

Developing a Research Agenda for Understanding the Stigma of Addictions Part I: 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 review of key studies from 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.

Results: Integration of this information led to Part I of this two part paper, development of a research paradigm seeking to understand phenomena of addiction stigma (eg, stereotypes, prejudice, and discrimination) and its different types (public, self, and label avoidance).

Conclusions and Scientific Significance: In Part II paper (*American Journal of Addictions*, Vol xx, pages xxx–xxx, this issue), we address how this literature informs a research program meant to develop and evaluate and stigma strategies (eg, education, contact, and protest). Both papers end with recommendations for next steps to jumpstart the addiction stigma portfolio. Here in Part I, we offer one possible list of key research issues for studies attempting to describe or explain addiction stigma. (*Am J Addict* 2016;XX:1–8)

Advocates, clinical service providers, and other stakeholders agree; the stigma of addiction worsens outcomes and wellbeing of substance use disorders (SUDs) as well as those who use

substances without leading to disorder. As a result, leaders at the World Health Organization globally,¹ as well as the Substance Abuse and Mental Health Services Administration (SAMHSA) in the United States, have called for research to better understand the nature of these problems and ways to counteract them. In fact, SAMHSA commissioned the National Academy of Science (NAS) in 2014 to summarize the state of the research literature on the stigma of behavioral health: mental illness and addictions. In their April, 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 The limited addiction research that does exist is mostly descriptive and lacks the conceptual and empirical sophistication of the mental illness stigma literature. 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 paper examines the status quo of research attempting to understand the stigma of addiction in order to craft an agenda for future research using lessons from the mental health arena. Part II paper (*American Journal of Addictions*, Vol xx, pages xxx–xxx, this issue) summarizes research and proposes a future research agenda for strategies to reduce stigma with a similar strategy. Hence, here in Part I, we summarize the state of the art of research that describes and explains mental health stigma in order to inform research agenda guiding future studies on addiction stigma. Part II is the practice and intervention paper; reviewing investigations on how mental illness stigma has been impacted in order to inform a similar research agenda on addiction stigma.

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We ground Part I and II with the four reviews on stigma and addiction found in the existing research literature. Lloyd discussed 185 papers addressing the stigma of problem drug users, though this review seemed to mix findings from empirical studies with concept or opinion papers.³ Schomerus et al. summarized the depth of the addiction stigma problem in a review of 17 population studies contrasting the stigma of alcohol dependence with mental illnesses.⁴ Kulesza et al. examined 28 studies that described correlates of addiction stigma focusing on sociodemographics and psychological predictors.⁵ Livingston et al. reviewed 13 studies that examined interventions to reduce addiction stigma.⁶ Specific findings of these reviews are integrated into our paper where relevant. We summarize conclusions from these reviews in Table 1 using the social psychology model of stigma—stereotypes, prejudice, and discrimination—defined more fully below. The point here is the relative paucity of research on addiction stigma when compared to investigations on the stigma of mental illness. Forty-nine research reviews of mental illness stigma have been found in the literature. These are based on analyses of more than 1,000 empirical studies on mental illness stigma and stigma change.⁷ Also notable is the quality of conceptual work that has evolved from these data. Reports on addiction stigma are mostly descriptive while the mental illness stigma literature is replete with frameworks and

paradigms that describe stigma’s impact and strategies for addressing it.

In this paper, we summarize research and conceptual models of mental health stigma that answer the question, What is stigma? We begin by using what is known about the stigma of addiction from the reviews in Table 1 framed in a social psychological model. We then describe basic types of stigma: public stigma, label avoidance, and self-stigma, structural stigma. The success of stigma elimination is marked by the degree to which affirming attitudes (eg, people recover and should have personal power over their lives) replace prejudice and discrimination. Research on affirming attitudes and mental illness is then summarized, extending insights of this work to addiction stigma. While mental health and substance use disorders are grouped together under the rubric of behavioral health by SAMHSA and discussed jointly in the DSM, we remind the reader that they are significantly different phenomena which are experienced differently by the community. Hence, benefits of extrapolating lessons learned from research on mental health stigma need to be tempered by realizations, where the two experiences are distinct. Examples are provided herein. The paper ends with directions for future research into addiction stigma. We also considered how findings from this relatively basic research will inform stigma change strategies which are then considered in Part II.

