"Anti-stigma programs should be led by people with lived experience."

Understanding and Addressing the Stigma Experienced by People with First Episode Psychosis

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Introduction

A recent report from the National Academy of Sciences (NAS, 2016) summarized the extensive research literature on the stigma of serious mental illness (SMI) in adults. Conceptual models that emerged provide a preliminary framework for understanding how stigma may harm people experiencing first episode psychosis (FEP). In this report, we attempt to understand the stigma of people with FEP, with the narrative divided into the two sections that were outlined in the NAS report: *What is the stigma of FEP?* and *How might this stigma be diminished?* This issue brief

in some ways represents a proposal of possibilities, given that extensive research specific to the stigma of FEP has yet to be completed. We make these proposals by considering specificdifferences between people with FEP and people with more chronic mental illnesses, including social and cognitive development, and the role of family. This brief uses the National Institute of Mental Health (NIMH) definition of FEP—that is, the first time a person experiences psychosis where the person has demonstrated some loss of contact with reality, often shown by symptoms of delusions, hallucinations, and incoherent speech (NIMH, 2008). First episodes can occur at any time in life, but here we focus on people ages 15 to 30.

What Is the Stigma of Serious Mental Illness?

Figure 1 grounds the experience of stigma in three social psychological structures—stereotypes, prejudice, and discrimination — that explain the experience not only of mental illness but also how it relates to racism, sexism, ageism, homophobia, and other types of egregious biases. Social psychologists view stereotypes as especially efficient means of categorizing information about social groups represented as generalizable beliefs about the group (Crocker, Major, & Steele, 1998). Stereotypes about mental illness include belief in a person's dangerousness, incompetence, and weakness of character. Just because people have knowledge of a set of stereotypes does not imply that they agree with them (Jussim, Nelson, Manis, & Soffin, 1995). People who are *prejudiced* endorse negative stereotypes ("That's right; all persons with mental illness are violent!") and generate negative emotional reactions as a result ("They all scare me!"). Prejudice — fundamentally a cognitive and affective response—leads to *discrimination*, the behavioral reaction (Crocker, Major, & Steele, 1998). Prejudice that produces anger can lead to hostile behavior (e.g., physically harming a minority group). Angry prejudice also may lead to withholding help or replacing health care with services provided by the criminal justice system. Fear leads to avoidance — for example, physicians do not want to provide the same level of care.

FIGURE 1: Structures and Types of Stigma				
The matrix is illustrated with an example from a person with FEP.				

STRUCTURES	TYPES			
		Public Stigma	Self-Stigma	Label Avoidance	Family Stigma
	Stereotypes	"He is dangerous."	"I am unreliable."	Diagnosis of FEP means "crazy."	Parents are to blame for child's FEP.
	Prejudice	Teacher is afraid of him.	"Who would want to employ someone like me?"	"I am ashamed to be seen as a psycho."	"They are bad parents."
	Discrimination	Teacher removes person from class.	Person quits job.	Person refrains from going to clinic to seek help.	Friends avoid parents.

Stigma Types

As shown in Figure 1, stereotype, prejudice, and discrimination manifest differently depending on the type of stigma. Public stigma, self-stigma, and label avoidance have their effects at the level of the person with psychiatric disabilities. Family stigma harms those associated with people with mental illness, such as families, friends, and care providers.

Public Stigma: Stereotype, prejudice, and discrimination can rob people labeled "mentally ill" of important life opportunities when the public believes and acts on the stigma. This has been especially noted in work settings, where employers fail to hire or provide reasonable accommodations to people with mental illness, or housing, where landlords hesitate to rent to them (Thornicroft, 2006).

Self-Stigma: By living in a culture steeped in stigmatizing images, people with mental illness may internalize these ideas and suffer diminished self-esteem, self-efficacy, and confidence in their future as a result. Self-stigma has been described in a regressive model beginning with *awareness* of stereotypes ("I know most people believe those with mental illness are dangerous."), *agreement* with them ("I agree. Most people with mental illness are dangerous."), and *applying* stigma to one's self ("I am mentally ill, so I must be dangerous."). This leads to diminished self-esteem ("I must be a bad person because I am mentally ill and dangerous.") and diminished self-efficacy ("I am not able to do most normal things because I am mentally ill."), resulting in the "why try" effect (Corrigan, Larson, & Rusch, 2009): "Why try to get a job? Someone like me isn't worth it." Note that self-stigma is *not* an inevitable result of mental illness. Many people struggle with their mental health challenges without feeling a sense of shame.

