The American Journal on Addictions, XX: 1–8, 2016
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ISSN: 1055-0496 print / 1521-0391 online
DOI: 10.1111/ajad.12436

Developing a Research Agenda for Reducing the Stigma of Addictions, Part II: Lessons From the Mental Health Stigma Literature

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Background and Objectives: Although advocates and providers identify stigma as a major factor in confounding the recovery of people with SUDs, research on addiction stigma is lacking, especially when compared to the substantive literature examining the stigma of mental illness.
Methods: A comprehensive review of the stigma literature that yielded empirically supported concepts and methods from the mental health arena was contrasted with the much smaller and mostly descriptive findings from the addiction field. In Part I of this two part paper (American Journal of Addictions, Vol xx, pages xxx-xxx, this issue), constructs and methods from the mental health stigma literature were used to summarize research that seeks to understand the phenomena of addiction stigma.
Results: In Paper II, we use this summary, as well as the extensive literature on mental illness stigma change, to outline a research program to develop and evaluate strategies meant to diminish impact on public and self-stigma (eg, education and contact).
Conclusions and Scientific Significance: The paper ends with recommendations for next steps in addiction stigma research. (Am J Addict 2016;XX:1–8)

INTRODUCTION

Advocates, clinical service providers, and other stakeholders agree; the stigma of addiction worsens clinical outcomes and well-being of substance use disorders (SUDs) as well as those who use substances without leading to disorder.[1] In 2014, SAMHSA commissioned the National Academy of Science (NAS) to summarize the state of the research literature in the stigma of behavioral health. In their 2016 report, "*Ending Discrimination Against People With Mental and Substance Use Disorders,* the NAS concluded that research on the stigma of addictions is rather slim, especially when contrasted to that on mental illness stigma.[2] For example, a literature review completed before January, 2016 uncovered 49 literature reviews representing more than 1,000 empirical articles on mental health stigma change compared to only four such reviews across the addictions. In addition, mental health stigma research has led to rich reviews discussing methods and models relevant to understanding and impacting stigma.[3] Lessons might be learned by extrapolating findings from the mental health stigma literature in order to boost dialogue about research agendas for addiction stigma.

The NAS organized its report by sections that examined ways to: (1) understand stigma and (2) use that knowledge to reduce stigma's impact. Part I of this two part series (American Journal of Addictions, Vol xx, pages xxx-xxx, this issue) addressed ways to understand the stigma of addiction. Stigma was described as a matrix of social psychological structures (stereotypes, prejudice, and discrimination) crossed with types, (eg, public and self-stigma) leading to affirming attitudes (recovery and self-determination) and behaviors (eg, reasonable accommodations). Two constructs especially germane to stigma and addiction emerged as key content areas

Received May 19, 2016; revised August 3, 2016; accepted September 5, 2016.
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across structures and types. (1) Research efforts to make sense of stigma and stigma change need to unpack perceptions and effects of those with substance use disorders versus individuals who use substances without any disorder. People are able to use drugs like alcohol or cocaine without necessarily meeting criteria for a substance use disorder. Might public stigma be moderated by lack of disorder? Relatedly, research needs to examine stigma and its effect depending on the substance. For example, substances perceived as illegal (such as heroin and cocaine) might yield more stigma or be more resilient to stigma change than drugs like alcohol or, more recently, marijuana. (2) Unlike the stigma of mental illness, addiction stigma probably gains its most pernicious effects from being intertwined with criminality. For example, research shows people who endorse greater legal penalties for substance use agree more with greater discrimination against people with SUDs.[4] Both these issues need to be incorporated into strategies meant to address addiction stigma.