TABLE 1. Findings from the research reviews on stigma and addictions sorted according to constructs in a social psychological model stigma

Social cognitive structures
Stereotypes and Prejudice
Anger ⁴
Blame ^{3,4}
Dangerous ⁴
Difficult backgrounds ³
Fear ⁴
Pity ⁴
Repulsion ⁴
Unpredictable ⁴
Discrimination
Social distance
Accommodations ^{3,4}
Health Care ³
Neighbors ⁴
Relationships ⁴
Work ⁴
Structural
Save finances by reducing addiction services ⁴
Compulsory treatment ⁴
Public shame through policing ³

Superscripts correspond with citations in the reference section of this paper. Note that one of the four articles solely reviewed studies on stigma change⁶ and one was limited to examining correlates of stigma such as demographics or diagnoses.⁵

WHAT IS STIGMA?

Modern conceptualizations of stigma as social injustice are traced to Erving Goffman, who framed stigma as a mark that leads to “spoiled identity.”⁸ He believed stigmas of all kinds (related to ethnicity, gender, sexual orientation, age, and illness) are a socially discrediting attribute causing people with the mark to being unjustly rejected. Goffman distinguished discredited stigma (the mark is obvious such as skin color leading to racism or body characteristics leading to sexism) from discreditable stigma (marks are hidden so that the public cannot tell whether a person belongs to a stigmatized group such as sexual minorities, mental illness, or SUDs). The hidden mark of mental illness and addiction is often label by association. For example, people seen coming out of the mental health clinic are believed to be “crazy.” People who report attending 12 step meetings are stained by the stigma of addiction.

Link and Phelan expanded on the definition of stigma: (1) it is fundamentally a label of an outgroup; (2) labeled differences are negative; (3) differences separate us from them; and (4) label and separation lead to status loss and discrimination.⁹ The NAS sought to ground its research summary on models of stigma that evolved from more basic science. Social psychology has identified structural, dynamic, and bio-behavioral models as foundations for stigma research. Structures of social cognitive psychology—eg, stereotypes, prejudice, and discrimination—is a parsimonious approach to making sense of a range of social injustices including racism,

sexism, ageism, and stigma’s pernicious effects on health. These structures have been incorporated into a matrix used to describe mental illness stigma with the other dimension of the matrices described by stigma types.¹⁰ See Table 2.

Stereotypes

Social psychologists have distinguished the largely private experience of stigma in general—stereotypes and prejudice—from the more public, behavioral result which is discrimination.¹¹ Stereotypes are harmful and disrespectful beliefs about a group. Table 1 lists several examples of stereotypes applied to people with addictions including blame, dangerousness, and unpredictability. Contrast these to some of the similarly egregious beliefs about people with mental illness include being: dangerous and unpredictable, to blame for their illness, and incompetent to achieve life goals such as a good job or living independently.^{12,13} The important research question is, how are stereotypes identified? Content validity is especially important among the usual psychometric concerns about developing measures of stereotypes specific to a stigmatized condition and requires a combination of mixed research methods. Stereotype identification often begins with qualitative research where the objects of stigma (eg, people with mental illness or addictions) provide their perspective on specific stereotypes.

What might be the growing list of stereotype candidates that describe people with addictions? Schomerus et al. began the effort to establish a content-valid measure of alcohol stigma.¹⁴ They conducted focus groups with people with alcohol dependence, providers, and family members to identify candidates for the stereotypes of alcohol addiction. They generated 16 stereotype candidates, several different from those seen in Table 1 such as unreliable, emotionally unstable, living on other’s expenses, and self-pitying. A similar set of qualitative interviews were conducted to identify candidates of stereotypes about “drug users.”¹⁵ Although the resulting analysis from the latter study yielded themes about the form of stigma, specific stereotypes per se did not emerge from their work.

