


# The Impact of Mental Illness Stigma on Seeking and Participating in Mental Health Care

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## Summary

Treatments have been developed and tested to successfully reduce the symptoms and disabilities of many mental illnesses. Unfortunately, people distressed by these illnesses often do not seek out services or choose to fully engage in them. One factor that impedes care seeking and undermines the service system is mental illness stigma. In this article, we review the complex elements of stigma in order to understand its impact on participating in care. We then summarize public policy considerations in seeking to tackle stigma in order to improve treatment engagement. Stigma is a complex construct that includes public, self, and structural components. It directly affects people with mental illness, as well as their support system, provider network, and community resources. The effects of stigma are moderated by knowledge of mental illness and cultural relevance. Understanding stigma is central to reducing its negative impact on care seeking and treatment engagement. Separate strategies have evolved for counteracting the effects of public, self, and structural stigma. Programs for mental health providers may be especially fruitful for promoting care engagement. Mental health literacy, cultural competence, and family engagement campaigns also mitigate stigma's adverse impact on care seeking. Policy change is essential to overcome the structural stigma that undermines government agendas meant to promote mental health care. Implications for expanding the research program on the connection between stigma and care seeking are discussed.

## Keywords

stigma, care seeking, serious mental illness

## Introduction

Serious mental illnesses can lead to significant distress and disability that undermines quality of life. Fortunately, researchers, service providers, and people with lived experience have joined forces to generate evidence-based interventions that help individuals attain life goals. Despite this promise, many people with serious mental illness do not seek out treatment when in need or fully participate once interventions have begun. The prejudice and discrimination that comprise the stigma of mental illness is one important reason for the disconnect between effective treatments and care seeking. Although the focus here is on mediating and moderating effects of stigma on care seeking and treatment participation, we realize that stigma explains only part of the puzzle why people might decide not to pursue mental health services or drop out of

services early. Other barriers might include personal, structural, political, and economic factors, but these are beyond the scope of one article. Two broad sets of barriers related to stigma may undermine care seeking and service participation: (a) *Person-level barriers* are attitudes and behaviors that affect health decisions, including stigma leading to avoiding treatment or dropping out prematurely, poor mental health literacy, beliefs of treatment ineffectiveness, lack of a support network that promotes care seeking, and perceived cultural irrelevance of many treatments; (b) *provider and system-level barriers* include lack of insurance, financial constraints, staff cultural

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incompetence, and workforce limitations that are all influenced by stigma.

After a review of research describing these two classes of stigma barriers, we consider programs and policies meant to enhance care seeking and treatment participation, including efforts that seek to decrease stigma, promote mental health literacy, enhance support systems, and encourage cultural competence. We also review public policy solutions, including the Affordable Care Act, that are intended to create a system that provides suitable care. The article ends with recommendations for moving science forward in this arena. Because our focus here is on U.S. mental health care, and because issues related to care seeking vary by socioeconomic and political processes across nations, our review and conclusions are necessarily limited by this focus. Still, many of the lessons learned herein may be applicable to public health systems elsewhere in the world.

### Defining Serious Mental Illness

Before considering why people with mental illness do not seek out services or fully engage in them, we summarize the latest research to help the reader understand the diverse manifestations and impacts of serious mental illnesses. The discussion includes brief mention of epidemiology and causal models. We then examine the literature on evidence-based interventions with demonstrated effectiveness in treating mental illnesses. The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2013) defines the syndromes considered serious mental illnesses, including those in the schizophrenia spectrum, anxiety and affective disorders, eating disorders, and personality disorders (American Psychiatric Association, 2013). Research mostly suggests that serious mental illnesses are caused by biological processes. Genetics (Pillai, Kalmbach, & Ciesla, 2011; Shi, Gershon, & Liu, 2008) or nongenetic risk factors, including in utero insult (such as illness or substance use and abuse during key developmental periods of pregnancy) or obstetrics complications (Matheson, Shepherd, Laurens, & Carr, 2011), have been implicated as causal agents. They are typically framed as vulnerability indicators, which, with environmental factors, lead to the illness per se (Uher, 2013). Stress, including trauma (Rudnick & Lundberg, 2012), is a common environmental factor that might yield mental illness in people vulnerable to specific disorders.

Course and outcome are often worsened by comorbid substance use and abuse (Davis, Uezato, Newell, & Frazier, 2008; Drake et al., 2006; Goldberg, Garno, Leon, Kocsis, & Portera, 1999; Strakowski, DelBello, Fleck, & Arndt, 2000). However, clinical research suggests that illness severity, course, and outcome are not defined by diagnosis per se but rather by the distress, dysfunctions,

and disabilities engendered by the disorder (Anthony & Liberman, 1992; Sanderson & Andrews, 2002; Sartorius, 2009). 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. Some people with schizophrenia are able to live with recurring auditory hallucinations without distress, pursue a career, and enjoy a full family life (Ralph & Corrigan, 2005).

Dysfunctions that arise from serious mental illness may have an impact on the four fundamental spheres of human psychology: affect; perception and cognition; motivation and behavior; and interpersonal functioning (Barch, 2005; Brekke, Kay, Lee, & Green, 2005; Johnson, 2005; Liberman, 2008; Mogg & Bradley, 1998). *Affect* includes distress and depression, the “uncomfortable” emotions marked by rumination and autonomic reactions for the former and intense sadness, anhedonia, and vegetative signs for the latter. Euphoria is the obverse, an overwhelming sense of intense pleasure and well-being, which can lead to significant risks when reaching the severity level of a manic episode. Affective symptoms might also manifest in disordered modulation, inappropriate affect for the situation, mood swings, or flat affect (Cohen & Minor, 2010). Problems in *perception and cognition*, including hallucinations, delusions, and formal thought disorder, are prominent features of psychotic disorders. People with anxiety disorders and depression may also be negatively affected by obsessive thoughts that lead to worry or guilt.

Many people with serious mental illness have problems with *motivation and behavior*. This may be observed as extremes: lethargic and amotivated behavior 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 atypical for them. The most serious dysfunctions are shown in catatonia as grossly disorganized behaviors or catalepsy. *Interpersonal or social functioning* is also challenged for many people with serious mental illness. Some may not have mastered basic communication, assertiveness, or problem-solving skills necessary to meet social goals (Liberman, 2008).

*Suicide and violence* are among the most serious consequences of mental illnesses. Research suggests that almost 4% of people in the general population report lifetime suicidal ideation, 1% report a plan for suicide, and 0.5% report past attempts (Borges et al., 2006; Crosby, Han, Ortega, Parks, & Gfroerer, 2011; Kessler, Berglund, Borges, Nock, & Wang, 2005). These ratios are significantly higher when the person has a serious mental

illness, with 18% to 55% of this group reporting suicide attempts (Fenton, McGlashan, Victor, & Blyler, 1997; Harkavy-Friedman et al., 2003; Mann, Waternaux, Haas, & Malone, 1999; Siris, 2001; Tarrier, Barrowclough, Andrews, & Gregg, 2004; Tondo, Isacsson, & Baldessarini, 2003). Violence among people with serious mental illness can also be high, with epidemiological research suggesting frequencies that are 2.5 times that of the comparable demographic populations (Arseneault, Moffitt, Caspi, Taylor, & Silva, 2000; Corrigan & Watson, 2005; Swanson, Holzer, Ganju, & Jono, 1990). Suicidal behavior and violence are unlike other symptoms and dysfunctions because of their potential irrevocability.

Distress and dysfunctions lead to disabilities, manifestations of the illness that prevent the person from achieving goals typical of their age and culture (Anthony, Cohen, & Farkas, 1990; Becker & Drake, 2003). Three goals are especially relevant to a good quality of life:

1. *Independent living*: Most adults in the Western world want to start a household that represents their lifestyle. This includes decisions about place, housing type, roommates and intimacy, décor, 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 good job. Meeting educational standards is often needed to do this. Employment also includes notions of vocation and affiliation. People want to work at places that meet their standards for 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 impacted by one's spiritual life.

### **Recovery and strengths**

The course of serious mental illness has been defined by onset, trajectory, and end state (Ciompi, 1980). Serious mental illnesses might begin with acute onset, with the person suddenly demonstrating full-blown illness, or onset may be insidious, slowly emerging over time (McGlashan, 2008; Yung & McGorry, 1996). Trajectory is the course of the illness and can involve waxing and waning of symptoms, dysfunctions, and disabilities. Trajectories might be simple and flat, where the impact seems relatively unchanging. Alternatively, trajectories might be undulating, where illness varies markedly in severity over time. In this case, individual symptom sets seem to come and go as the illness is exacerbated and remits.

Past perspectives on end state were generally pessimistic; for example, Kraepelin (1896) viewed schizophrenia as a progressive downhill course, with institutionalization an unavoidable outcome. Poor prognosis has been definitive of serious mental illness, often incorporated into editions of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 1980, 1987, 1994, 2000). Long-term follow-up research, however, paints a different picture. Many studies have followed people diagnosed with schizophrenia for 20 to 30 years and found that between one and two thirds met criteria for improvement or recovery (Bellack, 2006; Ciompi, Harding, & Lehtinen, 2010; Lysaker & Buck, 2008). Recovery as *outcome* has multiple definitions but generally rests on overcoming disabilities to meet goals despite one's symptoms (Davidson, Rakfeldt, & Strauss, 2010; Liberman, 2008). This frames recovery as an end state demonstrated by decreased symptoms and disabilities as well as attainment of age- and culture-appropriate goals for most Western adults, including independent living and a satisfying work and family life. Alternatively, recovery has been described as a *process* (Ralph & Corrigan, 2005). Regardless of whether personal goals have been attained, recovery as process is achieved when the person has replaced despair with hope, with the idea that achievement is possible even in the face of distress, dysfunction, and disability. Viewing recovery as process does not mean people need to demonstrate certain benchmarks such as symptom remission or expected goal attainment. Instead, this view asserts that people can live with disabilities and achieve personally meaningful goals that still lead to a life with personal dignity.

As recovery emerged as the guiding yardstick for mental health over the past two decades (e.g., see the final report of President Bush's New Freedom Commission; Hogan, 2003), notions of the person with mental illness have broadened to include strengths (Rapp & Goscha, 2004). Proponents of strengths models argue that full understanding of the person includes recognition of talents, goals, and confidence alongside symptoms, dysfunctions, and disabilities. Strengths are the resources that people spontaneously use to address personal challenges, including those in mental health. Hence, just as assessment identifies distress and dysfunctions that block personal goals, so must it recognize strengths that promote those goals. Just as interventions are meant to challenge symptoms and dysfunctions, so must they augment strengths.