Label Avoidance: People escape the harmful effects of a stigmatizing label — "Hey, there's Joe. He's a mental patient!" — by avoiding a place where they might get tagged with stereotypes: the mental health clinic. Hence, stigma is a significant barrier to seeking care and participating in ongoing services (Corrigan, Druss, & Perlick, 2014). Epidemiological research suggests that as many as one-third to half of people diagnosed with mental illness will not seek care when in need. Even more, about half of those who do enter treatment will drop out of treatment prematurely.

Family Stigma: Family members and friends also are affected by public stigma; parents and siblings of people with serious mental illness, spouses or other partners, and other family caregivers report feeling stigmatized and work to manage their self and public identity in various ways (Moses, 2014). A family member's role vis-a-vis the person with mental illness — parent, child, sibling, or spouse — relates to the nature and extent of the stigma the individual experiences.   Parents often are blamed for causing the stigmatized condition; siblings are viewed as genetically contaminated and possibly blamed for failing to help manage the condition; spouses also may be blamed for poor illness management, as well as possibly degraded based on their voluntary association with the marked individual; and children often are assumed to be genetically and/or psychologically contaminated by the parent's condition, which renders them "damaged goods" (Corrigan & Miller, 2004; Phelan, 2005).

There is an additional form of family stigma: vicarious stigma. This is the anger or sadness a family member feels when witnessing their loved one being hurt by stigma. Consider the mother who becomes tearful because her teenage daughter was not invited to prom because of her recent "psych hospitalization."

What Is the Stigma of FEP?

It is reasonable to think that research on stigma's effects on people with serious mental illness could be generalized to people with FEP; after all, FEP may be the beginning of a serious mental illness. Still, there are some significant differences between the groups that need to be considered when describing the stigma of FEP — differences that partly reflect the ongoing cognitive and social development of young people.

Young People Are Early in Their Mental Health Careers: Serious mental illness has been described as a "career" of sorts, a long period of life challenges and resolutions, discouragement, and accomplishment that, over time, molds a person's identity (Corrigan et al., 2015). The recovery model frames this evolving identity beyond one that is limited to gloom and doom to include the kind of hopes and achievement that govern most adult lives (Davidson, Rakfeldt, & Strauss, 2010). People with FEP typically find themselves at the very beginning of this "career" without any context for what it means. As a result, psychosis may be not only foreign but also frightening and overwhelming. Early-intervention programs hope to assist the person in making their experiences with psychosis short-lived and remitting (Byrne & Rosen, 2014). Hence, stigma is as foreign as these strange psychiatric symptoms. People with serious mental illnesses who have lived with stigma for a relative period of time may have begun to make sense of the stigmatizing event, realizing it may lead to self-stigma and the "why try" effect, or public stigma and a demand for rights. People with FEP do not have this orientation, so they may not be motivated to tackle stigma. This lack of awareness is by no means universal; many young people understand the stigma that arises with psychosis and become motivated to tackle its effects, as well as the challenges that emerge because of stigma.

Parents and Others Influence the Stigma of FEP: Although young people with FEP may be relatively unaware of stigma's pernicious effects, family and others in their social sphere often recognize it. Parents in particular may experience the double punch of FEP: the pain of seeing a loved one overwhelmed by psychotic symptoms, as well as the ache of the stigma that may engulf them. It may be parents, relatives, faith-based community members, or educators who understand the pernicious effects of stigma and become motivated to erase them. In addition, parents are victimized by family stigma—the public belief that a parent or family member somehow caused the young person's psychosis.

Alternatively, parents and family members may focus on the treatment of psychosis, so they are not as motivated to stop the stigma. In addition, parents often are the subject of family stigma, which may affect their capacity to deal with stigma, as well as their ability to participate in the young person's care.