The next step would be to use stereotype candidates that emerged from the qualitative work in a quantitative study in which the public and people with the lived condition are asked whether they agree, “Self-pitying is a stereotype about alcoholism.” Analyses of these data suggest the priority of different stereotype candidates; eg, the sample agreed most that “emotionally unstable” was a stereotype of alcoholism. Factor analyses of these data might lead to hierarchical constructs that are the base of addiction stereotypes. For example, the various stigmatizing beliefs of mental illness reduce to violence, incompetence, and blame.^{16,17} What, then, might be the hierarchical constructs that describe the stigmatizing stereotypes of addictions? The answer to this question is valuable for specifying targets of anti-stigma programs and for designing meaningful evaluations of these programs.

Prejudice and Discrimination

Stereotypes are unavoidable; they are learned as part of aging in a culture; eg, American children learn at a young age that “mental patients” are violent.¹⁸ Prejudice is agreeing with the stereotype leading to emotional and evaluative consequences.¹⁰ “That’s right! All those mental patients are violent and I fear them.” In path models, affective responses to stereotypes (another element of prejudice) are often mediators between stereotypes and its behavioral result, discrimination. For example, “because I fear people with mental illness, I will not hire them, rent to them, give them the same opportunities at school, or let them worship with my congregation.” Several emotional mediators were found in the Table 1 review: anger, fear, pity, and repulsion. We find from the mental health stigma research literature that three emotional responses mediate stereotypes and subsequent discriminatory behavior¹⁷: (1) fear causing unfair discrimination that undermines personal goals related to work, independent living, relationships, and health; (2) blame (believing people caused their mental illness) leading to anger and subsequently discrimination often in the guise of unnecessarily coercive treatments; and (3) and internalized blame (I caused my mental illness

TABLE 2. A putative matrix describing the stigma of addiction and corresponding attitudes

Social cognitive structures	Public	Self	Label avoidance
Stereotypes and Prejudice	“People with addictions are: dangerous, immoral, to blame for their disorder, criminal.”	“I am dangerous, immoral, to blame. Leading to lowered self-esteem and self-efficacy.”	“I perceive the public disrespects and discriminates against people with substance use disorders.”
Discrimination	“Therefore, employers will not hire them, landlords will not rent to them, primary care providers offer a worse standard of care.”	“Why try: someone like me is not worthy or unable to work, live independently, have good health.”	“I do not want this. I will avoid the label by not seeking out treatment.”
Affirming attitudes			
	Recovery		Self-determination

because I am weak.) leading to shame (decreased sense of self-esteem and self-efficacy). Research has yet to identify affective factors that mediate stereotypes and discrimination for people with addictions. Discrimination is more fully defined in the next section. Note here, however, that the three structures do not neatly sort into independent phenomena. For example, is shame an emotion that results from stereotypes or the behavioral result of prejudice (discrimination). Future research needs to make sense of the structural boundaries of elements in Table 2.

Stigma Types

Discrimination's impact becomes clear when realizing it varies by type^{19,20}; three types are summarized in Table 2 that emerged from the mental health stigma literature. For the most part, the review papers on addiction stigma did not distinguish between types with the research mostly examining public stigma. **Public** stigma occurs when the general population endorses stereotypes and decides to discriminate against people labeled with an addiction. This frequently manifests as social distance with examples from Table 1 including restricted opportunities in housing, work, and health care. Research in the mental health area also shows employers are less likely to hire and landlords are less likely to rent to people with mental illness.¹⁹ A particularly concerning form of discrimination in mental illness has been identified in the health care sector. People labeled with mental illness receive fewer primary care and specialty health services than those not labeled in this manner^{21,22} and receive fewer insurance benefits.^{23,24} Public stigma also leads to a greater call for coercive treatments for people with mental illness.²⁵ Some of these citations are relatively old suggesting this area might be an important focus of future research.

