders (Fox & Lipstein, 2020; Song & Wu, 2022). Meta-analyses and reviews of studies have yielded mixed conclusions (Austin et al., 2015; Shay & Lafata, 2015). Findings from randomized clinical trials (RCTs) showed SDM leads to enhanced satisfaction with and more knowledge about treatments and their providers. However, findings are mixed at best about whether SDM leads to a meaningful increase of treatment-related behaviors. Perhaps one reason SDM is limited for people with SMIs is the effect of their cognitive deficits. As a result of information-processing dysfunctions, some people are unable to understand the balance of advantages and disadvantages of specific health decisions. Toward this end, cognitive therapies have been developed and tested to enhance a person's treatment decisions and behaviors. Although some of these therapies have targeted thought contents (e.g., inaccurate beliefs about the harm of a medication), in the Beckian approach to cognitive behavior therapy—that is, challenging irrational thoughts that undermine some health decisions (Aguirre Velasco et al., 2020)—what has been more successful are cognitive rehabilitation attempts to diminish the processing deficits that undermine comprehension of these decisions. Cognitive adaptation training (CAT) is a good example that has a growing set of supporting evidence (Allott et al., 2020; Velligan et al., 2015, 2023). One-way cognitive rehabilitation addresses information-processing deficits is by providing tasks that exercise key processes, such as attention and memory (Reser et al., 2019). CAT is an example of the alternative, seemingly more effective, approach to cognitive rehabilitation—namely, the provision of compensatory strategies and environmental supports specifically built around real-world tasks of the individual. To help people with cognitive difficulties that result from SMI, they might work with a service provider, for example, to clear out old prescriptions and over-the-counter medications from the bathroom cabinet; set all current prescriptions in an organized, daily pill box; and record a message in the person's own voice tied to a computer alarm that reminds them “it's time to take my medication.”

Removal of Situational or Contextual Barriers to Self-Determination

Another set of approaches to enhancing SDM needs to identify and erase contextual hurdles to self-determination. Three ways of doing that are considered here: (a) educating stakeholders about the ethics and realities of self-determination, (b) reducing legislation and other government activities that restrict health decisions, and (c) streamlining interventions so participating in them is not onerous. Removing the hurdles is not enough, however. Policies and actions that encourage and support self-determination are equally important.

Education About Self-Determination

There is evidence that stakeholders are learning about recovery and ideas of self-determination it promotes. People with mental illnesses have been at the forefront of recovery, and research suggests more individuals with psychiatric disabilities are understanding and endorsing this perspective (White et al., 2020). More recently, family members have joined the movement (Corrigan & Lee, 2021; van Nistelrooij et al., 2017). Service providers seem to be last in their recognition and agreement (Hajizadeh et al., 2015). Still, there is sobering evidence of a seniority effect in some professions: Those practicing in the field longer are less likely to endorse ideas of recovery and self-determination. Many professional training programs have incorporated recovery and people in recovery into their training programs to stimulate interest in and educate newer generations of psychiatrists in the treatment paradigm shift (Gambino et al., 2016; Hornik-Lurie et al., 2018). Some evidence has suggested that endorsing recovery is associated with strengths-based approaches and community-based psychiatric rehabilitation (Thornicroft et al., 2016; Tse et al., 2016).

Laws and Policies That Promote Recovery

Education does not always lead to change in treatment behavior. Hence, efforts have been made to codify principles of recovery. In part, this has been vigorously debated in legislation related to such diverse issues as outpatient commitment (Enriquez, 2019; Thornicroft & Henderson, 2016) and psychiatric advanced directives (Belanger, 2017). More immediate to the mental health system than activities of the legislature are policies of the executive branch of government. The New Freedom Commission on Mental Health (2003) rested its 2003 report to the U.S. president based on a recovery-oriented system (Hogan, 2003). Other countries have joined the effort, too, including England, Australia, New Zealand, and the Netherlands (Craig, 2008; Davidson et al., 2008; Pilgrim, 2008). Most individual states have followed suit; specific

examples of a recovery orientation have included meaningful consumer and family involvement in government decisions, especially in terms of new spending; support of consumer-developed and consumer-operated services; consumer-responsive crisis planning and advance directives; and statewide recovery education programs (R. Barton, 1998; K. J. Gill, 2006; Jacobson & Curtis, 2000).