Here in Part II, studies are summarized to inform a research agenda for strategies to reduce the stigma of addictions. Anti-stigma efforts targeting two of the four types of stigma—public and self-stigma—dominate the mental health research literature and are reviewed here.[3] As spelled out more thoroughly in Part I, public stigma is the prejudice and discrimination that results when a population endorses stereotypes about a labeled group—people with mental illness or addictions—leading to lost opportunities undermining important life goals such as work, education, independent living, and relationships.[5,6] Given these pernicious effects, some people will avoid stigmatizing public labels by not engaging in mental health or substance use interventions thereby worsening the course and outcomes of their illnesses.[7]

Self-stigma is the loss of self-esteem and self-efficacy that results when someone with mental illness or addiction internalizes the stigma.[8] One result can be a sense of behavioral fatalism called the "why try" effect. "Why try to get a job; someone like me is not worthy." Anti-stigma efforts for public and self-stigma have been separated into education and contact approaches and are reviewed with this distinction. The paper ends with directions for future research into addiction stigma.

How Is Stigma Changed?

Although advocates and researchers agree that erasing stigma is essential for promoting health among people with mental illness and addictions, agendas guiding specific strategies vary in ways that reflect differing stakeholder constituencies. Three agenda from the mental health literature are summarized in Table 1—services, rights, and self-worth—and seem to make sense as heuristics for program development and evaluation in addiction stigma change. The agendas are defined in Table 1 by their rationale which emerge from descriptive and explanatory research on the stigma of mental illness summarized in Paper I. Table 1 then specifies tasks necessary to achieve each agenda; these tasks are briefly reviewed here and then more completely considered in the next section on strategies to decrease stigma. Table 1 ends by specifying stakeholder groups who tend to prioritize each agenda.

The Services Agenda

This agenda seeks to decrease stigma so people are more likely to seek out and engage in services when needed. As argued in Part I (American Journal of Addictions, Vol xx, pages xxx-xxx, this issue), label avoidance may lead people to avoid evidence-based services. One way to address label avoidance is by promoting mental health literacy through health communication campaigns; mental health literacy is education about mental illness which aids in its recognition, management, and prevention.[9] Individuals who better recognize their illness and corresponding treatment options might better avail those options. This agenda is typically driven by stakeholders who are confident in the benefits of evidence-based practices: professionally trained providers, family

TABLE 1. Three agendas for erasing stigma

Agenda	Rationale	Task	Stakeholders
Services agenda	Due to label avoidance, people do not seek out or remain in evidence-based practices.	Decrease the public stigma that is the foundation of label avoidance in order to increase care seeking and engagement.	Providers and others confident in benefit of services.
Rights agenda	Due to public stigma, people are not able to achieve important personal goals related, for example, to work, independent living, and health.	Decrease pubic stigma so people are better able to avail opportunities related to work, independent living, and health.	Advocates demanding social justice.
Self-worth agenda	Due to self-stigma, people are shamed and give up on the pursuit of their personal goals.	Replace self-stigma with sense of self-esteem and self-efficacy which promote individual achievement.	People with lived experience looking to replace shame with self-worth.

members, and people with lived experience who have benefited from specific strategies. An Australian program, called *beyondblue*, is a good example of this agenda. *Beyondblue* is a social marketing campaign which includes public service announcements (PSAs) that frame depression as a treatable disease. Research shows that the campaign has significantly penetrated the Australian population with more than 60% of Australians recognizing the campaign.[10] Campaign awareness is associated with better recognition of illnesses and greater understanding of the benefits of treatments.[11] Researchers have similarly proposed health literacy as a way to change addiction stigma and engage people in services.[12] One study showed literacy programs increased knowledge on substance use.[13]

Services agendas represent public health priorities to decrease illness impact by getting people into treatment. The agenda also stresses a second meaning in addictions consistent with public health goals: prevention. Health literacy programs educate target groups about risks and negative outcomes of substance use in order to dissuade them from ever joining the group of people with substance use disorders, Drug Abuse Resistance Education (DARE) is perhaps the best known education program meant to promote prevention. Typically offered to sixth through eighth graders by local police officers, participants sign a pledge not to use drugs or join gangs after being taught about the dangers of drug use in an interactive curriculum that lasts 10 weeks. Unfortunately, DARE does not do well in research. Results of a meta-analysis of eight rigorous studies of DARE yielded effect sizes far below those that might emerge for programs emphasizing social or general competencies.[14] Research is needed to better understand programs that will promote care seeking and prevention related to addictions.