The discriminatory results of public stigma for addictions is complex with its impact conflated with criminalization. In the Western World, pairing criminal behavior with addiction got a significant boost with the launch of the 1970s war on drugs by the Nixon administration. The war's effects were significant in the United States; 1 in every 136 adults was incarcerated for drug possession in 2005.²⁶ Although public sentiment about criminalizing people for drug possession has waned, (eg, the U.S. Department of Justice has been prompting criminal deinstitutionalization and alternatives to incarceration through the "Second Chance Act"), research shows people who agree with criminal penalties for drug use still endorse the stigma of people labeled with SUD.²⁷ Future research needs to unpack the relative impact of addiction and criminalization stigma as well as ways they interact.

Label Avoidance

Public stigma impacts care seeking of people with mental illness when it leads to label avoidance. Epidemiological research shows as much as 40% of people with serious mental illness do not seek out services when in need.^{28,29} Of those who do begin interventions, 20% do not seem to engage and drop out of services early. Stigma is one of many reasons why

this occurs. People avoid the discrimination that comes with stigmatizing labels by not going to clinics or interacting with mental health providers with whom the prejudice is associated.³⁰ Similar connections between stigma and care seeking have been established for people with addictions. Data suggests only about 25% of people with SUDs ever participate in any care.³¹ People who perceive higher stigma toward peers with SUDs are less likely to use treatment programs for alcoholism³² and less likely to participate in sterile syringe programs.³³ These are mostly small and compartmentalized studies; however, future research needs to tackle these questions more broadly and rigorously.

Self-Stigma

Self-stigma occurs when people with mental illness internalize corresponding prejudice.^{34,35} One model of self-stigma has four stages¹⁸: people are (1) **A**ware of the stigma of mental illness (also called perceived stigma: "The public thinks people with mental illness are dangerous"³⁶), which might lead to (2) **A**greeing with the stigma ("Yep; that's right. People with mental illness are dangerous!"), followed by (3) **s**elf-**A**pplication ("I'm mentally ill so I must be dangerous.") which (4) **n**egatively **I**mpacts 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."). Self-discrimination causes the "Why Try effect."^{37,38} "Why try to seek a job; someone like me is not worthy." "Why try to live independently; someone like me is not able."

Self-stigma seems to have an equally egregious effect on the well-being of people with addictions.³⁹ Research by Schomerus et al. partially validated the above model of self-stigma for people with alcohol dependence.¹⁴ Namely, people who apply stereotypes to themselves report greater harm to self-esteem which, in turn seemed to undermine drink-refusal self-efficacy. Other studies showed self-stigma of addictions to be associated with greater depression and anxiety as well as diminished psychological well-being.³⁹⁻⁴³ Interestingly, some addiction research suggests self-stigma does not always lead to harmful effects. One study showed people with higher self-stigma were likely to stay in treatment longer leading to higher abstinence.⁴⁴ This finding shows the complexity of stigma in addictions calling for research that looks at the varied directions of, in this case, self-stigma on the person who internalizes stereotypes.

Affirming Attitudes

Influencing stereotypes, prejudice, and discrimination in order to decrease the various types of stigma is not sufficient, just as efforts to erase racism should not be limited to stopping prejudice and discrimination against people of color. Social activists call for affirming attitudes that promote respect for ethnic groups as well as behaviors that increase opportunities for individuals in that group. Similarly, one mark of successful anti-stigma programs is increase in affirming attitudes related to mental health (summarized in Table 2). Two such attitudes