### **Evidence-based services**

Stigma becomes a particular concern when it undermines seeking out and participating in services with demonstrated effectiveness in reducing dysfunction and disability and promoting recovery, referred to as *evidence-based*

*services.* Clinical scientists have developed and tested effective interventions targeting symptoms and dysfunction for a range of psychiatric disorders, and professional groups have used the findings to establish practice guidelines for delivery of evidence-based services to help people with these disorders manage distress and disabilities in order to accomplish life goals (American Psychiatric Association, 1996, 2006; American Psychological Association, 2004, 2005, 2012, 2013). The U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) launched the National Registry of Evidence-based Programs and Practices (NREPP; SAMHSA, 2013) to track services for people with serious mental illness. Programs must meet several criteria to be listed in the registry, including using reliable and valid outcome measures; demonstrating fidelity to intervention; addressing missing data, attrition, and potential confounds; and using appropriate outcome analyses. NREPP also considers readiness for program dissemination, including availability of implementation materials, training resources, and quality assurance documentation. As of July 2013, NREPP listed 296 evidence-based programs for children and adults challenged by mental illness and/or substance abuse. Although there is some concern about the strength of all the evidence-based treatments in NREPP, these practice guidelines and the NREPP suggest that there is a broad armamentarium of services conceivably available to help people with serious mental illnesses. Common among these are symptom monitoring and medication management (Mellman et al., 2001), supported employment (Salyers, Becker, Drake, Torrey, & Wyzik, 2004), family interventions (Dixon et al., 2001), illness management (Drake, Goldman, et al., 2001), integrated treatment for dual disabilities (Drake, Essock, et al., 2001), and integrated primary and behavioral health care (Phillips et al., 2001).

### ***Care seeking***

Despite the availability of evidence-based services, epidemiological research suggests that many people who might benefit from care do not receive it. As we demonstrate below, stigma in its various manifestations often serves as a barrier to care seeking. Findings from the National Comorbidity Survey Replication showed that about 45% of respondents with a disorder who did not seek treatment reported low perceived need (Mojtabai et al., 2011). It is interesting that among respondents with a perceived need, desire to handle the problem on one's own was the most common reason given both for not seeking treatment (72.6%) and for dropping out of care (42.2%). In 1990, only 24.3% of individuals with a serious mental illness sought care. By 2003, 40.5% of individuals with a serious mental illness received treatment, a significant improvement over 1990, but still only a minority of

the population with a potential need for care (Kessler, Demler, et al., 2005). By 2011, 59.6% of people with serious mental illnesses reported receiving treatment (SAMHSA, 2012). SAMHSA (2012), among others, attributes these improvements to better availability of treatments, especially in a better informed primary care system. Nonetheless, even with these improvements, 40% of people with serious mental illness had not received care (SAMHSA, 2012), suggesting that the effects of stigma remain troublesome.

Many people who start mental health care drop out. Approximately one fifth of patients quit treatment prematurely, with over 70% of all dropouts occurring after the first or second visits (SAMHSA, 2012). Low-income and uninsured patients are at elevated risk for prematurely dropping out of care (Olfson et al., 2009). Rates and patterns of care seeking and dropout vary across age and demographic groups. Although mental disorders typically begin in young adulthood, young adults are less likely than middle-age or older adults to use mental health services (SAMHSA, 2012). Although rates of mental disorders are relatively similar across racial and ethnic groups, there is considerable variation in treatment rates across racial-ethnic groups. In 2011, whereas 16.6% of White adults received mental health services, only 7.6% of Blacks, 7.3% of Hispanics, and 6.5% of Asians received any treatment (SAMHSA, 2012). The relationship between race and mental health service use is at least partly mediated by socioeconomic status, with some poor ethnic-minority groups at greatest risk for low rates of treatment (Alegria et al., 2002). Issues of ethnicity, stigma, and care seeking are more fully unpacked in a separate section below.

It is important to note that choosing not to seek treatment or dropping out prematurely is not a phenomenon specific to mental illness or indicative of the disabilities that arise from these illnesses. Poor adherence is the rule rather than the exception across medical care as well as in the pursuit of wellness (O'Donohue & Levensky, 2006).

Hence, attempts to understand decisions about seeking mental health care are better understood within the broader context of seeking any kind of health care.

### ***Adherence or self-determination***

The preceding data suggest that many people decide not to seek out services or drop out prematurely. Models for understanding why some people choose to participate in care have evolved. Some providers believed that people do not participate in care because they are "resisting" health for some intrapsychic reason (Messer, 2002) and that they need to "comply" with treatment prescriptions. In turn, these providers at times promoted compliance through what might be perceived as coercive means, including inpatient and outpatient commitment, benign

coercion (e.g., exercise of a guardian's authority), diminished personal control (e.g., depot injections of antipsychotic medications, or benevolent trickery (e.g., not sharing with the individual the full range of side effects) (Burns, 2009; A. D. Redlich, Steadman, Robbins, & Swanson, 2006).

The term "adherence" is currently preferred to "compliance" as reflecting a more progressive approach to questions about why people do not participate in psychiatric care (Corrigan, Angell, et al., 2012). Adherence attempts to involve the person in treatment decisions, but providers continue to have a prominent role (A. Edwards & Elwyn, 2006; Simmons, Hetrick, & Jorm, 2010). Unfortunately, as with the term "compliance," there is a negative valence to the idea of "adherence"—by not, for example, taking one's medication, the person is somehow doing something wrong—that undermines service engagement. Models of adherence do not, for example, make allowance for reasoned decisions to opt to discontinue a prescribed medication in order to avoid its negative effects. In order to avoid such a value-laden perspective, adherence as treatment goal has been replaced by psychological models that seek to describe the decision-making process and subsequent health and wellness activity (Fishbein & Ajzen, 2010; Tanner-Smith & Brown, 2010). This important shift reframes research questions from narrow examination of whether the "patient" is doing what he or she should be doing to efforts at understanding the processes that affect independent decision making and behaviors related to health. Self-determination is an essential component in this process. Deci and Ryan's (2012) work on self-determination has been widely used for understanding this concept in health behavior. Self-determination rests on the assertion that human beings have a fundamental psychological need to be empowered and competent in seeking their goals with others. Satisfying these needs facilitates autonomous motivation, whereas blocking them promotes feelings of being controlled or amotivation.

### ***Self-determination in health care is "choice."***

Choice was prominently highlighted by President George W. Bush's New Freedom Commission (Hogan, 2003); specifically, this commission emphasized that people with serious mental illness must have choice over personal goals and traditional or nontraditional approaches to facilitate these goals. But choice is not just an ethic, not solely a "should" meant to guide good services. Choice is an observational and psychological reality. People are choosing all the time; they vote with their feet. They drop out of school if they believe it does not meet vocational or other developmental goals. They exercise daily if it is consistent with visions of wellness. They take medications when they perceive them to have a positive

impact. Psychological science needs to focus on such real, everyday behaviors in order to understand the choice process in terms of how and why people decide and act on health issues.

***Objectively defining the problem.*** In order to enhance research on barriers to mental health care, measures of seeking and participating in care have been defined beyond simple yes–no answers. Attendance is one seemingly easy-to-assess way service participation has been construed. For example, does the person show up at weekly scheduled sessions (Littell, Alexander, & Reynolds, 2001)? A ratio of made versus missed meetings could be an index of service participation. Although face-to-face meetings may be important, what the person does in the interim is also essential to progress. This might be called homework, goal-related efforts the person has attempted outside the treatment setting. Despite the seeming ease in which attendance and homework are represented as quantity and pattern over time, they can be surprisingly complex constructs to measure. Quantity, for example, may be simply assessed as hours a week for individual psychotherapy. Many evidence-based services for people with serious mental illness, however, are not described by such narrow constrictions. For example, participation in supported employment needs broader indices because service may be provided in short 20-min spurts for months or even years. Alternatively, services may not be well described by linear, continuous patterns. Service consumers may come and go from supported employment as their current goals dictate.

Service decisions and behaviors have also been evaluated in terms of "interactions," such as qualities of the consumer–provider relationship that facilitate interactions around an evidence-based service (Angell, 2006; Angell & Mahoney, 2007). Do consumers, for example, find exchange with providers satisfying and relevant to their needs (Howard, Rayens, El-Mallakh, & Clark, 2007; Skeem, Loudon, Polaschek, & Camp, 2007)? Trust, defined as an emotional connection in which the person feels hopeful that the service provider is directing efforts to address issues of concern, has been identified as one important component in creating satisfying consumer–provider relationships. (Behnia, 2008; Laughton-Brown, 2010). However, as services for people with serious mental illness are often provided by teams of providers with different professional training and treatment orientations (e.g., a psychiatrist focusing on medication versus a paraprofessional providing supported employment), studies of service interactions focusing on one-to-one exchanges with the primary clinician alone are limited. Peer-provided services have emerged as an especially important way to enhance interactions (Davidson, Chinman, Sells, & Rowe, 2006; Sells, Davidson, Jewell, Falzer, &

		TYPES			
		Public	Self	Label Avoidance	Structural
social cognitive S T R U C T U R E S	Stereotypes and Prejudice	<i>People with mental illness are dangerous, incompetent, to blame for their disorder, unpredictable.</i>	<i>I am dangerous, incompetent, to blame. [Leads to lowered self-esteem and self-efficacy]</i>	<i>I perceive that the public disrespects and discriminates against people with mental illness.</i>	Stereotypes are embodied in laws and other institutions.
	Discrimination	<i>Therefore, employers will not hire them, landlords will not rent to them, primary care providers will offer a worse standard of care.</i>	<i>Why try: Someone like me is not worthy or unable to work, live independently, have good health.</i>	<i>I do not want this. I will avoid the label by not seeking out treatment.</i>	Leads to intended and unintended loss of opportunity.

**Fig. 1.** A matrix describing the stigma of mental illness.

Rowe, 2006) and highlight another important characteristic of interactions: level of formality or lack thereof. More classic psychotherapies have trained practitioners for formal, sometimes aloof relationships. Providers of supported employment tend to be more informal and immediate. Consumer–provider exchanges are often dictated less by preconceived theory than by spontaneous demands of the moment.

Stigma is a significant barrier to care seeking and participation (Corrigan, 2004). More than 100 peer-reviewed, empirical articles have been published supporting some aspect of how stigma serves as a barrier (Clement et al., 2013). Research has demonstrated stigma to be a problem for elders (Graham et al., 2003), adults (Vogel, Wade, & Hackler, 2007), adolescents (Chandra & Minkovitz, 2007), and children (Adler & Wahl, 1998). The association between care seeking and participation has been examined in not only the overall population (Evans-Lacko, Brohan, Mojtabai, & Thornicroft, 2012) but in important subgroups, including veterans (Hoge et al., 2004), active military service members (Greene-Shortridge, Britt, & Castro, 2007), police officers and other first responders (Royle, Keenan, & Farrell, 2009), health care providers (Wrigley, Jackson, Judd, & Komiti, 2005), and parents making decisions about their children's health care (Hinshaw, 2005; Struening et al., 2001). Associations between care seeking and participation seem to be strongly moderated by gender (Levant et al., 2013; Pederson & Vogel, 2007) and ethnicity (Cheng, Kwan, & Sevig, 2013; Conner et al., 2010). We provide definitions of stigma in the next section and then attempt to explain its impact on care seeking as both a person-level and system-level variable.

## Stigma and Care Seeking

Stigma has evolved into a multifaceted concept from the “spoiled identity” first coined by Goffman (1963). He

believed stigma to be an attribute that is socially discrediting, leading people to being unjustly rejected. Link and Phelan (2001) defined stigma with four components distinguishing it from other social phenomena: (a) It is fundamentally a label of an out-group; (b) the labeled differences are negative; (c) the differences separate “us” from “them”; and (d) label and separation lead to status loss and discrimination. Corrigan (2005, 2013) extrapolated Link and Phelan's (2001) components into a matrix useful for understanding the stigma of disease and disability (see Fig. 1). The matrix is defined by two dimensions: the social-cognitive constructs that underlie stigma and the types that meaningfully impact the person with illness.