Convenience and Immediacy

Some services unintentionally throw up barriers because they are cumbersome, thus demanding time or resources that exceed personal limits. Service providers have sought to make specific practices more convenient. Framing this as convenience might seem to minimize their importance, but humans as a whole choose behaviors with the least demands. Hence, practical, grass-roots approaches to services have emerged. Some are obvious from where we sit today: Move services out of the office and beyond the 9-to-5 workday to offer assistance when and where the person needs it. No longer is the aim of treatment to obtain insight into a problem or learn social skills for difficult interactions. Instead, they are more obvious and immediate: Help the person get to the physician to investigate their chest cold or cash the social security check for today's groceries. The provider might actually get involved in these services. They might, for example, help the person make a schedule for taking the day's prescribed medications. This is an especially poignant and timely process for services meant to address people with SMIs who are homeless (Kaduszkiewicz et al., 2017; Upshur et al., 2018) or court involved (Horst et al., 2023; Munthe et al., 2016).

CULTURAL ADAPTATIONS OF SDM

SDM and self-determination with its base in competence and autonomy may stereotypically reflect individualist priorities of Western countries that may be foreign to some East Asian groups (Lee et al., 2015). Cultural values of autonomy, for example, seem contrary to those of relatedness and group cohesion (Iyengar & Lepper, 1999). Adopting choices made by trusted others uniquely enhances intrinsic motivation for many East Asian individuals. In this light, it makes sense that many East Asian patients living in the United States may more actively involve family members in decision-making efforts. Research has shown, for example, that family dynamics may supersede self-care concerns among many Asian Americans (Cho et al., 2015). Specific dynamics among some Chinese patients seem to include the essential

importance of family, deference to authority figures, maintenance of interpersonal harmony, and self-restraint (Lee et al., 2015).

Family-Centered Decision Making

There is a growing body of work on family-centered decision making (FCDM) for adults with SMI. The central question here is whether and how much family members, especially parents, should be actively involved in health care decision making. One study showed that a group of Korean American patients with cancer significantly preferred active family involvement in care-seeking compared with European American patients (Blackhall et al., 1995). Another study with a Southeast Asian sample showed that proponents of FCDM might favor withholding information from family members with cancer (Back & Huak, 2005). Researchers have also identified the importance of FCDM among some East Asians related to mental health care. For example, Chinese versus American preference for decision-making types was examined in a vignette study that described two approaches for Lily, a 30-year old woman with symptoms of depression (Gao et al., 2019): (a) SDM in which Lily is fully informed about interventions, weighs the costs and benefits of her options, and makes decisions and (b) FCDM in which Lily and her parents are informed about interventions, consider the pros and cons, and then her parents make the decisions. Results showed that European Americans viewed SDM as significantly more preferable than FCDM for Lily, whereas Chinese and Chinese Americans preferred FCDM.

Developing a manualized approach is an important next step, assuming research continues to support FCDM for significant groups of East Asian patients and their families. Such manuals have already been developed and tested for SDM (Agency for Healthcare Research and Quality, 2014) and may provide a preliminary framework for the development of FCDM. The SDM manual includes educating patients about illness and treatment options, helping them consider pros and cons of individual options, and teaching the provider basic counseling skills that facilitate this interaction. Although many of these principles and practices would seem equally important for FCDM, challenges may emerge in adapting the SDM manual to family-centered practices. The decision-making process needs to be better unpacked, especially when multiple family members are concerned. How, for example, might a list of pros and cons be generated, and who might direct the process? Is consensus a useful paradigm for translating costs and benefits into a decision? How are values of age and authority as well as corresponding deference understood in the process? What if there are attitudinal issues among family

toward the service provider? What is the role of the service provider in these dynamics?