represent conceptual evolutions in the mental health system: recovery and self-determination. Recovery reintroduces ideas of “future and aspiration” to describing serious mental illness. Contrary to classic notions of mental illness—eg, schizophrenia is marked by a progressive downhill course with prognostic expectations of never being able to live independently—long-term follow-up studies find that most people with mental illness are able to live a good quality life outside the mental health system.⁴⁵ This has led to psychiatric services that now foster hope in terms of attaining the person’s goals. Self-determination is promoted by supporting a person’s grasp of personal empowerment for themselves as well as by directing the community not to erect barriers to the process.⁴⁶ It is more transparently anchored in the belief that people with serious mental illness do have goals (eg, want to go back to work, live independently, and/or enjoy intimate relationships) which should be pursued and are achievable.

White et al. and other research groups have discussed how affirming attitudes such as recovery and self-determination seem to have different meaning for substance use disorders. Recovery is a continuum for mental illness, while it seems to be a clear end state for traditional models of addiction tied to categorical judgments of abstinence.⁴⁷ Beliefs about achieving goals may vary depending on whether someone assumes prior abstinence must be accomplished first. Recovery from mental illness is grounded in hope and regaining one’s agency. In some ways, recovery from addiction begins with hopelessness, hitting bottom.⁴⁸ Recovery from addictions is healing which only occurs when people recognize their powerlessness in the face of substances.⁴⁹ This powerlessness, by the way, also describes different perspectives on self-determination. Fundamental to mental illness are systems that empower people to define life goals for themselves and then select interventions that help them achieve those goals.⁵⁰ Self-determination may be tempered in 12 step and other addiction programs with concerns about impulsivity, where people are warned not to make treatment and other life decisions rashly because of past mistakes common to this with substance use disorders.⁵¹

Directions for Future Research

The NAS report on the stigma of behavioral health suggested development of a research agenda for better understanding, and subsequently impact, the stigma of addiction is limited by a dearth of research. In Table 1, we reviewed existing addiction research on stigma finding that studies have begun to list examples of social psychological structures—stereotypes, prejudices, and discrimination—specific to SUDs. We argued that this relatively thin portfolio could be augmented by the extrapolation of findings from the mental health research literature, keeping in mind that addiction and mental health are significantly different phenomena. Specific efforts here attempted to make sense of the three types of stigma—public, self, and label avoidance—as well as affirming attitudes related to recovery and self-determination. We meant for this review to yield an agenda to

guide future research meant to understand, What is the stigma of addiction? We do not suppose this is a definitive agenda as much as a heuristic to guide subsequent efforts.

Research methods to address these priorities must be of two broad kinds. (1) Internally valid, relatively small scaled studies that test hypotheses about stigma and stigma change. Hypothesis: stereotypes about addictions are inversely related to endorsing recovery and self-determination. Well-controlled studies typical of social psychology will yield internally valid tests of questions related to structures, types, and affirming attitudes. (2) Externally valid, big data studies examine stigma and stigma change in the population. Question: how does the United States population view specific stereotypes about addiction, especially across specific ethnic groups? Population studies obtaining representative samples are best able to make sense of stigma phenomena in the world. We think three areas are especially ripe for driving this agenda.

1. What are social constructs specific to addictions? Mixed method research is needed to identify and cross-validate the stereotypes of people with addictions. Studies need to better sort out convergence and divergence of addiction and mental health stigma. Convergence seeks to identify common stereotypes between the two behavioral health categories. For example, does the population see both people labeled with mental illness and those labeled with SUDs as “dangerous?” Divergence represents the stereotypes that distinguish groups. For example, does research show the public views people with SUDs as criminals but not people with mental illnesses? This task becomes even more complex as research matures to include the common experience of co-morbidities. Research needs to then examine whether stereotypes vary by SUDs: eg, tobacco, versus alcohol, versus illegal substance use. Stereotypes must be contrasted for people using substances compared to those challenged by use disorders. Research must also identify and validate meaningful affirming attitudes and behaviors for addiction. We began to make sense of this challenge by questioning how recovery and self-determination have currency for understanding addiction. The different definitions of recovery from SUDs need to be included in this work. Finally, does the three part typology for mental illness stigma—public stigma, self-stigma, and label avoidance—reflect the experience of addiction? Are their types of stigma in addictions not found for mental illness? This research will yield sound measures that, among other things, are essential for evaluating the impact of anti-stigma programs.
2. What are social level phenomena that impact stereotypes, prejudice, and discrimination? Research needs to examine how stigma of addictions covaries with public awareness of, and agreement with, criminalization of some substance use especially given the prolonged history of this association. It should also examine impact of disease models, and notions of abstinence, responsibility, and