Stigma Affects Youth with FEP in Different Social Spheres: Discrimination experienced by adults with mental illness often focuses on loss of opportunities in vocation and independent living. Youth with FEP are more concerned about stigma's impact in different areas: (1) school and how teachers, classmates, and friends react; (2) relationships, especially as the person enters the dating scene; and (3) extended family and how to let them know about the challenges of FEP. Concerns like these will influence the focus of anti-stigma programs.

Replace Stigma with Affirmation

Erasing stigma alone is not enough; success is achieved when prejudice and discrimination are *replaced* by affirming attitudes and behavior. Affirming *attitudes* related to recovery and self-determination replace notions of brokenness with ideas of hope and achievement. Recovery reintroduces ideas of "future and aspiration" to describe serious mental illness. Contrary to dated notions of inescapable poor prognoses, long-term follow-up research shows that most people with mental illness, including schizophrenia, are able to have a good quality of life outside of the mental health system (Harrison et al., 2001).

Out of recovery comes empowerment, the idea that people with mental illness must have final authority over not only their treatment but also the life goals that direct it. This means people with mental illness need to have equal status with family members, service providers, and others involved in their life trajectory. Some people believe personal empowerment and self-determination are different sides of the same coin. Self-determination is promoted by helping people grasp personal empowerment for themselves, as well as by directing the community not to erect barriers to the process. It is more transparently anchored in the belief that people with serious mental illness do have goals (e.g., want to go back to work, live independently, and/or enjoy intimate relationships) and that these goals are achievable and should be pursued.

Correcting community biases and structures that prevent social inclusion requires affirmative *actions*. Affirmative action was first introduced to the American political scene as an executive order signed by President Lyndon Johnson that directed federal contractors to develop hiring plans that increased the number of women and minorities in all job categories.   In this light, affirmative action might be viewed as a set of strategies that increase opportunities for a stigmatized group. One example is especially notable in terms of mental illness. According to the Americans with Disabilities Act (ADA), reasonable accommodations are provisions that promote community integration for individuals with disabilities. For example, employers must provide reasonable accommodations to employees with disabilities so they can competently do their jobs. Common examples include wheelchair-accessible work environments so that people with ambulatory disabilities can navigate the job setting. While it is more difficult to define reasonable accommodations for people with psychiatric disabilities, accommodations may include flexible schedules and job coaching so people with mental illnesses can cope with the stress of job demands without having to give up their careers.
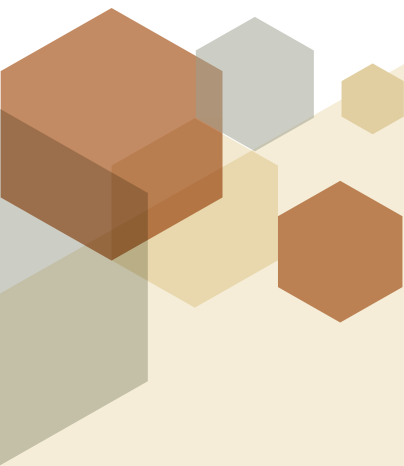
How Is the Stigma of Mental Illness Diminished?

The National Academy of Sciences (2016) report included consensus recommendations for decreasing the stigma of mental illness. The report distinguished between strategies meant to diminish public stigma versus self-stigma. We briefly review these recommendations, then pose reasonable extrapolations to address the stigma of FEP.

ERASING PUBLIC STIGMA

We begin with an important distinction: Addressing public stigma is guided by three different agendas — **services, rights,** and **self-worth** (Corrigan, 2015). Priorities that reflect advocates' motivations differ by agenda. The services agenda seeks to diminish label avoidance; proponents believe that engagement in evidence-based services will help people manage symptoms and accomplish personal life goals. Anti-stigma programs reflecting this agenda target beliefs that discourage people from seeking varied approaches to mental health care, including counseling, social work services, and psychiatry. The rights agenda is concerned about the prejudice and discrimination that lead to loss of opportunities—for example, employers who do not hire people with mental illnesses or landlords who do not to rent to them. This agenda reflects a civil rights approach to stigma change by challenging public beliefs that rob people of rightful opportunities related to their life goals. The self-worth agenda addresses harmful effects of self-stigma. Namely, stigma causes shame when people with mental illness internalize prejudice: "I must be a weak person because I have a mental illness." Proponents of the self-worth agenda develop programs that help people with mental illness replace stigma with a sense of hope, confidence, and self-esteem.