Social psychologists have distinguished the largely private experience of stigma—stereotypes and prejudice—from the more public, behavioral results. Stereotypes are harmful and disrespectful beliefs about a group. Especially egregious beliefs about people with mental illness include being dangerous and unpredictable, to blame for their illness, and incompetent to achieve most life goals, such as a good job or living independently (Angermeyer & Dietrich, 2006; Rüsche, Angermeyer, & Corrigan, 2005). Stereotypes may vary by mental health condition. For example, dangerousness is commonly attributed to mental illness and substance abuse. However, people with mental illness are often seen as incompetent, whereas substance abuse may be viewed as immoral. Stereotypes are unavoidable; they are learned as part of growing up in a culture: for example, the belief that all Irish men are alcoholics. Prejudice means agreeing with the stereotype, leading to emotional and evaluative consequences: “That's right! All Irish are alcoholics and I hate them.” Discrimination is the behavioral result of prejudice: “And because I do not respect the Irish, I will not hire them, rent to them, give them the same opportunities at school, or let them worship with my congregation.” Believing that people with mental illness are dangerous leads to fear, to employers not wanting to hire them or to primary

care providers offering below-standard medical care (Corrigan, 2005). Although changing population attitudes is a laudable goal, advocates believe that focus should be on discriminatory behaviors, the actions of others that block the pursuit of independent living goals related to work, education, and other arenas: "It would be nice if everyone accepted my mental illness, but at the end of the day I don't want someone blocking my right to work and live independently."

The impact of stereotypes, prejudice, and discrimination vary by type; four are summarized in Figure 1. Public stigma occurs when the general population endorses stereotypes and decides to discriminate against people labeled mentally ill. It impacts care seeking when it leads to label avoidance; people attempt to escape the unfair loss of opportunity that comes with stigmatizing labels by not going to clinics or interacting with mental health providers with whom the prejudice is associated (Corrigan, 2004). (The fear is that someone will think, "Hey that guy coming out of the psychiatrist's office must be wacko and incompetent!") Public stigma's effect on care seeking has been construed alternatively as treatment stigma, the prejudice bestowed on a person who receives mental health services (Vogel et al., 2007).

Self-stigma occurs when a person with mental illness internalizes this corresponding prejudice (Link, 1987; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001). A regressive model of self-stigma has four stages (Corrigan & Watson, 2002): People are (a) aware of the stigma of mental illness (also called *perceived stigma*: "The public thinks people with mental illness are dangerous"; (Phelan, Link, Stueve, & Pescosolido, 2000). This might lead to (b) agreement with the stigma ("Yep; that's right. People with mental illness are dangerous!"), followed by (c) self-application ("I'm mentally ill so I must be dangerous"), which has a (d) negative impact on self-esteem ("I am less of a person because I am mentally ill and dangerous") and self-efficacy ("I am less able to accomplish my goals because I am mentally ill and dangerous"), leading to shame. Self-discrimination also yields the "why try" effect (Corrigan, Larson, & Rusch, 2009). For example, "Why try to seek a job? Someone like me is not worthy"; or "Why try to live independently? Someone like me is not able." Structural stigma is the fourth type shown in Figure 1, encapsulated in the social and institutional policies and practices that undermine opportunities of people with mental illness (Corrigan, Markowitz, & Watson, 2004). Examples include lack of parity in health care coverage (Corrigan, Markowitz, & Watson, 2004), considering a person's past mental history in family law courts (Corrigan et al., 2005; Hemmens, Miller, Burton, & Milner, 2002), and failure to fund mental health research at levels similar to other health conditions (MacArthur, 2008). Structural stigma tends to impact care seeking more under

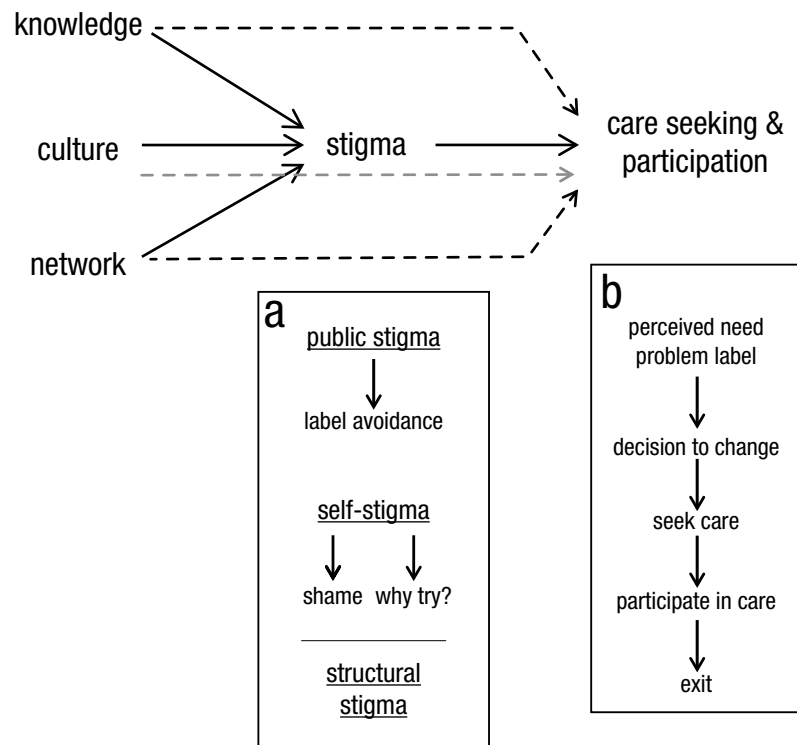
system-level barriers than at the individual level and hence is more fully reviewed in a separate section below.

### ***How stigma interferes with personal care-seeking decisions and behaviors***

Stigma impacts care seeking at personal, provider, and system levels. Figure 2 outlines the relationship between stigma and care seeking as a person-level event. Researchers have developed fluid models of care seeking and treatment participation reflecting the personal psychology of finding and acting on help (Kovandžić et al., 2011; Pescosolido, 1992). These models integrate cognitive perspectives (how people make a decision about beginning and staying in care) with social spheres (the interpersonal, familial, and cultural network in which decisions are made and lived out) in an evolving and iterative manner. A simplified version of these theories (as a linear and nonrecursive process) is offered in Box B of Figure 2 and is useful for examining in parallel where varied types of stigma (Box A) undermine care seeking and participation. Note that we view care and services broadly. Although medical practices (e.g., diagnosis and medication management) are the focus of care seeking in much of the American research literature, we also include individual and group psychotherapies and rehabilitation approaches (supported employment and housing); complementary medicines (e.g., acupuncture, Qigong, meditation, nutrition supplements); faith and other community-based influences; self- and mutual help; and bibliotherapies. Generically, we define an intervention as a planned activity with evidence base for helping the person meet life goals undermined by mental health challenges.

Care seeking and participation begin when a person experiences an unsettling physical, emotional, or interpersonal state that is perceived as problematic and in need of care. Labeling the problem as "stress," "psychiatric illness," or "mental health challenge" leads the person to seek care in the broad system of mental health services. Words that comprise labels are important in promoting care seeking. A college student, early in his or her illness, may be put off by having a "psychiatric illness" but willing to seek "counsel" for a "mental health challenge." Labeling may also be a signaling moment in which people spurn care seeking in order to avoid stigma: "I don't need to go to the shrink's office. I'm not nuts!"

In the presence of a perceived need framed as a mental health problem, people decide whether pursuit of treatment is appropriate for them. A transtheoretical or stages-of-change model is helpful for understanding this process (Prochaska & DiClemente, 1982). Determination to seek care is influenced by perceived costs and benefits of treatment options. Stigma in its various forms will



**Fig. 2.** The person-level relationship between stigma and care seeking.

influence these perceptions (Clement et al., 2013). Costs include stigmatizing labels that arise from treatment and worsened self-stigma and shame. The “why try” result of self-stigma may lead the person into believing treatment will not have any real positive impact: “I am not worthy of treatment, or I am unable to really participate.” People are likely to move forward when benefits seem to outweigh costs, perhaps when the stigma of mental illness is minimized.

People may seek care after a decision to change is made. Unfortunately, many drop out soon after; research suggests that up to 20% of people may discontinue treatment prematurely depending on type of treatment (e.g., medication versus talk therapy; Edlund et al., 2002). Stigma is a likely factor undermining treatment participation. Negative perceptions of mental health and treatment reflecting prejudices of mental illness can reemerge and derail interventions. The sense of poor self-efficacy commensurate with self-stigma harms participation in care. Care seeking ends when people exit services, that is, when they notify their provider that they have decided to stop treatment or when they discontinue participation without notice. A “cure” requiring no future treatment is not always the goal of ending care. Like all health and wellness considerations, challenges and successes vary depending on the person’s age, development, network, and life events.

The path model in Figure 2 suggests that care seeking rests on the person’s perceptions of mental health and interventions meant to enhance it. Research suggests that people with some mental illnesses lack insight or are not fully aware of their mental illness, thereby skewing these perceptions. Epidemiological research, for example, suggests that as many as half of people with such diagnoses as schizophrenia and bipolar disorder are unaware of their illness (Kessler et al., 2001). Lack of insight varies with the course of a person’s mental illness, changing with acuity of symptoms and response to some treatments. Still, poor insight has been viewed as incapacity to fully participate in care, leading some advocates to promote outpatient commitment and other coercive treatments (Link, Castille, & Stuber, 2008; Monahan et al., 2001; Wales & Hiday, 2006). Such categorical decisions about insight and mandated care ignore the complexity of illness awareness. Most people meeting criteria for poor insight do so in a varied manner: Although they may be unaware of some symptoms, they accurately perceive the status of much of the rest of their lives. Moreover, a coercive agenda can undermine the human dignity to fail (i.e., to make mistakes; Corrigan, 2011), and it undermines intrinsic motivation that may evolve from lessons learned. Failing to achieve personal goals is a central experience of the human condition, and it typically is important to personal development; coercion often and



unnecessarily robs people of this experience. A few events may trump the right to fail—for example, situations where the person is dangerous to self and others, situations that do seem to occur at a higher rate in people with mental illness (Corrigan & Watson, 2005; Elbogen & Johnson, 2009; Monahan, 1992). However, the public grossly overestimates dangerousness among people with mental illness (Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999; Swanson et al., 2002; Swanson et al., 2006); this is the stereotype, after all. Moreover, particularly heinous crimes, such as mass shootings, are often, inaccurately, ascribed to mental illness (Corrigan & Watson, 2005). Hence, public policy makers may need to be cautious about endorsing coercive treatment in cases of poor insight.