The Rights Agenda

The rights agenda seeks to erase the discrimination that results from stigma, replacing it with rightful opportunity. The rights agenda is endorsed most by those who have been victimized by stigma—in the work setting, housing market, or health care clinic—and, like other civil rights activists, demand replacing discrimination with opportunity. The UN Convention on the Rights of Persons with Disabilities echoes this concern; it asserts the full rights of people with all disabilities to life opportunities as citizens and workers as well as the provisions of reasonable accommodations to help people enjoy those opportunities. The rights agenda has been explicitly extended to people with mental illness in the US report of President George Bush's New Freedom Commission.[15]

The rights agenda may have less traction for people with addiction when the public is confronted with messages that legitimize this kind of stigma, especially in light of criminal activities. In Part I, research is discussed that showed people are more likely to withhold opportunities from substance users when they endorse criminal notions about addictions.[4] The rights agenda has not until recently, been widely endorsed by substance use advocates. Programs like the San Francisco Drug User's Union have relatively recently made fair treatment under the law among their primary principles requiring, among other things, proscription of discrimination.

Programs directed toward decreasing public stigma in order to promote personal rights of people with mental illness have largely been grouped into education (somewhat similar to mental health literacy campaigns used in the services agenda that contrast myths of a disorder with facts) and contact (decreasing stigma by promoting interactions among the public and people in recovery).[3] England's Time to Change program combined education and contact to influence British attitudes about mental illness. A comprehensive analysis was able to unpack education and contact effects showing both diminished negative activities to people who were aware of the program or who had contact with program participants.[16,17]

Self-Worth Agenda

Stigma causes shame with undermines self-worth. The self-worth agenda seeks to stifle these effects. On the mental health side, this agenda is prioritized by people with psychiatric disorders who feel shamed as a result of self-stigma. Efforts to address the self-worth agenda are often grounded in peer-support services.[18] Peers are people with past history of significant mental illness and/or addiction. Peer support services for mental illness combine emotional with instrumental support provided by individuals with lived experience who come together with the specific intent of bringing about social and personal change.[19] Peer support has assumed a similar important place in services for SUDs, in part because professionals often stigmatize addictions thereby giving unintentional messages of unacceptance.[20,21] Peer support is mutually beneficial through a reciprocal process of giving and receiving based on principles of respect and shared responsibility.[22] Peer support programs that target self-stigma and shame also seem to use education and contact strategies (described more fully below).

Do Agendas Compete?

Although the three agendas share common goals—to decrease the egregious impact of stigma on people with mental illness or addictions—they differ in constituencies, valued outcomes, and strategies to achieve these outcomes. As a result, advocates who prioritize agendas differently may fail to understand campaigns driven by different rationales and tasks. For example, those who erase stigma to promote service seeking might be unaware of the equally important goal of challenging the discrimination wrought by illness prejudice. Anti-stigma efforts promoting one agenda might have unintended consequences on another.[23] For example, PSAs like *beyondblue* promote care seeking for mental illness by framing common illnesses, such as depression, as treatable diseases. On one hand, framing depression as

familiar (like an illness) might decrease stigma and promote help seeking. However, "treatable disease" might also lead to an unintended effect; namely that people with depression are perceived as somehow different from everyone else. Recent research suggests differentness ("People with mental illness are different from me.") may be a more sensitive measure of stigma than endorsement of stereotypes (eg, "People with mental illness are dangerous.") because social desirability effects likely moderate the latter.[24] The impact of the *beyondblue* PSA was contrasted to a contact-based recovery video focused on the rights agenda where a person with serious mental illness shared his story of recovery.[24] Results of the RCT showed the recovery video had better effects on mental health stigma and empowerment than the *beyondblue* PSA.