The fact that there are differing agendas is significant because the goals of one agenda may interfere with the goals of another. For example, one approach to the services agenda has been to frame mental illness "like any illness" and, hence, treatable. However, this perspective may unintentionally promote the sense of difference that distinguishes people with the stigmatized label from everyone else: "People who are sick with mental illness are not like me." Difference in agendas also is important because the agendas may compete with each other in terms of actual implementation. Limited resources are available to roll out anti-stigma programs, especially as government organizations prioritize efforts to erase its impact. The various approaches to changing public stigma of mental illness have been described as three processes: protest, education, and contact.

Protest: Protest strategies highlight the injustice of specific stigmas, leading to a moral appeal for people to stop thinking that way: "Shame on you for holding such disrespectful ideas about people with mental illness!" Ironically, this kind of attitude suppression may yield a rebound effect so that prejudices about a group remain unchanged or actually become worse. Although there are both cognitive and social explanations of this kind of rebound, perhaps the simplest is the construct of psychological reactance: "Don't tell me what to think!"

Although protest may have limited impact for changing public *attitudes*, there is largely anecdotal evidence that protest can change some *behaviors* significantly. For example, NAMI Stigmabusters is an e-mail alert system that notifies members about stigmatizing representations of persons with mental illness in the media and provides instructions on how to contact the offending organization and its sponsors. NAMI has successfully convinced media groups to curtail disrespectful images of mental illness when promoting their products.

Education: Educational approaches to reducing stigma contrast myths with facts about mental illness. Educational strategies have included public service announcements, books, flyers, movies, videos, and other audio-visual aids to dispel myths about mental illness and replace them with facts. Evidence from education studies suggests that people with a better understanding of mental illness are less likely to endorse stigma and discrimination.

Some messages that drive education programs can cause unintended consequences. Consider, for example, programs that convey the message "Mental illness is a brain disease." This type of message is supposed to reduce blame for psychiatric illness —that is, the person did not choose to be this way, but rather the illness is the result of genetic inheritance. However, most research suggests that framing mental illness in biological terms *increases* stigma because the public believes people will not recover (Kvaale, Gottdiener, & Haslam, 2013). Biological explanations also promote "benevolence stigma," the belief that people with mental illness are innocent and childlike and, as such, must be cared for by a parental figure.

Contact: Contact between a stigmatized group and the public has significant effects on stigma change. Five elements enhance contact effects: (1) ***Equal status between groups:*** In the contact situation, neither minority nor majority group members occupy a higher status. This differs from the type of contact certain power groups have with people with mental illness (e.g., doctor/patient, landlord/resident, employer/employee). (2) ***Common goals:*** Both groups should be working toward the same ends. Some studies of "optimal" contact have used contrived tasks such as completing a puzzle. In more natural settings, this might include working together on a community project or solving a neighborhood problem. (3) ***No competition:*** The tone of the contact should be a joint effort, not a competitive one. (4) ***Authoritative sanction for the contact:*** This might mean the contact intervention is sponsored or endorsed by the management of an institution or community organization (e.g., the Board of Education or the Better Business Bureau). (5) ***Mild disconfirmation:*** Contact's benefits also are enhanced when contact with a person moderately disconfirms the stereotypes about his or her group. Individuals that highly disconfirm prevailing stereotypes may not be believed as representative; they may be viewed instead as "special exceptions." Contact with people who behave in ways consistent with the stereotypes about their group may reinforce stigmatizing attitudes or make them worse.