One other finding that should be taken into consideration when deciding whether to mandate therapies is that the impact of coercion on actual participation in treatments is mixed (Hiday & Ray, 2010; Link et al., 2008). People might be more likely to follow specific treatment prescriptions under close supervision (Gilbert et al., 2010). This has been studied most thoroughly in services related to the criminal justice system, for example, in outpatient commitment, often used by courts as repercussions in cases where the person does not comply with treatment appointments and receipt of in-the-community case management (Gilbert et al., 2010). Findings suggest that participants in outpatient commitment are likely to show significant decreases in subsequent arrest (Link, Epperson, Perron, Castille, & Yang, 2011; Swanson et al., 2001), fewer rehospitalizations (Swartz et al., 1999), and reduced incidence in violence (Swanson et al., 2000). However, one large-scale randomized controlled trial (RCT) showed that outpatient commitment had no significant effect on hospitalizations or arrests (Steadman et al., 2001). Researchers concluded that enhancement of services, not coercion, may be the active ingredient of outpatient commitment accounting for benefits here (Swartz & Swanson, 2004). Moreover, research suggests that a sense of procedural justice on the part of service recipients predicts better outcomes in mental health efforts in the criminal justice system (Canada & Watson, 2013; Watson & Angell, 2013). Namely, perceived fairness and equanimity of an exchange predicts the success of that intervention on service participation and recidivism. Hence, perceived coercion can undermine treatment engagement, even in cases of strong criminal court supervision.

### ***Impact of knowledge on stigma and care seeking***

The relationship between stigma and care seeking may be moderated by three additional variables, as shown in Figure 2: knowledge, culture, and network. Researchers

have argued that improper or insufficient knowledge about mental illness and its treatment leads to stigmatizing attitudes and discriminatory behavior (Thornicroft, Rose, Kassam, & Sartorius, 2007). In turn, knowledge and attitudes have been shown to be predictors of care seeking (Golberstein, Eisenberg, & Gollust, 2008; Rüschi, Evans-Lacko, Henderson, Flach, & Thornicroft, 2011; Schomerus & Angermeyer, 2008; Schomerus, Matschinger, & Angermeyer, 2009) and participation (Sirey et al., 2001). Mental health literacy has been more formally defined as information and beliefs about mental illness that aid in its recognition, management, and prevention (Jorm, 2012; Jorm et al., 1997). Mental health literacy exceeds knowledge per se and includes the extent to which information mastery and parallel skills lead to actual care seeking and participation. In this light, mental health literacy includes knowledge about preventing disorders, recognizing them when they develop, pursuing help when disorders become distressing, and using mental health first aid skills to support others in distress.

### ***Stigma, care seeking, and culture***

Earlier, we discussed how culture interacts with care seeking. Given that stigma is a social construction, it is influenced by socially important categories such as culture and ethnicity. For example, cultural norms and perceptions determine social indicators of mental illness, thereby impacting stigmatizing cues (Abdullah & Brown, 2011). These norms are the societal beliefs that comprise stereotypes as well as the climate in which these stereotypes are endorsed. Cultural values may also influence acceptability of discrimination. Research suggests that some cultural minorities in America are more likely to endorse stereotypes of mental illness, especially dangerousness, discriminating against people with mental illness as a result (Anglin, Link, & Phelan, 2006; Rao, Feinglass, & Corrigan, 2007; Whaley, 1997). In a comprehensive review of the literature, Abdullah and Brown (2011) dug beyond minority–majority dichotomies to consider how specific cultural beliefs influence mental illness stigma. Collectivist aspects of some Asian groups, for example, may lead to perceptions that disabilities of mental illness reflect flaws of the family (Lauber & Rössler, 2007; Sanchez & Gaw, 2007; Weiss, Jadhav, Raguram, Vounatsou, & Littlewood, 2001). This kind of shame is worsened when it suggests lack of conformity to social norms, a Confucian ideal (B. K. Kim, Atkinson, & Yang, 1999; Lam, Tsang, Chan, & Corrigan, 2006). As a result, Asians who endorse stigma are less likely to seek services when in need (Miville & Constantine, 2007; Shea & Yeh, 2008). Similarly, those of African heritage are influenced by communalism, kinship, and group identity (Tyler et al., 2008). This may lead to them distancing

themselves from the person with mental illness in order to protect the integrity of their kin (Abdullah & Brown, 2011). Sometimes culture might yield protective factors. African cultures, for example, prize spiritualism, viewing mental illness as handed down from a god, which might shield the person in grace, protecting him or her from stigma (Griffith & Baker, 1993; Mishra, Lucksted, Gioia, Barnett, & Baquet, 2009). In this light, endorsing stigma seems to be a prominent barrier to care seeking in African and African American groups (Alvidrez, Snowden, & Kaiser, 2008; Conner, Koeske, & Brown, 2009; Mishra et al., 2009).

Despite Abdullah and Brown's (2011) review, the relationship between culture and stigma is complex (Yang et al., 2007). In the Abdullah and Brown (2011) review, for example, disparate cultural groups were reduced to continent-level constructs (Asian or African). As Abdullah and Brown noted, Indians and Chinese in Asia may be as different from each other as Western Europeans are from East Asians. Moreover, assuming that a person of a specific ethnic group will act consistently with values of that group—for example, "All Chinese are collectivists and hence will be embarrassed for their family when a sibling has schizophrenia"—might be an alternative form of stereotype. Research has showed significant heterogeneity within a culture.

Culture's direct relationship with help seeking may also be understood in terms of health care disparities; that is, people of some ethnic minorities do not enjoy the same health resources and standards of care as the majority. Health care disparities have been framed in two ways: as limitations in available services or as cultural incompetence. The first is discussed more fully in the sections on provider and system barriers to care seeking. Limitations in cultural competence often reflect failure to consider differences in help seeking across cultures (Askim-Lovseth & Aldana, 2010; Sue, Cheng, Saad, & Chu, 2012). Factors that lead patients of color to feel alienated from health care clinics and providers include myopic preferences for Western healing beliefs (Padela, Gunter, Killawi, & Heisler, 2012), denigration of non-Western treatments (Su & Li, 2011), diminished trust (Kalbfleisch, 2009; Musa, Schulz, Harris, Silverman, & Thomas, 2009), different reactions to mental illness stigma (Abdullah & Brown, 2011; Yang et al., 2007), different understandings of mental illness (Martin, 2009; Vera et al., 1998), and ignorance of culturally different symptom expression (Hunter & Schmidt, 2010; Tófoli, Andrade, & Fortes, 2011). Exacerbating these differences may be the lack of culturally matched providers, though research on the size of this effect is often mixed (Cabral & Smith, 2011; Griner & Smith, 2006). Lack of language proficiency impedes quality care, too (G. Kim et al., 2011; Pérez-Stable, 2007).

### ***Impact of the person's network***

A special example of culture lies in one's social network: family, friends, coworkers, and others who influence stigma and its impact on care seeking. Research suggests that personal familiarity and experience with mental illness may be inversely related to stigma (Angermeyer, Matschinger, & Corrigan, 2004; Corrigan, Green, Lundin, Kubiak, & Penn, 2001); hence, family and friends with close relationships may be less likely to endorse stigmatizing attitudes and more likely to serve as resources to care seeking. However, other factors, such as negative prior experiences with mental health providers (Lefley, 1989), the availability of social supports within the family (Mitchell, 1989) and cultural beliefs and values, may lead family members to discourage care seeking. Although it has been suggested that some family members may stigmatize their relatives with mental illness (e.g., Moses, 2010), caution must be exercised to discriminate family stigmatization from normative family tensions and conflict that arise when family members first learn about the illness and how they can help (Lefley, 1989) or from family perceptions that society stigmatizes persons with mental illness, without endorsing these stereotypes themselves.

Impact of family-perceived stigma on care seeking may be mediated by family burden, defined in terms of both objective (e.g., day-to-day practical constraints in social and work life) and subjective (e.g., psychological distress engendered by the illness) components (Lefley, 1989; Magliano et al., 1998). For example, Perlick and colleagues (2004) found that greater family perceptions of devaluation and discrimination of both persons with the illness and their family members were associated with higher levels of burden. Indirectly, this seemed to yield less helpful family interaction patterns and lower levels of care seeking over a 6-month period. Although others have also reported an inverse relationship between burden and adaptive coping (e.g., Magliano et al., 1998), burden is not always associated with compromised coping and high perceived stigma. A study using cluster analysis to compare caregivers high in burden with those high in perceived stigma found that the group perceiving increased stigma were higher in mastery and perceived social support (Perlick et al., 2008). Further, although burden has been found to be associated with diminished care seeking, other studies have found that burden may promote care seeking, with families reporting greater burden seemingly more motivated to get their relative into services, especially for people early in their mental illness trajectory (Czuchta & McCay, 2001; Wong et al., 2008). Taken together, these studies suggest that burden and stigma both impact care seeking, though the nature of the relationship between these constructs may be

moderated by additional factors, such as phase of illness and education and support available to the family. A caveat about the term “burden” is in order: Although used in an extensive body of research, the term “burden” may reframe and reduce family interactions into negative portraits, ignoring the positive and uplifting experiences that emerge in these experiences (Ohaeri, 2003). As a result, researchers are calling for evolving notions of burden to include empowerment and recovery (Sartorius, Leff, Lopez-Ibor, Maj, & Okasha, 2005).

### **Family stigma**

Burden may be exacerbated by family or “courtesy” stigma, a term coined by Goffman (1963) that reflects families, friends, and others being objects of prejudice and discrimination because of their association with the person with mental illness. Like people with mental illness, some of their family members may be harmed by public and by self-stigma (Moses, in press; Phelan, Bromet, & Link, 1998; Struening et al., 2001; Van der Sanden, Bos, Stutterheim, Pryor, & Kok, 2013). Families report that friends, neighbors, and coworkers often blame them for their relatives’ mental illness or express disapproval because the relative has not quickly recovered. Others believe that family members are somehow infected by mental illness themselves and therefore avoid them. Some family members seem to internalize the stereotypes, leading to self-stigma. They might blame themselves for their relatives’ illness—believing, for example, that they are genetically flawed or were bad parents—which can lead to shame (Moses, in press). Some family members and friends are challenged by an additional type of stigma: vicarious stigma. This is the sense of sadness and helplessness a family member feels when observing a relative being the object of prejudice or discrimination because of the mental illness (Corrigan & Miller, 2004).

What effect does courtesy stigma have on care seeking? Although we are unaware of research directly examining this question, there seem to be negative effects of courtesy stigma that might undermine care seeking. Family members reporting public or self-stigma often feel alienated from neighbors and coworkers, people in a putative support network that might assist the family in its goals (Angermeyer, Schulze, & Dietrich, 2003; Magliano, Fiorillo, De Rosa, Malangone, & Maj, 2005; Perlick et al., 2007; Phelan et al., 1998). Alternatively, family members may feel ashamed and seek to keep family experiences related to mental illness a secret. Some family members report significant distress because of stigma, which worsens interactions among the family as well as the individual’s ability to cope. This broad and pernicious impact alienates the family from others, serving as an additional barrier to care seeking.

### **Provider-Level Barriers to Care Seeking**

Sometimes, stigma may influence providers, who unintentionally become barriers to care. Studies conducted in the 1980s and 1990s found that serious mental illnesses were rarely treated at therapeutic medication dosages or for sufficient durations, particularly in general medical settings, perhaps as a consequence of stigma. Using data from the 1990 National Comorbidity Survey, Wang, Demler, and Kessler (2002) estimated that only 20% of individuals with serious mental illnesses treated in general medical settings and 45.7% of those treated in specialty mental health settings received adequate treatment for their conditions (Wang et al., 2002). The low rates in general medical settings were ascribed to lack of provider knowledge about mental health treatments and of clinic-level supports for providing high-quality care.