anonymity on public versus self-stigma. This leads to an issue mostly unobserved in mental health and important for research on addiction stigma. How does stigma change interact with other goals of addiction and mental health interventions? For example, prevention is an important task in addiction work, sometimes adopting stigmatizing messages to accomplish preventive goals. For example, don't use drugs so you don't end up being a "criminal bum." This point is more fully developed in Part II.

3. What are individual level (psychological) factors that influence stereotypes, prejudice, and discrimination as well as corresponding affirming attitudes and behaviors? Space limitations in this paper did not permit review of these issues here; large scale research summaries show the public and self-stigma of mental illness vary by gender⁵² and ethnicity,⁵³ though the nature of these relationships is complex. Future research needs to examine how addiction stigma varies with diversity because this information will be useful for adapting anti-stigma programs to the specific needs of differing groups. Of special concern is whether understanding addiction and its stigma is conflated with ethnic groups that are especially the object of criminalization and perceived dangerousness; eg, African Americans.

This was not a comprehensive review of concepts from mental health that lead to better understanding stigma. Additional types have been described that fill out the Table 2 matrix. Structural stigma are governmental and other institutional policies and practices that undermine opportunities of people with mental illness.^{54,55} Examples include unequal parity in health care coverage.^{56,57} Associated stigma occurs when family and friends are impacted by public stigma.^{9,58-60} Studies have found, for example, that parents and siblings, spouses or other partners, as well as other family caregivers, report feeling stigmatized by the mental illness of their loved one and work to manage their self and public identity in various ways.⁵⁸ These types need to be added to the agenda of addiction stigma.

Affirming attitudes are not sufficient. They need to be matched by behavior change. Affirmative behaviors are official efforts that seek to decrease structural and other forms of stigma by purposively and strategically increasing the opportunities of a stigmatized group. Subsections of the Americans with Disabilities Act (ADA) are affirming behaviors by requiring reasonable accommodations for people with psychiatric disabilities to promote community integration. Reasonable accommodations are those provisions which employers must supply to employees with disabilities so they can competently do their job. This is obviously a beginning list. Research in this arena, however, will only be accomplished if advocacy organizations join with researchers. Among other goals, these organizations need to push the SAMHSA as well as health research funders specific to governments around the world, to support research in this area. ADA protections for addictions may be impacted by the effects of criminalization. Employers, for

example, are not violating the ADA when disciplining employees currently engaged in illegal use of drugs including discharge or denying employment (U.S.C. § 12114(a)(1994); *Shafer v. Preston Memorial Hospital Corporation* 107 F.3d 274 (4th Cir, 1997). Similarly, benefits from the Affordable Care Act for people with SUDs may be moderated by stigma. Stigma research needs to better inform practical applications for these and other government legislation.

These are just a sample of ideas that inform a stigma addiction agenda. Products of this agenda are valued to the extent they inform the advocates' agenda to decrease the egregious effects of stigma on people with SUDs. The NAS report concluded that "changing stigma in a lasting way will require coordinated efforts on the best possible evidence, which are supported at the national level. . ." (p. 7). Part II of this paper attempts to bridge addiction with mental health stigma research to begin to inform the "changing stigma" task.

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Declaration of Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this paper. 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 Part I of this paper was conducted separately from his NAS activity and with no resources of the NAS.

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