Strategies to Change Public Stigma

The first two agendas—services and rights—are typically pursued by strategies meant to decrease public stigma.[25] The most common approaches towards this goal are education and contact which are summarized in Table 2.[3] Educational approaches to stigma change for mental illness contrast myths with facts about psychiatric disorders and typically use public service announcements, books, flyers, movies, videos, and other audio-visual aids.[26] Evidence from education studies on mental illness stigma suggests that people with better understanding of psychiatric illness are less likely to endorse stigma and discrimination.[27,28] However, other research suggests increasing medical knowledge about mental illness per se does not seem to yield significant decrements in stigma. Results of a meta-analysis of sixteen population studies showed significant increase in public knowledge that mental illness is a brain disorder or genetically caused between 1990 and 2006.[29] However, this did not correspond with improvements in proxies of public stigma: the degree to which the public accepts a person with mental illness as neighbor or co-worker. In fact, results showed significant decreases in social acceptance of almost 20% for people with schizophrenia. Still, one recent RCT seemed to support education for mental illness and for addiction stigma. This population-based study showed public attitudes about mental illness, as well as SUDs (heroin and prescription painkiller addiction), diminish merely by informing the public that these conditions are treatable.[30]

Contact between people in recovery from mental illness and the general population may reduce public stigma; optimal contact interventions contain four elements.[31] (1) Equal status between groups: in the contact situation, neither minority nor majority group members occupy a higher status. (2) Common goals: both groups should be working toward the same ends. Some studies of contact have used contrived tasks such as completing a puzzle.[32] 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: the contact intervention is sponsored or endorsed by management of a business or by particular community organizations (eg, the Chamber of Commerce).

Extensive research has been done contrasting education and contact approaches to changing the public stigma of mental illness leading to large meta-analyses. The first concluded, based on review of 34 studies, that there seems to be strong evidence for education and contact approaches to changing public stigma.[33] The second summarized 79 studies, thirteen which were randomized controlled trials.[34] Results of this meta-analysis, differed from Griffiths et al and suggested adults who participated in contact with people in mental health recovery had significantly better changes in stigmatizing attitudes and behavioral intentions than those participating in education. Corrigan and colleagues also showed in vivo contact (where the person in recovery meets face-to-face with the targeted audience) had significantly better effects than video or online versions.[34] A subsequent analysis of these data suggests benefits of contact were maintained better over time than education.[35] However, a separate meta-analysis of 80 studies on the medium and long term mental illness stigma change failed to find a difference in contact and education effects.[36] Interestingly, adolescents seemed to be affected by education and contact differently. The Corrigan et al meta-analysis suggested education had better effects on teens than contact.[34] Perhaps this reflects research which shows how the impact of information has diminished effects on stereotypes as they become entrenched with age.[37]

TABLE 2. Strategies that address public and self-stigma

	Public stigma and label avoidance	Self-stigma
Education	Contrast myths versus facts of stigmatized disorders. $n = 7$	Challenge myths leading to selfstigma through facts and through cognitive restructuring. $n = 1$
Contact	Facilitate interactions between the public and people in recovery. $n = 3$	Promote empowerment through peer support and strategic disclosure. $n = 1$

Number of empirical studies found in the research literature for each of the four kinds of approaches are provided in each cell as insets ($n = x$). One study addressing public stigma and two studies addressing self-stigma did not correspond with either education or contact approaches.