A number of factors subsequently seemed to reduce provider-level barriers to care and increase rates of treatment for common mental disorders, particularly in general medical settings. Development of simple, self-administered depression screeners, such as the nine-item Patient Health Questionnaire (Kroenke, Spitzer, & Williams, 2001), made it easier to perform routine screening for depression and other common mental disorders in primary care settings. New medications, such as selective serotonin reuptake inhibitors, made it easier and safer for primary care providers to treat uncomplicated cases of depression and anxiety disorders. Between 1989 and 2000, the percentage of primary care visits leading to antidepressant prescriptions rose from 2.6% (approximately 6 million visits) in 1989 to 7.1% (approximately 20.5 million) in 2000 (Pirraglia, Stafford, & Singer, 2003).

For people with more disabling diagnoses, such as schizophrenia and bipolar disorder, considerable provider-level barriers still exist to high-quality treatment. Limited funding and provider shortages hamper access to care in community mental health settings, particularly in poor and rural areas (Hough, Willging, Altschul, & Adelsheim, 2011). In contrast to other countries where primary care providers deliver frontline care for more serious conditions (Reilly et al., 2012), there has been less opportunity in the United States to expand access to mental health services for this population in primary care settings. Improving primary care providers’ capacity to provide mental health care for people with serious mental illnesses will require training in medication and evidence-based psychosocial treatments as well as support from care managers and multidisciplinary teams.

## **Stigma and providers**

Most mental health professionals pursue their career for altruistic reasons (Burks, Youll, & Durtschi, 2012; Wakefield, 1993). Hence, it is surprising they might endorse stereotypes and discriminate against people labeled “mentally ill.” A comprehensive review found nine research surveys on mental health provider attitudes toward mental illness published between 1990 and 2004 that partially seemed to support this relationship (Angermeyer & Dietrich, 2006; Schulze, 2007). We augmented these findings with an updated literature scan, yielding an important population study conducted in Switzerland that compared responses of 1,073 mental health professionals with those of 1,737 of the Swiss general public (Nordt, Rossler, & Lauber, 2006). A review of all findings yields contrary trends. On the negative side, service consumers and their family often describe mental health professionals as the source of stigma, with specific providers frequently focusing on the disease and ignoring the person (Holzinger, Beck, Munk, Weithaas, & Angermeyer, 2003; Pinfold, Byrne, & Toulmin, 2005). Surveys of professionals find that as many as half failed to endorse recovery as an outcome for serious mental illness (Magliano, Fiorillo, De Rosa, Malangone, & Maj, 2004). Psychiatrists are often found to be more pessimistic about mental illness compared with general practitioners, clinical psychologists, and mental health nurses (Caldwell & Jorm, 2001). Mental health providers endorse stereotypes about mental illness, including perceptions of dangerousness, unpredictability, and blame (Kingdon, Sharma, & Hart, 2004; Magliano et al., 2004); they were likely to endorse greater social distance in some studies (Lauber, Anthony, Ajdacic-Gross, & Rössler, 2004). Conversely, other studies have found that mental health professionals are often optimistic about outcome (Kingdon et al., 2004), promote community-based interventions over institutions (Kingdon et al., 2004; Lauber et al., 2004), and endorse civil rights (Magliano et al., 2004; Zogg, Lauber, Ajdacic-Gross, & Rössler, 2003).

How might provider stigma impact the provision of care? Two bodies of research suggest that provider stereotypes undermine good practice. The first is from a 1990–2004 review (Angermeyer & Dietrich, 2006; Schulze, 2007) examining whether professionals withhold information about diagnosis and treatment. One study showed that almost half of participating psychiatrists did not share a diagnosis of schizophrenia with the patient unless specifically asked (Ucok, Polat, Sartorius, Erkoç, & Atakli, 2004), while a second showed that a majority of psychiatrists were more likely to fully share such information (Kingdon et al., 2004). Other research among people with lived experience of mental illness failed to show psychiatrists engaging their patients in such real-life

issues as finance, accommodations, and leisure (Killian et al., 2003; Schulze & Angermeyer, 2003).

The second body of research comes from the interface between mental health and primary care. People with serious mental illness experience health challenges yielding alarming morbidity rates (World Health Organization, 2001) and die, on average, 15 to 30 years younger than others in their cohort (Saha, Chant, & McGrath, 2007). Multiple risk factors contribute to premature mortality, including lifestyle factors (tobacco use, lack of physical activity, unhealthy diet), poor quality of medical care, and poverty, which may limit access to healthy eating, physical activity, and high-quality health care providers (Druss, Zhao, Von Esenwein, Morrato, & Marcus, 2011). Research suggests that stigma among primary care providers may, in part, contribute to lower quality of care in this population (Thornicroft, 2013). Compared with patients not identified with mental illness, studies have shown that health providers are less likely to refer patients with mental illness for mammography (Koroukian, Bakaki, Golchin, Tyler, & Loue, 2012), inpatient hospitalization after diabetic crisis (Sullivan, Han, Moore, & Kotrla, 2006), or cardiac catheterization (Druss, Bradford, Rosenheck, Radford, & Krumholz, 2000). Provider endorsement of stigma might influence these health care decisions (Jones, Howard, & Thornicroft, 2008; Thornicroft, Rose, & Kassam, 2007). One study examined the relationship between stigma and treatment decisions in primary care and psychiatric physicians and nurses (Corrigan, Mittal, et al., 2013). Results showed that providers who endorsed stigmatizing ideas about a patient with mental illness presenting for arthritic pain were less likely to refer the person for a consult and less likely to refill the patient’s analgesic prescription. This relationship was demonstrated equally across primary care and mental health providers. People with mental illness cannot obtain services when providers fail to offer them or do so contrary to practice standards.

## ***Mental health care providers as the object of stigma***

Stigma may also extend to providers of mental health care, exacerbating public stigma and increasing the likelihood that people will not seek services. Service providers are often stigmatized because of their professional identification, another form of Goffman’s (1963) courtesy stigma. A comprehensive review of more than 500 studies suggested that the public endorses varied stereotypes about psychiatry and psychiatrists (Sartorius et al., 2010). The practice of psychiatry is often viewed by the public as ineffective or possibly harmful, by medical students as having low status, by patients as failing to target essential problems, and by the media as a discipline without true scholarship. Psychiatrists are frequently viewed in a

similar negative light. The public views psychiatrists as low-status physicians who rely too much on medication. Medical students believe that psychiatrists “must be crazy.” Patient attitudes are often ambivalent, with some sincerely grateful for the efforts of their psychiatrists and others viewing them as controlling and distracted. The media sometimes represent psychiatrists as mad doctors, as super healers, or as exploitative practitioners. The review by Sartorius et al. is limited because it focuses solely on attitudes about psychiatry and psychiatrists. Still, it seems reasonable to assume that much of this bias would extend to other mental health disciplines.

Research is less clear regarding the impact of this kind of stigma on quality of care and subsequent seeking of services. Policy leaders have wondered whether this kind of prejudice dissuades promising students from joining mental health professions or whether it drives talented providers out of the discipline prematurely (Gaebel et al., 2011; Link & Phelan, 2001).

### **System-Level Barriers to Care Seeking**

There are a number of system-level barriers to high-quality mental health care, including lack of adequate mental health benefits, problems in geographic access to care, and fragmentation of services. Consider findings from the 2011–2013 National Comorbidity Survey, in which participants who perceived a need for mental health services and were unable to obtain them reported structural hurdles including financial barriers (15.3%), lack of availability of services (12.8%), and problems in transportation to care (5.7%; Mojtabai et al., 2011). Among people with severe mental illnesses, the importance of structural barriers became even more pronounced, with 26.0% reporting financial problems, 24.2% reporting lack of availability of services, and 13.4% reporting problems in transportation.

Since the birth of the modern insurance system in the United States, mental health benefits have not been offered on a par with general health benefits (Barry, Huskamp, & Goldman, 2010). Concerned about the potential for overuse of mental health services, private insurers and Medicare imposed high deductibles and copayments as well as lifetime caps on mental health benefits. High deductibles raised financial barriers to accessing mental health services, and people with serious mental illnesses who exceeded lifetime spending or hospitalization caps ran the risk of bankruptcy.

Geographic barriers may also constrain availability of public mental health services. More than one third of American counties do not have outpatient mental health facilities that accept Medicaid. Communities with a larger percentage of residents who are African Americans or living in a rural area are more likely to lack these

facilities. These findings speak to the importance of developing distance technologies, such as telemedicine, as well as to the importance of expanding primary care capacity to treat mental illness, to ensure access to mental health care in the public mental health safety net (Cummings, Wen, Ko, & Druss, 2013).

Although advances in medications and growth of mental health treatment in primary care have helped reduce provider barriers in recent years, system-level issues continue to limit access to high-quality services. In the 2011 National Survey on Drug Use and Health, 4.9 million adults ages 18 or older reported an unmet need for mental health care and did not receive mental health services. People with an unmet mental health need reported inability to afford care (50.1%), not knowing where to go for care (16.2%), and not having the time to go for care (15.1%) as the important barriers to obtaining access to care. Finally, people with mental illnesses who do receive ongoing services frequently obtain care from multiple providers, including substance use, medical care, and social service agencies. Lack of communication and coordination may result in adverse medication interactions, duplicative services, and lack of accountability across providers (H. A. Pincus et al., 2007).

### **Role of Structural Stigma**

Some of the inequities represented by system-level barriers are attributed to structural stigma, a macro-social process that represents policies of private and governmental institution that intentionally or unintentionally restrict opportunities of people with mental illness (Campbell & Deacon, 2006; Corrigan, Markowitz, & Watson, 2004; F. L. Pincus, 1999). One example of intentional institutional discrimination is state legislation that limits the civil rights of people with mental illness. Studies examining state legislation in the 1980s (Burton, 1990) and 1990s (Hemmens et al., 2002) showed that as many as 20 states restricted voting, jury duty, elective office, parenting, and marriage rights because of mental illness. These restrictions occurred partly because of stigmatizing beliefs that people with mental illness are not capable of being full citizens or family members (Pelletier, Davidson, Roelandt, & Daumerie, 2009). Unintentional manifestations of structural stigma offer examples germane to care seeking. Research has shown that endorsing stigma is inversely related to resource allocation. Subjects in an analogue study who endorsed the idea that people are to blame for their mental illness were less likely to provide more money to mental health programs in a government-fund allocation task (Corrigan, Watson, Warpinski, & Gracia, 2004). At a macro level, structural stigma translates to inequitable distribution of resources for mental health. Research monies are not at comparable levels to those

allocated to many physical illnesses despite the depth of impact caused by major mental health disorders (Link & Phelan, 2001).

## Public Health and Policy Solutions

The sets of barriers suggest directions for enhancing care seeking and participation. Here we review the research literature on ways to address person-, provider-, and system-level barriers to care.

### *Person-level approaches*

As outlined in Figure 2, the stigma of mental illness interferes with care seeking and participation because people seek to escape the social opprobrium of public stigma or the shame of self-stigma. Approaches to public and self-stigma have evolved separately and hence are reviewed here in turn. In addition, courtesy stigma experienced by families and care providers may undermine care seeking and participation; ways to challenge them are briefly considered in light of the discussion of public and self-stigma change. Finally, stigma and care seeking are moderated by mental health literacy, culture, and social network. Hence, ways to impact these processes are discussed.