WHAT THE EVIDENCE SUGGESTS

Extensive research has been done on education and contact approaches to public
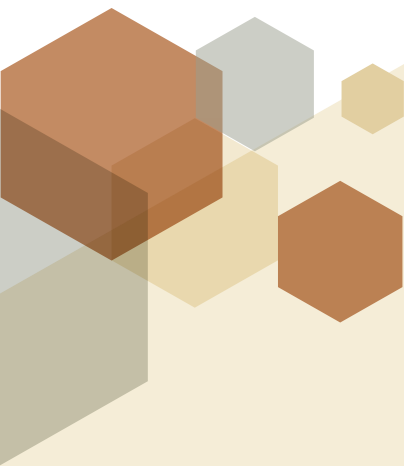
stigma change. One review of the literature summarized 79 studies, 13 of which were randomized controlled trials, the most rigorous form. Results of a meta-analysis of the latter group of studies showed adults who participated in contact had significantly better changes in stigmatizing attitudes and behavioral intentions than those in education (Corrigan, Morris, Michaels, Rafacz, & Rusch, 2012). The summary also showed in vivo contact (where the person meets face to face with the targeted audience) had significantly better effects than video or online versions. A subsequent analysis suggested that benefits of contact were maintained better over time than were benefits of education (Corrigan, Michaels, & Morris, 2015). Note, however, that *adolescents* seemed to be affected by education and contact differently. Education led to better attitude change than did contact. An education effect here may occur because young people may believe they are not fully educated about mental health and thus are open to learning facts about mental illness to counteract stigmatizing myths.

What about stigma elimination and mental health literacy? We believe these are two separate goals, with education approaches meant to influence both but sometimes causing different outcomes. Mental health literacy seeks to educate the public about the differing symptoms and disabilities of mental illness, as well as the variety of evidence-based practices that people in need might pursue (Jorm, 2012). Mental health first aid (MHFA) is a well-evaluated approach to promote mental health literacy that is widely taught around the world (Jorm, Kitchener, Kanowski, & Kelly, 2007). It is not yet clear whether the kind of DSM-like information provided in MHFA will reduce the stigma of mental illness. In fact, one study suggests that a focus on information may unintentionally worsen results (Corrigan, Powell, & Al-Khouja, 2015).

A Targeted Model of Public Stigma Change: An ideal result of stigma change would be population-wide rejection of prejudice and replacement of the prejudice with affirming attitudes and opportunity. A quick review of efforts to erase racism and sexism, however, shows this ideal will not be achieved soon. Hence, effective anti-stigma programs are targeted, identifying specific groups who are in power vis-a-vis the stigmatized person — for example, employers, landlords, police officers, legislators, and media executives. Advocates then define discriminatory behaviors that emerge from these groups as specific change goals—for example, the employer who has been reluctant to hire people with mental illnesses instead becomes more open to the option and provides reasonable accommodations to those with psychiatric disabilities. Once target group behavior(s) and attitude(s) are identified, the most appropriate strategy and content are selected. While the effect of protest on attitudes is unclear, it seems to be useful for eliminating undesirable behaviors such as negative images in the media and discriminatory housing and labor practices. Education appears to improve attitudes on a short-term basis and can be implemented relatively inexpensively. Contact is the most promising strategy. In addition to empirical evidence, contact has political significance.

Anti-stigma programs should be led by people with lived experience. The authors of this brief are proponents of civil rights for women and would quickly join any effort meant to promote them. However, we are men, so we are in the back seat on these efforts. Strategies meant to resolve sexism need to be led by those who experience

this kind of prejudice and discrimination. Men have essential roles as allies in the feminist anti-discrimination movement. Similarly, programs meant to erase the stigma of mental illness must be led by advocates with mental illness. Everyone else is an ally — an important role to be sure, but one that follows rather than sets the agenda. This can be foreign to service providers or family members who sometimes take the lead in decisions about a patient's or relative's health.

PUBLIC STIGMA CHANGE FOR PEOPLE WITH FEP AND THEIR FAMILIES

Contact and perhaps education strategies to address the stigma of FEP need to consider the special circumstances of first episode psychosis in relatively young people. First, who leads this effort? If we consider lessons learned from adults with serious mental illness, erasing the stigma of FEP ideally should be led by young adults with FEP. However, many people with FEP may not perceive the need and hence may not join or lead anti-stigma efforts. Research should examine the degree to which educating youth with FEP might motivate them to pursue anti-stigma strategies. However, in the spirit of recovery and empowerment, pushing young people with FEP toward tackling public stigma is not appropriate. Allies, especially family members, might have an important role here. In this case, the family needs to distinguish goals of tackling the young person's experience of stigma and discrimination (e.g., "John should not be allowed back in school after his first episode.") and the stigma faced by the family (e.g., "People at church disrespect me because John is in the hospital.").