Livingston et al's review of research on changing addiction stigma found ten studies addressing public stigma with seven targeting medical students or other provider groups.[38] Findings were generally positive with the single RCT showing reduction in stigmatizing attitudes.[39] Although Livingston and colleagues coded for differences in education versus contact, they did not report relative benefits. A subsequent pre-post study not included in the Livingston review showed education to have a muted effect on stigmatizing attitudes toward substance users.[40] Table 2 summarizes completed studies between education and contact for both public and self-stigma using findings from Livingston et al as well as others that arose from our review.[30,41]

Strategies to Change Self-Stigma

Approaches to addressing self-stigma might also be broadly divided into education and contact; see Table 2.[42,43] (1) Education programs seeking to decrease the self-stigma of mental illness combine strategies of contrasting myths and facts with cognitive restructuring meant to challenge irrational self-statements that represent internalized prejudice. (2) Contact efforts are based on assumptions that greater peer contact and support will lead to increases in empowerment and decreases in self-stigma. Strategic self-disclosure is an important element for availing peer support and promoting hope.

Education

Self-stigma may result from maladaptive self-statements or cognitive schemata that developed largely as a result of socialization.[27] People learn mental illness prejudice as they develop and subsequently internalize it when labeled.[44] Cognitive therapy has been shown to be an effective strategy for helping people change cognitive schemata that lead to anxiety, depression, and the consequences of self-stigma.[45,46] This approach targets maladaptive understandings of mental illness using a collaborative empirical framework. Therapists help their clients explore distressing cognitions, attempting to reframe them as beliefs rather than facts, reviewing evidence for and against beliefs, and seeking less distressing alternative interpretations.[47,48] Kingdon and Turkington expanded the cognitive therapy of psychosis to target catastrophic interpretation of symptoms and the stigma attached to mental illness generally.[49,50] They attempted to normalize the symptoms of therapy participants by comparing them to everyday experiences such as deprivation states. Similarly, in their research, Garety and colleagues strive for a positive understanding of psychosis that promotes social functionality.[48]

Three programs have in some ways combined education with cognitive restructuring to directly impact the self-stigma of mental illness: Healthy Self-Concept,[51,52] Self-Stigma Reduction Program,[53] and Ending Self-Stigma.[54] Results of RCTs on the first two programs were promising with participants showing reductions in self-stigma and improved hopefulness.[52,53] An additional approach to self-stigma change for mental illness, called Narrative Enhancement and Cognitive Therapy, combines cognitive restructuring and psychoeducation with narrative strategies meant to promote self-reflection and redefinition of one's mental health experiences.[55] Although an RCT failed to yield significant results,[55] a quasi-experiment with more than 100 participants conducted in Israel showed reduced self-stigma and improved self-esteem, hope, and quality of life.[56]

One study examined a variation of cognitive therapy—Acceptance and Commitment Therapy (ACT)—specifically on the self-stigma of people with SUDs.[57] In addition to psychoeducation, this program offered ACT for self-stigma where participants were encouraged to experience difficult feelings more directly while reducing automatic links to overt behavior. ACT in this program included cognitive defusion techniques where participants deliteralize content of thoughts; that is, focus more on process of thinking than content of thought. Results of a pre-post study showed participants decreased internalized shame and enhanced self-esteem.[57] Results of a subsequent RCT were equally impressive with similar benefits.[58]

Contact

Interactions with peers in mutual support programs for people with mental illness or with SUDs enhance personal empowerment, which in turn diminishes self-stigma.[59] In part, this requires people to "identify" with the mental health challenge, the treatment for the challenge, or the family/friend reactions to the challenge or treatment. The relationship between identity, disclosure and self-stigma is complex, however, suggesting positive relationships in some cases.[60,61] One study showed that effects of illness identity are influenced by perceived legitimacy of mental illness stigma.[62] Those who identified with mental illness, but also embraced the stigma of their disorder, reported less hope and diminished self-esteem. Conversely, persons whose sense of self prominently included their mental illness, and who rejected the stigma of mental illness, showed not only more hope and better self-esteem, but also enhanced social functioning as well. Identifying with mental illness does not automatically lead to more stress; it is the perceived legitimacy of the stigma that threatens identity and harms emotional health.[63,64]

Research about identity and addiction seems to echo studies about the risks of disease identification and mental illness. Namely, people who identify with their addiction are more likely to remain addicted and have poorer outcomes.[65,66] In fact, an adaptive goal of treatment might be to replace addiction identity with recovery identity.[67] No research was found similar to studies on mental illness; namely, that identifying with one's addiction experiences decreases self-stigma.