### *Addressing the public stigma of mental illness.*

Based on a review of the literature from social psychology, three approaches to addressing public stigma have emerged—protest, education, and contact—each with different strengths and limitations (Corrigan & Fong, in press; Corrigan & Penn, 1999). The question here is how approaches like these might diminish stigma in order to promote care seeking. Education programs have been widely used to undermine label avoidance. In their bare bones, these programs attempt to contrast the myths of mental illness with the facts.

Myth: People choose to be mentally ill because they are fundamentally weak.

Fact: Mental illness is largely a biological disorder; people are not to blame for it.

Educational programs often include the message that mental illnesses are treatable disorders followed by information regarding service availability in the geographic area. Government and large nongovernmental organizations have rolled this kind of approach into public service campaigns seeking to motivate viewers to ignore stigma and seek out services when in need. Australia's *beyondblue* has been in place since 2000 (Hickie, 2001) targeting anxiety and depression with

programs aimed specifically at young people; men; women; multicultural people; lesbian, gay, bisexual, trans, and intersex people; pregnant women and new mothers; and aboriginal people (Dunt et al., 2011). The public service campaign seems to have significantly penetrated the Australian population: Two separate surveys found that about 40% of teens were aware of the campaign (Jorm, 2009; A. Morgan & Jorm, 2007). An additional survey found that 61.9% of the Australian population recognized the campaign (Highet, Luscombe, Davenport, Burns, & Hickie, 2006). Awareness seemed to be related to better recognition of mental illnesses and beliefs about mental health first aid (Yap, Reavley, & Jorm, 2012). Other studies examined *beyondblue's* effects in Australian states that implemented the program versus those that did not. Results showed that awareness of the program was about twice as great in states and territories that rolled out the campaign versus those that did not (Jorm, Christensen, & Griffiths, 2005). Awareness seemed to be associated with better recognition of illnesses (Jorm, Christensen, & Griffiths, 2006) and greater understanding of the benefits of treatments like counseling and medication (Jorm et al., 2005).

The link to care seeking is less clear. Other countries have rolled out similar campaigns, though research on their penetration and impact is mostly lacking. SAMHSA produced the What a Difference a Friend Makes campaign, designed to encourage young adults to step up and support friends living with mental health problems. The Ad Council reported findings from an online tracking survey on What a Difference and found that 31% of a sample of 18- to 25-year-old adults recognized public service announcements (PSAs) from the campaign in March 2008 and that 28% did so in May 2009 (Corrigan, 2012). Impact is more difficult to assess, however. One method of assessment has been tracking visits to Web sites listed at the end of PSAs; the rationale is that viewers are seeking further information to better learn about and work against stigma; this, in turn, leads to better care seeking and service engagement. The Ad Council reported Web site traffic for What a Difference from the launch of the campaign in December 2006 through September 2008 with a monthly median of 64,098 visits. In the first month of the campaign, Web site visits increased to a high of 102,416 in September 2007. Average time spent on the Web site was almost 8 min. However, findings were a bit less sanguine for a second SAMHSA campaign, the Erase the Barriers initiative (Bell, Colangelo, & Pillen, 2005). Monthly visits to the site almost tripled, from 2,743 to 7,627, during its 8-month campaign beginning November 2004, highly significant indeed. The size of effect, however, is quite small. U.S. Census data at the time reported 124 million residents in the eight pilot states of Erase the Barriers. That means that 0.006% of people in these states

visited the Web site. Of additional concern, however, was the finding that 88% of visitors exited the Web site in less than 1 min; fewer than 30% of visitors returned to the site in the subsequent months.

One additional concern has emerged from public service campaigns like these (Corrigan & Fong, in press). The focus on mental illness being a treatable disease may accentuate the fundamental characteristic of stigma: difference (Link & Phelan, 2001), that is, the perception that “People with depression are different than everyone else.” It is unclear whether this kind of unintended consequence undermines the goal of promoting care seeking; however, it may exacerbate the discrimination that occurs from public stigma. Because “they” are different, employers may not want to hire them, landlords may not want to rent to them, or primary care doctors may provide substandard care. Other public service campaigns seek to combine both agendas, undermining label avoidance and public discrimination. One example is the United Kingdom’s Time to Change initiative, which seeks to promote care and to challenge discrimination so that people with mental illness have opportunities that are similar to those of everyone else (Smith, 2013). Awareness of Time to Change ranged between 38% and 64% and was associated with greater mental health literacy and less stigmatizing attitudes (Evans-Lacko et al., 2013).

**Contact.** Education approaches to stigma change are often augmented by contact: strategic interactions between people with lived experience of mental illness and targeted members of the public (Couture & Penn, 2003). Contact may occur face to face or over some medium like television, Facebook, or YouTube. Contact usually includes “on-the-way-down” summaries of the illness, “on-the-way-up” replies representing recovery, statements of the personally hurtful impact of stigma, and calls to action depending on target group—for example, to psychiatrists, who are called on to provide the same quality of care no matter how psychotic the person (Corrigan, Vega, et al., 2013). A recent meta-analysis showed contact yielding significantly better effects than education on attitudes about and behavior intentions toward people with mental illness (Corrigan, Morris, Michaels, Rafacz, & Rüsche, 2012). The summary also showed that in vivo contact had significantly greater impact than video or online versions. Despite the promise of adding contact to education, research does not seem to have examined its effects on care seeking.

**Addressing self-stigma.** Participating in treatment might exacerbate the self-stigma of mental illness, leading some people to opt not to seek care. In addition, the “why try” that results from self-stigma might lead to a person believing treatment might not work. A body of

research has emerged examining the impact of approaches to decreasing self-stigma and promoting personal empowerment (Mittal, Sullivan, Chekuri, Allee, & Corrigan, 2012). Approaches have been divided into three related groups: psychoeducation, disclosure, and peer support. Psychoeducation—reviewing facts about mental illness and the injustices of stigma—seems to be the most often evaluated of these, though some of the studies addressed self-stigma of substance abuse as well as mental illness. Findings from six published studies were mixed, with three yielding significant and positive findings (Mittal et al., 2012). Psychoeducation is often augmented with cognitive therapy where participants learn to challenge self-stigma framed as irrational beliefs. The literature here was also mixed, with two of five studies yielding positive findings (Mittal et al., 2012). Acceptance and commitment therapy (ACT) might be considered a “special” form of cognitive therapy used to address self-stigma (Luoma, Kohlenberg, Hayes, Bunting, & Rye, 2008). ACT combined mindfulness, acceptance, and values work in relation to self-stigma; results of a pre-/post-study yielded moderate effects. Although there is some guarded promise of these kinds of programs impacting self-stigmatizing attitudes, it is unclear whether this kind of change affects care seeking. Self-stigma and personal empowerment have been viewed as opposites on the same continuum (Muñoz, Sanz, Pérez-Santos, & Quiroga, 2011); hence, reductions in these kinds of beliefs might be replaced with greater self-efficacy, which might lead to better care seeking and service participation.

There may be unintended risks to psychoeducational approaches: Focusing on how people might eradicate their personal struggle with self-stigma may unintentionally perpetuate the notion that stigma is their problem, that it is another sequela of the illness for which they must be treated (Corrigan & Fong, in press). Many advocates believe that stigma is an injustice perpetrated by one’s community (Corrigan & Fong, in press). A focus on self-stigma, although necessary in the short term, should not distract advocates from the primary goal of erasing the societal prejudice from which self-stigma emerges.

Group identification, defined as feelings of strong ties to a socially defined collection of people (Jetten, Branscombe, Schmitt, & Spears, 2001), has been shown to diminish effects of self-stigma on the person with mental illness. People with mental illness who more highly identify with the “group” viewed that group positively (Rüsche et al., 2009) and were less likely to experience harm to self-esteem as a result of internalized stigma (Watson, Corrigan, Larson, & Sells, 2007). Coming Out Proud (COP) is a program designed to decrease self-stigma by helping people consider costs and benefits of disclosure as well as “safe” strategies to do so should they decide to “come out” about their mental illness (Corrigan,

Kosyluk, & Rüsich, 2013) Findings from an RCT were mixed but found positive impact for COP on stigma stress, secrecy, and group identification (Rüsich et al., in press). The investigators opined that decreased secrecy would likely lead to greater care seeking.

Disclosure and empowerment are augmented by peer support, people with lived experience providing aid, often in a mutual relationship. Early studies of peer support were largely positive, suggesting it led to improvements in symptoms, size of social network, and quality of life, though most of these studies were largely uncontrolled (Davidson et al., 1999). A more recent review considered findings from four RCTs on a broader array of outcomes, including hospitalization, care participation, symptoms, quality of life, and homelessness (Davidson et al., 2006). Three of four studies failed to find significant differences between peer support and control groups. The fourth showed that participants in peer support had significantly fewer hospitalizations and longer community tenure (Clarke et al., 2000). A fifth RCT has been completed since then and showed that those receiving peer support had fewer hospitalizations (Sledge et al., 2011). However, findings from this study were mostly negative for the impact of peer support on care seeking.

**Promoting affirming attitudes.** Many advocates and researchers believe that decreasing stigma is not sufficient. Programs need to also promote affirming attitudes such as recovery, empowerment, and self-determination (Corrigan, Powell, & Michaels, 2013). Most stakeholder groups are becoming better aware of recovery and the ideas of self-determination it promotes. People with mental illnesses have been at the forefront of promoting recovery attitudes, and research suggests that more individuals with psychiatric disabilities are understanding and endorsing this perspective (Cook et al., 2010). Family members have more recently joined the movement (D. Redlich, Hadas-Lidor, Weiss, & Amirav, 2010). Service providers seem to be late in recognition and agreement (Peebles et al., 2009; Tsai, Salyers, & Lobb, 2010). There is sobering evidence of a seniority effect in some professions, with those practicing in the field longer less likely to endorse ideas of recovery and self-determination. Many medical and residency training programs have incorporated recovery perspectives and people in recovery into their training programs in order to stimulate interest in and educate newer generations of psychiatrists in the treatment paradigm shift (Buckley et al., 2007; Razzano et al., 2010).

These models and a parallel research agenda have led to practical strategies for impacting self-determined health decisions and behavior (Umeh, 2009). *Shared decision making* (SDM) promotes self-determination through an exchange between patient and health

provider with three components: cost-benefit analyses, education, and support (Drake, Deegan, & Rapp, 2010; M. Edwards, Davies, & Edwards, 2009; Joosten et al., 2008). Of prime importance here is the goal of assisting decision making by helping the person examine costs and benefits of health options. Namely, the person is encouraged to identify and make sense of advantages and disadvantages of a specific service for specific problems (symptoms, disabilities, low quality of life) caused by the illness. This kind of assessment is facilitated by information so that the person better understands the disease, its corresponding treatment, and other relevant parameters.

The education process requires development of meaningful and user-friendly information channels. These might include face-to-face classroom endeavors. Other channels have been used to provide this information, with research on Internet applications becoming especially promising in recent years (Tanis, 2008). Among the concerns about the information channel is the question of who is the best agent to transmit this information. Consistent with social learning theory, researchers have shown that teaching agents who are relatively similar to the patient are likely to have the most impact. Peers can be especially potent teachers (Calhoun et al., 2010). Health-related decision making is fundamentally social intercourse between person and provider. Skills that enhance qualities of the exchange may positively affect treatment decision. These include active listening skills as well as person-centered notions of genuineness, empathy, and unconditional positive regard (Rogers, 1961; Rudnick & Roe, 2010).