First on the agenda should be identifying targets of stigma change. These may include changing teachers' attitudes so the young person can be fully integrated back into school after the first episode, or working with health providers who embrace interventions that promote recovery and empowerment. With the target comes the change goal. What specifically might the teacher do to integrate the student with FEP into school? Identifying change goals will inform the overall agenda of the program: decrease stigma to get more people with FEP into services, reduce discrimination, and undermine self-stigma.

Finally, who should be the contact? People with FEP may be too early in their mental health careers to take on the challenges of anti-stigma advocacy by coming out publicly with their experiences. People who have lived with their first episode for several years and feel better accommodated to its challenges may be good candidates for contact.

CHALLENGING SELF-STIGMA

Three approaches to addressing self-stigma have been developed and evaluated with some evidence about their efficacy and effectiveness (Yanos, Lucksted, Drapalski, Roe, & Lysaker, 2015): challenging self-stigma as irrational thoughts, facilitating decision-making about disclosure, and fostering personal empowerment.

Changing Self-Stigmatizing Cognitive Schemata: Self-stigma may be understood as maladaptive self-statements or cognitive schemata that have developed because people learn them in a stigmatizing world. The adverse effects of stigma are "located" not only in the social situation but also in the cognitive process of the

stigmatized individual — that is, the way an individual perceives and understands the social situation such that disrespectful messages emerge. Cognitive therapy is an effective strategy for helping people change cognitive schemata that lead to anxiety, depression, and the consequences of self-stigma. In this light, therapists help clients explore distressing cognitions, attempting to reframe them as belief rather than fact, empathically discussing how one might arrive at such beliefs, reviewing evidence for and against the beliefs, and trying to find less distressing alternative interpretations. Anti-stigma leaders have organized these strategies into a group-based intervention meant to diminish self-stigma called Ending Self-Stigma (ESS). The program uses nine sessions that include lecture, discussion, sharing, skills practice, problem-solving, and group support (Lucksted et al., 2011). Results of a pre- and post-program study showed participants decreased self-stigma and improved recovery orientation.

Deciding to Disclose: The mark that specifically signals mental illness is not really apparent to the public. Unlike race and gender, for example, there are few external cues that signal that an individual belongs to the group labeled "mentally ill." Put another way, people with mental illness may escape some of the harm caused by both public and self-stigma by not letting other people know they belong to this stigmatized group. However, the alternative — being in the closet — causes significant harm. Namely, people who feel they have to conceal important parts of their lives, such as experiences with mental illness, often report diminished well-being and self-worth. Many groups with concealable stigma are selectively disclosing, including lesbians in the work place, gay men, HIV-positive adults, postsecondary school students with learning disabilities, and childless women. Similar promise may exist for those with mental illness.

Opting whether and how to disclose is not a transparent decision that all people stigmatized with mental illness should pursue in a set manner. Some people like to carefully consider all of the benefits of an action (i.e., choosing to disclose one's mental illness), first listing as many as come to mind. They then write down the costs. Others just start writing down costs and benefits as they come to mind until they have them all listed. Costs and benefits also vary by situation. Disclosing is significantly different at work compared with how it is in one's neighborhood or with softball teammates. A person could conceivably decide to tell people at work but not in their neighborhood, or tell close friends but not the pastor. Hence, the costs and benefits of disclosing need to be listed separately for each setting.

Honest, Open, Proud (HOP) is a standardized program meant to help people challenge the self-stigma of mental illness (www.HOPprogram.org). Led by people with mental illness, HOP uses three sessions to help participants consider the pros and cons of disclosing, relatively safe ways to come out, and formats for telling one's story. Positive effects on adults and adolescents with serious mental illness have been supported in randomized controlled trials (Corrigan et al., 2015; Rusch et al., 2014).