If embracing illness identity has a potentially positive impact on mental health stigma, then disclosure of that identity might promote health and life benefits. Namely, strategically sharing aspects of one's illness and treatment might help people achieve personal goals.[68] Studies have yielded two

factors that describe the disclosure process among people with mental illness: benefits of being out versus reasons for staying in.[69,70] Being out with one's mental illness proved to be a protective factor against self-stigma's effects on quality of life and to augment a sense of personal empowerment that enhanced well-being. Interestingly, compared to other groups of people with concealable stigma, one study showed people with SUDs believed they were out of the closet more than people with mental illness.[71]

Despite these group level data, there are costs and benefits to an individual disclosing one's experiences with mental illness.[72,73] Opting whether and how to disclose, given personally perceived costs and benefits, does not lead to the facile decision that all people stigmatized with mental illness should pursue in a set manner. *Coming Out Proud* (COP) is a standardized program meant to help people challenge the self-stigma of mental illness.[74] Led by people with mental illness, COP is a three session program to help participants consider the pros and cons of disclosing, relatively safe ways of coming out, and formats for telling one's story. Results of two RCTs showed participation in COP, compared to a control group, led to significant reductions in stigma stress and secrecy.[75,76]

Livingston and colleagues' review of stigma change interventions for addictions yielded three studies that targeted self-stigma.[38] The single RCT among these showed significantly decreased alienation compared to a control.[77] Interestingly, some of what Livingston et al[38] viewed as stigma change efforts are different from what is reviewed here or typically considered part of anti-stigma efforts. This is noted in Table 2. For example, the self-stigma change strategy in the NIDA study was self-employment skills training.[77] The Livingston review did not sort strategies into education, cognitive restructuring, peer support, or disclosure. Future research needs to examine whether this kind of strategic disclosure has value for people with addictions.

Summary and Directions for Future Research

This review suggests research priorities for developing and evaluating strategies meant to reduce the stigma of addiction.

- The three agendas summarized in Table 1—services, rights, and self-worth—significantly impact advocate tasks because they require stakeholder constituencies to make sense of the rationale and goals for their specific anti-stigma programs prior to activating those programs. An important question for addiction stigma research is whether these agendas make sense. Might health campaigns that unintentionally promote the legitimacy of addiction stigma undermine the rights agenda? Perhaps more interesting, are anti-stigma efforts for addictions driven by additional agenda. Might difficulties with criminalization suggest additional goals of anti-stigma programs?
- Do differences in the impact of education and contact on the public stigma of mental illness, and to a lesser degree self-stigma, manifest in addictions? Largely absent from the mental health stigma literature has been consideration of strategies to address structural or institutional impact which might have a greater effect on addiction stigma. This should be included as a research target. Finally, how does criminalization interact with education and contact impact? Do the emotions evoked by criminalizing addictions undercut the impact of contact?

Summary

Public and self-stigma undermine the life opportunities of people with addictions. Although the research literature that might inform future science in addictions and stigma change is limited, significant strategies can be educed from the mental health stigma literature. Partnerships between advocates and researchers will help to advance this research. Towards this end, SAMHSA has charged a second NAS committee in June 2016 to examine how the general body of research about stigma and behavioral health might be translated to recommendations that might be embraced by the advocate's community.

Although Dr. Corrigan was a member of the NAS committee releasing its 2016 report titled "Ending Discrimination Against People With Mental and Substance Use Disorders," all the work leading to this paper was conducted separately from his NAS activity and with no resources of the NAS. This work was made possible in part through grants from the National Institute on Minority Health and Health Disparities (MD007925-01) and the Patient Centered Outcomes Research Institute (R-AD-1306-01419).

Declaration of Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this paper.

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