Ample research has examined SDM for a variety of illnesses and disabilities, including cancer (Gatellari, Butow, & Tattersall, 2001; van Roosmalen et al., 2004), heart disease (M. W. Morgan et al., 2000), and mental illness (Ludman et al., 2003; Malm, Ivarsson, Allebeck, & Falloon, 2003; Von Korff et al., 2003). Meta-analyses and reviews of studies have yielded mixed conclusions (Bauer, 2002; Joosten, de Jong, de Weert-van Oene, Sensky, & van der Staak, 2009; Nosé, Barbui, Gray, & Tansella, 2003). Findings from RCTs have showed that SDM leads to enhanced satisfaction with and more knowledge about treatments and their providers. Findings are less clear as to whether SDM leads to meaningful increase of treatment-related behaviors.

*Motivational interviewing* (MI) might be viewed as a form of SDM that addresses stages of change in treatment decision making. MI expands the simple cost-benefit balance sheet into a counseling process resting on four basic principles: expressing empathy, developing discrepancy, rolling with resistance, and supporting self-efficacy (Miller & Rollnick, 2002). Expressing empathy and reflective listening by the treatment provider establishes an



atmosphere of acceptance, helps the individual feel the counselor is fully present, and leads to development of a collaborative relationship. By developing discrepancy, the MI counselor does not try to persuade the individual to accept a diagnosis or treatment but elicits the individual's views of how a particular behavior might help achieve or interfere with particular goals. Rolling with resistance is a means of avoiding confrontation and the psychological reactance that therapist assertiveness typically elicits. Ambivalence or reluctance are not opposed but rather accepted as a natural part of the change process. Providing the individual with specific skills that are clearly connected to identified goals is often an important part of increasing self-efficacy. Research has examined motivational interviewing on treatment adherence for such varied disorders and conditions as HIV/AIDS (Dilorio et al., 2008; Golin et al., 2006; Parsons, Golub, Rosof, & Holder, 2007), smoking cessation (Thyrian et al., 2007), and schizophrenia (McCracken & Corrigan, 2008). One review on motivational interviewing for people with schizophrenia suggested that the intervention should be adapted for this group by addressing cognitive and interpersonal deficits that might impact the intervention (Drymalski & Campbell, 2009).

Perhaps one reason the benefits of SDM and MI are limited for people with serious mental illnesses is the impact of 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 (Wright, Kingdon, Turkington, & Ramirez Basco, 2008)—more successful has been cognitive rehabilitation attempting to diminish the processing deficits that undermine comprehension of these decisions. Cognitive adaptation training (CAT) is a specific example of cognitive rehabilitation with a growing set of supporting evidence (Velligan et al., 2002, 2008). One way cognitive rehabilitation addresses information-processing deficits is by providing tasks that “exercise” such key processes as attention and memory (Wykes & Reeder, 2005). CAT is an example of the alternative, what seems to be a more effective approach to cognitive rehabilitation—namely, the provision of compensatory strategies and environmental supports specifically built around real-world tasks of the individual. People with cognitive difficulties that result from serious mental illness 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 their own voice tied to a computer alarm that reminds them, “It's time to take my medication.”

**Courtesy stigma of families and providers.** Perhaps changing courtesy stigma experienced by families and service providers will facilitate care seeking among relatives with mental illness. Although a recent article framed the stigma change goals for families as being similar to those for people with mental illness—arguing for the need to develop programs that serve to diminish public and/or self-stigma so care seeking is enhanced (Larson & Corrigan, 2008)—only one study was found to actually test such an approach. Family members were randomized either to a group that watched *In Our Own Voice—Family Companion*, a 15-min videotape of family stories about stigma survival, followed by a 60-min discussion facilitated by family peers, or to a control group (Perlick et al., 2011). Results suggested that impact was moderated by anxiety; research participants in the treatment condition with relatively lower pretreatment anxiety reported significant reductions in self-stigma and secrecy.

Noting that mental health providers are often the source of stigma, advocates have developed programs meant to replace family views of medical students and residents from sources of stigma to promoters of empowerment (Schmetzer & Lafuze, 2008). The National Alliance of Mental Illness developed the Provider Education Program for this purpose (Mohr, Lafuze, & Mohr, 2000). This 10-week course is taught by two family members, two people with mental illness, and a mental health professional who is also a family member or consumer. The program seeks to frame the experience of mental illness in terms of competence and adaptation rather than as sickness and pathology. We are unaware of any research that has evaluated its impact or of other programs meant to address attitudes of mental health providers or of students pursuing careers in the field.

Professional organizations representing mental health care providers have also developed plans to address the courtesy stigma experienced by their members, with perhaps the best organized proposed by the World Psychiatric Association (WPA; Maj, 2008, 2009). Of special relevance to the goals of this article, proponents of the plan believed that antipathy to psychiatry or to its practitioners directly undermines participation in fundamental services the profession provides. In a review conducted for the WPA, Sartorius and colleagues (2010) summarized the limited research literature on strategies that have been tested to combat this kind of stigma. Efforts toward changing attitudes have targeted the medical student, general public, and media. Some studies with medical students showed that appreciation of therapeutic benefits combined with

patient contact improved the image of psychiatry and enhanced its attractiveness as a career (Coodin & Chisholm, 2001; Singh, Baxter, Standen, & Duggan, 1998); others studies showed the opposite effect (Baxter, Singh, Standen, & Duggan, 2001; McParland, Noble, Livingston, & McManus, 2003). An education program delivered by a psychiatrist to high school students on mental health issues increased appreciation of practitioners and increased care seeking (Battaglia, Coverdale, & Bushong, 1990). The media have been identified as an essential resource in changing stigma of psychiatry (Dichter, 1992; Stuart, 2006). One program sought to enhance news images of psychiatry by training psychiatrists on skills that improve reporter-to-practitioner interviews (Kutner & Beresin, 2000). Unfortunately, as with much of the work to change courtesy stigma of providers, research is scarce. As work to address courtesy stigma progresses, advocates caution that we should not be distracted from the central problem (i.e., the stigma experienced by people with mental illness), nor should we forget that mental health providers have often been the source of this stigma (Corrigan & Angermeyer, 2012; Sartorius & Schulze, 2005).

**Facilitating mental health literacy.** Earlier we reviewed literature suggesting that stigma change is promoted by knowledge; this same knowledge might directly impact care seeking and participation. Mental health first aid is a well-developed and tested approach to improving knowledge in order to enhance treatment participation (Jorm, 2012; Kitchener & Jorm, 2008). It was originally developed in Australia and has significant public health currency, having already been completed by more than 1% of Australians (Jorm & Kitchener, 2011) as well as being the centerpiece of U.S. legislation meant to address gun violence related to mental illness (HR 5996: Mental Health First Aid Higher Education Act of 2012); if passed, the U.S. bill would provide training to teachers, students, and campus staff nationwide. Outcome research on mental health first aid is promising: Findings from four RCTs showed that people who completed first aid training were likely to have mastered information about mental illness and to show diminished stigma (Jorm, Kitchener, Fischer, & Cvetkovski, 2010; Jorm, Kitchener, O'Kearney, & Dear, 2004; Jorm, Kitchener, Sawyer, Scales, & Cvetkovski, 2010; Kitchener & Jorm, 2004).

Population research, however, has not been as clear about the relationship between knowledge growth and stigma change. Examination of population surveys in East Germany in 1993 and 2001 showed an increase in mental health literacy but no change in the desire for social distance (Angermeyer, Holzinger, & Matschinger, 2009). A subsequent meta-analysis of 33 reports on 16 population studies from around the world showed steady increase in perceiving mental illness as a biological

disorder that should be treated (Schomerus et al., 2012). However, stigma about depression remained flat during this time; for schizophrenia it significantly worsened.

Mental health literacy seems to have a promising effect on care seeking. Individuals who better recognize their mental illness and its manifestations, as well as treatment options to address its varied impressions, might better avail themselves of those options (Jorm, 2012). This is especially important for facilitating rapid and early help seeking; the course and outcomes of serious mental illnesses are more benign the faster the person gets into care (Marshall et al., 2005; Perkins, Gu, Boteva, & Lieberman, 2005). Still, the exact connection between increased knowledge and care seeking is unclear. One comprehensive review showed that attitudes about seeking help for anxiety and depression became more positive with more knowledge about the disorders (Gulliver, Griffiths, Christensen, & Brewer, 2012).

**Addressing cultural barriers.** Addressing ethnic disparities is a priority of the American health system, with the Patient Center Outcome Research Institute, established with passage of the Affordable Care Act (ACA, 2010), includes the Health Disparities Research Advisory, which is meant to ensure that rollout and implementation of the ACA embraces efforts to replace disparities with full opportunities for people of color. Given that research contained in this portfolio is sizeable, and its review far exceeds the goals of this article, we focus on the narrow aspects of the problem as outlined earlier: the need to promote cultural competence among health care providers and address disparities in the health system.

Cultural competence is believed to include five components (Campinha-Bacote, 2002): *awareness*, or sensitivity to values and lifestyles of clients; *knowledge*, or mastery of information about other worldviews as well as biological variations among ethnic groups; *skill*, or a collection of relevant data regarding health problems; *encounter*, or face-to-face meetings with diverse peoples; and *desire*, or the motivation to ally with patients. A curriculum meant to enhance cultural competence in providers needs to integrate sensitivities to language, folk illness and treatments, and provider practice. A comprehensive review of the literature considered 34 studies of cultural competence programs largely targeting nurses and physicians, though only two of these studies were RCTs (Beach et al., 2005; Price et al., 2005). Participants completing these programs showed significant gains in knowledge about and attitudes toward culturally different groups. Increased cultural competence was shown to significantly improve patient satisfaction with treatment, although there was no evidence that greater satisfaction led to fuller participation in services. Research failed to show that enhanced competence positively impacted

patient outcomes. This review focused on competence in the general medical setting. A few studies found on cultural competence and mental health providers suggest similar promise (Bennett & Keating, 2008; Cowan, 2009; Williams, 2005), though clearly more research is needed.

**Promoting networks that promote care.** Another recommendation for promoting cultural competence is to integrate family into the treatment plan (Lopez, Barrio, Kopelowicz, & Vega, 2012; Sue et al., 2012). Actively involved families and friends are major resources in the support system of persons with psychiatric disabilities, providing direct support so the relative can achieve his or her treatment and life goals, as well as helping the person seek and participate in the broader panoply of services. Family education and support programs have been well tested for this purpose. Family education has been defined as a professional-led approach that includes empathic engagement, fact sharing, ongoing support, clinical resources during periods of crisis, social network improvement, problem solving, and communication skills (SAMHSA, 2009; World Schizophrenia Fellowship, 1998). Education has been presented to single families or to multiple family groups (Lucksted, McFarlane, Downing, Dixon, & Adams, 2012; McFarlane, Dixon, Lukens, & Lucksted, 2003). More than 40 RCTs on families with a relative with schizophrenia or with bipolar disorder showed improvements in multiple measures of family functioning as well as in the disabilities of the person with mental illness. Relapse and hospitalization were sharply reduced. Mastering information and skills that lead to care seeking and participation typically emerge as family education's active ingredients, leading to beneficial outcomes.