Fostering Personal Empowerment: The opposite of self-stigma is personal empowerment; being empowered means having control over one's treatment and one's life. Individuals who have a strong sense of personal empowerment have high self-efficacy and self-esteem. They are not overwhelmed by symptoms and

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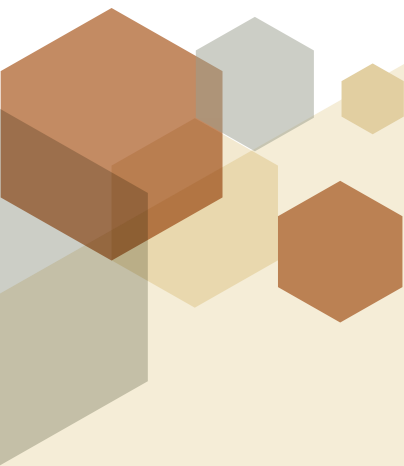
psychiatric labels. Rather, they express their sense of hope by taking an active role in their recovery. Empowerment approaches may be considered among the best ways to deal with self-stigma. Communities and health service providers can foster personal empowerment. At the most general level, fostering empowerment involves adopting a collaborative approach to treatment planning in which the "patient" ceases to be a passive recipient of services. At the very least, programs should form a treatment partnership, seeking feedback from consumers as to their satisfaction with the services offered and their suggestions for improvement.

Beyond this, truly empowering services promote self-determination in relation to employment opportunities, housing, and other areas of social life. Rather than a stigmatizing and coercive removal from the community, empowering approaches offer community-based support for continued efforts to adapt to community living. Supported employment and education, for example, are methods used to facilitate the inclusion of people with disabilities into the fabric of society.

The Paradox of Trying to Fix Self-Stigma: There is a paradox of which service providers and advocates need to be wary when trying to change self-stigma. Namely, focusing on self-stigma may frame the prejudice and discrimination that results as a problem solely for people with mental illness. Just as new disabilities and secondary complications can arise from an illness, stigma is another unfortunate result of having mental illness. Thus, people living with mental illness must learn to live with the stigma. This kind of perspective ignores the public's responsibility for creating and maintaining stigma. Although there is value in people with mental health challenges learning how to deal with the harm of stigma, it should not release the public from its responsibility. Big steps to diminishing self-stigma occur when people live in communities relatively free of public prejudice and discrimination. Conceivably, programs that successfully attack public stigma—that perhaps derail public stereotypes about FEP—may cut self-stigma off at the knees.

Changing the Self-Stigma of FEP: Not everyone who experiences mental illness is ashamed by it, and they might not all care about stigma. The experience is akin to the gay male who fails to realize that not only are homophobic statements about him immoral but that he can righteously choose to reject the shame heaped on him by a hostile society. A community of allies standing in solidarity would urge him to come out proud. Realization of the injustice of shame emerges as people live with the stigmatized experience over time—for example, for people with mental illness as they progress in their mental health "career." People with FEP may lack this awareness and may not understand the value of addressing self-stigma. Programs by peers with lived experience may help them gain insight into the effects of shame and how to address it.

The Honest, Open, Proud program has recently been adapted for adolescents with significant mental health challenges, with versions conducted within inpatient settings and in high schools. A recent randomized trial from Germany showed HOP to yield significant benefits on stigma-related stress, self-esteem, and well-being. Participants, however, often had struggled with mental illness for a period of time, not necessarily experiencing a first episode. Still, interventions that help the young person consider disclosure may lead to engagement in peer support. Future work needs to consider

strategies that might augment contact and disclosure, potentially because many of the symptoms and treatments are so new to the youth. Perhaps carefully selected education programs can help people make sense of this strange experience.

Final Considerations

Research summarized in the NAS report (2016) showed that the stigma of mental illness may be as disabling as the symptoms themselves and that ways to address the injustice have begun to emerge in the literature. This area of inquiry needs to be extended to the experiences of people with FEP, and the task needs to be governed by community-based participatory research (CBPR), in which people with lived experience join scientists as equal partners in all facets of investigation (Minkler & Wallerstein, 2008). In this way, strategies that erase stigma reflect the priorities of those experiencing it. CBPR has special merit for populations that have traditionally been disenfranchised from the health care system, as well as for the research enterprise meant to inform it by empowering them to change the system.

While we ground this brief in research, we do not believe the slow pace of research should limit community action. Stigma is harming people *now*. Advocates are anxious to move. We provided some suggestions herein that might lessen the public and self-stigma of FEP. Programs partnering with stakeholders should adapt them for local need. We just caution that stigma change does not occur as seamlessly as one might hope. Unintended consequences occur. The team putting together the anti-stigma effort should include some kind of user-friendly way to assess its impact.

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