Further Considerations

Despite FCDM's intuitive appeal, we need to revisit heterogeneity to further understand its effect. We do not mean to imply that all East Asian psychiatric patients, for example, would opt for FCDM in their mental health care. For example, the Gao et al. (2019) study showed acculturated Chinese—those living in America at the time of the study—were more likely to endorse SDM. Moreover, groups from other cultures may prefer FCDM. For example, research among Latinx individuals has described *familismo* (familism) and *respeto* (respect; Escobedo et al., 2018) as values that are likely to influence family roles in health decision making. Deference shown by adult children to their parents may affect choices about the child's health services. For that matter, service providers should not assume that European Americans, by virtue of their culture, will prefer SDM. Family-centeredness is likely to vary among patients of Western European heritage.

FCDM processes might vary by other social determinants, including gender and age of family member. For example, in many East Asian families, men are more typically viewed as family authorities than women (Qin & Chang, 2012). Hence, fathers may be viewed as more influential in health decisions, whereas actions based on those decisions may be carried out by mothers. Also, health decisions will change as adult children assume responsibility for health care of older parents with disabilities. Children, for example, might decide not to share diagnoses with parents challenged by a serious illness with poor prognosis. Male children may be most influential in these kinds of decisions. Interest in FCDM may vary by psychiatric diagnosis. Perhaps FCDM will be of greater priority for patients challenged by more disabling illnesses, such as schizophrenia.

Further, FCDM is not a monolithic experience. Although the development of an FCDM manual will inform providers how to engage patients in this form of decision making, it does not necessarily prescribe a portfolio of required steps. For example, patient and family may wish to limit the breadth of decisions or change family roles as illness moves from acute to relatively remitted phases, an experience that frames FCDM as a dynamic process; namely, individual patients change preferences over the course of illness and treatment. In the process, providers should remember that SDM and FCDM are not independent and static processes. Treatment may involve a continually changing mix of both two perspectives.

Patients, families, and providers should also be alert to potential negative consequences of FCDM. For example, bias, stigma, or language barriers may lead some family members to call for deferring treatment participation even when not in the patient's best interest. The choice between SDM and FCDM may also require ethical consideration. What happens, for example, if a patient and their family members disagree about the family's participation in decision making? As psychiatry has evolved, cognizance of the cultural lens in the interpretation of ethical provider behavior has increased (Okasha et al., 2008). Still, our interpretation of the Principles of Medical Ethics with annotations for psychiatry (American Psychiatric Association, 2013) prioritizes patient choice except when patients are under age of adulthood or currently dangerous to self or others. Mental health providers ultimately need to promote patient choice but seek to do so with some attention to cultural influence.

What Does the Research Say?

Although FCDM makes intuitive sense, we are surprised by the relative dearth of papers in the professional literature specific to that topic. Indeed, the handful of studies summarized here were among the few we found in the literature. This state of affairs begs for more studies, and investigations might consider two priorities. First, research should further explain preferences for SDM and FCDM and how heterogeneity of culture affects those preferences. The dynamic and mediating effects of social determinants and psychiatric diagnosis need to be included in this work. Second, effects of FCDM per se should be examined. This requires an FCDM manual and fidelity measure that could be the focus of RCTs. These RCTs may also look at feasibility, fidelity, and acceptability as well as effects on health and recovery. Assuming first-generation studies of FCDM are successful, subsequent research should identify individual differences that would help providers tailor FCDM for the patient's experience.

CONCLUSION

Personal control of one's service plan has evolved from problematic ideas that characterize people as unable to think clearly and act accordingly to those that rest on self-determination and the recovery it implies. Cultural views of self-determination need to be considered here, especially in terms of roles families might play in SDM. The goal throughout the remainder of this book is to foster a better understanding of actions that promote self-determination

throughout recovery-based systems. This becomes a priority in ongoing research meant to enhance care-seeking as well as training programs for providers at the base of this system.

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