It is unclear from these reviews what role stigma change has in these outcomes. Family education may unintentionally perpetuate old philosophies—the “patient” being treated for “chronic illness”—rather than progressive views, of the family assuming responsibility for recovery (Frese, Stanley, Kress, & Vogel-Scibilia, 2001; Glynn, Cohen, Dixon, & Niv, 2006). Still, analyses of survey data from the Schizophrenia Patient Outcomes Research Team (involving 825 persons with schizophrenia) suggest that having received family education in the prior year was significantly associated with three of four indicators of recovery, including empowerment and hope (Resnick, Rosenheck, & Lehman, 2004). Given that peer programs have significant beneficial effects on stigma, care seeking, and health, perhaps family-led education programs such as Journey of Hope or the National Alliance on Mental Illness's Family-to-Family will have similar benefits. Family-led programs combine strengths of traditional education programs with the first-person experiences of family members and sometimes with

those of the person with mental illness. Two large RCTs have examined their impact, revealing mixed findings. The first showed significant improvement in knowledge but no impact on proxies of stigma or empowerment (Pickett-Schenk, Lippincott, Bennett, & Steigman, 2008). The second showed similar gains in knowledge but also improvements on service system empowerment as well as community engagement (Dixon et al., 2011). This trend should guide future research to examine the impact of stigma and other mediators on care seeking and participation.

### **Legislative and regulatory opportunities to overcome system-level barriers to care**

State and federal legislation holds the potential to reduce system-level financial barriers for people with serious mental illnesses. The Americans With Disabilities Act of 1990 (ADA) is a broad and illustrative example of how legislation can address structural barriers to participation in the workplace. The reasonable accommodations clause of the ADA requires employers to set up and administer work settings that permit people with disabilities to competently do their work; in many ways, this is social redress for what might otherwise be construed as unfair workplace practices, a structural stigma. Incidentally, about 7 years after ADA was signed into law, the Equal Employment Opportunities Commission affirmed that the ADA applied to people with psychiatric disabilities (U.S. Equal Employment Opportunity Commission, 1997), in another example of structural stigma.

Beginning in the early 1990s, advocates made mental health parity—equality of insurance benefits across mental health and medical services—a major focus of their advocacy efforts. In 1999, President Bill Clinton directed the U.S. Office of Personnel Management to enact parity for mental health and substance abuse coverage in the Federal Employees Health Benefits Program by 2001. This law required insurers offering mental health benefits to federal employees to provide them on par with other medical benefits, including copayments, deductibles, and lifetime caps on services and expenses. An evaluation of this program found that parity did not yield an overall increase in plan premiums but reduced out-of-pocket expenditures for individuals using mental health services (Goldman et al., 2006). Under current managed care systems, this evaluation suggested that parity could be implemented with minimal cost to purchasers, a frequent concern raised by employers in implementing parity laws.

This data helped set the stage for passage of two landmark parity laws in 2008. In July of that year, the Medicare Improvements for Patients and Providers Act ended Medicare's discriminatory 50% coinsurance for outpatient

psychotherapy and services. That bill gradually reduced copayments to 20%, the same as for other medical services. The legislation has the potential to reduce financial burden and improve follow-through with care for senior and disabled Medicare recipients. Then, on October 3, 2008, the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 was signed into law, significantly expanding regulations from the Mental Health Parity Act of 1996 (Busch, 2012). These new laws require that health benefits be provided at parity with medical–surgical benefits across a range of types of services. Of importance is the law's requirement that managed care mechanisms such as utilization review be no stricter for mental health and substance use services than for other medical care. Mental health parity required that insurers who offer mental health benefits provide them on a par with medical benefits. However, it did not help people with mental disorders who had no insurance and also did not address the problem in fragmentation of services seen for people in treatment.

The Affordable Care Act (ACA, Public Law 111-148; Patient Protection and Affordable Care Act, 2010), passed in 2010, holds the potential to more fully address these system-level problems for people with serious mental illnesses. Beginning in 2014, health reform legislation will require most U.S. citizens to have health insurance and provide subsidies to some of those who do not. To cover working and near-poor individuals without insurance, new insurance exchanges provide opportunities for people without coverage to purchase insurance. For individuals with incomes up to 133% of the federal poverty level, states have the option to expand Medicaid coverage, with the federal government providing 100% federal financing for those newly eligible for Medicaid from 2014 through 2016. Several factors make this insurance expansion particularly important for improving care for people with mental disorders. First, people with mental disorders are more likely to be uninsured or underinsured than the general population, hence disproportionately represented among new enrollees in Medicaid and insurance exchanges (Garfield, Zuvekas, Lave, & Donohue, 2011). Second, both new exchange plans and Medicaid expansion programs are required to include mental health and substance use as essential benefits, at parity with other medical benefits. Taken together, the 2008 Mental Health Parity and Addiction Equity Act and the 2010 Affordable Care Act hold the potential to overcome long-standing financial barriers to obtaining mental health services.

In addition to expansion of health insurance, health reform legislation includes a series of demonstration projects and initiatives for reorienting health services to increase provider accountability and strengthen the role of primary care. Perhaps most relevant among these is a project that promotes Patient-Centered Medical Homes,

“an approach to providing comprehensive primary care . . . that facilitates partnerships between individual patients, and their personal physicians, and when appropriate, the patient's family” (American Academy of Family Physicians et al., 2007). The ACA proposed a new state plan option to permit Medicaid enrollees with at least two chronic conditions, or at least one serious and persistent mental health condition, to designate a provider as a health home. As of 2013, 12 states have been approved for these projects, most of which include people with serious mental illness as a target population. In addition, large demonstration projects funded through the Center for Medicare and Medicaid Innovation are testing how integrated care models can be taken to scale for patients with comorbid mental and medical disorders. These new policies will provide financial and organizational structures to support best clinical practices, including collaborative care models, and may ultimately help overcome system fragmentation and provider-level barriers to obtaining high-quality care.

## Conclusion: Moving Science Forward

Why don't people in psychiatric need seek out or engage in care? We addressed the question by examining ways in which stigma interferes with care-seeking decisions and behaviors at individual and system levels. Stigma was found to be a complex variable impacting decisions at public, self, and structural levels. These various types are influenced by knowledge, culture, and social network. Although stigma would seem to have its greatest effect at the level of the person, it may also influence provider behavior and system resources. The various manifestations of stigma and related factors serve as foci for public health strategies meant to promote care seeking, including programs meant to decrease the effects of public, self, and structural stigma. An omnibus approach to stigma change will likely not be effective; a one-size-fits-all approach might yield muted or even unintended results. Advocates need to learn from the complex research on stigma change to implement programs that improve care seeking while not exacerbating other forms of discrimination. These programs also need to be integrated with efforts to promote mental health literacy, cultural relevance and competence, and family–friend engagement. Antistigma efforts need to target providers at preservice education, in-service training, and ongoing practice, enhancing their skills to engage people with psychiatric challenges. Programs need to influence policies and communities to make sure systems reflect local interests and needs.

Stigma is only one part of the puzzle. Although many of the psychological processes reflected in stigma influence comprehension of a person's psychiatric need and

likelihood of seeking possible solutions, system-level variables are equally compelling. As indicated above, the person seeking care cannot do so if the community lacks treatment providers and clinics to offer services. For serious mental illness, this issue is typically influenced by government agendas: Does the legislature, for example, recognize rehabilitation services as a public health priority? People from minority ethnic groups may avoid treatment systems that do not reflect their cultural perspective on mental illness and corresponding care. Families alienated from service may unintentionally interfere with engagement of relatives challenged by mental illness.

Insights from this review help identify directions to advance research about this question. Three emerged as especially salient:

1. *From stigma to care participation to goals:* The path model provided in Figure 2 hypothesizes that reducing stigma will enhance care seeking and participation, which is assumed to decrease illness and help the person achieve personal life goals. Although this seems a reasonable assumption, it needs to be empirically tested. For example, might stigma-change programs affect only participation in treatments, which fail to have meaningful impact on patient-centered outcomes?
2. *When personal choice conflicts with community need:* Care seeking is largely represented here as a matter of personal decision and self-determination. There are times, however, when one's mental illness becomes a significant concern shared by the community, as when the person is a danger to self or to others. Most states have legislation that permits community interest to overrule self-determination in these instances, which may lead to the mandated or coercive treatments discussed earlier in the article. In the process, it changes the question from "Why don't some people seek care?" to "How do we get people into treatment?" This is a complex and highly debated issue, with some holding the view that dangerousness and appropriately assertive responses are among the most important mental health priorities, and others believing that dangerousness concerns are overinflated and distract the mental health system from variables that promote self-determination. The debate clearly has implications for affecting government funding priorities. Researchers need to recognize the concern and allow it to inform hypotheses, methods, analyses, and interpretations.
3. *Beyond an American-centered model:* The mission of this article was to make sense of care-seeking issues in the United States given recurring concerns that mental health challenges are growing in our

country despite efforts that have yielded effective interventions. The growing problem is sometimes understood in terms of media concerns about homelessness and violence. As a result, the model reviewed in this article reflects psychological and related variables that are dominant in Western culture. Self-determination, for example, is an idea rooted in a Western sense of individualism. Extrapolation of this first principle to cultures elsewhere in the world is challenging. One research group wondered how ideas of adherence and care seeking might play out in a Chinese culture, where decisions about mental health and corresponding treatment might reflect needs of the family as much as or more than the individual (Lam et al., 2010). Answering questions like these are not accomplished with facile translations of the American-centered research reviewed here. Consider, for example, how the individualism–contextualism continuum might inform attempts to extrapolate American research to East Asian countries. One might think of the Chinese as more community and family focused (contextualist), which would color their perspectives on stigma and care seeking. However, a recent study on mental illness stigma among employers from Beijing and Chicago found the Chinese group to endorse individualism significantly and robustly more than American employers did (Rao, Horton, Tsang, Shi, & Corrigan, 2010). Further confounding cross-national research is international politics and economics. Ability to promote a mental health agenda in the public sector is going to be influenced by the ability to fund priorities on the agenda. And this is a moving picture. Consider the Chinese and Indian economies, which have become dominant on the world stage over the past decade, changing their ability to address public health concerns.

As researchers move forward on this topic, they need to be mindful of their constituency. The goal of most clinical and services research is to inform the relatively homogeneous group of providers about effective methods to decrease symptoms and enhance goals. The focus here is on advocates seeking to decrease stigma and improve care seeking. Advocates are a more heterogeneous collection and may differ in terms of research goals and outcomes. Advocates include people with lived experience who may focus on how prejudice and discrimination of mental illness stigma impacts opportunities in work and independent living. The relation between care seeking and stigma might be secondary for them. Family members are another prominent advocacy group concerned about how symptoms and disabilities may be

ravaging relatives. They believe participating in evidence-based practices is central to a quality life (as well as reducing family burden) and hence want to reduce stigma with this focus. Advocates include care providers who are steeped in evidence-based practices and hence influenced by the need to promote them. Advocates are community and government leaders who, among other things, might be focused on resources and service systems. Stigma and stigma change are political agendas; researchers need to understand the diversity of the agenda as they seek to impact it.

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